

II. 研究分担報告

が高く、自由記述にも挙げられた精神的支援や療養上の世話に関する支援といった役割を担えるとういともいえないよう。

本研究の限界として、遺族を対象としており、必ずしも患者の評価と一致しない可能性がある。また、ひとつの診療所で診療を受けた遺族が対象であり、地域全体の評価として一般化することはできない。

E. 結論

ひとつの在宅療養支援診療所で在宅死亡まで診療を受けた遺族の視点から、ステーションの評価が得られ、ケアの質や診療所との連携に関して全般的に肯定的な評価が得られた。特に精神的な支援の評価が高かった。一方、課題も挙げられ、診療所とステーションが連携を取る際には患者家族のニーズに合わせ、両看護師の訪問頻度や役割分担などについて十分検討する必要性が示された。本研究から、遺族に評価を得ることは、職種間で課題を共有してケアの改善を図るための基盤となり、地域における緩和ケアの質の向上に貢献する可能性が示唆される。

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G. 知的財産権の出願・登録状況（予定を含む）

1. 特許取得

なし

2. 実用新案登録

なし

3. その他

なし

インターネットによる緩和ケア普及のための 情報発信に関する研究

研究分担者：山川宣

研究要旨

緩和ケア普及のための情報発信として、ホームページ（HP）を運用した。前年度に最終的な利用動向の解析は終了しており、本年度は研究終了後のHPについて検討をおこない、UMIN サーバーに報告書や一部のムービーを掲載することとした。

A. 研究目的

緩和ケアを地域に普及させるための手法として、情報提供手段の提供が重要と考えられた。そこで、インターネットでの情報発信を行い、検証した。

B. 研究方法

緩和ケア普及において必要な情報発信として、インターネットを利用する手法を検討するため、H20年度からH22年度まで公開したホームページ（HP）の利用動向（H20.4.1～H23.3.31）を、HP サーバー会社が提供している Urchin を行い情報収集、総PVや、HPのカテゴリ別のアクセス動向、配布資料のDL数などを計測した。

また、研究後に公開を続けているHPのメンテナンスをおこなうとともに、今後についても検討した。

（倫理面への配慮）本研究では個人情報扱っていない。

C. 研究成果

得られた情報の分析は、前年度までで終了しているため、新たな知見はえられていない。

今年度で研究が終了するため、これまで得られた成果の公開、マテリアルの扱いなどについて議論が行われた。

その結果、OPTIM レポートのPDF版およびムービー

などを、UMINのHPサービスを利用して継続公開することとした。

また、1月に行われたOPTIMシンポジウムの告知および申し込み書類の配付などをHPを利用して行った。

シンポジウムの結果報告については、新HPに掲載することとした。

D. 考察

昨年度までに報告した通り、OPTIM HPは情報発信手段として一定の役割を果たし得たと考えられる。しかし、利用される環境をどのように維持するかという点については、費用面・人的リソースの両面から、課題があると思われる。

特に利用者の多かったステップ緩和ケア（緩和ケアのマニュアル）については、継続公開できないか、検討を行った。しかし、既に研究終了後2年が経過しており、この間に発売され、比較的臨床で使用される薬剤が未掲載となっていることなど、内容面での刷新が必要と思われた。

そのためには、1）一定以上の知識の有る執筆陣の継続的な確保、2）それらを取りまとめ、内容のチェック等を行う責任者、3）人件費およびHPの作成に関わる維持費、が必要と考えられた。

各方面に働きかけたが、無償公開を続けるに当たって、これらを十分賄うことが困難であったため、全面的な公開継続は断念した。

II. 研究分担報告

一方で、OPTIM レポートおよび具体的な手技が視覚的に伝えられるムービーについては、今後改定の必要性が少なく、また既存の成書などで代替困難なことから、UMIN の HP サービスを利用し、継続的に掲載することとした。

必要がある。

E. 結論

HP は緩和ケアの情報発信に一定の役割を果たせるが、継続的に維持するための人的・金銭的な態勢を構築する

F. 研究発表

なし

G. 知的財産権の出願・登録状況（予定を含む）

なし

Ⅲ. 研究成果の刊行に関する一覧表

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書籍 (外国語)

| 著者氏名 | 論文タイトル名 | 書籍全体の 編集者名 | 書 籍 名 | 出版社名 | 出版地 | 出版年 | ページ |
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Ⅲ. 研究成果の刊行に関する一覧表


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Ⅲ. 研究成果の刊行に関する一覧表

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IV. 研究成果の刊行物・別刷

Patient-perceived usefulness and practical obstacles of patient-held records for cancer patients in Japan: OPTIM study

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Abstract

Background: Although the use of a patient-held record (PHR) for cancer patients has been introduced in many settings, little is known about the role of the PHR in palliative care settings and use in Asian cultures.

Aim: This study investigated the patient-perceived usefulness and practical obstacles of using the PHR specifically designed for palliative care patients.

Design: This study adopted a qualitative design based on semi-structured interviews and content analysis.

Setting/participants: Fifty cancer patients were recruited from two regions in Japan. They used the PHR for more than three months, and then were asked to participate in a face-to-face interview.

