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Abstract

Object: To investigate whether DNAR orders can be implemented in a standard nursing home in Japan, where routine Do Not Attempt Resuscitation (DNAR) orders are not yet common in many facilities including hospitals.

Method: Ninety-eight residents in a 100-bed nursing home were evaluated. All of the eligible residents and/or their family members were asked if they wanted to receive resuscitation, including mechanical ventilation.

Result: The residents were 54 to 101 years of age (mean 83.3), with 27 males and 71 females. After administering the questionnaire, ninety-two patients (94%) did not want resuscitation and mechanical ventilation.

Conclusion: In a nursing home, it was possible to obtain advance directives by which most residents/families rejected resuscitation and mechanical ventilation. This could avoid unnecessary and undesirable resuscitation procedures.

Key words: advance directives, DNAR order, end-of-life

Introduction

While euthanasia is not legally recognized in Japan, social problems were seen when physicians and other medical staff removed mechanical ventilatory support, according to the patient's family's wish, after starting mechanical ventilation on elderly patients[1]. These problems may occur because of the lack of advance directives, especially when patients and their family have never discussed end-of-life issues. It is reasonable that the lack of advance directives provides no opportunity to talk with each other; talking about end-of-life is regarded as taboo, especially among elderly in traditional Japanese culture [2] as in other Asian countries which believe in Buddhism, such as China [3]. In the United States, the health care staff in hospitals, nursing homes and other skilled nursing facilities, are required by the Patients Self-Determination Act of 1991 [4] to ask patients and residents if they have any advance directives for their health care, including Do Not Attempt Resuscitation (DNAR). However, in Japan, getting advance directives is not a common practice in many hospitals, nursing homes or other skilled nursing facilities. Frequently, the reason resuscitation and other heroic measures are initiated is because no one knows the wishes of the patient/resident or the family. This is particularly problematic in Japan because once mechanical ventilation has been instituted it cannot be terminated unless [4] the patient/resident fully recovers and does not require mechanical

ventilation or [5] the patient/resident dies. Advance directives from terminally ill patients and the elderly can help avoid unnecessary and undesirable resuscitation techniques, including mechanical ventilation, as well as reduction of medical cost. Although this kind of issue is inevitable, it has been thought to be taboo in Japan because of the traditional culture, as above mentioned.

Due to an aging society in Japan, the number of elderly who live by themselves increases each year [6,7], necessitating the establishment of a protocol for getting advance directives. This is the first report demonstrating advance directives in a Japanese nursing home. It is hoped that this will provide assistance for clinicians to help improve rapport with patients and their families to discuss advance directives.

Methods

Ninety-eight residents, who stayed more than one week between May 2006 and September 2006 in a 100-bed nursing home, were studied. The residents were asked the question, “Would you like to receive mechanical ventilation to save your life when necessary?” Eighty of the ninety-eight residents had mild to moderate or severe dementia and were not questioned as to their wishes for resuscitation, however, their next-of-kin were asked the question, “Would you like him or her to be on a ventilator when

necessary?" This study was approved by the Institutional Review Board.

Results

The residents were 27 males and 71 females. The mean age was 83.3 (range 54 to 101) years. The proportion of age and sex of the residents are shown in Table 1. The primary reasons for admission to the nursing home are: 40 (41%) Cerebrovascular disease, including trauma, 32 (33%) dementia, 22 (22%) orthopedic diseases and 4 others (Arteriosclerosis obliterans, rheumatoid arthritis, disuse atrophy of muscles and multiple myeloma). Dementia was classified with the Mini-Mental State Exam (MMSE). It is a reliable and valid measure of cognitive impairment and is used to assess memory, concentration and other cognitive skills.

Desire for Mechanical Ventilation prior to Questioning

Eighteen residents or their /next-of-kin (18%) expressed their wish not to be resuscitated if it became necessary before being questioned and, therefore, they were not asked their opinion again. Among the remaining 80 residents, the next-of-kin of six residents (6%) had expressed their wish to initiate mechanical ventilation to prolong

his/her life. The family of one resident (1%) requested mechanical ventilation only until another family member, who was away at the time, was able to see the resident before he expired. Once this family member saw the resident, they wanted mechanical ventilation to be withdrawn. There were no records of the wishes for the families of 73 residents (74%) as shown in Table 2.

