ORIGINAL ARTICLE

Strategies for caring for the peaceful death of cancer patients at home in Japan – A meta-synthesis of the literature

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ABSTRACT

This study aimed to identify strategies that enable the provision of high quality home care for dying patients with cancer. We searched the NPO Japan Medical Abstracts Society database through Ichushi-Web and selected literature that focused on home care for dying patients with cancer of Japanese origin. In particular, we chose research papers published between 2005 and 2015 that used the qualitative research methodology. The research subjects comprised patients (excluding children), family members of patients, and medical staff who were primary caregivers. We identified the following four research questions by reviewing 13 articles: "A. What enables patients to live at home until they die?", "B. What difficulties does a dying patient encounter while living at home until death?", "C. What represents effective support for patients living at home until they die?", and "D. What represents ineffective support for patients who live at home until they die?". All results were grouped depending on their relevance to these research questions. We identified 4 categories each pertaining to Research Question A (RQ-A) and RQ-D, and 3 each pertaining to RQ-B and RQ-C. We identified the following five factors that can promote the peaceful death of patients with cancer at home: 1) strong family bonds; 2) caring for the dying patient by the family, according to a framework provided by the medical staff; 3) a guaranteed unconstrained daily life; 4) support for the family's range of emotions; and 5) systematic support from visiting medical staff and the hospital.

Key Words: Cancer, End of life care, Home care, Literature review, Peaceful death

1. INTRODUCTION

Dying a peaceful death at home is a common hope in the world. People have concerns regarding death in their respective societies. For example, in the Hebrew Bible, death is considered good, or at least acceptable, after a long life. When a person dies in peace, there is continuity in the relationship with one's ancestors and heirs, and to the land in which one is buried.[1] Similarly, in Southern Ghana, it is believed that a good and peaceful death comes naturally after a long and well-spent life. Such a death preferably takes place at home, which is the epitome of peacefulness, surrounded by children and grandchildren.[2] Furthermore, some studies highlight the differences and similarities in peaceful death between ethnic groups and countries.[3–7] Our review about peaceful death at home in Japan will contribute to the understanding of death with regard to the Japanese culture and society.

In Japan, one in three people die due to cancer.[8] According

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to a survey by the Ministry of Health, Labor and Welfare,[9] if there is no cure for a disease and the patients are in the terminal stage, 12.7% of them prefer to stay at a hospital with a home doctor or at a cancer specialized hospital, 22.9% of them prefer to stay at a palliative care unit, 10.5% of them prefer to live at home until they die, and 48.3% of them wish to live at home as long as they can and then move to a general hospital or palliative care unit only when necessary. However, although about 60% of terminally ill patients want to live at home, only 12% actually die at home. According to patients, it is difficult to live at home until they die because of the "family's care burden" and "anxiety regarding sudden changes in the patient's health status".[9] Moreover, because of the increased availability of care for patients in hospitals after the Second World War, families have not experienced the death of a grandparent at home. Therefore, such families find it difficult to understand dying and death as a natural process, and they fail to utilize effective strategies for caring for a dying person.

With the revision of the medical payment system in 2015, home care was strengthened.[10] The Japanese government sought to promote the transition from hospital care to home care owing to the national financial difficulties related to the rising medical bills of the increasing elderly population, decreasing employable population, and decreasing total population.[11] If dying patients are forced to go home, their quality of life may decrease because the home care system is not prepared adequately for caring for dying patients. Therefore, it is important to identify effective strategies for caring for dying people to ensure a peaceful death at home.

Purpose

In order to identify the strategies for caring for the peaceful death of patients with cancer at home in Japan, we clarified the following four research questions through a review of the existing literature:

A. What enables patients to live at home until they die?

B. What difficulties does a dying patient encounter while living at home until death?

C. What represents effective support for patients living at home until they die?

D. What represents ineffective support for patients who live at home until they die?

2. METHODS

2.1 Research design

This meta-synthesis of prior studies utilized a qualitative and inductive methodology.[12, 13]

2.2 Inclusion/exclusion criteria for selecting literature

2.2.1 *Inclusion criteria*

(1) Focusing on the research theme of dying at home: This criterion was selected because successful dying at home was the main theme of the present study. Dying was defined as the period "from three months prior to death until death". This period was included in the definition of dying because it poses difficulties related to caring as the patient is required to face his/her imminent death and he/she experiences rapidly changing symptoms.

(2) The disease of focus was cancer: This criterion was employed because the dying process differs according to the type of disease. Characteristics of the dying process of patients with cancer include the patient's recognition of one's imminent death, and the experience of severe and rapidly changing symptoms before death.

(3) Subjects of the study are patients dying at home, family members caring for a dying person at home, or visiting nurses caring for dying patients: Though patients experience the dying process themselves, their family members are an integral part of the experience of dying at home, and visiting nurses are familiar with the actual situation of caring for the dying at home. Therefore, this criterion was employed to derive various viewpoints to identify the strategies for caring for dying patients at home.

(4) Country of research was Japan: This criterion was employed because patients' dying experiences, and family members' and visiting nurses' caring experiences are influenced by the medical and welfare systems of the country.

(5) The research methodology was qualitative and inductive: This meta-synthesis aimed to gather qualitative results from the existing literature, and to identify new categories and conceptualization in order to answer the four research questions. Therefore, this criterion was employed.

(6) The type of literature was original articles, and conference proceedings, technical materials, and interpretive articles for beginners were excluded. The selection of original articles guarantees the quality of the research.

(7) Period of search was one decade from March 2005 to March 2015: One decade was selected because it is generally the period selected in review articles.

(8) The articles were critiqued to examine if: 1) there was consistency between the purpose, methods, and results; 2) the results possessed sufficient validity; 3) the results included rich information and thick description: Consistency and validity of the purpose, methods, and results were ensured because we wanted to gather credible qualitative results

for the meta-synthesis. The presence of rich information and thick description in the results was ensured because such information would facilitate the creation of new categories and conceptualizations through the meta-synthesis by understanding the meaning of each result in detail.