Results: The content analysis revealed the following patient-perceived usefulness of the PHR: (1) increase in patient–staff communication; (2) increase in patient–family communication; (3) increase in patient–patient communication; (4) increase in understanding of medical conditions and treatments; and (5) facilitating end-of-life care discussion. The practical obstacles to using the PHR were also indicated: (1) the lack of adequate instruction about the role of the PHR; (2) undervaluing the role of the PHR and sharing information by medical professionals; (3) patients' unwillingness to participate in decision making; (4) concerns about privacy; (5) burdensome nature of self-reporting; and (6) patients' preference for their own ways of recording.

Conclusions: The PHR can be helpful in facilitating communication, understanding medical conditions and treatments, and facilitating end-of-life care discussion; however, for wide-spread implementation, resolving the obstacles related to both patients and health-care professionals is required.

Keywords

Advance care planning, community-based distribution, information sharing, palliative care, patient-held records

Introduction

Hospital care has become increasingly specialized and subdivided, and patients with chronic diseases tend to visit multiple health-care institutions.^{1,2} These circumstances can result in the fragmentation of care and, thus, patients may

face unnecessary hospital visits, repeated examinations, or unorganized treatments.^{2,3} Although one fundamental way to resolve this situation is to make patient health records readily available to all health-care professional regardless of their

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location,⁴ sharing patient information with other facilities is practically very difficult, because almost all institutions usually have a self-determined system of patient health records.

A patient-held record (PHR) is a convenient tool to help patients organize their health information so that multiple medical professionals can share the information effectively.^{5,6} In randomized clinical trials, cancer patients generally appreciated the use of the PHR as an organizer,⁷ or as an aid for their understanding and decision making.³ Although the global consensus is that patients should be more engaged in decision making regarding treatment,⁸ in palliative care settings this can sometimes be a challenging process for both patients⁹ and medical professionals.¹⁰ Furthermore, while the choice of treatment is discussed in advance, and preferably transcribed in documented form, such as an advance directive,¹¹ few patients had actually discussed this.^{12,13} Supporting aids for facilitating end-of-life care discussion are thus needed,^{10,14} and the PHR may be one of the effective strategies. However, few studies have reported the potential role of the PHR in palliative care settings. In addition, to date, all studies on the PHR have come from America and European countries, and no empirical studies have been reported from Asian countries.

This study thus aimed to explore the patient-perceived usefulness and patient-perceived practical obstacles to using the PHR in palliative care settings involving Japanese cancer patients.

Subjects and methods

Design and participants

This was a part of a regional intervention study to improve the quality of palliative care at the community level (Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study).¹⁵ The primary aim of the intervention was to standardize and improve the continuity of palliative care in the community, and the PHR was developed as a tool to improve the availability of patient information at the regional level and promote patient–staff communication.

To explore the potential patient-perceived usefulness of the PHR and practical obstacles to its use, a qualitative study using semi-structured interviews was conducted from January 2009 to January 2010. Adult cancer patients who used the PHR for at least three months in outpatient chemotherapy settings were interviewed. Patients with dementia or other cognitive impairments were excluded. The patients were recruited from two general hospitals: the Shonai General Hospital (Yamagata Prefecture) and the Seirei Mikatahara General Hospital (Shizuoka Prefecture) in Japan. The study was approved by the Institutional Review Boards of the participating hospitals.

Development of the PHR

Due to the lack of a standardized format for the PHR, we specifically designed it for cancer patients receiving palliative care through discussions among clinicians and researchers.

A pilot test was conducted with 10 patients, and the PHR was revised and completed. The PHR is available at <http://gankanwa.jp/tools/pro/pdf/karte2.pdf> (in Japanese).

The PHR is an A4-sized nine-page paper-covered folder divided into the following sections: patient's personal profile, patient's medical history, list of health-care institutions where the patient has received treatment, contact numbers in an emergency, the name of the designated person to receive proxy consent, patient-reported diary, a pocket to hold important papers, emergency instructions for the patient and family, and preferences for end-of-life care.

The PHR has two palliative care-specific features. Firstly, it contains a section on emergency instructions from medical staff to patients and families (e.g. when the patient has pain, he/she will do ...) to relieve concerns of patients and families of patients receiving palliative care. Secondly, it contains end-of-life care-related questions: patient preferences for informed consent, place of death, and a do-not-resuscitate (DNR) order.

Dissemination of the PHR

The PHR was firstly introduced to medical professionals at outpatient chemotherapy departments with a half-hour lecture of how to use it. Then, they were encouraged to use the PHR in the local area with their patients. The reason for selecting an outpatient chemotherapy setting as the study setting was that: (1) the patients have marked palliative care needs; (2) they often see multiple medical institutions (hospital outpatient, family physician, visiting nurse, palliative care specialist); and (3) they are likely to be very tolerant of this novel intervention. The instruction focused on the following: (1) sharing information is important to lessen the fragmentation of care; and (2) the managing of information by patients is useful to promote patient–staff communication, potentially leading to increased self-efficacy.

Interviews

The interview was semi-structured, audio-taped, and approximately 30–45 minutes long. All participants received the interview once at the hospital, and the interviewer was either a social worker (KK) or research nurse. The interview guide contained questions about the patient-perceived usefulness and practical obstacles of using the PHR in addition to the overall experience (e.g. How was the PHR useful for you? What was the practical barrier of the PHR for you? Did you answer the questions about end of life, and how did you feel?). The sample size was justified by recruiting participants until data saturation occurred.

