Patient Participation and Associated Factors in the Discussions on Do-Not-Attempt-Resuscitation and End-of-Life Disclosure: A Retrospective Chart Review Study

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Research article

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Abstract

Background

Patient participation is a key foundation for advance care planning (ACP). However, a patient himself/herself may be left out from sensitive conversations such as end-of-life (EOL) care discussions. The objectives of this study were to investigate patients’ participation rate in the discussion of Cardiopulmonary Resuscitation (CPR) / Do-Not-Attempt-Resuscitation (DNAR) order, and in the discussion that the patient is at his/her EOL stage (EOL disclosure), and explore their associated factors.

Methods

This is a retrospective chart review study. The participants were all the patients who were hospitalized and died in a university-affiliated teaching hospital (tertiary medical facility) in central Tokyo, Japan during the period from April 2018 to March 2019. The following patients were excluded: (1) cardiopulmonary arrest on arrival (CPAOA); (2) stillbirth; (3) under 18 years old at the time of death; and (4) refusal by their bereaved family. Presence or absence of CPR/DNAR discussion and EOL disclosure, patients’ involvement in those discussions, and their related factors were investigated.

Results

CPR/DNAR discussion was observed in 336 out of the 359 patients (93.6%). The patient participation rate was 33.3% (n= 112). Male gender (odds ratio (OR) = 2.37 [95% confident interval (CI) 1.32-4.25]), living alone (OR = 2.51 [1.34 - 4.71]) and one year or more from diagnosis (OR = 1.78 [1.03 - 3.10]) were associated with patient’s participation in CPR/DNAR discussion. EOL disclosure was observed in 341 out of the 359 patients (95.0%). Half of the patients (n=171; 50.1%) participated in the discussion. Patients who died of cancer (OR = 2.41[1.45-4.03]) and patients without mental illness (OR=2.41 [1.11-5.25]) were more likely to participate in EOL disclosure.

Conclusions

In this clinical sample, only up to half of the patients participated in CPR/DNAR discussion and EoL disclosure. Further attempts to facilitate patients’ participation, based on their preference, are warranted. A few sociodemographic, psychosocial, and medical factors that relate to patients’ participation in the discussion on CPR/DNAR and EOL disclosure were demonstrated.

Background

Advance care planning (ACP), which is defined as a process of assessment and person-centered dialogue to establish an individual's needs and goals of care,[1] enables individuals to define their goals and preferences for future medical treatment.[1, 2] ACP can improve the quality of patient-clinician communication, reduce unwanted admission to hospitals, increase the use of palliative care, and increase patient satisfaction and quality of life.[3]
Providing patients with appropriate information on the expected course of illness and prognosis,\cite{4, 5} and discussing with patients on their preference for medical care are essential parts of ACP.\cite{5} Necessary components of the discussion include the disclosure that a patient's life is at its end-of-life (EOL) stage and the discussion on whether and to what extent a patient prefers to receive life-sustaining at EOL.\cite{1} During these discussions, the topic of full-code Cardiopulmonary Resuscitation (CPR) and Do-Not-Attempt-Resuscitation (DNAR) orders often come up. Having EOL discussion with patients early in the course of their illnesses can result in higher concordance between patients’ prior-stated wishes and actually-received treatments, decrease aggressive care at the EOL, and lead to a better quality of EOL care.\cite{6}

The ways how ACP is implemented are influenced by many factors, such as cultural background, medical system, legal framework, patients’ sociodemographic and clinical characteristics, and preference of patients and their families.\cite{2} Respect for autonomy is an important value in medical ethics, and the involvement of patients themselves is an essential part of ACP. However, the level of patients’ involvement varies between different societies and clinical settings. Especially on sensitive issues such as CPR/DNAR orders and EOL disclosure, a patient himself/herself is sometimes left out from the discussion.\cite{7–9}

There have been only a few studies that evaluated the rate of patients’ participation in such discussions. The concerned studies have been limited to those involving a specific type of illness (e.g. cancer and heart failure) or limited to specific treatment settings (e.g. in palliative care units).\cite{7–13} Also, factors that associate with patient involvement in such discussions have yet been clear.