(9) The contents of the results in the literature were able to answer the four research questions of the present study: This study aimed to answer the four research questions mentioned earlier, and to develop new categories by synthesizing the results reported in the literature. Therefore, we selected only those articles that fulfilled this criterion.

2.2.2 *Exclusion criteria*

Studies on children aged less than 20 years were excluded: Studies on children were excluded because they may not be able to express their decisions easily and they need special care as compared to adults.

2.3 Procedure of gathering and selecting literature

2.3.1 *The database*

We used the Igaku Chuo Zashi web version of the NPO Japan Medical Abstracts Society (2015 up-dated),[14] which is Japan's largest medical literature database. We gathered bibliographic information of studies from about 4,000 Japanese magazines collated by Dr. Shiro Amako, since 1903. It contains over 10,000,000 studies gathered from medical, dentistry, pharmacy, nursing, and other related fields.

2.3.2 *Procedure of searching and selecting literature to meet the inclusion/exclusion criteria*

In the first step, we searched for Japanese studies published from March 2005 to April 2015, by using the web version of Igaku Chuo Zashi (Inclusion Criterion 4 and 7). We used keywords such as home care, cancer, and terminal stage (Inclusion Criterion 1 and 2). The search was restricted to original articles (Inclusion Criterion 6). In the second step, we read the title and abstract, and confirmed whether they met Inclusion Criterion 1, 2, 3, and 5. Studies that did not meet these inclusion criteria were excluded. Additionally, studies on child patients with cancer were excluded, according to the exclusion criteria.

In the third step, we carefully read and critiqued all articles to confirm whether they met Inclusion Criterion 8. Studies which did not meet these criteria were excluded. In the fourth step, we confirmed whether the studies included rich information in the results to help us develop new categories and whether they answered our four research questions (Inclusion Criterion 8 and 9). If they did not meet these inclusion criteria, they were excluded. All these steps were executed by the first author and were supervised by the second author.

2.4 Integration of the data in the literature

2.4.1 *Outline of the selected literature*

Information pertaining to the selected studies is presented in Table 1, including publication year, subjects of the study, theme of focus, period of data gathering, data gathering method, analysis method, and references.

2.4.2 *Integration of data and development of new concepts*

This phase of the study aimed to integrate the selected literature and to derive answers to the four research questions. For instance, Research Question A (RQ-A) was, "What enables patients to live at home until they die?" In the first step, we carefully read the results of the selected literature and identified descriptions pertaining to this question. In the second step, we extracted the descriptions and developed one-sentence codes that answered the research question. Similar codes were merged to create lower categories. In the third step, each lower category was labeled to answer the research question. In the fourth step, by repeating the above steps, sub-categories were developed from similar lower categories, and subsequently, categories were developed from similar sub-categories. Finally, a category name or label was created for RQ-A.

This procedure was repeated for RQ-B, RQ-C, and RQ-D. All steps were performed by the first author and were supervised by the second author.

3. RESULTS

3.1 Outline of the selected literature

In the first step, we identified 142 studies from the Ichushi-web database. In the second step, these were narrowed down to 72 studies by reading the titles and abstracts. In third and fourth steps, after reading and examining the full-text versions of the articles, we identified 13 studies that met the nine inclusion criteria and one exclusion criterion.[15–27]

An outline of the selected studies is presented in Table 1. In the 13 selected studies, 8 studies examined family as a subject (#1, #2, #5, #7, #8, #9, #10, and #12), 2 pertained to patients and their family (#4 and #11), 2 pertained to family and medical staff (#6 and #13), and 1 pertained to home care nurses (#3).

Table 1 also shows the period of data gathering. Four studies involved data gathering before a patient's death (#4, #9, #11, and #12), while 8 collected data after the patient's death (#1, #2, #5, #6, #7, #8, #10, and #13). In Study #3, the time of data gathering is unknown. Methods of data gathering were as follows: semi-structured interviews (used in 10 studies; #1, #2, #5, #6, #7, #8, #9, #10, #12, and #13) focus group interviews (used in #3), non-participant observation and semi-structured interviews (used in #4), and participant observation and semi-structured interviews (used in #11).