Analysis

Content analysis was conducted, because the primary aim of this study was to collect and categorize the patients' experiences concerning the patient-perceived usefulness

and practical obstacles to using the PHR. Records of the interviews were transcribed and anonymized. Firstly, two researchers independently identified terms that described the patients' experience regarding the use of the PHR, and then coded them to generate categories and themes from the perspective of similarities and differences. Discrepancy was resolved through discussions among the researchers, under the supervision of an experienced palliative care specialist (TM) and a certified community care nurse (AY). Secondly, two researchers (different from the above) independently determined whether each participant made remarks that belonged to any of the categories and, again, discrepancy was resolved through discussions. Finally, the generated categories were pooled into more abstract supra-categories according to the similarities and theoretical explanations based on the full agreement of the authors. Due to limited space, we report the sub-categories with numbers and some example quotations for several categories.

Results

During the study period, a total of 52 patients were recruited, one patient refused to participate, and one patient stopped using the PHR due to deterioration of their general condition. We thus finally obtained 50 participants: 29 were from Yamagata and 21 were from Shizuoka. The mean age was 66 years (SD = 12), and 70% ($n = 35$) were male. The primary tumor sites were the prostate ($n = 19$), stomach ($n = 11$), breast ($n = 8$), colon ($n = 3$), pancreas ($n = 3$), kidney or bladder ($n = 2$), lung ($n = 1$), esophagus ($n = 1$), bile duct ($n = 1$), and unknown ($n = 1$).

From 50 interviews, we obtained 190 meaningful units, and a total of 26 sub-categories and 11 categories with two themes emerged. Themes included: (1) the patient-perceived usefulness of the PHR and (2) the patient-perceived practical obstacles to using the PHR.

Patient-perceived usefulness of the PHR

The content analysis identified five benefits of using the PHR: (1) increase in patient–staff communication; (2) increase in patient–family communication; (3) increase in patient–patient communication; (4) increase in understanding of medical conditions and treatments; and (5) facilitating end-of-life care discussion.

(1) Increase in patient–staff communication. The PHR was used as a tool to facilitate communication between patients and medical professionals. Some patients indicated that writing in their PHR made it easier to communicate compared to directly speaking to physicians ($n = 4$). The PHR was especially welcomed when the patients needed to discuss complicated or personal topics. Some patients stated that they could explain their conditions more accurately or express their wishes more easily ($n = 10$), so that relationships between patients

and staff were more 'frank' ($n = 4$). They referred to their experience that physicians and nurses could understand what they felt by reading the PHR and offer appropriate treatments, and that they were relieved to know that staff understood their conditions ($n = 5$).

I note my level of pain in it [PHR] and show it (to staff). It's good and easy to report my pain by writing on paper. (Patient 4: Male, 70, pancreas)

(2) Increase in patient–family communication. The PHR was used as a tool to help patients communicate with their family. Patients could share their records with their family ($n = 7$), so that their family could understand the patient's medical conditions more easily. Patients could also use the PHR to convey their decisions or feelings about their disease to family members ($n = 3$).

I have my family, and I think it's good to show this [PHR] to young people in my family. I can describe my condition and ask for their cooperation, or have a talk. (Patient 2: Female, 68, colon)

(3) Increase in patient–patient communication. The PHR was used as a tool to help patients communicate with other patients. The PHR made patients feel 'connected with other patients' ($n = 3$), and opened a line of patient–patient communication ($n = 3$). They knew that a person who had the same-design PHR was a cancer patient, so they felt connected and started to communicate with each other.

The woman sitting next to me said, 'Oh you have the same one [PHR] as me', and I said, 'Today, many people have the same one', and we started talking. We knew this is for cancer patients, but we didn't talk about the disease at first. We talked about hobbies, field work, and gardening. Well, I realize some people want to hide their disease, but, maybe, we both wanted someone to talk to. I felt a connection with her and she seems like a friend. In this sense, the PHR creates a connection with someone who I don't know at all, someone I can talk to. (Patient 16: Female, 66, breast)

(4) Increase in understanding of medical conditions and treatments. Many patients reported that the PHR helped them to understand their medical conditions and treatment. Patients could better understand the current state of their disease ($n = 16$) and the treatment they were receiving ($n = 17$). Some patients referred to their experience that looking back on the PHR gave them an opportunity to observe themselves, and they became more active in participating in their own treatment ($n = 5$).

(5) Facilitating end-of-life care discussion. The PHR was used as a tool to help patients think about end-of-life care. Some patients stated that they realized the importance of declaring their preference for informed consent, place of death, and DNR order, when they read the questions ($n = 5$); they could organize their feelings by writing notes in the PHR ($n = 4$).

Some patients also wanted someone to know their future decisions ($n = 5$); they wanted to leave messages to their family or clinical staff so they could understand their ideas in case something happened to them.

I leave messages for my family (in the PHR). My family may think I want to stay at home, but our children have their own families so we [my husband and I] don't want to bother them. We write that if our children don't have enough money, we want not to stay at home. We can organize our ideas through writing. (Patient 26: Female, 73, breast)

In my case, I write it myself. My husband knows about my disease very well, and my kids also know, but I don't tell them my (wishes) in certain cases. I'm not willing to say some things, but, in case something happens to me, I think this [PHR] is useful to express my wishes. (Patient 28: Female, 73, stomach)

Patient-perceived practical obstacles to using the PHR

Content analysis identified six patient-perceived obstacles: (1) the lack of adequate instruction about the role of the PHR; (2) undervaluing the role of the PHR and sharing information by medical professionals; (3) patients' unwillingness to participate in decision making; (4) concerns about privacy; (5) burdensome nature of self-reporting; and (6) patients' preference for their own ways of recording.

