Original

Differences in recognition of life-prolonging treatment for medical workers and non-medical workers: Need for support by nurses for elderly patients and their families in decision-making

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Abstract: Background: With the aging of Japan's society elderly people over 65 years account for 23.1% of the population, and hospitals and institutions are crowded with patients who are incapable of making decisions regarding their own LST.

Objectives: This study aims to assess how much healthcare professionals and elderly people in the community know about LST, whether they wish for the use of LST for end-of-life care, and to what degree they wish each LST and to explore the roles of nurses in the healthcare team. Methods: A questionnaire survey was conducted in one hospital with a sample of 129 healthcare workers working in a hospital and 49 elderly people who were members of a senior citizens' club. Results: No statistically significant difference was found between the physicians and the nurses in all survey items. However, significant differences were observed between the professionals and the non-professionals. The professionals were more likely to decline life-sustaining treatment than the non-professionals, who may have different views of LST and need some appropriate guidance before end-of-life decision-making.

Conclusion: Findings suggest that nurses need to get involved in discussions with physicians and patients or families.

Key words: life-sustaining treatment / decision-making / elderly people / communication between doctors and nurses

INTRODUCTION

What is most important in quality end-of-life care is patient autonomous decisions regarding life-sustaining treatments (LST)^{1,2)}. However, it is difficult to elicit elderly patients' preferences for the use of LST. Older people in Japan often do not express their wishes to their family members or their physicians, but just want to be alive and kicking until they die, trying hard not to be burdens on their close relatives³⁾. According to a comparative study, Japanese living in Japan are more likely to rely on physicians and family members for decision-making, compared to Japanese Americans⁴⁾. Even most American physicians were reported to think their spouses or family members definitely or probably knew their wishes in the event of personal decision-making incapacity⁵⁾. Moreover, even if they are expressed, patients' preferences for LST change over time and with changes in health status⁶⁾. Eventually, patients become incapable of making autonomous decisions due to dementia and impaired consciousness⁷⁾, and there occurs a shift in decision-making responsibilities from patients to family members⁸⁾.

It is true that the best strategies depend on values and beliefs among patients and their family members⁹. Unfortunately, however,

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previous studies confirmed that there was poor agreement between surrogate decision-makers and patients⁵⁾. Family caregivers displayed poor knowledge about LSTs, and most relied on their own views in decision-making rather than on what they thought their relative would have wanted¹⁰⁾. Moreover, family stress is very high unless advance directives, verbal or written, guide family members¹¹⁾. Furthermore, family members sometimes encounter a heavy burden of decision-making which can cause conflict among them⁸⁾. Subsequently, managing the conflict can threaten patient end-of-life care and quality of life.

Thus, healthcare teams (in Japan) get involved in these decision-making processes because they understand the prognosis of patients and plans for future treatment. However, the attitudes of professionals involved are influenced not only by the patient's condition but also by their professional orientations and personal values¹²⁾. For example, most clinical social workers are known to believe that elders should have the right of physician-assisted suicide¹³, and hospital clerks who are also often involved in informal consultations about financial and daily matters have no experience of professional training. In addition, the vague definition of the term LST may allow healthcare workers to have different opinions about each LST. This situation may impair interdisciplinary collaboration, which can create family confusion.

Throughout the above decision-making processes nurses play important roles as members of healthcare teams and advocates for patients and families as well. To offer adequate information, provide professional advice and effectively support family decision-making, they need to establish a relationship of trust with patients, families and other healthcare professionals and understand the differences of knowledge and values concerning LST among healthcare workers, patients and families.

This study aims to assess how much

healthcare professionals and elderly people in the community know about LST, whether they wish for the use of LST for end-of-life care, and to what degree they wish each LST and to explore the roles of nurses in the healthcare team.