Table 1. An outline of the selected research studies

Number	Year	Subjects	Research focus	Term of data gathering	Methods		References
					Data gathering	Analysis methods	
#1	2014	Family	Experience of care for dying at home	From 1 to 3 years after death	Semi-structured interview	Qualitative inductive analysis	[15] Takagi I. Experience of Family Living Separately Providing Cancer Patient End-of-Life Care. Bulletin of Hokkaido Bunkyo University. 2014; 19(2): 150-160.
#2	2014	Family	Self-care	Within 1 year after death	Semi-structured interview	Modified-Grounded Theory Approach by Dr. Kinoshita	[16] Miyabayashi K, Furuse M. Analysis of Self-care in Family Caregivers Who Cared for Terminal Cancer Patients at Home. Japanese Journal of Research in Family Nursing. 2014; 19(2): 150-160.
#3	2013	Visiting nurses	Family support	Unknown	Focus group interview	Qualitative inductive analysis	[17] Yamamura E, Nagasawa K, Makita H, et al. Family Nursing Practice by Visiting Nurses with Families Caring for Terminal Cancer Persons at Home. Journal of Seirei Society of Nursing Science. 2013; 4(1): 1-5.
#4	2013	Patient/ family	Status at night	During care for dying	Non-participant observation, and semi-structured interview	Qualitative inductive analysis	[18] Honda Y. Nighttime Care for Terminal Patients at Home: A Case Study. Japanese Journal of Research in Family Nursing. 2013; 19(1): 40-53.
#5	2012	Family	Family support	From 3 to 8 months after death	Semi-structured interview	Qualitative inductive analysis	[19] Yamashita M, Amano T. Thinking family support from family's thought of care for dying cancer patient at home. Journal of Kagawa Prefectural Nursing Association. 2012; 3: 17-20.
#6	2011	Family/ medical staffs	Difficulty in caring for the dying	More than 6 months after death	Semi-structured interview	Qualitative inductive analysis	[20] Ishii Y, Miyashita M, Sato K, et al. Difficulties Caring for Terminally Cancer Patients at Home: Family Caregivers' and Homecare Providers' Perspectives. Journal of Japanese Society of Cancer Nursing. 2011; 25(1): 24-36.
#7	2010	Family	Commitment	From 6 to 18 months after death	Semi-structured interview	Qualitative inductive analysis	[21] Sekine M, Nagato K, Nojima S. The Commitment of Families Who Care for a Family Member with Terminal Cancer at Home. Japanese Journal of Research in Family Nursing. 2010; 16(1): 2-10.
#8	2009	Family	Experience of caring for the dying	From 4 to 19 months after death	Semi-structured interview	Modified-Grounded Theory Approach by Dr. Kinoshita	[22] Makita H, Ooishi K, Yamamura E, et al. The Terminal Caring Experiences of Women Who Cared for their Husbands at Home during the Terminal Stages of Cancer -Terminal Care Involving Continuous Support from Doctors and Visiting Nurses. Japanese Journal of Research in Family Nursing. 2009; 15(1): 51-57.
#9	2009	Family	Enriching event	During care for dying	Semi-structured interview	Qualitative inductive analysis	[23] Ishimoto M. Enrichment Processes in Family Caregiving at Home for Terminally Ill Cancer. Journal of Japanese Society of Cancer Nursing. 2009; 23(1): 31-43.
#10	2008	Family	Experience of caring for the dying	From 45 to 315 days after death	Semi-structured interview	Qualitative inductive analysis	[24] Yokota M, Akimoto N. Experiences of Family Members who cared for End-Stage Cancer Patients at Home. Journal of Japanese Society of Cancer Nursing. 2008; 22(1): 98-107.
#11	2006	Patient/ family	Experience of caring for the dying	During care for dying	Participant observation, and Semi-structured interview	Qualitative inductive analysis	[25] Shigesawa H, Ando S, Maekawa A. The Experiences During Treatment at Home of Elderly Cancer Patients in the End-of-life and of Family Caregivers. Journal of Japan Society of Nursing and Health Care. 2006; 8(1): 31-39.
#12	2006	Family	Factors of continuing care for the dying at home	From 7 days before dying to 2 months after dying	Semi-structured interview	Qualitative inductive analysis	[26] Horii T, Mitsuki S, Shimada R, et al. Factors related continuing home care for cancer patient-from analysis of interview data of two cases. Bulletin of School of Nursing, Kyoto Prefectural University of Medicine. 2006; 15: 34-42.
#13	2005	Family/ visiting nurses	Experience of care for dying	From 1 month to 10 month after death	Semi-structured interview	Grounded theory approach	[27] Kobayashi H. The Emotional Experience of Caregivers who cared for Dying Family Member at Home and the Support of the Visiting Nurse. The Japanese Red Cross Kyushu International College of Nursing, Intramural Research Report. 2005; 3: 77-90.

Note. 1. Research subjects as "Family": #1: younger sister (1); #2: wife (5), child (4), daughter-in-law (1); #4: wife (1); #5: wife (2), child (1), grandchildren (1), daughter-in-law (1); #6: spouse (3), child (4); #7: wife (3), husband (1), sister (2), children (5); #8: wife (9); #9: wife (6), husband (1), children (6), daughter-in-law (2); #10: wife (6), daughter (2), daughter-in-law (2), son (2), husband (2); #11: wife (4), husband (1), daughter-in-law (3), unknown (1); #12: child(2); #13: wife (1), child (2). 2. Research subjects as "Patient": #4: colon cancer (1); #11: gall bladder cancer (1), collon cancer (4), liver cancer (1), bladder cancer (1), malignant pleural mesothelioma (1), gastric cancer (1)

3.2 Meta-synthesis about the four research questions

Among the 13 studies examined, 8 studies (#2, #5, #7, #8, #9, #10, #11, and #12) pertained to RQ-A, "What enables patients to live at home until they die?". Further, the family was the subject in 7 studies (#2, #5, #7, #8, #9, #10, and #12), while the patient and his/her family were the subjects in Study #11. A total of 132 codes were created from these 8 studies, which were integrated into the following 4 categories (see Table 2): [A-1. The family has a strong will to take care of the dying patient at home and there is a strong bond between the family and the patient], [A-2. The family is mentally prepared to cope with the difficulties of dying by feeling connected by the support of the medical staff], [A-3. The family devotes care and shares irreplaceable time together while continuing with their daily life], and [A-4. The family's life is enriched by the experience of caring for the patient, spending quality time, and receiving words of thanks and pleasure from the patient].

Table 2. Findings related to RQ A: "What enables patients to live at home until they die?"