(1) *The lack of adequate instruction about the role of the PHR.* Patients often did not understand the role of the PHR properly ($n = 13$), and they stated that they were not sure why they should use the PHR even if they received instructions several times.

(2) *Undervaluing the role of the PHR and sharing information by medical professionals.* Many patients referred to their experience that some medical professionals did not understand the value of using the PHR to share information with staff in other facilities ($n = 12$). They experienced that not all medical professionals participating in their treatments responded adequately when the patients showed the PHR, so patients could not recognize its value.

I take notes, but my doctor doesn't read them. I file papers by myself. If he reads my writing, and checks my pain and medicine, or sees me at any time, then I think it would have been encouraged. (Patient 11: Female, 44, breast)

(3) *Patients' unwillingness to participate in decision making.* Many patients did not actually want to be involved in decision making: they stated that they wanted to 'leave the decisions to their doctor' ($n = 25$). In addition, some patients did not want to think about the future ($n = 7$), and they reported that it was too early to think about end-of-life-related questions.

There are many treatments, chemotherapy, and so on, but I don't think about my disease deeply, often because it will change my

life. There is a variety of treatments, radiation, and other things, but I leave it to my doctor. (Patient 39: Male, 70, prostate)

When I have this [PHR], I don't feel anything. But, when I read it, I am shocked. The questions (about advance directives) made me feel like, 'Well, do I need to answer this now?' Well, does this apply to me? I think these are important at the end, but for me now? I thought, 'I have some more time left.' So, I didn't answer. (Patient 22: Female; 46, stomach)

(4) *Concerns about privacy.* Some patients did not use the PHR because of privacy issues. They did not want anyone to know that they have cancer, so they wanted to avoid being seen using the PHR ($n = 5$). In addition, some patients did not want to share their 'personal' information with others ($n = 10$), and hesitated to show their notes in the PHR to someone because they wrote their 'honest feelings'. Some patients referred to the risk of losing private information ($n = 2$).

(5) *Burdensome nature of self-reporting.* Some patients simply stated that they did not like taking notes due to viewing it as burdensome or unnecessary ($n = 15$), especially when their conditions were stable. These patients sometimes stopped using the PHR because they had 'nothing special' to write in it. In addition, a patient maintained that he had no energy left to record notes in the PHR, and some patients did not like carrying the PHR because it was too big ($n = 4$).

It's bothersome for me every week now. I have used the same medicine every week. My symptoms don't change a lot, so the same situation continues. It's bothersome to take the same notes every time. If anything changes, it's fine, but there are only little changes, so it's a bit bothersome. (Patient 27: Female, 45, breast)

(6) *Patients' preference for their own ways of recording.* Some patients have a preferred way of recording the course of their treatment. They already have their own notebooks ($n = 4$), or simply prefer talking ($n = 1$).

Discussion

This is the first study to investigate the patient-perceived usefulness and practical obstacles to using the PHR in an Asian population, and also one of the few studies about the PHR specially designed for palliative care settings. The findings are generally consistent with those from Western countries, but several unique aspects emerged.

Firstly, we found that the PHR was regarded as useful in facilitating communication and understanding at various levels; some patients using the PHR tended to talk to their physicians more easily and ask them more questions. This is consistent with previous studies which showed that if physicians or nurses accessed the summary records of their patients, they took a significantly longer time in consulting with their patients;¹⁶ reading written information or taking notes clarifies what patients have heard from physicians, thereby decreasing their fear and uncertainty,^{17,18} and the use

of the PHR improves communication between patients and health-care professionals.¹⁹ These findings indicate that the use of the PHR could overcome the difficulty of information sharing and facilitate patient–doctor communication for at least some patients.

Of interest is that some patients in this study reported that the PHR facilitated not only patient–doctor communication, but also patient–patient communication. This is a novel finding, and suggests using the PHR could improve the social network of patients through the visible message of ‘comrades’ for some patients.

Secondly, some practical obstacles against disseminating the PHR identified in this study are of importance. In this study, obstacles to disseminating the PHR are related to both medical professionals (inadequate instruction about the role of the PHR; undervaluing the role of the PHR and sharing information by medical professionals in the region), and patients (unwillingness to participate in decision making; concerns about privacy; burdensome nature of self-reporting; own ways of recording). These findings are very consistent with the results from Western countries that health-care professionals often do not acknowledge or welcome the use of the PHR;^{16,19,20} patients felt discouraged by professionals’ disinterest in the PHR,⁷ and wide-spread acknowledgement of the PHR by health-care professionals at a regional level is of great importance to disseminate it.¹⁹ Regarding patient barriers, previous studies similarly indicated the same-designed PHR could be a stigma for cancer patients;²¹ patients already had duplicated other notebooks or evaluated the PHR as very burdensome.⁷ That is, these findings confirm that implementation of the PHR throughout the region would require repeated instruction to patients at various levels throughout the region, maximum efforts to improve acknowledgement of the PHR of all medical professionals throughout the region, and careful consideration about patient privacy. Furthermore, some patients do not want to use the PHR because of unwillingness to participate in decision making and the burdensome nature of self-reporting and, thus, the wide-spread use of the PHR would require substantial long-term efforts anyway.

