



Integrating home palliative care in oncology: a qualitative study to identify barriers and facilitators

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Abstract

Purpose Access to and close links with home palliative care services are essential to ensure seamless transitions between care settings in anticancer treatment. However, the timing of referrals to home palliative care services is often delayed. We explored barriers to and facilitators of improving the integration of home palliative care and medical oncology experienced by healthcare professionals in Japan.

Methods This qualitative study involved semi-structured focus groups and individual interviews conducted via a web conferencing system. Participants were 27 healthcare professionals, including oncologists, palliative care physicians, home palliative care physicians, nurses from both cancer hospitals and home visit nursing agencies, and social workers from cancer hospitals.

Results Barriers and facilitators were grouped into three themes: (1) perspectives and ideas on integrating oncology and home palliative care; (2) barriers; and (3) facilitators. Barriers included seven sub-themes: lack of referral criteria for home palliative care services; financial elements related to home palliative care services; patients' lack of understanding of the illness trajectory; collusion in doctor-patient communication about imminent death; frequent visits to cancer hospitals; variations in home palliative care services; and problems in providing treatment and care at home. Facilitators included two sub-themes: relationships between oncologists and home palliative care physicians, and cancer hospital staff experience/knowledge of home palliative care.

Conclusion This study identified barriers and facilitators to integrating home palliative care and oncology. Some barriers experienced by professionals were comparable with barriers to early integration of palliative care into oncology.

Keywords Neoplasms · Early palliative care · Palliative home care · Delivery of healthcare · Integrated · Medical oncology · Qualitative research

Introduction

More than half of patients with advanced cancer prefer to die at home [1], but the wish for a home death remains unfulfilled for many patients [2]. Home palliative care increases the chance of dying at home and reduces the symptom burden for patients with cancer [3, 4]. As with early involvement of palliative care for patients with advanced cancer [5], early activation of integrated home-based palliative cancer care programs has been shown to have a positive effect on end-of-life care [6]. Early referral to home palliative care would also help to increase the number of patients with advanced cancer who could die at home [7, 8].

Previous studies demonstrated that the median period of referral to home palliative care for patients with cancer was less than 2 months before death [9, 10]. Many bereaved

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families regard the timing of referral to home palliative care as late [10]. These studies suggested that the timing of referrals to home palliative care is often delayed, and a strategy to improve late referrals is needed. A possible way to achieve this is integrating home palliative care and medical oncology. However, few studies have investigated barriers to the early integration of home palliative care in oncology [11, 12]. The present study aimed to identify barriers to and facilitators of improving the integration of home palliative care and oncology. The results will help to inform development of an integration model applicable to the outpatient setting.

The two main types of specialized palliative care services in Japan are inpatient hospices/palliative care units and hospital palliative care consultation teams [13]. Typically, inpatient hospices/palliative care units are part of general hospitals and provide end-of-life care for patients with advanced cancer. Almost all designated cancer hospitals have outpatient palliative care services. However, specialized palliative care services for outpatients remain insufficient. Specialized home palliative care services/hospice care services at home are undeveloped and the number of community palliative care teams remains small. Although the number of clinics with a home hospice function rapidly increased over the past decade, the home death rate of patients with cancer did not markedly increase. Home-based palliative care is provided by medical facilities (including clinics, specialized home care clinics, and home care divisions of hospitals) in collaboration with home-visiting nurses. Home palliative care physicians work in clinics, clinics with a home hospice function, or in the home care division of hospitals. Both medical insurance and long-term care insurance are applied to nurse visits and the fee for social workers. However, to be eligible for home palliative care services, patients must have difficulty in transportation to visit outpatient medical facilities. If patients with cancer cannot visit outpatient medical facilities independently, introduction of home palliative care services for patients undergoing chemotherapy is covered by medical insurance. Social workers mainly belong to the offices of home care providers, hospitals, or nursing homes.

