



Trust in Physicians, Continuity and Coordination of Care, and Quality of Death in Patients with Advanced Cancer

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Abstract

Background: Provider-centered factors contribute to unexplained variation in the quality of death.

The relationship between health care providers and patients, bidirectional communication, and consistency of longitudinal care planning are important provider-centered factors.

Objective: To explore whether the level of trust in health care providers, the quality of continuity of care, and the level of coordination of care among home health care providers are associated with the quality of death for cancer patients dying at home.

Design: This study was a part of a nationwide multicenter questionnaire survey of bereaved family members of cancer patients evaluating the quality of end-of-life care in Japan.

Setting/Subjects: We investigated 702 family members of cancer patients who died at home.

Measurements: The quality of death was evaluated from 9 core domains of the short version of the Good Death Inventory (GDI). We measured 5 factors on a Likert scale, including patient and family trust in health care providers, continuity of care by home hospice and hospital physicians, and coordination of care among home hospice staff.

Results: A total of 538 responses (77%) were obtained and 486 responses were analyzed. Trust in health care providers was correlated with the GDI score ($r = 0.300\sim 0.387$, $p < 0.001$). The quality of

care coordination was associated with the GDI score ($r = 0.242$, $p < 0.001$).

Conclusions: Trust of the patient and family in home hospice staff, as well as coordination of care among hospice staff, are associated with the quality of death for cancer patients dying at home.

Key Words: Quality of death, trust in health care providers, continuity of care, coordination of care, patients with advanced cancer, home care

Running Title: Trust in HCPs, coordination of care, and QOD

Introduction

When patients have advanced cancer, achieving a good quality of death (QOD) is an important issue for patients, family members, and health care providers (HCPs). Although, several factors related to QOD have been reported^{1,2}, a recent longitudinal cohort study on the factors related to QOD pointed out that the vast majority of the variance in QOD remains unexplained and several patient-centered and provider-centered factors are thought to contribute to this unexplained variance^{1,3}.

Bidirectional communication between health care providers and patients, their overall relationship, and consistency of longitudinal care planning are typical provider-centered factors that could be modified to improve QOD. Therefore, it is worth exploring bidirectional communication between health care providers and patients, as well as their overall relationship and consistency of longitudinal care planning, in patients with advanced cancer³. Dying at home is thought of as the most valuable factor in determining QOD for the patient and family^{4,5}, so it is worth exploring provider-centered factors related to QOD in the home care setting, which could also be applied to improving the quality of health care in other settings.

Bidirectional communication between health care providers and patients and their overall relationship are exemplified by trust and rapport, and make an essential contribution to QOD in patients with advanced cancer^{6,7}. Several previous studies have indicated that trust in the physician

reduces the anxiety of patients^{8,9}, improves decision making¹⁰⁻¹², and increases adherence to the oncologist's recommendations¹³⁻¹⁵.

Consistency of longitudinal care requires both coordination and continuity of care. Coordination of care has attracted considerable attention as a measure of cancer care quality, and access to well-coordinated end-of-life care in all settings is advocated by international policy standards¹⁶⁻¹⁸. Specific areas of concern with regard to continuity of specialist care have emerged since the late 1980s, including the care of patients with HIV/AIDS, cardiovascular disease, and cancer, reflecting the increased complexity of managing chronic disease, with continuity being regarded as an important component of end-of-life care for multidisciplinary professionals¹⁹.

Against this background, the objectives of the present study were to explore whether the quality of trust of the patient and family in health care providers, the quality of continuity of care, and the quality of coordination of care among health care providers were associated with QOD in patients with advanced cancer receiving home care.

Methods

This study was part of a nationwide survey of bereaved family members of cancer patients that evaluated the quality of end-of-life care in Japan (the Japan Hospice and Palliative care Evaluation study 3: J-HOPE3)²⁰, which was a multicenter questionnaire survey of bereaved family members of

cancer patients who died at hospital, in palliative care units, or at home. The present study was a subanalysis of the main study that focused on bereaved family members of cancer patients who died at home.