The third finding of this study is related to the role of the PHR specially designed for palliative care patients in facilitating end-of-life discussions. This PHR contains questions about a patient’s preferences regarding informed consent, place of death, and DNR order, as an important topic to be addressed in this setting.¹¹ In this study, questions about end-of-life care preferences in the PHR helped some patients to think about their future and preferred end-of-life care, and many patients appreciated the importance. On the other hand, some patients reported that they were shocked when they received the PHR containing end-of-life questions, because they felt it was ‘too early’ to think about these questions. Although in-advance discussion is associated with a better psychological status of patients²² and the PHR can be a starting point of in-advance discussion about end-of-life care,

individualized assessment about the timing of handing the PHR and careful follow-up are required.

In addition, the findings of this study provided some important insights to disseminate the PHR for Asian populations. In this study, the majority of patients interviewed stated that they did not use the PHR, because they were unwilling to participate in decision making and wanted to leave important decision to their physicians. This is a similar finding to a UK observation that some patients regarded the PHR as an ‘an unwelcome reminder’ and felt more anxious.⁷ There is a general tendency whereby Japanese patients are not willing to hear bad news or want to leave decision making to physicians.^{23,24} These findings therefore mean that implementation of the PHR may be more difficult in some Asian populations, where sharing the decision-making process may not be entirely welcomed by all patients.

Another aspect of interest is that Japan already has a well-established system for disseminating a medical handbook for *Maternal and Child Health*. This handbook is a type of PHR for pregnant women, introduced in 1942. Now, the usage rate is nearly 100%,²⁵ and all pregnant women are asked to bring this handbook to their physicians or nurses before seeing them. This phenomenon suggests that, in Japanese culture, patients could be ready to accept the PHR if they receive adequate instruction and all medical professionals involved in patient care acknowledge the PHR. Nonetheless, as this study revealed the implementation difficulties in the previous studies, organizational changes in the health-care system so that all medical professionals involved in patient care appropriately acknowledge the role of the PHR is a key feature for its successful implementation.

This study has several limitations. Firstly, as this study is based on the content analysis of interviews of 50 cancer patients, generalizations should be carefully discussed. Secondly, the potential influence of patient gender and cancer sites was not explored due to the small number of participants. Thirdly, as the participants used the PHR for only three months, the effect of the long-term usage of the PHR is unknown. Finally, this study only focused on the patient-perceived usefulness and obstacles to using the PHR, and future studies with other primary end-points will be needed.

In conclusion, the PHR can be helpful in facilitating communication, understanding medical conditions and treatments, and facilitating end-of-life discussion; however, for wide-spread implementation, resolving the obstacles related to both patients and health-care professionals is required.

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Conflict of interest

None declared.

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Preferred place of care and place of death of the general public and cancer patients in Japan

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Abstract Dying at a favorite place is one of the important determinants for terminally ill cancer patients. The primary aim was to clarify (1) differences in preferred place of care and place of death among the general public across four areas across Japan and (2) preferred place of care and place of death among community-representative cancer patients. A cross-sectional mail survey was conducted on 8,000 randomly selected general population. We examined preferred place of care and place of death using two vignettes and obtained a total of 3,984 (50%) responses. For the pain scenario, approximately 50% of the general public throughout four areas chose home as their preferred place of care; and for the dependent-without-pain scenario, about 40% chose home as preferred place of care. In cancer patients, for both scenarios, approximately 40% chose home as the preferred place of care, and they were significantly less

likely to choose home. The most preferred combination of place of care and place of death was home hospice for both groups. Although there were statistically significant differences in preferred place of care and place of death among the four regions, the absolute difference was less than 8%. Independent determinants of choosing home as place of care included concern about family burden and being unable to adequately respond to sudden changes out of working hours. In conclusion, establishing more accessible home and hospice service is strongly required through arranging regional resources to reduce family burden, alleviating patient-perceived burdens, and improving 24-h support at home.

Keywords Preference · End-of-life · Home · Palliative care · Hospice

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Introduction

Dying at a preferred place is one of the most important determinants for terminally ill cancer patients in Japan and across the world [1, 2]. Understanding the preferred place of care and place of death is therefore the first step in ensuring adequate resources for patients [3–5], and multiple preference surveys in UK, USA, and other countries have been conducted to clarify the preferred place of care and place of death [6–8]. In these surveys, the general public and cancer patients generally chose home as the preferred place of care and place of death [6].

In Japan, a series of national surveys was conducted by the Ministry of Health, Labor, and Welfare in 2008 to reveal the preferred place of care and place of death [8]. Home was the preferred place of care in general, with 29% of respondents reporting that they wanted to receive care at home and be admitted to a hospice if necessary, and 23% preferring to receive care at home and be admitted to hospital if necessary. Another 11% chose home until death, while a considerable number of respondents reported that they want to be admitted to hospice earlier and stay until death (18%) or be admitted to hospital earlier and stay until death (10%). In summary, 63% of the general public chooses home as the place of care, and as place of death if physical and social conditions were acceptable if presented with terminal cancer. At the same time, this survey also demonstrated that less than 10% believed home death is achievable; the reasons listed included burden to family (80%), concerns about sudden changes in physical conditions (54%), cost (33%), unavailability of physicians visiting home (32%), unavailability of emergency hospital beds (32%), unavailability of nurses visiting home (19%), inadequate home environment (16%), lack of round-the-clock services (15%), and lack of family caregivers (15%). The absolute figures of each response did not change compared with the same surveys in 1998.