Methods

Study design

This study used a qualitative design. Data were collected in semi-structured focus groups and individual interviews conducted via a web conferencing system. We chose qualitative methods as the most appropriate research design to explore the individual experiences of healthcare professionals without the limitations of preconceived ideas. Focus group interviews were used to gather professionals' perceptions of barriers to and facilitators of improving the integration of

oncology and home palliative care. Each focus group comprised participants from the same profession and the same healthcare setting. We felt that focus groups with similar backgrounds would prompt participants' understanding and reflect the healthcare setting context. Individual interviews were used to collect data from participants who could not attend a focus group interview for any reason. This study followed the criteria for reporting qualitative research set out in the Consolidated Criteria for Reporting Qualitative Research guidelines [14].

Sampling and recruitment Participants were purposefully selected for the individual and focus group interviews from among healthcare professionals (nurses, physicians, and social workers) working in services providing palliative care or medical oncology. The researchers individually contacted and sampled potential eligible participants via telephone or email. Participants for this study were drawn from four designated cancer hospitals, six clinics with home hospice functions, and four home visit nursing agencies in Aichi prefecture. Aichi prefecture is the fourth most populous prefecture in Japan and includes urban areas near Nagoya city and the surrounding rural areas.

Data collection

The focus groups and individual interviews were held between January and March 2021, and were scheduled after multidisciplinary team meetings. The focus groups and individual interviews were scheduled for 1 h and followed a semi-structured topic guide, which was produced by the researchers (Table 1). The topic guide comprised open-ended questions and a set of prompts for each question. An example question is as follows: "What are some barriers [facilitators] in your setting to improving the integration of oncology and home palliative care?" A previous systematic review reported that for the full benefits of palliative care to be realized, continuity by a multidisciplinary team is needed for at least 3–4 months [15]. Therefore, we interviewed healthcare professionals about introducing home palliative care services to patients undergoing cancer treatment with a prognosis of 3 months or longer. Three pilot interviews (including five participants) were conducted to test the interview guide. All interviews were led by two nurses with experience of qualitative research and home palliative care (AY and a research nurse from the Research Association for Community Health: not an author) using a web conferencing system. The interviewers also took field notes. No person was present during the interviews besides the participants and researchers. Written informed consent was obtained from all participants before the focus groups and individual interviews, including consent for audio-recording.

Table 1 Interview guide

Theme	Aim	Questions
1: Identifying known improvement strategies and experiences	To identify strategies that had been recently used to improve the integration of oncology and home palliative care	Tell me about the organization you are in Do you have some experiences with early integration of home palliative care? Can you give an example? How does the current organization differ from the organization in the past?
2: Identifying barriers and facilitators	To identify factors (barriers and facilitators) that influence strategies to improve the integration of oncology and home palliative care	What are barriers/facilitators in your setting to improving the integration of oncology and home palliative care? Can you tell me more about... Can you give an example?
	To identify barriers in the economic and political context that influence strategies to improve early integration of home palliative care	What are the barriers to improving the integration of oncology and home palliative care in the economic and political context?
	To identify barriers in education that influence strategies to improve early integration of home palliative care	What are the barriers to improved integration of oncology and home palliative care in the educational context?
	To identify barriers in regional palliative care system that influence strategies to improve early integration of home palliative care	What are the barriers to improved integration of oncology and home palliative care in the regional palliative care system?
3: Supplement	To identify important aspects in the early integration of oncology and home palliative care that had not yet been discussed	What aspects do you think are good? Is there anything else you would like to discuss?

Data analysis

All interviews were transcribed verbatim and checked against the audio recordings to ensure consistency. Thematic analysis [16, 17] was performed by two researchers. First, the researchers independently read the transcripts and coded the data based on categories of barriers and facilitators in integration of home palliative care and oncology. Preliminary codes were then chosen for blocks of text or words identified as meaning units. Next, the researchers grouped similar preliminary codes into preliminary sub-categories. Codes and associated text fragments were shared among the researchers in Japanese. Next, categories were formed using sub-categories related to the research questions (identification of barriers and facilitators to integrating home palliative care and medical oncology). Finally, we translated the data into English, and shared and confirmed the themes, sub-themes, and associated text fragments among the researchers in English. The interview sample was determined when thematic saturation was reached.