Therefore, the current study aimed to investigate patients’ participation rate in the discussion of CPR/DNAR orders and EOL disclosure among the patients who died in a hospital due to any cause of illness. Their associated factors were also explored.

**Methods**

**Cohort Description**

This is a retrospective chart review study. The study was conducted in Keio University Hospital, a university-affiliated teaching hospital (tertiary medical facility) in central Tokyo, Japan. All the patients who were hospitalized and died in the study site during the period from April 2018 to March 2019 were eligible. The following patients were excluded: (1) cardiopulmonary arrest on arrival (CPAOA); (2) stillbirth; (3) under 18 years old at the time of death; and (4) refusal by their bereaved family.

**Outcome measures**

The co-primary outcomes were participation of a patient himself/herself in (1) the discussion on CPR/DNAR and (2) the discussion where a clinician disclosed that the patient is at his/her end-of-life stage (EOL disclosure). These information, with related patients’ characteristics, were obtained from the
medical chart. The presence/absence of the discussion was confirmed by a discussion by two researchers (AA and DF).

**Discussion on CPR/DNAR**

We examined discussion on preference on CPR (mechanical ventilation and chest compression) and DNAR in the event of cardiopulmonary arrest with a low probability of recovery. The following information was obtained; (i) presence/absence of the discussion on CPR/DNAR, (ii) the date of discussion on CPR/DNAR (number of days before death), (iii) participants in the discussion (patient, family, and medical staff), (iv) preference of CPR or DNAR, and (v) the reason why the patient did not participate in the discussion (when the patient was absent from the discussion).

**EOL disclosure**

We defined EOL disclosure as the prognostic announcement by treating physicians to patients and/or their families that the patient is at his/her end-of-life stage. The following information was obtained; (i) presence/absence of EOL disclosure, (ii) the date of EOL disclosure, (iii) participants in EOL disclosure; (iv) whether there was a chance for the patient to participate in the discussion on a later date (if the patient did not participate in the first discussion).

**Patients’ characteristics**

Patients’ sex, age, marital status, family structure, cause of death, length of time since the diagnosis to death, length of the last hospital stay, number of hospitalization in the last two years, history of mental illness were collected. The following conditions were defined as mental illness: schizophrenia, mood disorders, neurosis, dementia, epilepsy, mental retardation, pervasive developmental disorders, substance abuse, and continuous use of psychotropic drugs. Delirium was not regarded as a mental illness.

**Statistical analysis**

Since this is an explanatory study, we did not set target sample size. After descriptive analyses, the participants were divided into two groups (whether or not a patient participated in CPR/DNAR discussion and EOL disclosure, respectively), and the characteristics of the patients were compared between those groups. Categorical variables and continuous variables were compared using chi-square tests, and non-parametric tests, respectively. Multivariate logistic regression analyses were conducted to explore factors that associate with patients’ participation in the discussions. A p-value of <0.05 was considered statistically significant. All analyses were conducted using IBM SPSS version 24.0 and 25.0 (IBM Corp., Armonk, NY, USA).

**Ethical consideration**

This study conformed to the Declaration of Helsinki and was approved by the ethics committee of Keio University Hospital (Approval number: 20190034). Permission to collect and analyze data was given by
the bereaved family by opt-outs.

Results

Sample characteristics

Among the 377 patients who were hospitalized and died during the study period, 19 patients were excluded (CPAOA: n = 12, stillbirth: n = 2, and under 18 years old: n = 5). Finally, the data of 358 patients were subjected to analyses (Supplemental material 1).