Categories			
Sub-categories	**Lower categories**	**Study Number & Code**	
A-1. The family has a strong will to take care of the dying patient at home and there is a strong bond between the family and the patient.			
1) The patients have the ability to make decisions and have a strong will to live in their own home.	The patient had a strong will and hoped to stay at home.	#5)	Family wanted to do everything that they could because the patient hoped to stay at home.
		#12)	The patient said "I want to stay at home and I do not want to return to the hospital. Staying at home is the most comfortable for me".
	The patients had the time and ability to make decisions regarding their life and death.	#11)	The patient decides and selects the treatment strategies.
		#11)	The patients have hope about palliative symptoms and becoming better.
	The patients endeavored to do their best in order to live positively.	#11)	The patients hope to spread pleasure in daily life and to interact to with society.
		#11)	The patients endeavored to do their best.
	The patients tried to accept his/her inevitable death philosophically.	#11)	The patients realized that their death was inevitable and endeavored to adapt to get the worth of their body condition.
2) The family has a strong will to care for the dying patient at home.	Family comes together in order to care for the patient at home.	#2)	The family spends time with each other.
		#2)	All family members cooperated to care for the patient at home.
		#7)	The family and patients respect each other and all family members come together.
	Family considers caring for patients as an obligation and took responsibility as whole family.	#7)	The family fulfills the obligations of care at home as an obvious responsibility of the family.
		#10)	The family feels that caring for patients is the responsibility of the entire family.
	The family realizes and prepares for the patient's inevitable death.	#7/8)	The family accepts and prepares for the patient's inevitable death.
	The family believes that providing care at home is the best option.	#7)	The family decides to care for the patient at home and believes that it is the best option.
	Family sets care goals.	#2/7)	Family set care goals and makes the efforts to achieve them.
	Family devotes care for patients at home.	#2/7)	Family prioritizes and devotes time for caring for the patient and sacrifices their daily life.
		#7)	Family members think that they could accomplish caring for the patient at home.
		#7)	Family records the patient's daily symptoms.
3) The family respects the patient and hopes to support him/her.	Family respects and sustains the patient's resolutions.	#2)	Family empathizes with the patient's suffering and pain.
		#7/10)	Family respects and sustains the patient's will and resolutions.
	Family hopes strongly for the patient's well-being and survival.	#7)	Family supports the patient's hope.
		#10/11)	Family hopes strongly and prays for the patient's well-being and survival.
	Family worked towards meeting the patient's wishes.	#12)	Family wants to meet the patient's wishes and they put in effort to achieve the goal.
	Family had deep affection for the patient.	#10/11)	Family hoped to be together with the patient as long as possible.
		#12)	Family decided to care for the patient without hesitating because caring for patients was viewed as a way to repay the favors done by them.
		#12)	Family shared deep affection and good memories with patients.
A-2. The family is mentally prepared to cope with the difficulties of dying by feeling connected by the support of the medical staff.			
4) Family prepared for the sudden changes and death of the patient and the changes in the family's life after the patient's death.	Family tried to relieve anxiety regarding the patient's inevitable death.	#12)	The family had to remind themselves that the patient's death was inevitable.
		#12)	Family gathered information and shared it with others in order to relieve their own anxiety of the patient's imminent death.
	Family prepared for sudden changes in the patient's condition.	#10)	Family gathered information in order to have a better perspective of the patient's condition until death.
		#12)	Family was prepared for any sudden change in the patient's condition and tried not to feel panicked and upset.
	The time until the patient's death helped the family prepare for life after the patient's death.	#9/10)	Family discussed and sought ways of preparing their own life after the patient's death.
5) Family and patient had a sense of security because of the support of the medical staff.	Care by medical staffs brought the patient and family together and offered them a sense of security and satisfaction regarding care.	#7/10)	Family felt that they could care for the patient with the help of home care nurses and could help the patient face death.
		#10)	Home care nurses were necessary for patients, and the family and patient realized the need for to be supported by medical staff.
		#10/12)	Family and patients felt satisfied and felt a sense of security by accepting the care of the medical staff.

(Table 2 continued on page 28)

Table 2. (continued.)

Categories			
Sub-categories	**Lower categories**	**Study Number & Code**	
A-3. The family devotes care and spends time together while continuing with their daily life.			
6) Patient and family spend quality time together	Family continued to care for the patient while continuing with their usual daily life.	#7/8)	Family continued to care for patient while keeping up with the family’s usual daily life.
	Patients and family realize that they should be able to share quality time together.	#5)	Family thought it was good for to cry to their heart’s content, and to call and touch the patient without being concerned of what others think.
		#9)	The patient and family shared time together and stayed together, and they could feel the changes in the weather and season together.
		#9)	Patient’s condition was getting worse, but he/she could just be himself/herself with family members.
7) Family could face the challenges of caring for the dying patient because they were aware that the terminal stage had a time limit and that it was not endless.	Family could face the challenges of caring for the dying patient because they were aware that the terminal stage had a time limit and that it was not endless.	#8)	Family could face the challenges of caring for the dying patient because they were aware that the terminal stage had a time limit and that it was not endless.
8) Family had opportunities to be released from care burdens.	Family had opportunities to be released from care.	#7)	Family tried not to work too hard to provide care because they became tired.
		#10)	Family sought joyful time when they could be released from the responsibility of caring.
A-4. The family’s life was enriched by the experience of caring for the patient, spending quality time, and receiving words of thanks and pleasure from the patient.			
9) Bonds between the family, patient, and friends became stronger.	Bonds between the family and friends became stronger.	#7/10)	Family felt supported by their friends and neighbors.
	Bonds between the patient and the family became stronger.	#5/10)	Other family members worried and were kind toward the primary caregiver. She felt happy about the kindness of other members.
		#7/8/10/11)	By caring for patients, family bonds deepen and the family comes together as one. The family reminded each other of the importance of family.
10) Patient and family could spend irreplaceable quality time and felt at peace when they were together without binding hospital rules.	Patient and family spend unfettered time at their own pace, without being bound by hospital rules. If they were in a hospital, they could not do that.	#9)	Family and patients drank beer at birthdays and had a joyful time.
		#9)	Patient could enjoy smoking, which he could not if he were at the hospital.
		#9)	When patient’s condition was good, patient and family enjoyed driving.
	Family and patient experienced peace of mind when they spent time at home together.	#10)	Family and patient experienced peace of mind when they spent time at home together.
		#11/12)	Patient felt a sense of security, fulfillment, and happiness in living at home.
11) Family’s outlook toward life was deepened by the experience and care	Family felt satisfied and experienced a sense of relief, because they could care for the patient at home until his/her death.	#5/10)	The patient died naturally and humanely without an oxygen mask and/or intravenous drip injection and died while being surrounded by family. The family felt satisfied about the patient’s peaceful death, and maybe the patient was satisfied too.
		#5)	Family felt they were able to repay the patient for all his support in the past.
		#5)	Family felt relieved that they could provide care till the patient’s death without falling sick.
	Caring for the dying and his/her death became an important experience for the family, and the family's outlook toward life deepened.	#5/10)	Family realized that caring for the dying was a good life experience, and they were well-trained and grew as an individual through the caring experience.
		#11)	Family noticed changes in themselves and it deepened their outlook toward life.
12) Family felt rewarded and pleased when the patient expressed thanks and satisfaction.	Family feels pleasure when the patient expresses thanks and is satisfied.	#5)	The patient feels anorexic but he could eat a home-made dinner. He thanked for it and said that it was delicious. I felt happy to see this.
		#5/9/11)	All patients thanked the family, and he did not ask for unreasonable things.
		#9)	Patients tell the family (spouse) “I love you”.
		#8/10)	The patient was worried that the family was tired; family gets energy from patient’s tender words.