We mailed anonymous questionnaires to the bereaved families in May 2014, and mailed questionnaires again to the non-responding families in June 2014. Completion and return of the questionnaire was regarded as indicating consent to participation in this study, and families who did not want to participate were asked to return the questionnaire with “no reply.” Ethical and scientific validity was confirmed by the institutional review boards of all participating institutions, and this study was approved by the institutional review boards of Tohoku University and the other participating institutions.

Participating Institutions

We recruited participating institutions from the 51 home hospice services that were members of Hospice Palliative Care Japan (HPCJ) prior to 1 July 2013. We sent letters to these 51 institutions and 22 participated in the study.

Participants and procedures

A cross-sectional, anonymous, self-reported questionnaire survey was conducted between May and July 2014. We asked each institution to identify and list up to 80 bereaved family members of

patients who had died prior to 31 January 2014. The inclusion criteria were as follows: (1) the patient died of cancer, (2) the patient was aged 20 years or older, and (3) the bereaved family member was aged 20 years or older. The exclusion criteria were as follows: (1) the patient received palliative care for less than 3 days; (2) the bereaved family member could not be identified; (3) terminal treatment or death occurred in an intensive care unit; (4) the candidate participant had severe psychological distress as determined by the primary care physician and nurses; and (5) the candidate participant was incapable of completing the self-reported questionnaire because of cognitive impairment or visual disability. The questionnaire was sent to the bereaved family members identified by each participating institution along with an explanation of the survey and return of the completed questionnaire was regarded as indicating consent to the study. We asked participants to return the completed questionnaire to the study secretariat office (Tohoku University) within 2 weeks. We sent a reminder to non-responders after 1 month. If they did not wish to participate in the study, they were asked to check a “no participation” box and return the incomplete questionnaire.

Good Death Inventory - short version

We evaluated the 9 core domains of the short version of the Good Death Inventory (GDI) as the primary endpoint (freedom from physical and psychological discomfort, staying in a favorite place, maintaining hope and pleasure, not being a burden to others, spending time with the family, maintaining independence, living in a comfortable environment, being respected as an individual, and fulfillment at the end of life; range of the total score: 9 to 63 points). The short version of the GDI was developed on the basis of qualitative interviews and a large-scale quantitative study²¹⁻²³. The original version of the GDI has 10 core domains and 8 optional domains, with a total of 54 items. The 10 core domains evaluate items that Japanese people consistently rate as important, while the 8 optional domains evaluate items that are only sometimes considered to be important depending upon individual values^{22,24}. The short version of the GDI consists of 18 items (one for each domain), and its validity and reliability have been confirmed²². We deleted one core domain of the GDI (trusting health care staff), because we assessed trust of the patient and family in HCPs as an explanatory variable. We asked participants “How do you think the patient felt during the end-of-life period? Please write the appropriate number next to each statement.” and then asked each question, e.g., “Do you think the patient was free from physical distress.”

Participants evaluated each domain by using a 7-point Likert-type scale (1: strongly disagree to 7: strongly agree). The total score was calculated by summing the scores for all items, with a high total

score indicating a good death.

Questionnaire

Because of the lack of an existing specific tool for evaluating the opinions of bereaved family members about trust of the patient and family in health care providers, continuity of care, and coordination of care among health care providers, we developed an original questionnaire on the basis of a literature review and discussion among the authors of this study²⁵⁻²⁹. We measured the level of patient and family trust in health care providers, the quality of continuity of care, and the level of coordination of care among health care providers on a 6-point Likert-type scale (1: strongly disagree to 6: strongly agree). Patient and family trust in health care providers was assessed by investigating three factors (Appendix 1), which were patient and family trust in the oncologist (four items), patient and family trust in the home hospice physician (four items), and patient and family trust in the home hospice nurses (four items). Quality of continuity of care by health care providers was classified into two factors (Appendix 1), which were quality of continuity of care by the home hospice physicians and hospital physicians or by the home hospice staff and hospital staff (two items). The quality of coordination of care among health care providers was classified into two factors (Appendix 1), which were coordination of care between the home hospice physician and home hospice nurse or coordination between the care manager and home hospice nurse (two items). Internal consistency of these subcategories was confirmed by explanatory factor analysis and calculation of Cronbach's α , showing that internal consistency was acceptable for all subcategories

(Cronbach's $\alpha=0.79$ to 0.89).