The patient characteristics are shown in Table 1. Two thirds of the deceased patients were male and the patients’ mean age was 70 years old. Approximately 60% of the patients died of cancer.
| Characteristics                           | n (%)     |
|-----------------------------------------|-----------|
| Age, years (mean, SD)                   | 69.9 ± 15.1|
| Gender: Male                            | 229 (64.0%)|
| Marital status: Married                 | 236 (65.9%)|
| Family structure                        |           |
| Living alone                            | 67 (18.7%)|
| Couple only                             | 134 (37.4%)|
| Living with other families              | 157 (43.9%)|
| Number of hospitalization in the last two years (mean, SD) | 3.5 ± 3.0 |
| Diagnosis                               |           |
| Cancer                                  | 206 (57.5%)|
| lung                                    | 47 (13.1%)|
| lymphoma                                | 18 (5.0%)|
| colorectal                              | 15 (4.2%)|
| gastric                                 | 12 (3.4%)|
| uterine                                 | 11 (3.1%)|
| renal                                   | 10 (2.8%)|
| gallbladder, bile duct                  | 9 (2.5%)|
| pancreatic                              | 9 (2.5%)|
| leukemia                                | 9 (2.5%)|
| others                                  | 66 (18.4%)|
| Non-cancer                              | 152 (42.5%)|
| Respiratory disease                     | 54 (15.1%)|
| Cardiovascular disease                  | 29 (8.1%)|
| Liver disease                           | 16 (4.5%)|
| Cerebrovascular disease                 | 15 (4.2%)|
| others                                  | 38 (10.6%)|
| Presence of mental illness: yes         | 51 (14.2%)|
**Discussion on CPR/DNAR**

Discussion on CPR/DNAR was observed in 336 out of the 358 patients (93.9%). Twenty-one patients and their families had no opportunity to discuss CPR/DNAR due to unexpected death. In one patient, there was no written information on CPR/DNAR discussion (Figure 1).

Of the 336 patients who had CPR/DNAR discussion, 112 patients (33.3%) participated in the discussion. Among them, 91 patients (81.3%) participated in the first discussion, and the rest participated in later opportunities (after a discussion was held between the family and the physician in charge). The most common reason for patients’ not participating in the first discussion was the patient's decreased consciousness (n=119: 48.6%), followed by doctors’ judgment (n=107: 43.7%) and requests by their family (n=11: 4.5%). In those first discussion, approximately 60% of the patients reached DNAR order (with patient: 63.7%, without patient: 57.1%), 10% retained full-code CPR (with patient: 9.9%, without patient: 13.1%), and 30% undecided (with patient: 26.4%, without patient: 29.8%). The presence or absence of the patient in the discussion did not have significant influence on the decision. Eventually, 96.4% of the patients made DNAR decisions.

The characteristics of the patients who participated in the CPR/DNAR discussion are shown in Table 2. The patients who were male, younger, living alone, without mental illness, with a larger number of hospital admission in the last two years, with a longer period from diagnosis of the main disease until death, and who died of cancer were more likely to participate in CPR/DNAR discussion.

The logistic regression analysis using these factors as independent variables demonstrated that male gender (odds ratio (OR) = 2.37 [95% confident interval (CI): 1.32-4.25]), living alone (OR = 2.51 [1.34-4.71]) and one year or more from diagnosis (OR = 1.78 [1.03-3.10]) were associated with participation of patients themselves in the CPR/DNAR discussion (Table 3).
Table 3  
Odds ratios for participation in CPR/DNAR discussion

| Variable                          | Odds ratio | 95%-CI  | p-value |
|-----------------------------------|------------|---------|---------|
| age                               | 0.99       | 0.97-1.01 | 0.30   |
| male gender                       | 2.37       | 1.32-4.25 | <0.01  |
| number of hospitalization         | 0.99       | 0.91-1.07 | 0.78   |
| living alone                      | 2.51       | 1.34-4.71 | <0.01  |
| cancer (vs. non-cancer)           | 1.72       | 0.98-3.01 | 0.06   |
| absence of mental illness         | 2.16       | 0.87-5.35 | 0.095  |
| more than one year from the diagnosis (vs. less than one year) | 1.78 | 1.03-3.10 | 0.04   |

CI=confidence interval

**EOL disclosure**

EOL disclosure was observed in 341 out of the 358 patients (95.3%). Seventeen patients and their families had no opportunity to participate in EOL disclosure because they died of unexpected sudden physical change. (Figure 2)

Of the 341 patients who had EOL disclosure, 171 patients (50.1%) participated in the discussion. Among them, 137 patients (81.1%) participated from the first opportunity and the rest participated at later opportunities (after a discussion was held between the family and the physician in charge). The most common reason for patients’ not participating in the first opportunity was decreased consciousness (n=108: 52.9%), followed by doctors’ judgment (n=83: 40.7%) and by families’ requests (n=8: 3.9%).