Further, 8 studies (#2, #5, #6, #8, #10, #11, #12, and #13) addressed RQ-B, “What difficulties does a dying patient encounter while living at home until death?”. Among these 8 studies, family was the subject in 5 studies (#2, #5, #8, #10, and #12), the patient and his/her family were the subjects in 1 study (#11), and the family and medical staff were the subjects in 2 studies (#6 and #13). Seventy-five codes were obtained from these 8 studies, and the following 3 categories were identified by reading the articles (see Table 3): [B-1. Difficulties in accepting a patient’s inevitable and imminent death, and feeling powerless], [B-2. The family feels responsible for providing medical assistance. They feel helpless and fear the unknown situations that might arise during the patient’s dying process], and [B-3: The family makes sacrifices to care for the patient].

Ten studies (#1, #2, #3, #5, #7, #8, #9, #10, #12, and #13) pertained to RQ-C, “What represents effective support for patients living at home until they die?”. Among these, the family was the subject in 8 studies (#1, #2, #5, #7, #8, #9, #10, and #12), the family and visiting nurses were the subjects in Study #13, and a visiting nurse was the subject in Study #3. From the analysis of the 10 studies, 68 codes were obtained, and the following 3 categories were identified (see Table 4): [C-1. Visiting nurses lighten the atmosphere at home], [C-2: The family and patient experience a sense of security when highly specialized medical staff provide continuous care accurately], and [C-3: Patients feel satisfied about having the opportunity to live freely at home].

Table 3. Findings related to RQ B: "What difficulties does the dying patient encounter while living at home?"

Categories Sub categories	Lower categories	Study number & Code	
B-1. The family faced difficulties in accepting the patient's inevitable and imminent death, and felt a sense of powerlessness			
1) Family found it difficult to accept the patient's inevitable and imminent death.	Family felt sad when they came to know about the patient's inevitable and imminent death.	#5)	When the family heard about the patient's imminent death, they were surprised and shocked, and their mind was blank.
		#10)	When the family learned about the patient's imminent death, they could not suppress own their emotions.
	Family felt sad about having to let go of the patient.	#5/13)	Family felt sad about letting go and could not accept the patient's death.
2) Family felt a sense of powerlessness.	Family felt powerless because they had nothing to do.	#2/12)	Family could do nothing when the patient was suffering from pain and experienced adverse symptoms. Family felt powerless.
		#10)	Family could not provide ideal care, so they experienced a sense of inadequacy.
	Family could not bear to see the patient's sufferings.	#6/11)	When patient complained of adverse symptoms, the family was bewildered and sad.
		#6)	Patients suffered unbearable symptoms.
	Family had bottled up emotions	#12)	Family had bottled up emotions
3) Family felt hopelessness because they noticed that the patient strongly hoped to live but he/she could not do.	Family felt hopelessness because they noticed that the patient strongly hoped to live but he/she could not.	#10/12)	Family felt sad because they noticed that the patient wanted to live.
		#13)	Family felt burdened as they were required to provide continued support
	Family felt a sense of guilt as they were not to be able tell the patient the truth about how many days he/she had left.	#6)	Family members' opinions were split and contradictory as to whether the bad news about the remaining days should be told to the patient.
		#12)	Family felt guilty about not telling the patient the truth about his/her remaining days.
B-2. The family feels responsible for providing medical assistance. They feel helpless and fear the unknown situations that may arise during the patient's dying process.			
4) Family felt helpless and feared the unknown situations that may arise in the absence of the medical staff during the dying process.	Family felt fear and anxiety about unknown and uncertain situations leading to the patient's death.	#2/5)	Family was embarrassed as they did not know what to expect at the end of life.
		#10/11)	Family felt that the patient's condition worsened and felt anxious about the uncertain future.
		#8)	Family's emotions fluctuated as the patient's condition worsened.
	Family felt helpless in the absence of the medical staff.	#10)	Family felt helpless and irritated because the medical staff were not beside them all the time.
	Family felt anxious about their first-time experience of caring for the dying.	#6)	Family felt anxious and faced difficulties in caring for the dying for the first-time.
		#6)	Family felt helpless because they had nobody to rely on for care.
5) The family experiences tension and pressure that they expect to be released with the patient's death.	Family felt tensed and pressurized that they hoped for the patient's death in order to escape from the tension and suffering of waiting for the imminent death.	#8)	Family hoped for the patient's death in order to be released from the family's tense time and to release the patient's suffering.
		#10)	Family felt tensed about the imminent death.
6) Family felt responsible for providing medical assistance despite being amateurs.	Family found it difficult to cope with the symptoms that they had never seen before.	#5)	When the patient's condition worsened and several symptoms appeared (e.g., fever, side effects of opioids, insomnia), the family felt severely tensed regarding caring for the patient.
		#6/11)	When delirium appeared, the family was bewildered.
	Family faced difficulties, fear, burden due to the lack of knowledge and skills pertaining to medical procedures and caring for dying patients.	#5/6/10)	Family faced difficulties and feared medical procedures (e.g., endotracheal suctioning, intravenous drip infusion dropped rapidly)
		#6/10/12)	Family faced difficulties and burden due to the lack of knowledge and skills about care (e.g., support for excretion on bed, the patient wanted to go to the toilet just before death).
	Family felt responsible for carrying out medical procedures.	#5)	Patient's condition worsened after a family member performed a medical procedure (administered medication); the family felt guilty and shocked although their procedure was right.
B-3. The family made sacrifices to care for the patient.			
7) Family experienced physical and mental difficulties during caring and hardly had any time for themselves.	Family experienced physical and mental difficulties during caring.	#5/6)	Family found it difficult to remain composed during caring. Family became mentally unstable while caring for the patient.
		#6/10)	Family worried about their own physical condition and broke down.
		#11)	Family felt fatigued and was in a poor physical condition.
	Family was very busy and had no time for themselves.	#6)	Family was very busy and preoccupied.
	Family knew about the demands of managing a job along with caring for the patient at home.	#2/6)	Family had no choice but to leave the job in order to care for the patient at home.
	Family had to make several sacrifices for caring for the patient at home.	#6/11)	Family must sacrifice their daily routine because they were required to spend 24 hours in caring for the patient.
		#11)	All family members were involved in providing care.
8) The primary caregiver felt burdened because she did not receive support from other family members.	The primary caregiver did not receive support from other members and was burdened by having to engage in patient care alone.	#6)	No one knew about care skills in the family; a specific family member had the burden of caring for the patient.
		#11)	Family members were not compatible, therefore one member had to take up the burden of care. She did not receive support from other members.
	There were differences of opinions in the family about care due to intervening relatives.	#6)	Family members' opinion was split about whether the patient should be provided end of life care at home or at the hospital due to intervening relatives.