The primary palliative care physicians recorded patient background characteristics (age, sex, primary tumor sites, and duration of home care), while the families reported the caregiver's age, sex, and relationship to the patient.

Statistical Analysis

We first analyzed the distribution of the each of 9 core domains of the short version of GDI and the response rates for each domain (defined as the sum of "somewhat agree", "agree", and "strongly agree"). Then we calculated the total score for the 9 core domains of the short version of GDI as the GDI score for each participant (range: 9 to 63 points). Subsequently, we investigated coefficients for associations and conducted univariate analyses using linear regression. We defined a correlation coefficient of less than 0.30 as indicating a negligible correlation, while 0.30 to 0.50 was a weak positive correlation, 0.50 to 0.70 was a moderate positive correlation, 0.70 to 0.90 was a strong positive correlation, and 0.90 to 1.00 was a very strong positive correlation³⁰. Significance was accepted at $p<0.05$ and analyses were done with SPSS-J software (ver. 22.0; IBM, Tokyo, Japan).

Results

A total of 791 family members met the inclusion criteria, but 82 were subsequently excluded from

analysis (Figure 1). We sent out 702 questionnaires, and 538 questionnaires (77%) were returned. Since 52 family members refused to participate, we analyzed a total of 486 responses (90% of the returned questionnaires). Characteristics of the participants are summarized in Table 1. The mean age of the patients who died was 74.3 ± 11.5 years and 57.8% were men. The most frequent primary tumor was lung cancer, followed by hepatobiliary/pancreatic cancer. The duration of home care was 77.7 ± 150.0 days. The mean age of the bereaved family members was 62.6 ± 11.9 years and 25.9% were men. The bereaved person was most frequently the husband/wife of the patient, followed by a child of the patient.

Quality of death

Agreement rates for the GDI domains are shown in Table 1. The average GDI score was 45.0 ± 7.9 . The agreement rate (sum of "somewhat agree", "agree", and "strongly agree") was over 80% for the following items: "Being able to stay in one's favorite place", "Trusting the physician", "Living in a comfortable environment", and "Being valued as a person".

Trust in health care providers

Nearly all of the bereaved family members reported that the home hospice physician (92.5%, n=359) and home hospice nurses (95.5%, n=354) were available to consult about their concerns,

while 73.9% (n=357) reported that the hospital physician was available to consult about concerns (Table 2). Similarly, over 90% of the bereaved family members reported that the home hospice physician (91.1%, n=350) and the home hospice nurses (93.7%, n=347) respected the values of the patient and family, while 70.4% (n=348) reported that the hospital physician did so (Table 2). In addition, the majority of the bereaved family members reported that the home care hospice physician (80.1%, n=347) and home hospice nurses (87.2%, n=344) had a comprehensive care approach, while only 54.7% (n=344) reported that the hospital physician had a comprehensive approach (Table 2). The mean scores for trust in the oncologist, trust in the home hospice physician, and trust in home hospice nurses were 4.07 ± 1.21 , 4.82 ± 0.93 , and 4.97 ± 0.84 , respectively (Table 3).

Continuity of care

Only half of the bereaved family members reported that the hospital staff and home hospice staff seemed to be familiar with each other (54.8%, n=336) or that the hospital physician and home hospice physician seemed to be familiar with each other (46.0%, n=335) (Table 2). The mean score for the quality of continuity of care by home hospice staff and hospital staff was 3.41 ± 1.53 (Table 3).

Coordination of care

Nearly all of the bereaved family members reported that home hospice staff provided care that was coordinated and consistent, with the rate being 97.2% (n=353) for coordination between the home hospice physician and home hospice nurses or 94.4% (n=342) for coordination between the care manager and home hospice nurses (Table 2). The mean score for the level of coordination of care among home care hospice staff was 5.02 ± 0.78 (Table 3).