Desire for Mechanical Ventilation after Questioning

The families of the six residents who initially wanted to use mechanical ventilation and the one family who had been wishing to prolong the resident's life until members arrived, changed their mind and expressed their intention not to use mechanical ventilation after understanding the characteristics of the machine and learning that it is not legal to terminate the machine while the heart is beating, even when there is very little hope for recovery. Among the 73 families who had not expressed their wish, one family expressed their desire to use mechanical ventilation when necessary. Among the remaining 72 families, five could not make a definite conclusion and 67 expressed their wish not to use mechanical ventilation. Thus, eventually after asking the question related to receiving mechanical ventilation, 92 families ($18 + 6 + 1 + 67 = 92$) were against the use of mechanical ventilation. See Table 2.

Interval Between Initial Questionnaire and Final Response

The majority (84%) of the families made a decision immediately at the time of questionnaire as to whether they wanted mechanical ventilation or not. Five families had to discuss the issue with additional family members and thus, responded several days later. Two families had to consider the question longer and responded after one week. Three families could not come to a decision at the time of this writing. Two families responded immediately saying “I have no idea.” Thus five families (3 + 2 = 5) could not make a decision to decline mechanical ventilation, resulting in a “yes” for the use of mechanical ventilation, when necessary (Table 3).

Reason for the Change in Decision

The families of six of the seven residents who wanted mechanical ventilation prior to the questionnaire came to the nursing home and discussed with the physician, in person, the use of mechanical ventilation. Each of the families decided immediately to decline the usage of mechanical ventilation after understanding its nature. The daughter of the seventh resident had expressed the desire for the use of mechanical ventilation when asked over the phone, since she could not come to the nursing home at that time. Five

months later, she visited her mother at the nursing home. She was asked again, in person, and she decided to decline the usage of mechanical ventilation. One resident's husband passed away after the decision to accept mechanical ventilation had been made and the remaining family member, her brother-in-law, did not wish for mechanical ventilation. The family of one resident had not intended to wish for mechanical ventilation, but their desires were misunderstood, resulting in the conclusion that the resident wanted full resuscitation efforts.

In general, family members are not well aware of the negative nature of the ventilator for the aged. Once they fully understand the significance of mechanical ventilatory support, they tend to decline the mechanical ventilation. See Table 4. Two residents did not have dementia and expressed their wish as "I let the family decide."

Residents Who Received Mechanical Ventilation

For the six residents who resulted in receiving mechanical ventilation, only one family (a son of the resident) expressed his wish clearly and said "yes" when asked if he wanted mechanical ventilation. The remaining five residents resulted in the implementation of mechanical ventilation because they could neither decide nor give a definitive response as to whether or not they wanted to institute mechanical ventilation.

See Table 5.

Discussion

Having advance directives, with or without DNAR orders, in nursing homes as well as in hospitals is common in the United States. Messinger-Rapport reported that 40% of nursing home residents have DNAR orders [5] and Terry reported that figure is over 60% [8]. In contrast to this, advance directives are very rare in Japanese nursing homes and not yet common for many Japanese hospitals. Of the 115 nursing homes in Japan's Chiba prefecture, including the facility in this study, none of the 20 randomly sampled nursing homes routinely obtained advance directives or resultant DNAR orders.

It has been demonstrated that there is a misunderstanding among physicians when asking about advanced directives. Physicians tend to think that patients who are not so severely ill or old don't like to discuss this issue. In fact, patients do not want to discuss this kind of issue, regardless of age and medical condition [9]. We speculate that these misunderstandings by clinicians may prevent the discussions related to advance directives. In such cases, no one knows the residents' and/or next-of-kin's wishes for the adoption of resuscitation procedures including tracheal intubation followed by mechanical ventilation. In urgent situations, this (not asking or not knowing their

wishes) results in the routine administration of resuscitation, which occasionally ends up being against the resident's or the families' wishes of allowing the residents to pass away as a natural consequence without such intervening procedures. This is especially a problem in Japan because termination of mechanical ventilation while the patient is still alive, regardless of the prognosis, is regarded as murder by the legal system.