METHODS

1. Participants

Participants in this study were 129 healthcare workers (physicians, nurses and hospital clerks) working in a community-based hospital and 49 elderly people who participated in the elderly party event of a senior citizens' club. The hospital is located in the Chugoku region, Japan and has an acute stage treatment ward with 120 beds and a convalescent ward with 60 long-stay beds. The convalescent ward has a protocol that requires preferences concerning LST from family members when elderly patients are hospitalized. 2. Instrument

A self-administered questionnaire was developed for this study. It consisted of sociodemographic variables including age, gender and occupation for health workers, and of four questions: (1) Which treatments do you think are LSTs?; (2) Do you want any LSTs?; (3) Where would you like to pass away?; (4) To what degree do you want each LST? In Question 1, the following 13 items were used as LSTs based on a report from the Medical Law Review Committee (Japan Medical Association, 2004): oxygen, transfusion, total parental nutrition, tube feeding, fluid replacement, cardiac massage, mechanical ventilation, intubation, vasopressin, anticancer, defibrillation, dialysis and narcotics. Participants were asked to choose more than one. Questions 2 & 3 are multiple choice questions. In Question 4, participants were asked to indicate the degree to which they wanted each LST on a 5-point Likert scale (0 = Don't want at all, 4 = Strongly want).

3. Data Collection

A survey packet that included a questionnaire

1. Basi	c informati	on							
	1) Age,	2) Sex							
	3) Your occupation or organization you belong to				0 a physician, 2 a Nurse, 3 a receptionist at a hospital, 4 a senior club member,				
					(5) others				
	4) What d	o you think	about your healt	th status?	(1)fairly he	①fairly healthy, ②averagely healthy, ③just average, ④a little bit ill, ⑤ fairly ill			
2. Which treatments do you think are life sustaining treatments?									
1) Oxygen, 2) Transfusion, 3) Total Parental Nutrition, 4) Tube feeding, 5) Fluid replacement, 6) Circulation, 7) Mechanical Ventilator,									
	8) Intubation, 9) Vasopressin, 10) Anticancer, 11) Defibrillation, 12) Dialysis, 13) Narcotics								
3. Would you wish life sustaining treatments of you are in the terminal stage?									
	1) Yes, 2) No, 3) Follow the decisions of phy				nysicians or family members,		4) I won't know until it happens		
4. Whe	ere would li	ke to pass a	way?						
	1) own ho	me,	2) hospitals,	3) institut	ions,	4)others			
5. Wha	ut life susta	ining treatr	nents would you	want as a pa	atient?				
_			Stroi	ngly want	Want	I don't know	Rather don't want	Don't want at all	
	1) Oxygen	ı							
	2) Transfu	usion							
	3) Total Pa	arental Nut	rition						
	4) Tube feeding								
	5) Fluid re	eplacement							
	6) Circulation								
	7) Mechanical Ventilator								
	8) Intubation								
	9) Vasopr	9) Vasopressin							
	10) Antica	incer							
	11) Defibr	illation							
	12) Dialys	sis							
	13) Narco	tics							

Table 1. Established Questionnaire for the present study

(Table1) and a cover letter describing the purpose, methods and the rights of the participants was distributed both to all health workers at each ward and to all members of the senior citizens' club during a meeting. It was emphasized that consent was implied by the return of the questionnaire. Completed questionnaires were collected anonymously through the collection boxes. The consent of the subject was carried out by the recovery of the questionnaire.

4. Data Analysis

A Chi-square analysis and a binomial test were conducted for Questions 1, 2 & 3 to determine group differences. Scores from the scale were analyzed with the Wilcoxon (ranked-pair) and the Kruskal-Wallis tests to identify differences between the four groups of participants. The Statistical Package for the Social Sciences Japanese version 16 was used.

5. Ethical considerations

Prior to the survey, the study was approved by the research ethics committee of the hospital. Ethical approval was obtained from the president of the senior citizens' club, whom had examined the research project including the purpose, methods and the rights of the participants, such as voluntary participation, confidentiality, and anonymity. The study was conducted from December 2006 and January 2007.

RESULTS

1. Participant demographics

Out of the 188 questionnaires distributed to the health workers in the hospital, 127 completed questionnaires were returned (67.6% response rate), and 49 seniors' club members returned completed questionnaires at the end of the club meeting, and some refused to receive a survey packet. As a result, there were 176 participants in total: 151 women (85.8%) and 25 men (14.2%). The average age was 49.28 (SD 18.33). Out of 176, 10 were physicians (5.7%, 7 men and 3 women), 83 nurses (47.2%, all women), 34 clerks (19.3%, 27 women and 7 men) and 49 elderly people (27.8%, 38 women and 11 men). Only 2 out of 49 elderly people answered the fourth question, so data from elderly people concerning



■ Physicians ■ Nueses ■ Receptioninsts ■ Elderly people

Figure 1. Frequencies of participants thought to be life sustaining treatments

the fourth question were excluded.2. Interventions considered LSTs

Overall, there were 4 interventions more than 50% of the participants thought were LSTs: mechanical ventilation (69.9%), cardiac massage (56.2%), intubation (55.1%) and defibrillation (54.0%). Less than 30.0% thought the other interventions were LSTs.

