Physician's Communication in Code Status Discussions for Terminally Ill Cancer Patients in Inpatient Hospice/Palliative Care Units in Japan: A Nationwide Post-Bereavement Survey

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Physician's communication in code status discussions for terminally ill cancer patients in inpatient hospice/palliative care units in Japan: a nationwide post-bereavement survey

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Abstract

Context: Cardiopulmonary resuscitation (CPR) is one of the most important end-of-life care decisions. However, the experience of bereaved families during code status discussions is not well documented.

Objective: The aims of this study were to describe the degree of emotional distress of bereaved families when discussing code status, identify their perceived areas for improvement and determine associated factors.

Methods: This study is part of a nationwide post-bereavement survey, the Japan HOspice and Palliative care Evaluation 3 (J-HOPE3) study. Questionnaires were sent to the relatives of cancer patients who had died in palliative care units in Japan in 2014.

Results: From an analysis of 338 questionnaires, 37% of families reported high emotional distress during code status discussions and 32% reported a need for improvement. Multiple logistic regression analyses revealed the following were associated with high-level distress: the family had hoped for the miraculous and spontaneous recovery of the patient (odds ratio [OR] 2.4, 95% confidence interval [CI] 1.31-4.43, p=0.0049), the family felt they could not voice their opinion about CPR (OR 2.07, CI 1.12-3.81, p=0.02), or the physician failed to adapt the explanation to the family's preparation level (OR 0.36, CI 0.18-0.68, p=0.0015). Factors identified for improvement were: holding discussions in a relaxing atmosphere conducive to questioning (OR 0.36, CI 0.16-0.80, p=0.012), and ensuring the physician adapted the explanation to the family's preparation level (OR 0.47, CI 0.23-0.96, p=0.037).

Conclusion: We recommend the development of educational programs for code status discussions to improve the experience of bereaved family members.

Key message: This post-bereavement study revealed 37% of families had high-level emotional distress and 32% of families indicated a need for improvement in code status discussions. The associated factors suggested that physicians should pay more attention to family members' emotions and readiness rather than hastily deciding on code status.

Key words: palliative care; neoplasms; code status discussion; cardiopulmonary resuscitation; inpatient palliative care unit; post-bereavement survey

Running title: Code status discussions in inpatient hospice/palliative care unit.

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Introduction

Cancer is a common life-threatening disease and constituted the second leading cause of death worldwide in 2018[1]. Previous studies have suggested that cancer patients wish to be involved in decisions regarding their end of life medical care[2]. Determining resuscitation procedures, the so-called 'code status', is one of the most important end-of-life care decisions, and may contribute to greater support for a family's self-efficacy[3], and reducing depression and complicated grief in bereaved family members[4]. Conversely, these may raise very sensitive and potentially distressing issues for the patient and their family[5]. In addition, aggressive medical care at the end of life was associated with worse patient quality of life and higher risk of major depressive disorder in bereaved caregivers[6].

In the past decade, patients and their families have been increasingly involved in discussing code status in specialist palliative care settings. In the UK, after the Tracey Judgment in 2014, code status must be discussed with patients or their proxies unless they have indicated they did not wish to be involved or the discussion is likely to cause physical or psychological distress[7,8]. In hospice settings, the proportion of patients who did not discuss 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders decreased from 57% in 2013 to 19% in 2015[8]. In Japan, patients are increasingly required to agree to a ‘do not resuscitate’ (DNR) ward policy when admitted to an inpatient hospice/palliative care unit (PCU). Thus, in Japan, code status discussions are often triggered by the requirement of agreeing to the DNR policy for admission to inpatient hospice/palliative care units. Seventy-six percent of patients who died in inpatient hospice/PCU in 2010 had DNACPR orders. Of these, if the patients themselves had sufficient decision-making capacity, 28% of code status discussions were held with family members only, 48% with the patient and family, and only 20% were with the patient only [9]. Due to the cultural background of family-oriented decision-making, family members play an important role in code status discussions in Japan. So, how many patients and their families experience emotional distress through code status discussions, and how can these distresses be improved? These are the clinical questions of this study.