Factors influencing the quality of death

Associations between various factors and the GDI score are shown in Table 3. There were significant weak positive correlations between the GDI score and trust of the patient and family in the oncologist, home hospice physician, and home hospice nurses ($r = 0.300\sim 0.387$, $p < 0.001$). Quality of continuity of care showed a negligible association with the GDI score that was not significant ($r = 0.111$, $p = 0.054$), while the quality of coordination of care had a negligible, but significant, correlation with the GDI score ($r = 0.242$, $p < 0.001$). Univariate linear regression analyses with adjustment for the patient's age and sex showed several significant positive associations; trust of the patient and family in the home hospice physician had the strongest association with the GDI score ($p < 0.001$), followed by trust in the home hospice nurses ($p < 0.001$) and quality of coordination of care among home hospice staff ($p < 0.001$).

Discussion

To the best of our knowledge, this is the first large-scale study to reveal that bereaved family members who reported trust in their HCPs and good coordination of care were more likely to report that their loved one experienced good QOD.

The first important finding of this study was that trust of the patient and family in HCPs (trust in each health care provider, availability for consultation about the concerns of family members, respect for the values of the patient and family, and a comprehensive care approach) was associated with QOD in patients with advanced cancer. This result indicates that bereaved family members who reported trust in their HCPs were more likely to report that their loved one experienced good QOD.

According to a recent study, the therapeutic alliance between patient and oncologist has a positive influence on adjustment of caregivers to bereavement that lasts into the early months of bereavement⁶. In addition, a recent systematic review of 36 articles regarding the definition of good death indicated that a good relationship with health care providers was an important specific theme for good death among patients, family members, and health care providers³¹. The conclusions of these previous studies were consistent with our findings that trust of the patient and family in health care providers based on consideration of patient/family values and psychosocial aspects associated with adjustment to bereavement had a positive association with QOD from the perspective of bereaved family members.

It was noteworthy that trust of the patient and family in the home hospice physician showed a stronger association with the GDI score than trust in the oncologist. Similarly, the mean score for trust of the patient and family in the home hospice physician was higher than that for trust in the oncologist. These were evocative results, because the oncologist generally spends longer with patient and family than the home hospice physician. Thus, the chief novel finding of our study was that trust between the patient/family and home hospice physician represents a core aspect of high-quality end-of-life medical care and contributes to a good death. This implies that the home hospice physician should make efforts to maintain good communication with the patient/family regarding their concerns, respect patient/family values, provide comprehensive care, and thus earn the trust of the patient and family. On the other hand, the relatively low score for trust in oncologists implies that the oncologist's behavior (e.g., consulting about concerns of family members, respecting the values of the patient and family, and addressing both daily life and the patient's physical condition) could be modified to improve caregivers' experience of end of life care and subsequent bereavement.

The second important finding of this study was that perceived continuity of care provided by hospital and home hospice staff might not be associated with QOD in patients with advanced cancer.

Haggerty et al. proposed the classification of continuity into three categories, which are informational continuity, relational continuity, and management continuity³². Based on this concept, informational continuity corresponds to perceived continuity of the care provided by hospital staff

and home hospice staff. Regarding such informational continuity, our results were inconsistent with those of a recent large-scale mixed-methods study, which revealed that good communication and cooperation among hospital staff and home hospice staff achieved informational continuity with a positive effect on daily practice from the perspective of health care providers and an increase of the home death rate³³. A possible cause of this discrepancy is that it may be difficult for the patient and family to recognize the influence of continuity on the quality of care, while other possible causes are that the questionnaire might not have adequately explored continuity of care or accurately assessed the perspective of bereaved family members. Thus, further investigation will be needed to develop adequate tools for assessing perceptions of the patient and family about quality of continuity of care.

It was noteworthy that bereaved family members reported low score for the perceived continuity of care provided by hospital and home hospice staff. This indicated that it was difficult for the patient and family to recognize the quality of continuity of care, even though several care processes were implemented by each region. Thus, we need to encourage sharing and visualization of continuity processes among hospital and home hospice staff.