The numbers of interventions that more than 50% of each group thought were LSTs were 6 for the physicians, 4 for the nurses, 3 for the clerks, and none for the elderly people (Fig. 1). There was no statistically significant difference between the physicians and the nurses. However, there were significant differences between the nurses and the clerks in the following interventions: total parental nutrition (p=0.000), tube feeding (p=0.035), cardiac massage (p=0.033), mechanical ventilation (p=0.000), intubation (p=0.000), vasopressin (p=0.000) and dialysis (p=0.026). There were also significant differences between the clerks and the elderly people in the following: total parental nutrition (p=0.036), cardiac massage (p=0.046), mechanical ventilation (p=0.030) and

defibrillation (p=0.000).

Table 2 shows the interventions each group thought were LSTs in descending order. There was practically no difference between the physicians and the nurses, and compared to the healthcare professionals, the clerks showed noteworthy differences in oxygen, anticancer, vasopressin and total parental nutrition, and so did the elderly people in oxygen, intubation, defibrillation, total parental nutrition and vasopressin.

Participants' wishes for the use of LST

Figure 2 shows the participants' wishes for the use of LST for end-of-life care. In general, only 4.7% of the participants indicated they wanted LST, 66.9% declined LST, 4.7% indicated they would follow decisions of physicians and family members, and 23.7% indicated they did not know until the time came.

Experience of hospitalization is a factor which may influence patient wishes for the use of LST. Among the participants with experience of hospitalization, 5.0% wanted LST, 64.2% declined, 5.8% indicated they would follow decisions of physicians and family members, and 25.0% Kayo NOMURA

indicated they did not know until the time came. Among those without experience of hospitalization, on the other hand, 2.3% wanted LST, 74.4% declined, 2.3% indicated they would follow decisions of physicians and family members, and 20.9% indicated they did not know until the time

Table 2.	Ranks of frequer	ncies that participan	ts thought to be	life sustaining teratments
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ranking	Groups						
	Physicians	Nurses	Receptionists	Elderly people			
1	Mechanical	Mechanical	Mechanical	Oxygen (47.4%)			
	Ventilator (100%)	Ventilator (97.6%)	Ventilator (72.7%)				
2	Intubation(90%)	Intubation(84.3%)	Defibrillation(72.7%)	Mechanical Ventilator (42.1%)			
3	Cardiac massage (70%)	Cardiac massage (79.5%)	Cardiac massage (60.6%)	Cardiac massage (31.6%)			
4	Defibrillation(60%)	Defibrillation(73.5%)	Intubation(42.4%)	Fluid replacement (31.6%)			
5	Vasopressin (60%)	Total Parental Nutrition(41.0%)	Oxygen(27.3%)	Narcotics (27.8%)			
6	Total Parental Nutrition(50%)	Vasopressin (38.6%)	Anticancer(18.8%)	Tube feeding(26.3)			
7	Tube feeding(40%)	Tube feeding(37.3%)	Tube feeding(18.2%)	Transfusion (22.1%)			
8	Transfusion(40%)	Transfusion(24.1%)	Narcotics(18.2%)	Intubation (22.1%)			
9	Dialysis(40%)	Dialysis(22.9%)	Fluid replacement(12.1%)	Defibrillation (21.1%)			
10	Fluid replacement (10%)	Fluid replacement(19.3%)	Transfusion(9.1%)	Total Parental Nutrition (21.1%)			
11	Oxygen(0%)	Oxygen(14.4%)	Dialysis(6.1%)	Anticancer (21.1%)			
12	Anticancer(0%)	Anticancer(13.3%)	Vasopressin(3.1%)	Vasopressin (10.5%)			
13	Narcotics(0%)	Narcotics(6.0%)	Total Parental	Dialysis (5.3%)			
			Nutrition (3.0%)				



Figure 2. Results of if participants wish life sustaining treatments if they are in the terminal stage

came. As a result, those without experience of hospitalization were more likely to decline LST.