Several studies have been conducted on how best to discuss it with patients and their families. Compared with participants who only heard a verbal description, participants who viewed a video of goals of care and actual practice were more likely to prefer comfort care and avoid CPR[10,11]. As for communication styles, previous studies have illustrated the importance of shared decision-making[12]. In addition to giving information about CPR, such as resuscitation rates, it is important to discuss goals of care of the patient first, then code status[13,14]. The physician guiding the discussion should focus on psychosocial aspects while showing empathy, honesty and sensitivity to different levels of understanding, and ensuring an atmosphere where patients feel comfortable asking questions[2,12–16]. In addition, a qualitative study of bereaved families who underwent a code status discussion found that they considered it important for health care providers to provide psychological support to the patient's family. Responses also revealed that agreeing to the DNACPR policy involves many negative emotions including guilt, ambivalence, and conflict[17,18].

Thus, no studies have investigated how many patients and families feel distressed by code status discussions, although multiple studies have been conducted on specific methods of code status discussion. In addition, no quantitative study has been conducted to date that examines the intentions of bereaved families as revealed by qualitative research.

The aims of this study were to describe the degree of emotional distress of bereaved families when discussing code status, determine associated factors, and identify areas to improve the communication method for discussing code status.

Methods

This study was conducted as part of a nationwide survey of the bereaved families of terminally ill cancer patients to evaluate the quality of hospice and palliative care in Japan (the Japan HOspice and Palliative care Evaluation study 3: J-HOPE3). We conducted anonymous, self-administered questionnaires from May 2014 to July 2014. We asked each institution to provide 80 families of patients who had died between October 2011 and January 2014, consecutively in order of most recent death. The average time between the death of the patient and the sending of the questionnaire of J-Hope3 study was 257.3 ± 101.3 days (mean ± SD)[19]. Questionnaires were sent by each participating institution to the family members of patients who had died at their respective inpatient hospice/palliative care units, along with a letter explaining the details of the study. We asked that the respondent be adult family members who were the main caregivers of the patient during their stay in the inpatient hospice/palliative care unit, and who had the best knowledge of the treatment the patient received. The research participants were asked to post their completed questionnaires to the research secretariat at Tohoku University within two weeks. We sent out a reminder to all non-responders a month after having sent out the questionnaire. Details of the questionnaire survey are described in the protocol paper of J-HOPE3[19]. This study was conducted with the approval of the ethics committee of Tohoku University School of Medicine (No: 2013-1-334) and the ethics committees of all participating institutions.

Participants and Procedure

Study participants were family members of 966 cancer patients who died in 133 hospice palliative care units. The study participants of the present study were chosen randomly from all participants of the J-HOPE3 study. Family members were eligible to participate if all three of the following criteria applied: 1) the patient died of cancer, 2) the patient was 20 years of age or older, and 3) the bereaved family member was 20 years of age or older. Exclusion criteria were any of the following: 1) the patient stayed in inpatient hospice/palliative care for less than three days, 2) family members could not be identified, 3) the patient died of treatment-associated causes, 4) the potential participants had difficulty in completing the self-administered survey (e.g., cognitive impairment, visual impairment). Exclusion criteria 1) was set because the main study, J-HOPE 3, was designed to assess the quality of specialist palliative care and we considered that bereaved families could not assess the quality of care if the hospital stay was short. Also, exclusion criteria 3) was set in order to avoid causing further psychological burden to the families of patients who experienced treatment-related death. Sample size was not examined in detail beforehand because this study used a subpopulation of a larger study. However, we considered an effect size (ES) of 0.35 (between a small ES of 0.2 and a medium ES of

0.5) to be clinically significant, and calculated a sample size of 130 cases x two groups using $\alpha = 0.05$ and a power of 0.8. We confirmed in advance that we would be able to obtain the required number of samples in view of the total number of questionnaires sent to families.

Questionnaires

The questionnaire was developed by the authors based on literature review. Content validity was confirmed by discussions among ten conveniently sampled palliative care specialists. Face validity was confirmed by a pilot test on five conveniently sampled bereaved families.

Primary endpoints

The primary end points of this study were the degree of emotional distress of bereaved families in code status discussions and the need to improve the physician's communication in the code status discussion. Due to the lack of validated measurement tools, a questionnaire was developed by the authors.

The degree of a bereaved family's emotional distress was estimated by the answer to "how distressed were you when you discussed CPR with the doctor?", rated on a five-point Likert scale (1: not distressed, 2: slightly distressed, 3: somewhat distressed, 4: distressed, 5: very distressed).

The need for improving the communication in code status discussions was identified by the families' answer to "how much improvement do you think was needed in the communicating method, when you received information about CPR?", rated on a four-point Likert scale (1: no improvement, 2: some improvement, 3: considerable improvement, and 4: much improvement).