Ethical considerations

The Institutional Review Board and Ethics Committee of Nagoya City University Graduate School of Medical Science approved this study protocol (60–20-0138, December 10, 2020). All participants were provided with a detailed description of the purpose and methods of this study before attending the focus groups or individual interviews. We obtained written informed consent from all study participants via postal mail. Participants were provided feedback on the findings of this study.

Results

After 14 interviews (eight focus group and six individual interviews) involving 27 participants, no new themes arose and the research team judged that data saturation had been reached; therefore, no additional interviews were arranged. Twenty-seven health professionals (five oncologists, five palliative care physicians, five home physicians, nine nurses, and three social workers) attended the interviews. Participants' characteristics are presented in Table 2. All professionals who were approached agreed to participate. Three themes emerged from the data: (1) perspectives and ideas on integrating oncology and home palliative care, (2) barriers to referral to home palliative care, and (3) facilitators to introducing home palliative care services (Table 3).

Table 2 Participants' characteristics ($N=27$)

Gender	Male	14
	Female	13
Age, years	Median (range)	50 (36–66)
	Mean (SD)	48.9 (8.0)
Institution	Designated cancer hospital	16
	Clinic with home hospice function	7
	Home visit nursing agency	4
Profession	Oncologist	5
	Palliative care physician	5
	Home physician	5
	Nurse	9
	Social worker	3
Clinical experience, years	Median (range)	19 (1–40)
	Mean (SD)	20.7 (9.6)
Clinical experience in treating/caring cancer patients, years	Median (range)	16 (1–29)
	Mean (SD)	16.4 (7.4)
Clinical experience in treating/caring for patients with advanced cancer, patients/year	≤ 10	2
	11–49	6
	50–99	8
	≥ 100	11
Clinical experience in treating/caring terminally ill patients with cancer, patients/year	≤ 10	10
	11–49	8
	50–99	4
	≥ 100	5

SD standard deviation

Perspectives and ideas on integrating oncology and home palliative care

This theme encompassed participants' beliefs that explicit disclosure of the benefits or necessity of introducing early home palliative care was important. Although medical professionals generally have positive attitudes toward early introduction of home palliative care services, many participants commented that patients' perceptions of the benefit of introducing home palliative care were a key component of integrating home palliative care in oncology. Participants also reported that factors contributing to late referrals were associated with patients, families, physicians, and the healthcare system. It is necessary for healthcare professionals to develop an understanding of the home

care system and the ability to convey the benefits of home palliative care to patients in an easy-to-understand manner.

Barriers to referral to home palliative care

This theme included seven sub-themes: (1) lack of referral criteria for home palliative care services; (2) financial elements related to home palliative care services; (3) patients' lack of understanding of the illness trajectory; (4) collusion in doctor-patient communication about imminent death; (5) frequent visits to the cancer hospital; (6) variations in home palliative care services; (7) and problems in providing treatment and care at home.