Relationships of participants' health status with their willingness to decline LST were also examined. All participants that rated themselves 'very ill' declined LST, followed by 70% of those who rated themselves 'not healthy', 70.8% 'normal', 57.6% 'rather healthy', and 64.7% 'very healthy', respectively.

Although more than 50% of each group declined LST, the rates of the participants who declined LST differed from group to group: 90% of the physicians, 76.8% of the nurses, 50.0% of the clerks, and 55.8% of the elderly people. The rates of the two professional groups were higher than the others. Significant differences were found between the physicians and the nurses who wished for the use of LST (p=0.013), between the nurses and the clerks (p=0.012) and between the clerks and the elderly people (p=0.033) (Fig. 2).

A place for dying

In general, 57% of the participants indicated they wanted to die at home, followed by 33% for

hospitals, 3% for institutes and 7% for other places. Although dying at home represents an ideal among Japanese and is officially recommended, still 43% participants chose the other places. Out of 66.9% who declined LST, 54.5% chose their own home as a place for dying, 33% hospitals. All participants who wished for the use of LST and 66.7% who indicated they would follow decisions of physicians and families wanted to die at hospital. Moreover, 40% of the physicians, 60.0% of the nurses, 56.3% of the clerks and 58.5% of the elderly people indicated they wanted to die at home, while 50% of the physicians, 31.3% of the nurses, 28.1% of the clerks and 36.6% of the elderly people chose to die at hospital. The physicians were likely to choose hospitals and the other groups chose their own homes.

5. The degree to which participants wanted each intervention

Figure 3 shows the degree to which three occupation groups wanted each intervention. There were only three interventions both the physicians and the nurses indicated they wanted:



Figure 3. Degrees of requirements for life sustaining treatments concerning occupations

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narcotics, oxygen and fluid replacement, while both the physicians and the nurses declined mechanical ventilation, intubation and cardiac massage, and the nurses declined defibrillation and total parental nutrition as well. No significant differences were found in any intervention between the physicians and the nurses. Overall, however, the clerks indicated they wanted more interventions more strongly for end-of-life care than the healthcare professionals.

There were 8 interventions which the clerks indicated they wanted: oxygen, narcotics, fluid replacement, anticancer, transfusion, total parental nutrition, vasopressin and dialysis, while there were no interventions which the clerks indicated they declined.

Significant differences were observed between the clerks and the physicians in the following: transfusion (p=0.031), total parental nutrition (p=0.002), tube feeding (p=0.022), cardiac massage (p=0.022), mechanical ventilation (p=0.012), intubation (p=0.010), vasopressin (p=0.020), dialysis (p=0.033) and narcotics (p=0.050). Significant differences were also found between the clerks and the nurses in the following: transfusion (p=0.001), total parental nutrition (p=0.002), tube feeding (p=0.000), cardiac massage (p=0.000), mechanical ventilation (p=0.000), intubation (p=0.010), vasopressin (p=0.000), anticancer (p=0.006), defibrillation (p=0.000) and dialysis (p=0.001).

Figure 4 shows the degree to which four response groups wanted each intervention. Both the participants who indicated they wanted LST and who declined LST wanted oxygen, fluid replacement and narcotics, and they indicated they did not know whether to use the other interventions. The participants who indicated they would follow decisions of physicians and family members were likely to accept any of the treatments and mostly wanted to die at hospital. The participants who indicated they did not know until the time came were likely to accept the following: narcotics, oxygen, fluid replacement, total parental nutrition, anticancer and transfusion, and did not know whether to use the others. Most of them wanted to die at home.



Figure 4. Degrees of requirements for Life sustaining treatments concerning four choices

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There was no significant difference in the degree to which they wanted any intervention between the participants who wanted LST and those who did not. However, significant differences were observed between the participants who declined LST and those who indicated they would follow decisions of physicians and family members in the following interventions: cardiac massage (p=0.017), mechanical ventilation (p=0.008), intubation (p=0.015), vasopressin (p=0.012) and defibrillation (p=0.031). The participants who declined LST and those who did not know until the time came showed significant differences in the following interventions: transfusion (p=0.006), total parental nutrition (p=0.000), tube feeding (p=0.000), fluid replacement (p=0.034), mechanical ventilation (p=0.008), intubation (p=0.001), vasopressin (p=0.006), anticancer (p=0.021) and dialysis (p=0.001).