The third main finding of this study was that the quality of coordination of care among home hospice staff might be associated with the QOD of patients with advanced cancer, although the association was weak. This result indicates that bereaved family members who reported good coordination of care were more likely to report that their loved ones experienced good QOD. This

finding is consistent with the results of a preliminary study showing that shared goals among home hospice staff, which are not only directed towards symptom management but also to helping the family cope with the death and dying of a loved one, are essential for building an interprofessional team³⁴. It is possible that coordination of care only had a weak association with QOD because it is an indirect measure, even though coordination of care is required to develop an interprofessional team that can assist the family to cope with death and dying and can appropriately support the patient and family. Therefore, further research is required to determine how coordination of care by an interprofessional team is associated with QOD among patients with advanced cancer.

The strengths of this study were that it was a large multicenter investigation with a high response rate, but there were also several limitations. First, we could not rule out recall bias because of the study design. However, several previous studies performed from 3 to 12 months after death of the patient have suggested that this may be a reasonable interval in consideration of recall bias and the grieving process³⁵⁻³⁸. Second, our findings were obtained retrospectively from family members, so there may have been differences between their perspective and that of the cancer patients³⁹. However, this limitation does not necessarily reduce the usefulness of our findings, because Teno et al. noted that when measuring end-of-life care outcomes retrospectively, it is important to ask bereaved family members to report their own perceptions about the quality of end-of-life care based on direct observation, interactions with HCPs, and overall assessment of care⁴⁰. Third, there were potential

biases based on the participants' state of grief and bereavement; e.g., the overall emotional state might affect how participants recalled the end of life of their loved ones, and participants might report an overall negative or positive orientation without discriminating between instruments or survey items. Thus, we need to interpret the results of this study with caution.

Conclusions

Trust of the patient and family in home hospice staff and the quality of coordination of care among home hospice staff were associated with QOD for cancer patients dying at home. However, further investigation is needed to explore the influence among trust in home hospice staff, coordination of care, and the QOD of cancer patients dying at home because our study only demonstrated an association.

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Declaration of Conflicting Interests

The author(s) have declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Appendix 1 Category and question of questionnaire

Category	Question	Scale
1. Trust of the patient and family in the oncologist	Have you had trust in the hospital physician? Have you felt it was available to consult with the hospital physician about concerns of family members? Did hospital physician respect the values of the patient and family? Did hospital physician have a comprehensive care approach, addressing both daily living and the patient's physical condition?	
2. Trust of the patient and family in the home hospice physician	Have you had trust in the home care physician? Have you felt it was available to consult with the home care physician about concerns of family members? Did home care physician respect the values of the patient and family? Did home care physician have a comprehensive care approach, addressing both daily living and the patient's physical condition?	6-point Likert-type scale; 6: strongly agree, 5: agree, 4: somewhat agree, 3: somewhat disagree, 2: disagree, 1: strongly disagree
3. Trust of the patient and family in home hospice nurses	Have you had trust in the home care nurses? Have you felt it was available to consult with the home care nurses about concerns of family members? Did home care nurses respect the values of the patient and family? Did home care nurses have a comprehensive care approach, addressing both daily living and the patient's physical condition?	
4. Quality of continuity of care provided by home hospice and hospital staff	Did you perceive the hospital staff and home care staff were familiar with each other?	
5. Quality of coordination of care among home hospice staff	Did you perceive the hospital physician and the home care physician were familiar with each other? Did you perceive the coordination of care between the home care physician and home care nurses? Did you perceive the coordination of care between the care manager and home care nurses?	

Table 1 Characteristics of the Patients and Caregivers

	n	%
Patients		
Age (mean \pm standard deviation)	74.3 \pm 11.5	
Sex		
Male	281	57.8
Female	205	42.2
Primary tumor sites		
Lung	101	20.8
Liver, bile duct, pancreas	98	20.2
Stomach, esophagus	72	14.8
Colon, rectum	66	13.5
Prostate, kidney, bladder	37	7.7
Uterus, ovary	24	5.0
Breast	23	4.7
Head and neck, brain	15	3.1
Blood	14	2.9
Others	36	7.4
Duration of home care (days)	77.7 \pm 150.0	
Bereaved family members		
Age (mean \pm standard deviation)	62.6 \pm 11.9	
Sex		
Male	126	25.9
Female	353	72.6
Relationship with the patient		
Husband/wife	254	52.8
Child	163	33.9
Daughter-in-law or son-in-law	31	6.4
Parent	14	2.9
Sibling	10	2.1
Others	9	1.9
Good death inventory (mean score \pm standard deviation, agreement rate[†])		
Being free from physical distress	5.13 \pm 1.48	73.1
Being able to stay at one's favorite place	6.08 \pm 1.26	89.4
Having some pleasure in daily life	4.90 \pm 1.55	63.0
Not causing problems for others	3.35 \pm 1.59	62.2
Spending enough time with the family	5.39 \pm 1.48	78.7
Being dependent in daily activities	3.44 \pm 1.87	34.9
Living in calm circumstances	5.64 \pm 1.23	85.4
Being valued as a person	6.12 \pm 1.02	95.4
Feeling that life is complete	4.87 \pm 1.79	61.1