Factors potentially associated with primary endpoints

To identify factors associated with primary endpoints, we asked participants about 1) timing and patient's condition at the time of code status discussion, 2) the family's emotional state when discussing code status, 3) family's experience of the code status discussion. These items were determined by the authors based on discussion of previous studies.

1) Timing and patient condition: we investigated the timing of conversations and the patient's condition at the time of the first code status discussion with the doctor (six items) using binary questions (yes or no). These six items were developed based on discussion among authors.

2) Family's emotional state: we requested participants rate their degree of agreement with six statements regarding their emotion during the first code status discussion with their doctor such as "I was burdened as if I were making decisions concerning the life of a loved one", based on a previous study[17] using a five-point Likert-type scale.
3) Family's experience: we requested participants rate their degree of agreement with 13 statements on their experience of communication strategies in the first code status discussion with the physician using a five-point Likert-type scale. These 13 items were prepared with reference to the recommendations from previous studies, guidelines and current usual practice of hospice/palliative care enrollment in Japan[5,10–12,14,16,17,20].

Participant characteristics

We asked each responsible physician of the participating institution to extract the patients' age, sex, primary cancer site from the medical record. We asked bereaved family members for their age, sex, relationship with the patient, and educational background in the questionnaire.

Analysis

For the comparison, we classified respondents into two groups according to their emotional distress level: high-level distress group (“5: very distressed” or “4: distressed”) and low-level distress group (answers 1-3). We assigned two additional groupings based on the family-perceived need for improvement: an improvement group (“4: much improvement”, “3: considerable improvement”, or “2: some improvement”) and a no-improvement group).

To explore the factors influencing the levels of emotional distress regarding the code status discussion and the need for improvement experienced, we conducted a univariate analysis on five background variables (patient’s age, sex, bereaved family member age, sex, educational background), 13 items on family members’ experience of the physician’s communication behaviors, and six items on the timing of conversations and the patient’s condition at the time of the first code status discussion. To facilitate interpretations, all questionnaire responses were categorized as strongly agree/agree versus others. Educational background was categorized as tertiary level education versus others. We conducted a univariate analysis using a Student’s *t*-test, Chi-square test or Fisher’s exact test, as appropriate. To assess the results in 30 comparisons, using the Bonferroni correction, the statistical significance was defined as 0.002 ($\fallingdotseq$0.05/30). We regarded P-values from 0.002 (≒0.5/30) to 0.02 as marginally statistically significant.

We conducted a multiple logistic regression analysis using forward elimination. All potential predictors with statistical significance or marginal statistical significance by univariate analyses were entered in the equation as independent variables. To facilitate interpretation, patients were assigned into two groups according to age (younger than 70 years versus others). We similarly classified family members into two groups (younger than 60 years versus others). All analyses were conducted by JMP 11.2.1 (SAS Institute Inc., Cary, NC, USA).

Results

Of the 966 bereaved families to whom the questionnaire was sent, 723 responded. Of these, 74 refused to answer the questionnaire. Of the 649 responses, 266 responses were a blank answer because they had no opportunity for code status discussion with their physician. Of the remaining 383 responses, 45 were excluded due to missing data in primary endpoints. We ultimately analyzed questionnaires from 338 patient families. Table 1 shows the backgrounds of the patients and bereaved families of the study.

The degree of family-reported emotional distress and the need for improvement

The emotional response in code status discussions (percentage, 95% CI (Confidence Interval)) was rated by the families as: not distressed (14%, 10-18), slightly distressed (17%, 13-21), somewhat distressed (33%, 28-38), distressed (26%, 21-31), and very distressed (11%, 8-14). The perceived need for improvement in communication about CPR was rated as: no improvement (68%, 63-73), some improvement (23%, 19-28), considerable improvement (7%, 4-10), and much improvement (2%, 1-4). Family-reported distress and perceived need for improvement correlated weakly but significantly (Spearman's correlation coefficient = 0.39, $p<0.0001$).

Factors potentially associated with primary endpoints

Table 2 shows the timing of conversations, the patient’s condition, the family’s knowledge about CPR and emotion at the time of the first discussion about CPR.

Timing of the discussion and patient condition: With regard to the timing of the discussion, excluding the duplicates, 81%（95% CI: 76–85%）of family members answered the first code status discussion was conducted just before or during admission to the inpatient hospice/palliative care unit. As for the patient's condition from the family's perspective, although about 60% of patients had known their approximate prognosis, only 23% of patients had indicated a prior preference for CPR.