DISCUSSION

For the final end of the elderly, it is necessary to support the elderly to make the best choices. In order to do so, consultation and advice on decision making is important, while providing appropriate knowledge and information for LST. The following is a discussion of the recognition of doctors, nurses, and clerical staffs who are involved in hospitals.

1. Differences in recognition of doctors and nurses for LST

The present study found no statistically significant difference between the physicians and the nurses in interventions considered LST, wishes for the use of LST nor the degree to which they wanted each LST, whereas significant differences were found between the professional and non-professional groups in all the survey items.

With regard to the professional groups, however, 5% to 14.5% of the nurses included oxygen, anticancer and narcotics among LSTs, while all the physicians denied these three interventions were LSTs, indicating that the physicians would accept these three interventions for end-of-life care. Moreover, whereas the physicians were more likely to decline LST compared to the nurses, were ready to choose a hospital as a place for dying and accept decisions of their attending physicians and families, the nurses were less likely to decline LST, more likely to choose a home as a place for dying and, instead of accepting decisions of their attending physicians and families, more than 20% of them showed a lack of decisiveness concerning the use of LST for endof-life care. These results, though not significant, were in line with previous studies which suggested that the physicians might use advance directives as a means to limit LSTs and to ensure aggressive pain management^{14, 5)}. Furthermore, the physicians' attitudes may reflect their confidence in other physicians, while the nurses' reluctance to follow decisions of physicians and families and choose a hospital as a place for dying may be associated with their lack of confidence in physicians' decision-making.

LSTs are administered for various purposes including emergency care, long term care, terminal care, palliative care and grief care for families. Physicians and nurses may have negative views of LST, but they seem to view each LST with different goals in mind according to patient condition, disease or professional subculture¹⁵⁾. For example, Carmel, Werner & Ziedenberg¹²⁾ reported that nurses might perceive tube feeding more as feeding or part of basic nursing, while physicians might view it as a medical intervention, and also that the physicians said they would provide less treatment than nurses to cancer patients in the terminal stage of the disease. Clearly, therefore, each healthcare team may involve various views of LST and may have difficulty reaching an agreement. Even though they reached an agreement for implementing LST, physicians and nurses sometimes may disagree about

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which treatments to be used for end-of-life care¹⁶⁾, partly because the goals for patients' treatment remain unclear due to a lack of communication or explanation¹⁵⁾.

2. Features of the non-professional groups

The present study found that the nonprofessional groups put emphasis on some interventions which the professionals did not recognize as LSTs, and that the rates of the clerks and elderly people who declined LST were significantly lower. These results were in line with previous studies reporting that physicians and nurses were unlikely to emphasize the value of life per se, whereas patients were more inclined to prioritize this¹⁷, and also that physicians are inclined to withhold treatment from a hopelessly ill patient, whereas most members of the general public tend to recommend it¹⁴.

Half of the clerks and the elderly people declined LST and most of the rest indicated they did not know until the time came, especially 40% of the clerks showed a lack of decisiveness concerning the use of LST. However, the clerks indicated they wanted all interventions. Their attitudes toward LST were quite different from those of the physicians, who declined LST or indicated they would follow the decisions of their physicians or families. The clerks have opportunities to observe patients and families as well as physicians and nurses and their wishes may reflect they are in a dilemma rather than learn from the professionals.

It was also found that most of the participants without experience of hospitalization were likely to decline LST, and also that the lower the participants rated their health status, the more likely they were to decline LST. Many of the participants who declined LST still chose as a place for dying a hospital where LST is readily available. This implies that the participants know their own homes are not suitable for caring for elderly people who need help with all of the daily activities, and that they do not want to be burdens on their families. The potential main family caregiver may work outside the home in many families.