The findings provide useful insights about the preferred place of care and place of death of Japanese cancer patients, but existing studies have major limitations. First, there have been no surveys specifically targeted at cancer patients; thus, it is difficult to apply the results from the general population directly to cancer patients. Second, considerable differences may exist among various areas in Japan in medical resources, social resources, the delivery system of palliative care, and cultural backgrounds, rendering the findings from a national representative sample may not be always applicable to specific regions such as urban vs. rural areas [9, 10]. We thus believe that comparing the preferred place of care and place of death among different areas in Japan and clarifying the preferred place of care and place of death in cancer patients specifically are both of value.

In addition, although identifying predictors of preference about place of care and place of death is helpful for understanding how patients decide where they live at the end of their life, only a few studies have examined such determinants [6, 11–14]. In particular, it would be important to clarify the impact of concerns about home care on the preference of place of care and place of death because large surveys in Japan revealed that excessive apprehension significantly contributed to late referrals to specialized palliative care services [15], and few empirical studies have specifically addressed this topic [6, 11–14].

The primary aim of this study was to clarify (1) the differences in preferred place of care and place of death of the general public among different areas in Japan and (2) preferred place of care and place of death of cancer patients. Additional aims include clarifying concerns and values about home care of the general public and cancer patients and examining the effects of such concerns on preferred place of care and place of death.

Subjects and methods

We conducted a cross-sectional mail survey of the general public as part of a larger regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. This survey was performed at the initial phase of the OPTIM study, the details of which are reported elsewhere [16]. The institutional review board for the OPTIM study approved the ethical and scientific validity.

Study regions

This survey was conducted in four regions where the OPTIM study was employed. These areas were selected based on different palliative care system development across Japan: Tsuruoka (170,000 people, Yamagata prefecture), Kashiwa (670,000 people, Chiba prefecture), Hamamatsu (820,000 people, Shizuoka prefecture), and Nagasaki (450,000 people, Nagasaki prefecture). The systems in Kashiwa, Hamamatsu, and Nagasaki provide palliative care chiefly led by a national cancer center, a general hospital, and a general practitioner association, respectively, while the system of palliative care in Tsuruoka is not organized.

Although we had acknowledged that the study areas had been selected for the regional intervention study not for region-comparison studies about preferred place of death, we had determined that the use of this sample for this study was reasonable, because these four areas are typical as a representative from geographically and culturally different regions throughout Japan: Tsuruoka is typical rural area in North Japan, Kashiwa is a typical city around the capital region, Hamamatsu and Nagasaki are typical cities in

Central and West Japan, respectively. In addition, the most urban cities such as Tokyo and Osaka had been surveyed as one of the sample areas in the 2008 survey by the Ministry of Health, Labor, and Welfare [8].

Study subjects

For this survey, we initially identified 8,000 subjects in the general population by a stratified two-stage random sampling method of residents of the four areas. We selected 50 census tracts for each area and then selected 25 individuals, aged 40–79 years, within each census tract, thus identifying 2,000 individuals for each area. The census tracts usually cover 200 families to conduct national census surveys in Japan. We randomly sampled 50 census tracts in each prefecture and then sampled 25 individuals in each census tract according to the national census method in Japan. We mailed questionnaires to potential participants in June 2007 and sent a reminder postcard 2 weeks later.

Questionnaire

To enable comparisons with previous findings using a national sample, we decided to use the same questionnaire used by the Ministry of Health, Labor, and Welfare [8]. This questionnaire surveyed the respondents about preferred place of care and place of death using two brief scenarios. The first scenario described a terminally ill cancer patient with pain and given a prognosis of 6 months or less (the pain scenario), while the other scenario described a terminally ill cancer patient without pain, but dependent on others in their daily activities (without pain and dependent scenario). Choices with simplified combination definitions were: (1) home until death (home–home); (2) receive care at home, and admitted to hospice if necessary (home–hospice); (3) receive care at home, and admitted to hospital if necessary (home–hospital); (4) admitted to hospice earlier and stay until death (hospice–hospice); (5) admitted to nursing home and stay until death (nursing home–nursing home); (6)

admitted to hospital and stay until death (hospital–hospital); or (7) receive aggressive treatment at cancer center (cancer center–cancer center) [17]. Hospice meant in this study was palliative care units or inpatient hospice, and home-based hospice was regarded as home.

To clarify concerns about home care, we asked the respondents to rate the levels of agreement on the five point Likert-type scale from 1 (disagree) to 5 (strongly agree) for five items: concern of being unable to achieve adequate pain relief, unable to adequately respond to sudden changes in out-of-hours care, family physician visiting home is unavailable, family burden is heavy, and home care is too expensive. In addition, to explore respondent values about home care, we also asked the respondents to select one of three choices that best suited their chosen scale value to describe living and dying at home: (1) “dying at home is the best, if family respite and expert advice are available”; (2) “dying at home is undesirable despite any health care systems, due to perceived heavy burden to family”; and (3) “unsure”.

To establish the respondent background, we asked the respondents to report age, gender, length of stay in that region, and presence or absence of family members with cancer. To identify cancer patients, we asked the respondents to report whether they suffered from any of a list of 15 specific diseases including cancer.

Statistical analyses

Data distributions were calculated separately for the general public from each region and for cancer patients. Comparisons were performed using the chi-square test.