Table 4. Findings related to RQ C: "What represents effective support for patients living at home until they die?"

Categories		
Sub-categories	**Study number & Code**	
C-1. Visiting nurses lightened the atmosphere at home.		
1) Each visit of the nurse brightened the atmosphere at home.	#5)	Patient was looking forward to the nurse's visit.
	#13)	Family was relieved of their worries after speaking with visiting nurses.
	#13)	Family felt happy to see the patient's calm and meek face although his/her face was full of pain when he/she was only with the family.
	#5/13)	All visiting nurses were good people and they brightened the home atmosphere.
2) Visiting nurses provided care that the family could not as amateurs.	#3/5)	The care skills of the visiting nurses were excellent and painless.
	#12/13)	Visiting nurses provided care that the family could not as amateurs.
3) Visiting nurses could notice differences in the usual atmosphere and supported family during the dying process.	#3)	Visiting nurses could understand the family's non-verbal communication and they did not overlook any changes in the usual home atmosphere.
	#3)	During the terminal stage, visiting nurses supported family without any regret.
C-2. Family and patient felt a sense of security that the medical staff provided specialized and continuous care accurately.		
4) Family experienced a sense of security owing to visiting nurses' frequent visits.	#5/12)	Visiting nurses came home in the morning and evening as the patient's death drew close. The family felt encouraged by this.
5) Family and patient felt relieved with the care provided by highly specialized visiting nurses, which the family could not provide as amateurs. The family learnt care skills from visiting nurses.	#1)	Visiting nurses provided family and patient professional advice.
	#3/5)	Care skills of visiting nurses were excellent and painless.
	#12/1)	Visiting nurses provided care that the family could not as amateurs.
	#5/7/8/10)	Family and patient felt relieved and realized the support and kindness of visiting nurses.
	#8/10)	The support of the medical staff was necessary for the family and they felt secure when they received the same.
	#10)	Family learnt care skills from visiting nurses and cooperated with the medical staff while providing home care.
	#12)	Family and patient were satisfied with the hospice care provided at home.
6) Family and patient found it helpful that visiting nurses helped them cope with their difficulties properly and timely.	#5)	Family felt glad that the visiting nurse considered the primary caregiver's condition.
	#12)	Family and patient felt helpful that visiting nurse consulted and judged them properly about their annoyances.
7) Visiting nurse prepared the family to care for the patient at home by establishing good relationships and holding discussions with the family.	#3)	Visiting nurse listened about the history of the family and made efforts to discuss the family's wish about life and death.
	#3)	Visiting nurse established good relationships with the family, which enabled them to care for the dying patient at home.
8) Family and patient found it helpful to receive information about important contacts and services from the medical staff.	#5/7)	Family found it helpful to be taught about contact information during emergencies by medical staffs.
	#5/7)	Family and patients found the information about rental bed and visiting nurses provided by the hospital.
9) When the family hesitated about proving care at home, the medical staffs encouraged them to accept the same.	#2)	Family could think medical staffs were my friends.
	#3)	Family and patient found the teachings of the medical staff helpful.
	#3)	Medical staff supported and encouraged the family's decision about whether they could care at home.
	#5)	The family considered caring for the patient at home if the doctor could come home as needed.
C-3. Patient felt satisfied about the opportunity to live freely at home.		
10) Patient felt happy and touched about having the freedom to live at home.	#9/12)	Patient felt happy that, at home, he could smoke and drink beer on birthdays despite being sick.
	#9)	Patient went out and travelled with the family, and enjoyed life in the present.
	#12)	Patient felt happy listening to his/her children's voice, cooking sounds, seeing the family work together, and seeing his/her pet near the bed.
	#7/12)	Patient felt happy to be a part of the family's daily life as usual.
	#12)	Patient had fun painting.

RQ-D, "What represents ineffective support for patients who live at home until they die?" was addressed in 3 studies (#5, #6, and #12). Among these studies, the family was the subject in 2 studies (#5 and #12), and the family and medical staff were the subjects in Study #6. From these 3 studies, 36 codes were created, which were integrated into the following 4 categories (see Table 5): [D-1. Visiting nurses' care system (e.g., number of visits, visiting time, details of medical staff) is not adequate for the patient and the family], [D-2. The family and patient experienced distrust toward the medical staff], [D-3. The family and patient feel discontent about the poor cooperation between the hospital and visiting care staff], and [D-4. The family is unable to acquire necessary information about home care services, and medical and welfare insurance].

4. DISCUSSION

4.1 Strategies for caring for the peaceful death of patients with cancer at home in Japan

We identified 4 categories each pertaining to RQ-A and RQ-D, and 3 each pertaining to RQ-B and RQ-C. By integrating all the categories we obtained the strategies (components and care strategies) for caring for the peaceful death of patients with cancer at home in Japan (see Table 6).