One way to avoid such a tragedy is to get advance directives routinely in nursing homes and hospitals. Thus, the physicians in the facility in which this study was conducted started getting advance directives in terms of the use of mechanical ventilation for all of the residents in the nursing home.

In this study, ninety-two (94%) of the 98 residents/families chose to request a DNAR order after the questionnaire. One possible explanation for this high percentage might be due to the information provided to help make sure that the residents and/or next-of-kin were fully informed of what it means to be resuscitated and receive mechanical ventilation. The following comments related to mechanical ventilation were explained to the patients and/or their families.

- Mechanical ventilation can cause pain and discomfort to the resident, especially at the time of intubation.
- Mechanical ventilation does not cure heart or lung dysfunction. It supports

ventilation and gas exchange, but does not return the lung to normal function. This situation is similar to kidney dialysis, which has no power to improve renal function no matter how many years you rely on it. Thus, naturally, there is no guarantee that the resident will recover, even if he/she remains on mechanical ventilation. In fact, realistically it is unlikely the resident will return to a normal healthy state because of the age and relatively limited vital organ function.

- In addition to the pain and discomfort at the time of intubation and initiation of mechanical ventilation, the need for a tracheostomy may arise. A tracheostomy is generally considered if the patient requires mechanical ventilation for more than two or three weeks. This is a surgical procedure with complications of its own.
- These hardships the resident has to endure could be mental torture for themselves and for their family members, especially when this situation may last for months or even years and he/she still may not be able to fully recover.
- The medical expenses incurred from the intensive care unit and mechanical ventilation are far from negligible, while you may say you are rich enough and afford it.
- In Japan, and in other countries throughout the world, once mechanical ventilation has been initiated, it cannot be stopped legally until the patient improves or dies.

Even if the family is aware of the hardship the patient has to endure and they may want to stop it, they are not able to because it is illegal.

Previous studies reported that knowledge of the elderly regarding life-sustaining procedures was poor, and that they overestimated the effectiveness of CPR [10-14]. However, they tend to choose a DNAR order after they received and understood more information related to the procedures. In addition, most residents appear either to have their own experiences of admission in acute care wards or have friends/relatives admitted into a hospital due to critical illness. These personal experiences of such procedures and exposure to the ward might have affected their attitudes towards end of life decisions to avoid possibly futile procedures.

Several problems were encountered before, during and/or after the process of explaining the situation to the residents and families. Family members of 15 residents did not want to come to the nursing home for the meeting because they lived very far away. In these fifteen cases, the physician discussed the situation with them over the phone. This is not optimal since clear communication without seeing each other is often difficult, especially on such delicate topics. It is important to establish rapport and trust with the resident and family before discussing this issue. When trying to setup a phone call to have an appointment for the conversation, some family members appeared to

avoid the meeting. Such avoidance may be their way of expressing their thought that they do not want to consider the option of DNAR. It is important to respect their avoidance and it should be interpreted as a sign to initiate mechanical ventilation when it is needed.

Some family members did not like discussing this topic; it was obvious from their facial expressions. Because an elderly person and his/her family could easily get nervous when talking about issues related to death, getting advance directives is stressful, even for attending physicians. Thus, it is reasonable that physicians tend to be reluctant to discuss these issues with the residents and their family members.

In the United States, there is a low frequency of a living will (LW) in patients admitted to adult ICUs (0 to 13%) [16-18] and in units for the chronically critically ill (16 to 38%) [19,20], even though all of the patients should be given the opportunity to discuss advance directives according to the Patient Self-Determination Act (PSDA). Nevertheless, obtaining advance directives allows many residents/family members to be free from undesirable mechanical ventilation.