The characteristics of the patients who participated in the EOL disclosure are shown in Table 2. The patients who were younger, living alone, without mental illness, with a larger number of hospital admission in the last two years, with a longer period from diagnosis of the main disease until death, and who died with cancer were more likely to participate in the EOL disclosure.

The logistic regression analysis demonstrated that dying of cancer (OR=2.41[1.45-4.03]) and without mental illness (OR=2.41 [1.11-5.25]) are associated with patients’ participation in the EOL discussion (Table4).
## Table 4

### Odds ratio for participation in EOL disclosure

| Variable                          | Odds ratio | 95%-CI       | p-value |
|-----------------------------------|------------|--------------|---------|
| age                               | 0.99       | 0.97-1.00    | 0.09    |
| male gender                       | 1.36       | 0.81-2.28    | 0.25    |
| number of hospitalization          | 1.06       | 0.97-1.15    | 0.22    |
| living alone                       | 1.83       | 0.97-3.47    | 0.06    |
| cancer (vs. non-cancer)            | 2.41       | 1.45-4.03    | <0.01   |
| absence of mental illness          | 2.41       | 1.11-5.25    | 0.026   |
| more than one year from the diagnosis (vs. less than one year) | 1.66       | 0.99-2.77    | 0.054   |

CI=confidence interval

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**Association between the participation in CPR/DNAR discussion and EOL disclosure**

There was a significant association between the patients’ participation in CPR/DNAR discussion and the patients’ participation in EOL disclosure (Spearman’s rank correlation coefficient = 0.49, p < 0.05).

**Discussion**

In the current study, the authors elucidated 1) prevalence of EOL discussion and CPR/DNAR discussion, 2) participation rate of patients in those discussions, and 3) the factors associated with such participation. To the best of authors’ knowledge, this is the first study to elucidate the factors that relate to patients’ participation in the discussion on CPR/DNAR and EOL disclosure.

Approximately 5% of deceased patients had no chance of EOL discussion (including CPR/DNAR discussion), mostly due to unexpected in-hospital death. Considering that unexpected in-hospital cardiac arrest occurs in a nonnegligible proportion of hospitalized patients,[14] all the patients who admit to the hospital may be eligible for discussion on EOL care in preparation for deterioration. Indeed, the American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care recommends that physicians should initiate a discussion on CPR/DNAR with all the patients admitted for medical and surgical care.[15]