This study clarified that the treatments which the clerks thought to be LSTs differed from those the physicians, the nurses and even the elderly people thought were LSTs. This suggests that the clerks may have superficial and fragmentary knowledge of LST acquired by listening to the professionals or getting more interested in medical care because of their job. The clerks also seemed to have unique values that differed from those of the physicians, the nurses or even the elderly people. Although they are not members of the healthcare team, the clerks are more easily consulted by patients and families about finances and even treatments than other health workers in such a community-based hospital as theirs. However, because of insufficiency of medical knowledge they could be false information sources for families, who in turn might be confused, thus, the consultation roles of clerks should be fully discussed.

3. Desired frequency of treatment that is classified according to the hope of life extension treatment

Previous studies found that half of the middleaged and elderly indicated they did not need aggressive treatment for their own end-of-life care18), and that the majority of families did not wish for aggressive life-sustaining treatment for their relatives' end-of-life care¹⁹⁾. However, in many cases people who expressed their negative views of LST wished for the use of some LSTs for long term end-of-life care, probably not as LSTs²⁰. In the situation where the intention of the patient itself and the intention of the family might be different, it can be said that it is necessary to confirm the intention of the family enough about the hope for the LST. In such cases, under the current official recommendation, the healthcare team, not the individual physician, is supposed to take responsibilities for guiding the best decision-making based on patients' and/or

their families' preferences.

In this situation nurses were reported to believe that there was currently a lack of good, mutual and supportive communication¹⁵⁾. In three out of four cases, for example, physicians did not discuss their end-of-life decisions with patients¹²⁾, and the physicians seldom consulted the nurses about decision making¹⁵⁾. As a matter of course, patients often remain handled without respect for their autonomy and nurses are not always adequately informed about physicians' discussions with patients¹⁵⁾, and often find themselves in awkward positions, placed between physicians and patients or families. It is clear that there is no supportive communication between professionals and patients or mutual communication between professionals. It would be impossible for nurses to act as advocates for those in their care (Japanese Nursing Association's Code of Ethics, 2003; ICN Code of Ethics 2006; Nursing & Midwifery Code of Conduct, 2008). However, physicians reported that, although nurses are involved in most end-of-life decisions, they are seldom the ones initiating discussion or making the decisions¹⁵⁾. This may imply that nurses may be expected to play more important roles in the decision-making process, and in doing so they need to be more assertive. For example, the hospital involved and many nursing homes ascertain patient preferences concerning end-of-life care and a place for dying on admission²¹⁾, so it will be nurses' role to encourage patients and their family members to have enough discussion to make any optimal final decisions regarding whether and to what degree LST should be administered.

4. Limitations of this study and future research

This questionnaire survey suffers from a number of limitations. The healthcare workers' sample represents the population of only one hospital, the elderly people's sample was drawn from those who happened to attend a meeting, and the sample did not include families. Thus, results may not be generalizable. 5. Suggestions for nursing practice

Physicians and nurses are recommended to discuss LST with each other and with patients and families to take concerted action to provide quality care for patients and their families. Nurses are also recommended to improve communication skills and build assertiveness.

COI

The author declares no conflict of interest associated with this manuscript.

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医療従事者と非医療従事者における延命治療に関する認識の違い 一意思決定における高齢患者とその家族への看護師による支援 の必要性—

野村佳代

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要旨:背景:日本社会の高齢化に伴い,65歳以上の高齢者が人口の23.1%を占めるが,病院や施設でのLSTに関する自己決定が不可能な患者が多い。

目的:本調査は、LSTに関して医療従事者や高齢者がLSTについてどのように理解しているの か,終末期ケアとしてLSTを望むかどうか,それぞれのLSTごとの希望の有無を明らかにする。 方法:病院に勤務する129人の医師と看護師と事務職と,高齢者クラブに所属する49人の高齢 者を対象として,アンケート調査を実施した。

結果:全項目において, 医師と看護師間では有意差は認められなかった。しかし, 医療従事者 と非医療従事者間では有意差が認められた。医療従事者は, 非医療従事者よりも延命処置を拒 否する可能性が高く, LSTの見解を変化させる可能性があることから, 終末期における意思決 定に関する適切な指針が必要であることを示した。

結論:看護師が医師や患者、家族との延命処置に関する話し合いに関わる必要性を示唆した。

索引用語: 延命処置 / 意思決定 / 高齢者 / 医師-看護師コ ミュニケーション