Table 3 Themes and sub-themes with illustrative quotations

Theme/sub-theme	Quotations
Theme: Perspectives and ideas on integrating oncology and home palliative care	<p>“I was asked about the merits of home palliative care services, but I have few successful experiences, so I can’t talk about the merits of introducing it in detail.” (oncologist, designated cancer hospital)</p> <p>“If home palliative care is increasingly integrated for patients undergoing anticancer treatment, it will be possible to convey the specific benefits for cancer patients and the characteristics of patients who should be introduced to home palliative care. I think I can, I think we can explain the benefits concretely if the experience of oncologists and hospital nurses increases.” (oncologist, designated cancer hospital)</p>
Theme: Barriers to referral to home palliative care	
Sub-themes	
1. Lack of referral criteria for home palliative care services	<p>“In general, eligibility criteria for home care services are patients who cannot visit outpatient medical facilities. If cancer patients received chemotherapy in [an] outpatient medical oncology setting, we [have] concern about introducing home palliative care services due to the eligibility.” (home physician, clinic with home hospice function)</p> <p>“...if cancer patients cannot visit outpatient medical facilities independently, introduction of home palliative care services for cancer patients undergoing chemotherapy would be applicable. The oncologists’ recognition of [whether] the [patient was] eligible or not for home care service could be a facilitator or barrier to integration of oncology and home palliative care.” (home physician, clinic with home hospice function)</p>
2. Financial elements related to home palliative care services	<p>“...patients 70 years old or younger and young adult patients often refuse [services] with [a] fee because they do not want to receive palliative care at home if it costs a lot of money. Not a few patients want to request home palliative care if they feel sick...” (social worker, designated cancer hospital)</p> <p>“Especially in young patients, insurance is mostly 30%, so it’s still expensive. Anti-cancer drugs are also very expensive, so I wonder if visiting them is quite difficult.” (nurse, home visit nursing agency)</p> <p>“...it is not easy for cancer patients to use long-term care insurance; we experience that long-term care insurance and long-term care support cannot keep up when the physical condition of cancer patients suddenly deteriorates.” (home physician, clinic with home hospice function)</p> <p>“Due to problems with the medical system for young patients, long-term care insurance cannot be used for patients with cancer if patients are under 40 years old.” (home physician, clinic with home hospice function)</p>
3. Patients’ lack of understanding of the illness trajectory	<p>“In advanced cancer patients, trajectory of performance status decline to the end-of-life stage in the final few months of life. Patients’ awareness of illness and prognosis is generally poor...” (oncologist, designated cancer hospital)</p> <p>“Home palliative care is more likely to be accepted by patients who can imagine that they will become immobile in the future, or who are explaining possible changes in the future.” (home physician, clinic with home hospice function)</p>
4. Collusion in doctor-patient communication about imminent death	<p>“The doctors in cancer hospital do not want to pronounce bad news and the patients do not want to hear it. After all, the [end-of-life] discussions are postponed, and patients are referred to home palliative care after their general condition deteriorates.” (home palliative care physician, clinic with home hospice function)</p> <p>“...after all, there are patients who do not want to think [about] their prognosis, and even if they were asked about future medical care in casual conversation, they avoid the topic [saying] that ‘it is not the time now.’” (nurse, home visit nursing agency)</p>

Table 3 (continued)

Theme/sub-theme	Quotations
5. Frequent visits to the cancer hospital	“Frequent blood transfusions or weekly regimen of intravenous chemotherapy cause...patients come to the hospital frequently, so it’s easy to talk to their oncologist at [the] cancer hospital and think that it’s not necessary for a healthcare professional to come home...Especially patients with hematological malignancy tend not to be referred.” (social worker, designated cancer hospital)
6. Variations in home palliative care services	“Especially in rural areas, few clinics provide home palliative care services.” (oncologist, designated cancer hospital) “A wide variety of home palliative care physicians...” (nurse, home visit nursing agency) “...many home physicians are not familiar with the side effects of cancer treatment, so if during anti-cancer treatment, the burden will be biased to some home palliative care physicians.” (oncologist, designated cancer hospital)
7. Problems in providing treatment and care at home	“There were some patients or caregivers [that] have unwillingness to invite healthcare professionals to their home.” (home palliative care physician, clinic with home hospice function) “...complex medical procedures and care [may mean they] have difficulty in providing in home palliative care services.” (home physician, clinic with home hospice function)
Theme: Facilitators to home palliative care	
Sub-themes	
1. Relationships between oncologists and home palliative care physicians	“If the oncologist can explain the personality of the home palliative care physician to the patient, I think that home palliative care can be introduced smoothly.” (nurse, cancer hospital) “Face-to-face relationships between oncologists and home palliative care physicians are important...” (home palliative care physician, clinic with home hospice function)
2. Cancer hospital staff experience/knowledge of home palliative care	“If a nurse at a cancer treatment hospital has actually seen a patient receiving home palliative care, I think it will be easier to imagine how a patient receiving cancer treatment [can] spend time at home.” (social worker, designated cancer hospital) “...oncologists also need to be trained in home palliative care...” (home palliative care physician, clinic with home hospice function) “...nurses in cancer hospital understand how patients live at home...” (nurse, designated cancer hospital)