Family's emotion: 87% of family members thought they did not want to prolong suffering and 30-40% of those had a sense of burden or guilt, or perceived a decisional conflict or inability to speak up.

As shown in Table 3, 88% of families answered that discussion took place in a quiet place where privacy was protected and 83% reported the atmosphere was conducive to asking questions. In addition, 57% of families indicated the physician adapted the explanation to the level of the family's preparation. Approximately 52% of families reported that agreement to a DNR policy was required for admission to inpatient hospice/palliative care units. In contrast, only 4% of family members answered the physician showed actual CPR being performed using videos or diagrams and similarly, only 6% were provided with the expected success rate of CPR.

Factors associated with the emotional distress of bereaved families in code status discussions

Compared with the bereaved family members who had low-level emotional distress, family members with high-level distress were significantly more likely to answer that they could not be sure to make the right decision, felt burdened as if they had the patient's life in their hand, hoped for a miraculous and spontaneous recovery of the patient, felt guilty about ending the life of a loved one and felt like they could not voice their opinion about CPR. Also, they were less likely to report that the physician adapted the explanation to their level of their preparation. In addition, these were family members of younger patients, and more likely to report that the patient had distressing physical symptoms with marginal statistical significance.

Multiple logistic regression analyses revealed that associated factors of high-level distress of the family were that the family had stated that they had hoped for a miraculous and spontaneous recovery of the patient (OR: 2.4, 95% CI 1.31–4.43, p=0.0049), and felt like they could not voice their opinion about CPR (OR: 2.07, 1.12–3.81, p=0.02). The experience of the physician adapting the explanation to the level of their preparation was negatively associated with high-level distress of the family members (OR: 0.36, 0.18–0.68, p=0.0015). These findings are presented in Table 4.

Factors associated with family-reported areas for improvement in physician's communication in code status discussions

Compared with the bereaved family members who did not feel the need for any improvement (no improvement group), family members with a perceived need (improvement group) were significantly more likely to answer that they felt burdened with the decision, hoped for a miracle and the patient getting well, felt guilty about ending the life of a loved one, and felt like they could not voice their opinion about CPR. In addition, they were more likely to report that they could not be sure to have made the right decision with marginal statistical significance. The improvement group was significantly less likely to report to have had enough time to discuss the issue over several sessions, that the atmosphere was conducive to asking questions, that the physician adapted the explanation to their level of preparation and that the physician listened to their feelings and concerns as well as explained the patient's medical condition. They were also less likely to report that they were informed in a quiet place where privacy was protected with marginal statistical significance.

Multiple logistic regression analyses revealed that the affirmations to "the atmosphere of the discussion was relaxing enough to ask questions" (OR: 0.36, 0.16–0.80, p=0.012) and "the physician adapted the explanation to the level of their preparation" (OR: 0.47, 0.23–0.96, p=0.037) were negatively associated with a family-perceived need for improvement. These findings are presented in Table 5.

Discussion

Discussion of results

One important finding from this study is the family's assessment of the physician's communication during code status discussion. Thirty-seven percent of family members reported high levels of emotional distress and 32% of these reported a need for improvement in communication in code status discussions.

The second and most important finding of this study is the identification of factors associated with both family-perceived emotional distress and need for improvement in code status discussions. Factors positively associated with family-perceived high-level emotional distress were having hoped for a miracle and spontaneous recovery, and having felt like the family could not voice their opinion on CPR. Univariate analysis supported previous qualitative studies that reported the code status discussion can raise negative emotions such as guilt, ambivalence, conflict[17] and that while they did not want to intensify the patient's suffering, they sometimes found it emotionally difficult to accept death[18]. The family's experience of the physician adapting the explanation to their level of their preparation was negatively associated with high-level emotional distress. This finding, taken together with the univariate analysis results, strongly supports the findings of previous studies that quality communication and psychological support from health care professionals are of paramount importance[17], and strongly recommended[14,15].

Factors negatively associated with a family-perceived need for improvement were that the atmosphere of the discussion was relaxing and conducive to asking questions and that the physician adapted the explanation to their level of preparation.

Taken together, the association of the need for improvement and the family member's feeling of conflict, guilt and ambivalence, and its negative association with the family's experience of emotionally sensitive communication, our study strongly supports the conclusions of qualitative research[17], review articles[2,14,15] and the delphi study[16].