[†]Sum of answer "somewhat agree", "agree", and "absolutely agree"

Table 2 Agreement rate and mean score of each items

Items (1 to 6 points)	Response rate† (%)	Mean ± standard deviation
1. Trust of the patient and family in the oncologist		
Level of trust in the hospital physician	80.9	4.61 ± 1.26
Availability of the hospital physician for consultation about concerns of family members	73.9	4.18 ± 1.37
Hospital physician respected the values of the patient and family	70.4	3.98 ± 1.42
Hospital physician had a comprehensive care approach, addressing both daily living and the patient's physical condition	54.7	3.53 ± 1.49
2. Trust of the patient and family in the home hospice physician		
Level of trust in the home care physician	92.0	4.98 ± 1.01
Availability of the home care physician for consultation about concerns of family members	92.5	4.92 ± 1.02
Home care physician respected the values of the patient and family	91.1	4.89 ± 1.05
Home care physician had a comprehensive care approach, addressing both daily living and the patient's physical condition	80.1	4.52 ± 1.27
3. Trust of the patient and family in the home hospice nurses		
Level of trust in the home care nurses	94.6	5.07 ± 0.94
Availability of home care nurses for consultation about concerns of family members	95.5	5.10 ± 0.92
Home care nurses respected the values of the patient and family	93.7	4.95 ± 1.00
Home care nurse had a comprehensive care approach, addressing both daily living and the patient's physical condition	87.2	4.73 ± 1.15
4. Quality of continuity of care provided by home hospice staff and hospital staff		
Hospital staff and home care staff seemed to be familiar with each other	54.8	3.55 ± 1.59
The hospital physician and the home care physician seemed to be familiar with each other	46.0	3.29 ± 1.64
5. Quality of coordination of care among home hospice staff		
Level of coordination between the home care physician and home care nurses	97.2	5.15 ± 0.81
Level of coordination between the care manager and home care nurses	94.4	4.91 ± 0.90

†Sum of "somewhat agree", "agree", and "highly agree"

Table 3 Potential factors related to modified GDI score

Category	Mean ± standard deviation	Cronbach's alpha	Pearson's correlation coefficient	P value	linear regression		
					Regression coefficient	95% confidence interval	
1. Trust of the patient and family in the oncologist (4 items, 1 to 6 points)	4.07 ± 1.21	0.885	0.308	<0.001	2.10	1.36-2.84	<0.001
2. Trust of the patient and family in the home hospice physician (4 items, 1 to 6 points)	4.82 ± 0.93	0.870	0.387	<0.001	3.44	2.50-4.38	<0.001
3. Trust of the patient and family in the home hospice nurses (4 items, 1 to 6 points)	4.97 ± 0.84	0.867	0.300	<0.001	2.89	1.83-3.95	<0.001
4. Quality of continuity of care provided by home hospice and hospital staff (2 items, 1 to 6 points)	3.41 ± 1.53	0.887	0.111	0.054	0.61	0.04-1.22	0.049
5. Quality of coordination of care among home hospice staff (2 items, 1 to 6 points)	5.02 ± 0.78	0.792	0.242	<0.001	2.46	1.29-3.63	<0.001

Pearson's Correlation coefficient with Good Death Inventory: : < 0.3 indicates a weak correlation, 0.3–0.5 indicates a moderate correlation, and > 0.5 indicates a strong correlation.

Regression coefficients were calculated using the Good Death Inventory as the dependent variable with adjustment for patient age and sex.