Lack of referral criteria for home palliative care services

Oncologists were concerned about introducing home palliative care services if patients with cancer received chemotherapy in the outpatient medical oncology setting because of the eligibility for medical insurance. Eligibility for home palliative care services under the medical insurance system in Japan requires patients to have difficulty in independently visiting outpatient medical facilities. There is no explicit mention of whether patients undergoing chemotherapy can receive home palliative care services. Oncologists’ recognition of eligibility for home care services could therefore be a facilitator or barrier to integrating oncology and home palliative care. Lack of referral criteria for home palliative care services emerged as an issue.

Financial elements related to home palliative care services

Fees for home palliative care services were thought to be a barrier to introducing home palliative care. In the public health insurance coverage system in Japan, patients younger than 70 years need to pay 30% of medical fees and those aged 70 years or older pay less. Participants reported that financial burdens were especially notable for young adult patients with cancer.

Participants reported that there was a problem associated with long-term care insurance in Japan. Home-visit nursing is covered by either medical insurance or long-term care insurance, but long-term care insurance limits the number of visits. To be covered by medical insurance, home-visit nursing can only be used when the cancer is in the terminal stage. Participants were concerned that long-term care insurance

alone may not be able to provide enough nurse visits for patients with a high degree of independence.

Patients' lack of understanding of the illness trajectory

Patients' lack of understanding of their illness trajectory or lack of awareness of their prognosis also presented a barrier to introducing home palliative care. Healthcare professionals were concerned that patients and their families did not know about the accelerated deterioration in activities of daily living during the patient's final month.

Collusion in doctor-patient communication about imminent death

Poor understanding may be the result of an association between doctors' activism and patients' adherence to the recovery plan. Participants reported that "collusion" between doctors and patients may contribute to false optimism [18]. For example, participants reported patient perceptions that even if their oncologist explained that their cancer was incurable, they hoped that anticancer treatment would continue. It was also thought to be the result of a phenomenon that both the patient and the oncologist carry a burden relating to the end-of-life discussion, meaning that the end-of-life discussion was postponed. For example, oncologists may not want to explain that it was incurable, although this reluctance was also assumed to result from the actions of both the patient and the oncologist.

Frequent visits to the cancer hospital

Frequent visits to the cancer hospital were another identified barrier to introducing home palliative care. Frequent hospital visits made it difficult to schedule home visits. In addition, frequent medical examinations from oncologists made it difficult for home physicians to establish a rapport with patients.

Variations in home palliative care services

Participants reported that there were variations in home palliative care services. They stated that some home physicians may not think that it is necessary to integrate home palliative care services in oncology. For example, in rural areas, few clinics provided home palliative care services.

Problems in providing treatment and care at home

Patients' unwillingness to invite healthcare professionals to their homes was also a barrier. Participants reported that some patients and their families who were offered home

palliative care services declined these services because they were hesitant about a healthcare professional visiting their home. In addition, home palliative care services could not manage complex medical procedures. Failure to adjust medical procedures and care to those that can be performed at home made it difficult to introduce home-based palliative care.

Facilitators to introducing home palliative care services

Two sub-themes emerged from the data that described this theme: relationships between oncologists and home palliative care physicians, and cancer hospital staff experience/knowledge of home palliative care.

Relationships between oncologists and home palliative care physicians

Participants reported that introducing home palliative care would go smoothly if physicians at cancer hospitals and physicians who practiced home care were personally familiar with each other. Face-to-face relationships between oncologists and home palliative care physicians could contribute to integration. However, other participants noted that it was difficult for all physicians to have face-to-face relationships. For example, even if oncologists and home palliative care physicians worked in the same medical service area, they had few opportunities to meet. In addition, there was insufficient time to hold meetings about patients' treatment.