The third finding of this study is the determination of the current status of code status discussions of patients admitted to inpatient hospice/palliative care units in Japan. Fifty-seven percent of families indicated that the first explanation about CPR took place just before admission, and 52% of families reported that agreeing to a DNR policy was required for admission. This may mean that approximately half of code status discussions take place because consent to a DNR policy is required for admission. This result was consistent with an unpublished survey conducted by Hospice Palliative care Japan in 2013, which found that in 135 of 190 facilities (71%), admission is conditional on either the patient or the family agreeing to the DNR policy at the time of admission. Moreover, 34% of family members answered the first code status discussion was held after inpatient hospice/palliative care admission. Hence, for advanced cancer patients who were willing to be admitted to inpatient hospice/palliative care, we estimate most code status discussions may be conducted by a palliative care physician, referring physician in charge, or health care professional working in hospice/palliative care administration and discharge planning section. As pointed out in previous studies, a trusting relationship between the patient and their family with the health care provider is important when discussing code status[2,14]. However, given the condition outlined above, patients may be asked to agree to the DNR policy by healthcare professionals with whom they do not have a sufficiently trusting relationship, which may increase their distress.

Implications to practice

Based on our findings, we consider the following are important to improve code status discussions; 1) create an atmosphere where family members can comfortably ask questions; 2) start by discussing the goals of care, taking particular care with asking the patient and their family about their understanding of the condition and disease prognosis; 3) proceed with the discussion at a pace that aligns with their readiness and avoid haste when deciding the code status; and 4) allow families to fully express their feelings and thoughts.

It may also be useful for code status discussions to occur separately, and with the oncologist, rather than as part of the admission process to the inpatient hospice/palliative care unit. This will avoid patients and their families being asked to agree to a DNR policy as a condition of admission to a palliative care unit, by a palliative care physician with whom a trusting relationship has not been fully established.

In addition, improving the system of hospice/palliative care admission and developing educational programs around code status discussions for referring physicians and health care professionals engaged in hospice administration may be crucial. Development of the educational program should be evidence-based, such as incorporating the results of this study, but also involve patients and bereaved families as described in a previous study[21].

Strengths and limitations

The strength of this study is that it was the first large-scale questionnaire survey for family members of advanced cancer patients aiming to describe their degree of emotional distress and perceived need for improvement of communication in code status discussions.

This study had several limitations. First, while this response rate of 75% is considered above average, of the 649 bereaved families who responded, only 338 were included in the analysis, due to many families being unable to recall the code status discussion. Therefore, it is difficult to apply the results of this study to all bereaved families admitted to palliative care units. Second, due to a lack of validated instruments, primary end points were measured without psychometric evaluation such as reliability and validity. Additionally, another questionnaire was also developed based on literature review and specialist discussion. For more accurate assessment, it would be advisable to conduct a qualitative study of the patient's and family's experience of the code status discussion, develop a questionnaire based on the qualitative study, and conduct a psychometrical validation before conducting the study. Third, the study subjects were limited to family members of patients admitted to inpatient hospice/palliative care, so the findings of the study might not be applicable to family members in other settings. Fourth, in the present study we did not investigate who conducted the code status discussion, so it is unclear who should be informed of these results. Fifth, this survey was carried out in 2014 and the results may not be applicable today. Sixth, this study was based on a retrospective evaluation of bereaved family member's experience, and recall bias could exist. Confirmation of the findings will require prospective studies.

In conclusion, when discussing code status, 37% of family members reported emotional distress and 32% of these reported a need for improvement. With distress and a perceived need for improvement being associated with code status discussion suggests physicians should be more attentive to family members' emotions and readiness and not decide on code status in haste. The experience of the bereaved family members may be improved through evidence-based development and implementation of educational programs for code status discussions. Additionally, changing the structure of admission to inpatient hospice/palliative care units to ensure code status discussions are conducted by doctors with an established relationship with the patient/family may be effective improvement.