4.1.1 *Strong family bonds*

[A-1. Families have the will to care for a dying patient at home based on strong bonds between the family and patient]. [B-3. The family makes sacrifices to care for patients]. These categories show that caring for a dying patient at home requires a strong bond between the patient and his/her family. Living together and loving each other for a lifetime strengthens the family bond. Therefore, a strong bond is a foundation and a prerequisite for successful caring for a dying patient at home, and it is sustained by the family's sacrifices. Our study showed the importance of the strong bond between patients and their family in peaceful death at home, but the present authors think that all patients cannot have a strong bond. The first reason is that, according to family pathology,[28] abuse, domestic violence, and codependence on adult children are common in families. In other words, a deep emotional relationship with one's family brings not only love, but also hate or ambivalence. The second reason is that the family structure in Japan has changed over the years. For example, before the Second World War, a common family type included living with three generations of couples—an individual and his spouse, his parents, and his child/children. Due to the high economic growth after the war, nuclear families began to increase. Now, the family structure is diverse and small, and includes different structures such as living alone, aged couple, single mother, etc.[8] Furthermore, other problems faced when caring for a patient at home have been pointed out, for example, an elder caring for another elder, caring for a patient with severe dementia in an aging couple, a younger family member having to resign his/her job to care for a patient, and abuse by a caregiver in the family.

The Japanese government is promoting home care instead of hospital care because of the increase in the number of elderly people and the severe deficits in the medical economy.[11] However, it is important that we must not rely only on the strong bond within the family and the family's efforts to care for the dying at home. We must promote home care while carefully assessing family relationships. If patients do not have a strong familial bond, we may have to relinquish care for dying at home.

Table 5. Findings related to RQ D: "What represents ineffective support for patients who live at home until they die?"

Categories		
Sub-categories	**Study number & Code**	
D-1. Visiting care system (e.g., number of visits, visiting time, member of the medical staff) is inadequate for the patient and family.		
1) Visiting care system was inadequate.	#5)	Family wanted the visiting doctor and nurse visit for at least ten minutes a day, everyday.
	#5)	Family found it hard to talk to medical staff on the telephone though the consultation was open for 24 hours, because the telephone operator was not the same visiting nurse in charge.
2) The visiting care services were not adaptable to individual needs.	#6)	The visiting care services were not adaptable to individual needs.
	#6)	Family did not know what to ask the helper.
D-2. The family and patient experienced distrust toward the medical staff.		
3) The family could not consult the visiting doctor because they were not confident about him.	#6)	Family could not consult the visiting doctor because they were not confident about him.
	#6)	Family refrained from calling the visiting doctor at night because they did not feel confident about him.
4) Family and patient felt distrust about the poor knowledge of the visiting staff and the poor relationships between the visiting staffs.	#6)	The relationship between the medical staff was bad, and it influenced patient care.
	#6)	The knowledge of the visiting nurses was limited, and the care provided was inadequate.
	#6)	Family and patient did not trust the visiting doctor because he did not express empathy, and the family did not agree with doctor's treatment plan and thought that there were other options.
	#6)	Family wanted to change visiting doctors but they could not do so.
D-3. The family and patient feel discontent about the poor cooperation between the hospital and visiting care staff.		
5) Family felt discontent about the poor cooperation between the hospital and visiting care staff.	#5)	Cooperation between the hospital and home care staff was not good.
	#6)	When the patient's physical condition worsened at home, he/she had to seek treatment in a larger hospital because the cooperation between the large hospital and home care staff was bad.
6) Quality of care at home care was different from that received in the hospital.	#6/12)	Patient and family could not get better care from the medical staffs at home as compared to that received in a hospice or general unit at a hospital.
D-4. The family could not acquire the necessary information about home care services, and medical and welfare insurance.		
7) Family experienced difficulties in acquiring information about home care services.	#6)	Family faced difficulties because they did not have information about home care services.
	#6)	Family did not receive information about a funeral from the medical staff.
8) Family faced difficulties because they did not have information about medical and welfare insurance.	#6)	Family did not have information about long-term care insurance.
	#6)	Family did not know the difference between health insurance and long-term insurance.
9) Family did not receive enough explanation about opioids and their consent was not sought.	#6)	Family did not receive an explanation from the visiting doctor about opioids and they presumed that opioids hastened the patient's death.

Table 6. Strategies for enabling peaceful death for cancer patients at home in Japan

	Strategies that aid a peaceful death		Findings related to Research Question A to D
1)	Strong family bonds	A-1.	Family has strong will to care for the dying patient at home based on the strong bond between the family and patient.
		B-3.	The family made sacrifices to care for the patient.
2)	The family cares for the dying patient according to a framework provided by the medical staff	A-2.	The family was mentally prepared to cope with the difficulties of dying by feeling connected by the support of the medical staff.
		C-2.	Family and patient experience a sense of security when highly specialized medical staff provide continuous care accurately.
		C-1.	Visiting nurses lightened the atmosphere at home.
3)	A guaranteed unconstrained daily life	A-4.	The family's life is enriched by the experience of caring for the patient, spending quality time, and receiving words of thanks and pleasure from the patient.
		C-3.	Patients feel satisfied with the opportunity to live freely at home.
		A-3.	The family devotes care and shares quality time while maintaining the family's usual daily life.
4)	The provision of effective support for dealing with the family's range of emotions	B-1.	Difficulties in accepting the patient's inevitable and imminent death, and feeling powerless.
		B-2.	The family feels responsible for providing medical assistance. They feel helpless and fear the unknown situations that might arise during the patient's dying process.
5)	Developing home care systems with meticulous consideration	D-1.	Visiting care system (e.g., number of visits, visiting time, member of the medical staff) was inadequate for the patient and family.
		D-2.	The family and patient experienced distrust toward the medical staff.
		D-3.	The family and patient feel discontent about the poor cooperation between the hospital and visiting care staff.
		D-4.	The family is unable to acquire the necessary information about home care services, and medical and welfare insurance.

4.1.2 *Care for the dying patient by the family, according to a framework provided by the medical staff*

[A-2. The family is mentally prepared to cope with the difficulties of dying by feeling connected and through the support from the medical staff]. [C-2. The family and patient experience a sense of security when highly specialized medical staff provides accurate care]. These categories reveal the difficulties of caring for a patient dying at home due to terminal stage cancer. The symptoms of terminal stage cancer are severe, and the patient's physical condition can change every minute. In a hospital, the medical staff copes with the symptoms and changing physical conditions. However, at home, the family must cope with them.

In general, family members are not prepared for coping with such symptoms and changing physical conditions.[29] Therefore, professional care provides the family and patient with a sense of security. Furthermore, visiting nurses may enhance a family's ability to cope with changing physical conditions and symptoms without the help of medical staff. Hospital nurses must assess a family's ability to cope with the difficulties of caring for a patient at home. If they notice a lack in their ability to do so, they must not force the family to care for the patient at home.