To explore the predictors of choosing home as preferred place of care, we compared the subject backgrounds and concern items about home care between those who chose home as place of care (i.e., home–home, home–hospice, home–hospital) and those who chose a place other than home (i.e., hospice–hospice, nursing home–nursing home, hospital–hospital, cancer center–cancer center) for each scenario. We then performed a multivariate logistic regression

Table 1 Subject backgrounds

| | General public | | | | Cancer patients |
|--|----------------------|-----------------------|----------------------|----------------------|----------------------|
| | Tsuruoka | Kashiwa | Hamamatsu | Nagasaki | |
| <i>N</i> | 994 | 1106 | 947 | 937 | 189 |
| Gender (male) | 44% (<i>n</i> =442) | 46% (<i>n</i> =507) | 46% (<i>n</i> =439) | 39% (<i>n</i> =370) | 52% (<i>n</i> =99) |
| Age (year) | 61±11 | 59±10 | 59±10 | 60±11 | 64±9.6 |
| Length of stay in the region (>5 years) | 90% (<i>n</i> =896) | 95% (<i>n</i> =1054) | 93% (<i>n</i> =876) | 91% (<i>n</i> =855) | 99% (<i>n</i> =187) |
| Experience that one of the family members had cancer | 54% (<i>n</i> =536) | 54% (<i>n</i> =592) | 49% (<i>n</i> =465) | 58% (<i>n</i> =540) | 60% (<i>n</i> =113) |

Total of some items do not add to 100% due to missing data

analysis of the dependent variable of choosing home as preferred place of care using all variables identified by univariate analyses as statistically significant ($P < 0.05$).

Results

Of the 8,000 questionnaires sent out to the general population in the four regions, we obtained a total of 3,984 (50%) responses, distributed as follows: 994 (50%, Tsuruoka), 1,106 (55%, Kashiwa), 947 (47%, Hamamatsu), and 937 (47%, Nagasaki). Of these, 189 responses were classified as “cancer patients”. Table 1 summarizes the demographic variables of all the respondents.

There were statistically significant differences in preferred place of care and place of death for the general public across regions for both scenarios ($P < 0.001$). In general, however, these differences were small (Table 2), with the absolute difference in percentages for each item among the regions less than 8%.

For the with-pain scenario, approximately 30% of all respondents chose home–hospice, while about half chose home as preferred place of care. For the dependent-without-pain scenario, approximately 20% of the respondents across regions chose one of home–hospice, hospice–hospice, or nursing home–nursing home, while approximately 40% chose home as preferred place of care.

For both scenarios, approximately 40% of the cancer patients chose home as preferred place of care, and 20–25% chose home–hospice as the preferred place of care–place of death (Table 3). There was a statistically significant difference in preferred place of care and place of death between cancer patients and the general public ($P < 0.001$ for both scenarios): lower percentages of home–home choice (e.g., 4.2% of cancer patients vs. 9.7% of general public for the with-pain scenario, and higher percentages of hospital–hospital choice (e.g., 20% of cancer patients vs. 8.0% of general public for the with-pain scenario).

Regarding concerns about home care, approximately 80% of both the general public and cancer patients agreed or strongly agreed that family burden is heavy, and approximately 70% agreed or strongly agreed that they were unable to adequately respond to sudden changes in out-of-hours care (Table 4). In addition, more than half of respondents agreed or strongly agreed that family physician visiting their home was unavailable and home care was too expensive, while approximately 40% agreed or strongly agreed that they were unable to achieve adequate pain relief at home.

In addition, the scale values ascribed to home care were split among the responses. Approximately 40% of respondents believed that dying at home is the best option if family respite and expert advice is available, while a similar number believed that dying at home is undesirable despite any

Table 2 Preferred place of care and place of death among the general public

| Place of care | Place of death | With pain | | | | Dependent without pain | | | |
|----------------|------------------------|---------------------|---------------------|----------------------|---------------------|------------------------|---------------------|----------------------|---------------------|
| | | Tsuruoka (n=994) | Kashiwa (n=1106) | Hamamatsu (n=947) | Nagasaki (n=937) | Tsuruoka (n=994) | Kashiwa (n=1106) | Hamamatsu (n=947) | Nagasaki (n=937) |
| Home | Home | 11% (n=110) | 11% (n=118) | 9.3% (n=88) | 7.4% (n=69) | 6.6% (n=66) | 5.2% (n=58) | 5.4% (n=51) | 4.7% (n=44) |
| | Hospice, if necessary | 25% (n=244) | 31% (n=346) | 30% (n=286) | 29% (n=273) | 19% (n=186) | 23% (n=249) | 22% (n=212) | 22% (n=202) |
| Hospice | Hospital, if necessary | 13% (n=128) | 8.7% (n=96) | 12% (n=109) | 11% (n=102) | 11% (n=112) | 7.9% (n=87) | 10% (n=95) | 9.4% (n=88) |
| | Hospice | 12% (n=116) | 18% (n=200) | 17% (n=160) | 17% (n=162) | 17% (n=168) | 24% (n=261) | 24% (n=226) | 23% (n=218) |
| Hospital | Hospital | 12% (n=119) | 5.3% (n=59) | 7.5% (n=71) | 7.6% (n=71) | 13% (n=132) | 6.9% (n=76) | 7.5% (n=71) | 9.0% (n=84) |
| | Nursing home | 14% (n=141) | 11% (n=122) | 10% (n=95) | 10% (n=95) | 23% (n=224) | 21% (n=235) | 17% (n=165) | 17% (n=159) |
| Cancer centers | Nursing home | 9.5% (n=94) | 11% (n=122) | 6.8% (n=64) | 9.2% (n=86) | 6.7% (n=67) | 9.0% (n=100) | 5.7% (n=54) | 6.3% (n=59) |
| | Cancer centers | | | | | | | | |