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Table 1. Background of study patients and their families

Patients		N=338
Age (mean±SD)		73±12 years
Sex	Male	50% (n=169)
	Female	48 % (n=163)
Primary tumor sites	Lung	21% (n=72)
	Pancreas	11% (n=37)
	Stomach	9% (n=31)
	Colon	7% (n=22)
	Liver	6% (n=21)
	Head and neck	5% (n=17)
	Rectum	5% (n=16)
	Gallbladder and bile duct	4% (n=15)
	Breast	4% (n=14)
	Bladder	3% (n=11)
	Uterus	3% (n=11)
	Ovary	3% (n=9)
	Esophagus	2% (n=7)
	Malignant lymphoma	2% (n=7)

	Kidney	1% (n=4)
	Brain tumor	1% (n=4)
	Multiple myeloma	1% (n=3)
	Soft tissue	1% (n=3)
	Leukemia	0.6% (n=2)
	Others	7% (n=23)
Families		
Age (mean±SD)		58±11 years
Sex	Male	33% (n=113)
	Female	65% (n=221)
Relationship to the deceased patient	Child	42% (n=143)
	Spouse	36% (n=122)
	Son/daughter-in-law	8% (n=28)
	Brother/sister	5% (n=18)
	Parent	3% (n=9)
	Others	5% (n=16)
Educational background	Junior high school / elementary school	7% (n=24)
	High school	38% (n=128)

	College	24% (n=81)
	University	26% (n=89
	Graduate school	2% (n=7)
	Others	1% (n=2)

Percentages do not add up to 100% due to missing values.

Table 2. Timing, patient condition, family's knowledge about CPR and emotional state at the time of first conversation about CPR

	Number of family members (N=338)	Percentage (95% CI) [a]
Timing and patient condition[b]		
The patient had distressing physical symptoms.	267	79 (75-83)
The patient was able to talk.	263	78 (74-82)
The patient knew their approximate life expectancy.	198	59 (54-65)
The patient and/or the family member received an explanation about CPR right before the patient was admitted to the hospice/palliative care unit.	187	57 (52-62)
The patient and/or family member received an explanation of CPR only after admission to the hospice/palliative care unit.	110	34 (29-40)
The patient had prior preferences for CPR.	75	23 (19-28)
Family's emotional state[c]		
I (the family member) didn't want to prolong the suffering.	293	87 (83-90)
I (the family member) felt like I could not voice my opinion about CPR.	137	41 (36-46)

I (the family member) felt guilty about ending the life of a loved one.	136	41 (36-46)
I (the family member) felt burdened as if I had the patient life in my hand.	131	39 (34-45)
I (the family member) could not be sure if it was the right thing or not.	115	35 (30-40)
I (the family member) thought, "Maybe a miracle will happen and the patient will get well”.	100	30 (25-35)

[a] CI, confidence interval

[b] The percentage of family members who answered ‘yes’ to each of the binary questions was provided.

[c] The number and percentage of family members who answered ‘strongly agree’ or ‘agree’ on a 5-point Likert scale for each question was described.

Table 3. Family's experience with the physician's communication about CPR

Factors	Number of families[a] (N=338)	Percentage (95% CI)[b]
Informed in a quiet place where privacy was protected	297	88 (84-91)
The atmosphere was relaxing enough to ask questions	280	83 (79-87)
The physician listened to my feelings and concerns as well as explained the patient's medical condition.	221	66 (61-71)
The physician asked me (the family member) to sign a written consent form regarding the policy on CPR.	197	61 (56-67)
The physician adapted the explanation to the state of my preparation	192	57 (52-62)
The physician told me (the family member) that in order to be admitted to a hospice/palliative care unit, I (the family member) needed to agree to a DNR.	174	52 (47-58)
There was enough time to discuss the issue in several sessions.	158	47 (42-52)
The physician said that he thought this was the best choice for the patient.	126	38 (33-43)
The physician told me that he could alleviate the patient's suffering with or without CPR.	95	29 (24-34)
The doctor explained whether CPR would be painful for the patient.	84	25 (21-30)

The physician explained the expected outcome with or without CPR.	67	20 (16-25)
The physician explained the success rate of CPR in detail.	20	6 (4-9)
The physician explained with diagrams or videos that showed actual CPR being performed.	14	4 (2-7)

[a] The number and percentage of family members who answered ‘strongly agree’ or ‘agree’ on a 5-point Likert scale for each question.