One possible way to decrease or overcome the discomfort in talking about the issue is to explain, thoroughly, the necessity and importance of asking the question.

The discomfort of asking the question, “Would you want him/her to be mechanically

ventilated when necessary?”, may be diminished with the following questions and statements:

- I apologize in advance for asking the following question, but it is very important to ask you to avoid unnecessary and/or undesirable procedures which you may not want.
- The reason to ask the question is to fulfill your wishes and the wishes of your family member. Unless we know what those wishes are, we cannot meet them. However, answering the question is a right, not a duty. You have no obligation to answer. You only have the right to answer. We have a duty to decide, but you do not. When you do not decide, that means we have to go ahead and start mechanical ventilation, when it is deemed necessary.
- While mechanical ventilation cannot be stopped once it is started, you can change your mind as many times as you like before we initiate it.
- Some family members could not answer clearly and told the physician they would inform him later and ended up giving no answer. Two or three phone calls were placed to ask whether a decision had yet been reached, however, if they still could not decide, it was decided that it was not appropriate to ask further, since they have no duty to decide and no answer is one kind of answer.

Getting advance directives does not result in the reduction of medical care. Halpern, et al. have demonstrated that medical procedures and survival times in patients at an oncologic intensive care unit did not correlate with whether LWs were confirmed or not [21].

As for medical economics, expansion of medical expense is a serious problem in every country, especially where an aging society is developing. Unfortunately, unnecessary intubations and admissions to the intensive care unit are widely performed without the patients' and /or their family's sufficient consent in Japan. Osakabe, et al documented that medical cost for the elderly in emergency medical care unit was 2.5 to 3 times more expensive than for younger patients. Medical expenses needed for the elderly to be completely recovered would cost as much as \$80,000 (US dollars) per person, which is 50 times more expensive than non-elderly patients admission cost in emergency unit [15]. While the survival rate is controversial [22-24], ventilated elderly patients seem to have higher disability compared with otherwise identical patients who survived without mechanical ventilation [25].

Discussing the problems related to the medical cost for terminally ill elderly patients has been taboo in Japan. These problems, as well as the one we encountered and mentioned above, are the possible reasons physicians tend to be reluctant to discuss

these issues with the residents and their family members. Physicians must understand these facts and provide the patients and their family correct information, which should result in getting advance directives.

It is believed that getting advance directives would result in the reduction of unnecessary procedures and medical staff labor as well as saving medical costs, without a decline in quality of medicine. While some families are well informed by mass media or other methods about the meaning and the character of resuscitation and mechanical ventilation, others are quite ignorant about it. In such cases, the physician needs to explain the situation thoroughly and patiently. This is time-consuming, but should be rewarded by the avoidance of possible future problems. This is especially rewarding socially in terms of saving the limited medical resources when the resident and or family members change their opinions and end up not desiring the use of mechanical ventilation. Taking the time to discuss this issue with the resident and family should allow for advance directives and reduce the number of times family members object to continuation of mechanical ventilation once it has been initiated.

After this study, the authors decided to be flexible at the time of the residents' admission and accept the family members' wish not to ask the same question to the resident if he/she was over 80 years of age and quite disabled, even if the resident did

not have dementia. As a result, the patient was placed on a DNAR list to avoid the presumably rare, but possible, conflict between the resident and family members on this matter. While there could be criticism for ignoring the autonomy (self-determination, a basic human right) of the resident, the rationale would be the following:

- It is the family members who have to bear the burden of taking care of the resident, even when he/she becomes in a persistent, vegetative state receiving mechanical ventilation.
- It is not felt that the potential benefit to the resident being mechanically ventilated can be greater than the hardship the family members face because of the age and the poor organ function, in addition to the well-known poor outcomes of mechanically ventilated aged patients. In other words, residents are not losing much when being deprived of their autonomy. It is felt that they could gain a lot by not having to experience the hardship of mechanical ventilation. The low percentage of survivors (1%) for residents who arrest while in a nursing home (4) should support this idea.
- Thus, it would still be ethical not to abide by the principle of respecting the resident's autonomy and avoid being a fundamentalist, considering the family members' mental and possibly economical hardship.