Only one-third of our participants had a chance to participate in their CPR/DNAR discussion, and only a half had a chance to participate in the EOL disclosure. These participation rates are higher than those in the previous studies in Japan, which ranged from 0 to 6%,[10, 12, 13] but lower than in those of the
studies from USA, Switzerland, and Finland, which ranged from 37 to 80%. The definitions of EOL discussions vary among the studies and simple comparison is difficult, however, there are several possible reasons. First, the rate of patients’ participation increases as the time of the survey becomes more recent. The rise in the participation rate probably reflects the growing interest in ACP. Second, the participation rate can be influenced by the legal background and health care system of the belonging society. Patient involvement ought to be higher in the societies where advance care planning and/or advance directive are mandatory in a certain situation (e.g. USA[20] and Taiwan[21, 22]). Third, cultural perspectives and patients’ (and family’s) preferences that stem from them can be influential. Authentic Japanese culture lay value in ambiguity rather than explicitness compared to Western societies. For example, research on the concept of “good death” indicated that many Japanese do not want to know the seriousness of their condition. While 96% of USA patients emphasized that “knowing what to expect about one’s physical condition” helps them achieve a “good death”,[23] only 50% – 69% of Japanese patients agreed to such conception. A nationwide survey demonstrated that the majority of Japanese general population considered “dying without awareness that one is dying” as an important factor to achieve a good death, and approximately half of the general population considered that “not being informed of bad news” is an important issue during the last days of life.[24] Decreased consciousness hampered approximately one third of the patients from participation in the CPR/DNAR discussion. The discussion should have been initiated earlier for these patients. In principle, ACP should be better started earlier than later, especially in patients who have life-threatening diseases,[2, 4], however, actual timing of ACP is more complex since it is influenced by many factors such as patient’s preferences, readiness, and medical conditions.[1, 2, 15] Using routine assessments, such as the Advance Care Planning Readiness Scale (ACPRS),[25] may help promote ACP. Paladino, et al demonstrated that a systematic intervention comprising training of clinicians based on a manual (the Serious Illness Conversation Guide: SICG), family materials, and system changes (patient identification using the “surprise question”, email reminders, and documentation templates on ACP) resulted in the improved implementation of serious illness conversations.[26] Approximately 40% of the patients did not participate in their first discussion due to the judgment by their treating physicians. According to an international study that surveyed physicians’ attitudes toward patient autonomy, 82% of the Japanese palliative-care physicians agreed that patients should be informed first (rather than family first) of their serious medical condition,[27] however, the current study elucidated that, in reality, physicians tend to talk to the family first.

Medical professionals’ readiness, in addition to patients’ and families’ readiness, matters in initiating ACP. Medical professionals need to have the necessary skills and show an openness to talk about diagnosis, prognosis, death, and dying with individuals and their families.[1] Chu et al demonstrated that the implementation of palliative care training for healthcare providers and a program to routinely implement ACP for hospitalized patients with chronic life-limiting illness is feasible and successful in Taipei.[21] Providing physicians with appropriate educational opportunities and training, such as end-of-life care, psychological support for patients and their families, and communication skills training is essential.
The current study elucidated the factors that relate to patients’ participation in the discussion on CPR/DNAR and EOL disclosure. Whether a patient him/herself participates in the discussion on CPR/DNAR is mostly influenced by sociodemographic factors rather than medical factors.

Male patients are more likely to be involved in a discussion on CPR/DNAR. There have been only a few studies that examined the association between gender and patients’ involvement in CPR/DNAR discussion. In a multisite registry study in the United States, Perman et al. reported that women are more likely than men to establish DNAR. Other studies, including a study that enrolled hospitalized older adults who required a surrogate decision-maker in the United States and a Taiwanese study that enrolled cancer patients, demonstrated no significant gender difference. We speculate that there are some paternalistic perspectives in Japan that autonomy is more emphasized among men than women, while women need to be “protected” from serious medical information. A further large-scale, multisite survey is needed to uncover potential mechanisms of gender difference.

The patients who live alone are more likely to participate in CPR/DNAR discussion. Probably this is due to a practical reason that patients living alone lack clear proxy decision-makers. Without a DNAR discussion, there is a risk of providing unnecessary life-sustaining treatment in case of sudden changes in their physical conditions and causing discomfort to the patient due to the treatments against their wishes.

The patients who had one year or more from the diagnosis were more likely to participate in CPR/DNAR discussion. This result was consistent with the previous Japanese study. The longer the course of the illnesses is, the more prepared the patients become for their future (including death). Trust between the patient and the treating physician may be cultivated during the course of the illness. The treating physicians have more opportunities to understand the patient's background, personality, and sense of value, which makes sensitive discussion with the patient easier.

The patients who died of cancer were more likely to participate in EOL disclosure than patients who died of non-cancer illnesses. This is probably because the course of non-cancer diseases, such as heart failure and chronic respiratory diseases are generally less predictable than cancer. However, clinical practice such as using of the “surprise question” - a simple question for clinicians to ask themselves “Would I be surprised if this patient died in the next 12 months?” - can help identify patients at high risk of death who might benefit from palliative care services. This surprise question has been shown to have good predictability in patients with cancer, decompensated heart failure, and end-stage chronic kidney disease.