[b] CI, confidence interval

Table 4. Factors associated to family-reported emotional distress when communicating about CPR

	Univariate analysis			Multivariate analysis[a]		
	Odds ratio	95% CI[b]	*P* value	Odds ratio	95% CI[b]	*P* value
				R2=0.18, Nagelkerke's R2=0.29		
Background						
Patient's age under 70	1.95	1.24-3.07	0.0035	1.5	0.88-2.56	0.13
Patient's sex male	1.00 (reference)	-	-	-	-	-
Patient's sex female	1.17	0.75-1.84	0.48	n.e.[c]	-	-
Age under 60	1.11	0.71-1.73	0.65	n.e. [c]	-	-
Sex male	1.00 (reference)	-	-	-	-	-
Sex female	1.26	0.78-2.03	0.34	n.e. [c]	-	-
Educational background	0.64	0.41-1.00	0.052	n.e. [c]	-	-
Timing and patient condition						

The patient had distressing physical symptoms.	0.46	0.25-0.84	0.011	0.53	0.26-1.03	0.062
The patient was able to talk.	0.75	0.43-1.30	0.31	n.e. [c]	-	-
The patient knew their approximate life expectancy.	0.87	0.55-1.37	0.54	n.e. [c]	-	-
The patient had prior preferences for CPR.	0.98	0.57-1.69	0.95	n.e. [c]	-	-
The patient and/or the family member received an explanation about CPR right before the patient admission to the hospice/palliative care unit.	0.82	0.52-1.30	0.41	n.e. [c]	-	-
The patient and/or the family member received an explanation of CPR only after the patient admission to the hospice/palliative care unit.	0.8	0.50-1.28	0.35	n.e. [c]	-	-
Family's emotional state						
I (the family member) did not want to prolong the suffering.	0.83	0.44-1.59	0.59	n.e. [c]	-	-
I (the family member) could not be sure if it was the right thing or not.	2.82	1.76-4.52	<0.0001	1.77	0.96-3.26	0.07

I (the family member) felt burdened as if I had the patient life in my hand.	3.07	1.93-4.88	<0.0001	1.35	0.69-2.59	0.38
I (the family member) thought, "Maybe a miracle will happen and he/she will get well".	4.31	2.63-7.08	<0.0001	2.4	1.31-4.43	0.0049
I (the family member) felt guilty about ending the life of a loved one.	3.13	1.97-4.97	<0.0001	1.11	0.55-2.20	0.78
I (the family member) felt like I could not voice my opinion about CPR.	3.19	2.01-5.07	<0.0001	2.07	1.12-3.81	0.02
Family's experience						
Informed in a quiet place where privacy was protected	0.67	0.34-1.30	0.23	n.e. [c]	-	-
There was enough time to discuss the issue in several sessions.	0.64	0.41-1.00	0.049	n.e. [c]	-	-
The atmosphere was relaxing enough to ask questions.	0.65	0.36-1.16	0.14	n.e. [c]	-	-
The physician adapted the explanation to the state of my (the family member's) preparation.	0.42	0.27-0.66	0.0002	0.36	0.18-0.68	0.0015

The physician listened to my (the family member's) feelings and concerns as well as explained the patient's medical condition.	0.57	0.36-0.91	0.018	1.18	0.61-2.34	0.62
The physician said that he thought this was the best choice for the patient.	1.14	0.72-1.80	0.58	n.e.[c]	-	-
The physician told me that for admission to a hospice/palliative care unit, I (the family member) needed to agree to a DNR.	1.24	0.79-1.95	0.35	n.e.[c]	-	-
The physician used diagrams or videos that showed actual CPR being performed.	0.97	0.32-2.97	0.96	n.e.[c]	-	-
The physician explained the success rate of CPR in detail.	0.96	0.37-2.47	0.93	n.e.[c]	-	-
The physician explained the expected outcome with or without CPR.	0.97	0.56-1.70	0.92	n.e.[c]	-	-
The physician told me that he could alleviate the patient's suffering with or without CPR.	0.86	0.52-1.42	0.56	n.e.[c]	-	-
The doctor explained whether CPR would be painful for the patient.	1.1	0.66-1.84	0.7	n.e.[c]	-	-

The physician asked me (the family member) to sign a written consent form regarding the policy on CPR.	1.71	1.06-2.76	0.029	n.e.[c]	-	-

The families who rated their emotional distress level as very distressed or distressed (high-level distress group) were compared with the others (low-level group). Multiple logistic regression analyses used the high-level group as dependent variable.

[a] Multivariate logistic regression using forward selection (likelihood ratio). All factors with p<0.02 identified in univariate analysis were entered.