This study has one limitation. This is a retrospective study in a very small population.

Retrospective studies may be less reliable in terms of the data collected.

Conclusion

It is possible to obtain advance directives in a nursing home without confronting extraordinary troubles or complaints. In most cases, aged residents and family members of the aged denied the initiation of mechanical ventilation. Implementing advance directives in the nursing home has a potential to enhance the residents' and their family members' satisfaction by conducting medical practice which is consistent with their wishes.

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Conflict of interest statement

The authors have no conflicting interests.

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None declared.

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Table 1. Age and Sex of Residents

Age (years)	Male	Female	Total Number	Percent
50 – 59	1	1	2	2%
60 – 69	2	1	3	3%
70 – 79	7	15	22	22%
80 – 89	12	37	49	50%
90 – 99	5	16	21	21%
100 +	0	1	1	1%
Totals	27	71	98	100

Table 2. Desire For Mechanical Ventilation; Before and After Questionnaire

	Before Questionnaire	After Questionnaire
Desire	Number (%)	Number (%)
Yes	6 (6)	1 (1)
No	18 (18)	92 (94)
Temporary	1 (1)	0 (0)
No record	73 (74)	
Unknown		5 (5)
Total	98 (100)	98 (100)

Yes means “want mechanical ventilator support if it is necessary”.

No means “does not want mechanical ventilatory support, even if it is necessary”.

Temporary means “wants mechanical ventilatory support until family arrives”.

No Record means “the resident and/or family had not expressed their wishes previously”.

Unknown means “resident and/or family unable to make wishes known”.

Table 3. Interval Between the Question and the Final Response (80 families)

Time frame of response	Want mechanical ventilation	Dementia		Number (%)
		Yes	No	
Immediate Response	No	52	14	66 (83)
	Yes	0	1	1 (1)
	No idea	2	0	2 (3)
Within One Week	No	5	0	5 (6)
Beyond One Week	No	3	0	3 (4)
Pending (Considering)		2	1	3 (4)
		64	16	80 (100)

Table 4: Reason for Change in Decision to Accept Mechanical Ventilation

Age	Sex	Health Status	Desires before Questioning	Desires after Questioning
83	F	Hemiplegia, Wheel Chair, Dementia	One of the children staying overseas and family could not decide when asked over the phone	Talked in person and decided not to use the ventilator
85	F	Dementia, Wheel Chair	Husband had asked for the ventilator	The question was asked to the brother-in-law, since there were no children and the husband had died
77	F	Hemiplegia, Able to Walk, Dementia	Wanted the ventilator if there was hope	After explaining that all patients have some hope, she did not want the ventilator.
79	M	Hemiplegia, Wheel Chair, Dementia	Daughter had not understood the nature of the ventilator	After learning what it meant, she did not want mechanical ventilation
83	M	Hemiplegia, Wheel Chair, Dementia	The family had not wanted the ventilator. They wanted to prolong life, but without using a ventilator	The misunderstanding was resolved
74	F	Hemiplegia, Wheel Chair, Dementia	Asked for the ventilator without really understanding its meaning	After learning what it meant, they did not want the ventilator
88	F	Fracture, Able to Walk, Dementia	When asked over the phone, they wanted to use the ventilator	After discussing the issue in person, they did not want the ventilator

Table 5. Residents Who Resulted in Mechanical Ventilation When It Was Necessary

Age	Sex	Reason for Deterioration	Mobility Status	Response of the Family
75	M	Hemiplegia	Wheel Chair	Wanted the resident to live more
79	F	Parkinson	Wheel Chair	"No idea"; could not decide
86	M	Hemiplegia	Wheel Chair	"No idea"; could not decide
81	F	Fracture	Wheel Chair	"We will answer later"; however, no reply for more than one year
80	F	Stroke	In Bed with PEG	"We will answer later"
80	M	Hemiplegia	Wheel Chair	"We are considering it"

* PEG, Percutaneous Endoscopic Gastrostomy Tube