Total of some items do not add to 100% due to missing data

Table 3 Comparison of preferred place of care and place of death between cancer patients ($n=188$) and the general public

| Place of care | Place of death | With pain | | Dependent without pain | |
|----------------|------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| | | Cancer patients ($n=189$) | General public ($n=3984$) | Cancer patients ($n=189$) | General public ($n=3984$) |
| Home | Home | 4.2% ($n=8$) | 9.7% ($n=385$) | 2.1% ($n=4$) | 5.5% ($n=219$) |
| | Hospice, if necessary | 25% ($n=48$) | 29% ($n=1149$) | 20% ($n=38$) | 21% ($n=849$) |
| | Hospital, if necessary | 12% ($n=23$) | 11% ($n=435$) | 14% ($n=26$) | 9.6% ($n=382$) |
| Hospice | Hospice | 13% ($n=24$) | 16% ($n=638$) | 21% ($n=39$) | 22% ($n=873$) |
| Hospital | Hospital | 20% ($n=37$) | 8.0% ($n=320$) | 16% ($n=31$) | 9.1% ($n=363$) |
| Nursing home | Nursing home | 12% ($n=22$) | 11% ($n=453$) | 15% ($n=28$) | 20% ($n=783$) |
| Cancer centers | Cancer centers | 7.9% ($n=15$) | 9.2% ($n=366$) | 6.3% ($n=12$) | 7.0% ($n=280$) |

Total of some items do not add to 100% due to missing data

health care systems due to the perceived heavy burden to family (Table 4).

The respondents who chose home as place of care in with-pain scenario were significantly more likely to be younger, and significantly less likely to have concern of being unable to achieve pain relief, of being unable to adequately respond to sudden changes in out-of-hours, that family burden is heavy, and that home care is too expensive (Table 5). Independent determinants of choosing home as place of care were: age, concern of being unable to adequately respond to sudden changes in out-of-hours, and concern family burden is heavy.

The respondents who chose home as the place of care when presented with the dependent-without-pain scenario were significantly more likely to be male and significantly less likely to be concerned about being unable to adequately respond to sudden changes in out-of-hours care and a heavy family burden (Table 5). Independent determinants of choosing home as place of care with the dependent-without-pain scenario were male, concern of being unable

to adequately respond to sudden changes in out-of-hours care, and concern about family burden.

Discussion

This is the first survey, to our knowledge, that compares preferred place of care and place of death of the general public among multiple areas in Japan and that addresses preferred place of care and place of death in cancer patients. One of the most important findings was of minimum difference in preferred place of care and place of death of the general public among all respondents and across all regions surveyed in this study. Indeed, the data in this study were similar to those from the national sample surveyed by the Ministry of Health, Labor, and Welfare [8]. One difference was our finding that regional demographic characteristics such as availability of beds, hospital provision, and differences between rural and urban areas are significant determinants of actual place of death [9], although this is not

Table 4 Concerns and values about home care of general public and cancer patients

| | Total ($n=3,984$) | General public | | | | Cancer patients ($n=189$) |
|---|------------------------|-------------------------|--------------------------|--------------------------|-------------------------|-----------------------------------|
| | | Tsuruoka ($n=994$) | Kashiwa ($n=1,106$) | Hamamatsu ($n=947$) | Nagasaki ($n=937$) | |
| Concerns | | | | | | |
| Unable to achieve adequate pain relief | 38% ($n=1,502$) | 40% ($n=402$) | 37% ($n=413$) | 39% ($n=373$) | 34% ($n=314$) | 40% ($n=68$) |
| Unable to adequately respond to sudden changes out-of-hours | 69% ($n=2,761$) | 67% ($n=665$) | 73% ($n=804$) | 72% ($n=684$) | 65% ($n=608$) | 68% ($n=129$) |
| Family physician visiting home is unavailable | 55% ($n=2,201$) | 49% ($n=485$) | 66% ($n=727$) | 57% ($n=539$) | 48% ($n=450$) | 57% ($n=107$) |
| Family burden is heavy | 81% ($n=3,241$) | 80% ($n=791$) | 83% ($n=916$) | 84% ($n=793$) | 79% ($n=741$) | 79% ($n=149$) |
| Too expensive | 52% ($n=2,058$) | 50% ($n=495$) | 51% ($n=563$) | 51% ($n=487$) | 55% ($n=513$) | 52% ($n=99$) |
| Values | | | | | | |
| Dying at home is the best, if family respite and expert advice available | 39% ($n=1,535$) | 47% ($n=391$) | 46% ($n=458$) | 45% ($n=368$) | 41% ($n=318$) | 37% ($n=63$) |
| Dying at home is undesirable despite any health care systems, due to perceived heavy burden to family | 31% ($n=1,227$) | 36% ($n=300$) | 34% ($n=331$) | 35% ($n=290$) | 39% ($n=306$) | 46% ($n=78$) |
| Unsure | 16% ($n=657$) | 17% ($n=140$) | 20% ($n=198$) | 20% ($n=165$) | 20% ($n=154$) | 17% ($n=28$) |

Data are percentages of the responses of “agree” or “strongly agree” for each item