[b] CI, confidence interval

[c] n.e., not entered,

Table 5. Associated factors of family-reported need for improvements in code status discussion

	Univariate analysis			Multivariate analysis[a]		
	Odds ratio	95% CI[b]	*P* value	Odds ratio	95% CI[b]	*P* value
				R2=0.21, Nagelkerke's R2=0.32		
Background						
Patient's age under 70	1.36	0.85-2.18	0.2	n.e. [c]	-	-
Patient's sex male	1.0 (reference)					
Patient's sex female	1.42	0.89-2.27	0.14	n.e. [c]	-	-
Age under 60	1.16	0.72-1.85	0.54	n.e. [c]	-	-
Sex male	1.0 (reference)					
Sex female	0.72	0.44-1.18	0.19	n.e. [c]	-	-
Educational background	0.8	0.50-1.28	0.052	n.e. [c]	-	-
Timing and patient condition						

The patient had distressing physical symptoms.	1.03	0.58-1.83	0.91	n.e. [c]	-	-
The patient was able to talk.	0.77	0.43-1.39	0.39	n.e. [c]	-	-
The patient knew their approximate life expectancy.	0.92	0.57-1.49	0.73	n.e. [c]	-	-
The patient had prior preferences for CPR.	1.15	0.65-2.03	0.64	n.e. [c]	-	-
The patient and/or family received an explanation about CPR right before the patient admission to the hospice/palliative care unit.	1.18	0.74-1.90	0.49	n.e. [c]	-	-
The patient and/or family received an explanation of CPR only after admission to the hospice/palliative care unit.	0.87	0.53-1.43	0.58	n.e. [c]	-	-
Family's emotional state						
I (the family) did not want to prolong the suffering.	0.88	0.45-1.72	0.7	n.e. [c]	-	-
I (the family) could not be sure if it was the right thing or not.	1.79	1.10-2.91	0.018	0.78	0.39-1.54	0.48

I (the family) felt burdened as if I had the patient life in my hand.	2.53	1.57-4.07	<0.0001	1.65	0.81-3.36	0.17
I (the family) thought, "Maybe a miracle will happen and he/she will get well".	2.71	1.65-4.47	<0.0001	1.49	0.76-2.92	0.24
I (the family) felt guilty about ending the life of a loved one.	2.97	1.83-4.81	<0.0001	1.67	0.80-3.48	0.17
I (the family) felt like I could not voice my opinion about CPR.	2.7	1.67-4.37	<0.0001	1.58	0.82-3.05	0.17
Family's experience						
Informed in a quiet place where privacy was protected	0.36	0.18-0.70	0.0022	0.82	0.35-1.92	0.64
There was enough time to discuss the issue in several sessions.	0.33	0.20-0.55	<0.0001	0.76	0.40-1.45	0.4
The atmosphere was relaxing enough to ask questions.	0.15	0.08-0.28	<0.0001	0.36	0.16-0.80	0.012
The physician adapted the explanation to the state of (the family member's) preparation.	0.22	0.13-0.36	<0.0001	0.47	0.23-0.96	0.037

The physician listened to (the family member's) feelings and concerns as well as explained the patient's medical condition.	0.21	0.13-0.34	<0.0001	0.51	0.26-1.03	0.06
The physician said that he thought this was the best choice for the patient.	0.74	0.45-1.21	0.22	n.e. [c]	-	-
The physician told me (the family member) that for admission to a hospice/palliative care unit, I (the family member) needed to agree to a DNR.	1.27	0.80-2.04	0.31	n.e. [c]	-	-
The physician used diagrams or videos that showed actual CPR being performed.	0.64	0.17-2.38	0.5	n.e. [c]	-	-
The physician explained the success rate of CPR in detail.	0.22	0.05-0.99	0.031	n.e. [c]	-	-
The physician explained the expected outcome with or without CPR.	0.51	0.27-0.96	0.035	n.e. [c]	-	-
The physician told me (the family member) that he could alleviate the patient's suffering with or without CPR.	0.66	0.38-1.13	0.13	n.e. [c]	-	-

The doctor explained whether CPR would be painful for the patient.	0.95	0.56-1.63	0.86	n.e.[c]	-	-
The physician asked me (the family member) to sign a written consent form regarding the policy on CPR.	1.54	0.93-2.54	0.091	n.e.[c]	-	-

The families who rated the need for improvement as ‘much’ or ‘considerable’ or ‘some’ (improvement group) were compared with the others (no improvement group). Multiple logistic regression analyses used the perceived need for improvement group as dependent variable.

[a] Multivariate logistic regression using forward selection (likelihood ratio). All factors with $p<0.02$ identified in univariate analysis were entered.

[b] CI, confidence interval.

[c] n.e., not entered.