[C-1. Visiting nurses lighten the nervous atmosphere in a family]. This category highlights the work of visiting nurses. They not only provide direct care but also help in changing the atmosphere at home. Thus, visiting nurses must notice their own invisible ability and intentionally use it to improve the quality of care and the family's sense of security.

4.1.3 *A guaranteed unconstrained daily life*

[C-3. Patient feels happy about being able to live freely at home]. [A-4. The family's life is enriched by the experience of caring for the dying patient and spending quality time with the patient. Receiving words of appreciation and seeing the happiness of the patient make the family happy]. These categories show the positive aspects of caring for the dying patient at home. Continuing the daily routine and spending time together is the real pleasure of home care, and caring for the dying can become a valuable experience for the family. Additionally, family members' view of life changes owing to the experience of caring for the dying patient. In order to gain such positive experiences, it is important to know whether the family views caring as valuable. Therefore, visiting nurses should assist the family in their caring experience by listening to them and approving their caring methods.

[A-3. The family devotes care and shares quality time with the patient while continuing with their usual daily life]. This category shows that the patient as well as the family requires support from the medical staff. Successful caring of the dying patient requires the family to take adequate rest and to be relieved of caring responsibilities when needed. Therefore, we must ensure that visiting nurses provide the family time for themselves.

4.1.4 *Provision of effective support for dealing with the family's range of emotions*

[B-1. The difficulties faced by the family in accepting a patient's inevitable and imminent death, and feeling powerless]. A sense of powerlessness was observed in nurses' grieving process,[30] and both nurses' and family's experiences are similar. Thus, this category shows the common emotions of people who commit to caring for the dying patient, regardless of whether they are professionals or amateurs. If the family feels powerless and begins to think negatively, the visiting nurses should explain that such feelings are common while providing care. They can also acknowledge the family's commitment in providing good care for the patient.

[B-2. The family feels responsible for providing medical assistance, and feels helpless and fears the unknown situations that may arise during the patient's dying process]. This category reveals the family's anxieties regarding caring for the dying patient and facing death. Visiting nurses must prevent panic on encountering sudden changes in the patient's condition by politely explaining the possible situations that might arise. In addition, when the family member performs a medical procedure and the patient's condition worsens, he/she may be shocked and may suffer from guilty conscience owing to the result of the procedure. Similar experiences have been reported by nurses care for dying patients.[30] Even though there is no causal relationship between the actions of a final caregiver, he/she is bound to feel responsible by connecting one's actions with the patient's worsened condition, because she/he performed the procedure and confirmed its effect directly. Therefore visiting nurses and doctors must explain the family the need to avoid feeling responsible because there is no cause and effect relationship between their caregiving actions and the patient's condition. Even if there is relationship, medical staff must assume all responsibility for the consequences because they provide instructions to the family about medical procedures.

4.1.5 *Developing home care systems with meticulous consideration*

[D-1. Visiting care systems (e.g., numbers of visits, visiting time, member of medical staff) were inadequate for the patient and the family]. [D-2. The family and patient experienced distrust toward the medical staff]. [D-3. The family and patient felt discontent about the not receiving the necessary information about home care services, and medical and welfare insurance]. [D-4. The family is unable to acquire the necessary information about home care services, and medical and welfare insurance]. This category was developed based on three studies, and it suggests the need to develop medical welfare systems for home care, visiting care systems, appropriate relationships with the medical staff, and collaboration between the hospital and home care facilities. We must consider the content of services in order to modify the utility of systems. We must arrange for a third-party organization to consult with the family,[31] and to collaborate with the hospital and home care service.[32]

4.2 Limitation

This present findings have limited generalizability because they were based on Japanese literature alone, and may have been influenced by the Japanese social conditions, and medical and welfare systems (see below). Therefore, readers must consider the differences between their own country and Japan. However, caring for dying people is a common requirement and the five core findings of this study may be applied universally.

4.3 Recommendations for understanding the Japanese context

If readers use these is results for their nursing practice and research, they must understand the differences and similarities between Japan and their country in terms of the about situation of caring for a dying patient at care in home. For instance, your reference, the condition of caring for the dying in Japan is as follows: 1) Place of death: 82.5% people died at home in 1951. However, the incidence of dying at a hospital increased due to high economic growth, and 75.2% died at a hospital in 2014.[32] The government is promoting care for people dying patients at home because of the increase in the aging rate and rising medical costs. Therefore, in future, more people may die at home. 2) Medical and welfare insurance system: Medical insurance is a system of public health insurance for the whole nation. Visiting nurses could be covered under long-term care insurance or, medical insurance, or they could be paid at patient's own expense. When covered by long-term insurance and medical insurance, patients pay only partial charges, but the service is limited to only a certain number of visits and specific care services based on the level of care required. 3) Developing clinical collaboration between hospital and home care: Medical staffs need to work towards promoting cooperation between hospital care and home care. 4) Cancer nursing: Patients with cancer in the terminal stage aged over 40 years can use the services of visiting nurses through long-term care insurance, but patients aged less than 40 years cannot avail this service. 5) Specialists in the care for dying cancer patients at home are certified nurse specialists (cancer nursing or home care nursing) who hold by educating at master degree, and certified nurses (palliative care, cancer pain management nursing, or visiting nursing) who have received by educating for a 6-month training. They receive a request consultation from generalist nurses. 6) Education for generalist nurses have a wide variety of educational opportunities such as , for example courses offered by the End-of-Life Nursing Education Consortium (ELNEC),[33] seminars conducted by the by Japan Nursing Association, several related academic meetings, and trainings offered by each hospitals.

5. CONCLUSIONS

The essence of promoting the peaceful death of patients with cancer at home is found in: 1) strong family bonds, 2) caring for the dying patient by the family according to a framework provided by medical staff, 3) a guaranteed unconstrained daily life, 4) provision of effective support for dealing with the family's range of emotions, and 5) developing home care systems with meticulous consideration.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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