Cancer hospital staff experience/knowledge of home palliative care

Participants reported that oncologists and nurses working in cancer hospitals who had experience of home palliative care services enabled the introduction of home palliative care smoothly. Participants thought that this was not limited to medical care for patients especially with cancer. It was thought to be easier to introduce home palliative care services if cancer hospital staff knew what the home palliative care physicians were likely to think about or were aware of preparation for home care.

Discussion

This study explored the barriers and facilitators to integrating home palliative care for patients with advanced cancer undergoing chemotherapy using a qualitative approach. Three overarching themes were identified: (1) perspectives and ideas on integrating oncology and home palliative care,

2) barriers to referral to home palliative care, and 3) facilitators to introducing home palliative care services.

An important finding of this study was the clarification of barriers to referral to home palliative care services. Some of the barriers to introducing home-based palliative care into oncology identified in this study overlapped those found in other studies. A previous study reported barriers related to disease and treatment, including the disease trajectory, therapeutic decisions, institutional/organizational barriers, and emotional aspects among oncologists [19]. In addition, the local political-economic context such as financial arrangements and effective organizational regulations may also be a barrier [20]. That is, some barriers in home-based palliative care (e.g., patients' lack of understanding of their illness trajectory, collusion in doctor-patient communication about imminent death, and variations in palliative care services) were consistent with barriers to early palliative care. However, lack of referral criteria for home palliative care services including hospice programs was noted as a specific issue for home palliative care in this study. Although referral criteria for outpatient specialty palliative cancer care have been discussed [21], we are unaware of any existing criteria for referral of outpatients to home palliative care services. In addition, some barriers were consistent with general palliative care, whereas others were specific to home palliative care [11]. Home palliative care is not yet standard for every patient with advanced cancer despite the advantages of home palliative care services.

The second important finding of this study was the clarification of facilitators of referral to home palliative care services. A major facilitator identified was relationships between oncologists and home palliative care physicians. In a study focused on implementation of regional comprehensive palliative care for patients with cancer, improved communication and cooperation among regional healthcare professionals was reported to be central to improved services [22]. Establishing a structure to improve communication between healthcare professionals may therefore be an important element of regional palliative care, including home palliative care services. Providing education could also be a facilitator. For example, education for healthcare professionals in cancer hospitals may be required to promote the holistic nature of home palliative care services and help professionals realize the potential benefits to patients, families.

Strengths and limitations of this study

To our knowledge, this was the first qualitative study to explore the experiences of integrating home palliative care into oncology care among home palliative care teams and healthcare professionals working in medical oncology. We also captured their perceptions of barriers and facilitators.

The multidisciplinary nature of our sample allowed us to gain insights into this topic from different perspectives (e.g., physicians, nurses, and social workers).

This study had several limitations. First, our findings have limited generalizability, because the qualitative approach did not allow for the transferability of findings. This study was conducted among Japanese healthcare professionals, and there are differences in healthcare systems, insurance systems, and the availability of home palliative care services in various countries. Second, the sample size was small. However, data saturation was achieved as participants were purposefully selected. All study participants were healthcare professionals; patients' or patient families' perspectives may have been different.

Conclusion

Several reasons emerged to explain the difficulty of introducing home palliative care services. Barriers relate to the economic context, regional palliative care system, patients' poor prognostic awareness, patients' sense of abandonment when referred to home palliative care services, and the burden on oncologists relating to end-of-life discussions. This study identified facilitators to improving the integration of home palliative care into oncology. The analysis of the interviews allowed us to explore potential strategies for integrating home palliative care services in oncology. Further research could focus on the development of an intervention model to support early integration.

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Author contribution All authors were investigators in this study and participated in the study design, interpretation of the study results, and in the drafting, critical revision, and approval of the final version of the manuscript.

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Data Availability To protect participants' privacy, no original data can be released. Deidentified data from this study are kept by AY and are available upon reasonable request.

Declarations

Ethics approval The proposal for this study was submitted for approval to the Institutional Review Board and Ethics Committee of Nagoya City University Graduate School of Medical Science.

Consent to participate All participants provided written informed consent.

Consent for publication Participants consented to the submission of this research for publication.

Conflict of interest AY is the Chairman of Research Association for Community Health.

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