The patients with a mental illness were less likely to participate in EOL disclosure. Various mental conditions were included in the current study, and they were roughly classified into the following three categories; psychological distress (depression and anxiety), serious mental illnesses (schizophrenia, bipolar disorder, and psychotic depression), and cognitive disorders (e.g. dementia). Several studies showed that accurate prognostic understanding is associated with elevated depression and anxiety, thus it is well-understandable that clinicians feel afraid that telling their patient that he or she is at his EOL stage may worsen his or her mental conditions. However, since EOL discussions are associated with
less aggressive medical care near death and early hospice referrals,[9] and there is some evidence that most metastatic cancer patients want detailed prognostic information,[38] disclosing accurate prognostic information while minimizing psychological distress of patients is a challenging but important issue.[39] Clinicians may consider that patients with serious mental illnesses or cognitive disorders lack decision-making capacity and are not eligible for EOL discussions. The presence of serious mental illness and cognitive disorders does not directly mean that a patient lacks decision-making capacity, clinicians should try their best to let the patient involved in decision making while considering patients’ mental capacity.[40]

The current study has a few limitations. First, since this was a retrospective, chart review study, some potential factors that may influence patients’ participation in CPR/DNAR and EOL disclosure, such as the patient’s decision-making capacity, were not examined. Second, since this was a single-center study with moderate sample size, the generalizability of the results is limited. The study site was an urban acute-care hospital without a palliative care unit, and a substantial proportion of patients were transferred to another hospital or transited to a home-based hospice program at their EOL. The discussion on CPR/DNAR and EOL care may be held in such places. Third, the quality of the chart documentation may differ depending on the doctor who wrote it. Also, undocumented covert discussions between clinicians and patients were not detectable.

Conclusions

Despite these limitations, our study provided a real-world clinical practice of EOL discussion and CPR/DNAR in patients with various diseases. We elucidated a few sociodemographic, psychosocial, and medical factors that associate with the participation of patient him/herself in such discussions. In this clinical sample, patients’ participation in CPR/DNAR discussion and EoL disclosure was modest. Further attempts to facilitate patients’ participation, based on their preference, are warranted.

Abbreviations

ACP: advance care planning
CPAOA: cardiopulmonary arrest on arrival
CPR: Cardiopulmonary Resuscitation
DNAR: Do-Not-Attempt-Resuscitation
EOL: end-of-life

Declarations

Ethics approval and consent to participate
This study conformed to the Declaration of Helsinki and was approved by the ethics committee of Keio University Hospital (Approval number: 20190034). Permission to collect and analyze data was given by the bereaved family by opt-outs in this chart-based retrospective study.

**Consent for publication**

Not applicable.

**Availability of data and materials**

Our IRB does not permit the data to be shared publicly.

**Competing Interests**

MM has received grants and/or speaker's honoraria from sixteen pharmaceutical companies within the past three years but he has no financial or any other kind of personal conflicts with this paper. Other authors do not report any conflict of interest.

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**Author's contributions**

AA and DF conceived and designed the study. AA, MK, and DF collected and analyzed data. AA drafted the manuscript and DF helped drafting the manuscript. TK and SH were involved in interpretation of the data mainly in physical aspects. AA, MT, MM and DF were involved in interpretation of the data mainly in psychosocial aspects. All the authors read and approved the final version of the manuscript.

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**Table**

Due to technical limitations, table 2 xlsx is only available as a download in the Supplemental Files section.

**Figures**
Figure 1
Discussion opportunities and patient participation in CPR/DNAR discussion CPR: cardiopulmonary resuscitation, DNAR: do not attempt resuscitation, IC: informed consent

Figure 2
Discussion opportunities and patient participation in EOL disclosure EOL: end of life, IC: informed consent

**Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

- Supplementalmaterial1.docx
- AbeTable2.xlsx