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# Factors influencing attitudes toward end-of-life care by care workers at special nursing homes for the elderly : a longitudinal study in Japan

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## ABSTRACT

**Aim:** The aim of the present study was to clarify that the effects of accumulated experience in end-of-life care and communication skill on the attitudes of care workers' toward end-of-life care.

**Methods:** A study implemented 2012 to 2014. Two hundred and fifty-three questionnaires were returned (40.2%), and 170 were fully completed by care workers in special nursing homes. We sorted the responses into two groups by experience level: the experienced end-of-life care (EE) group and the inexperience end-of-life care (IE) group. Responses were also sorted by communication skill level: a high score communication (HSC) group and a low score communication (LSC) group. A two-way repeated measure analysis of variance was used for the statistical analysis.

**Results:** The EE group was more likely to be younger ( $P = .04$ ), to have a longer duration of employment ( $P < .001$ ), and to have participated in an EOL care seminar in their facility ( $P = .02$ ) than the IE group. Attitudes toward end-of-life care were significantly different between the EE and IE groups ( $df = 2, F = 3.35, P < .05$ ). Attitudes toward end-of-life care were not significantly different when comparing the HSC and LSC groups ( $df = 2, F = 0.17, P = .85$ ). The communication skill between the HSC and LSC groups differed significantly at 2012, 2013, and 2014.

**Conclusions:** The accumulation of end-of-life care experience prompted a positive change in attitudes toward end-of-life care. Meanwhile, communication skill had no significant effect to change attitudes toward end-of-life care.

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**Key words:** care worker, end-of-life care, longitudinal study, nursing home

## Introduction

Japanese society has experienced dramatic demographic changing in aging population and rapidly increasing single-person household of elderly. In Japan, regarding end-of-life (EOL) care, approximately 44% of the general population preferred to be their home<sup>1)</sup>. Special nursing homes (SNHs) are being set up by long-term care insurances. SNHs have undertaken the task to provide care for their residents who are frail and of a single-person household. SNHs are the homes for their residents. The government's policy of end-of-life (EOL) care incentivize promoting EOL care at SNHs. In order to promote EOL care at SNHs, the government shows criterions such as preparation of private rooms for

EOL persons, formulation of facility policies, and easy accessibility to medical professionals. Recently, the proportion of residents who die in the SNHs has gradually increased<sup>2)</sup>. A SNH consists of at least one doctor (working on a part-time basis is permitted), three nurses, and thirty-one care workers per hundred residents<sup>3)</sup>. Thus, care workers are major providers of care in SNHs. Mainly, care workers provide assistance in bathing, going to the bathroom, meals and other matters<sup>4)</sup>. Although the educational curriculum for care workers includes very little training on EOL care, they must necessarily assume an important role in providing EOL care. Care staff need emotional support and specialized training, but those are lacking<sup>5-7)</sup>. Many care home staff still avoid discussions about death and dying<sup>8)</sup>.

Although the percentage of residents dying within the facility has increased, the SNHs as a site of death still composes only 3.2% of the total<sup>2)</sup>. In order to promote EOL care in SNHs, one of the factors, is that it is necessary that care workers improve attitudes toward EOL care.

Previous study suggested that a longer duration of employment were related to positive attitudes toward EOL care<sup>9)</sup>. Another study reported that duration of employment was related experienced EOL care<sup>10)</sup>. We predicted that it is more important to experience EOL care than the long duration of employment. We consisted supposition that the accumulated experience in EOL care contributes to positive attitudes toward EOL care. Previous study also suggested that higher communication skill were related to positive attitudes toward EOL care<sup>9)</sup>. Communication is important for quality EOL care<sup>11, 12)</sup>. After training, staff reported improved communication<sup>13)</sup>. However, other studies reported that the effectiveness of the communication skills training could not be confirmed<sup>14, 15)</sup>. It is need that to clarify how communication skill improves attitudes toward EOL care.

The aim of the present study was to clarify that the accumulation of EOL care experience and the communication skill of care workers effects change in care workers' attitudes toward EOL care.

### Methods

The study was conducted from 2012 to 2014 in Sapporo, Japan. At first, we obtained information on SNHs throughout Sapporo through their websites and submitted requests to each SNH's director<sup>16)</sup>. SNHs selected over 100 beds due to limited staff size. If they agreed to participate in the study, we distributed a questionnaire to care workers at their SNHs. We requested that care workers participate in the survey three-times, namely, first in October 2012, second in October 2013, and for the third time in October 2014. We confined survey results to care workers who agreed to participate in these three-time surveys with written informed consent. A participant returned a fulfilled questionnaire to the Department of Public Health, Sapporo Medical University by mail directly.

The questionnaires were almost the same the three-times they were administered, consisting of questions about experience in EOL care, attitudes toward EOL care, and factors influencing EOL care, in addition to demographic characteristics. EOL care is defined

as help for all those with advanced, progressive, and incurable illnesses to live as well as possible until they die<sup>17)</sup>. The present study defined that EOL care means care at a SNHs for the dying elderly until death. Attitudes toward EOL care were measured with the Japanese version of the assessment instrument the Frommelt Attitude Toward Care of the Dying Scale Form B (FATCOD-B-J) which scale was found to be a valid and reliable tool<sup>18, 19)</sup>. We used the FATCOD-B-J short version scale which consisted of two factors of six items<sup>18)</sup>. Those factors are "positive attitudes toward caring for dying persons" and "recognition of the importance of caring for dying persons and their families". The summed score of six items on a five-point scale were calculated for each subject with a range from six to thirty. A higher summed score indicates a more positive attitude toward EOL care.

Factors influencing EOL care were selected from the questionnaire for this study with reference to our previous study and some other studies as well<sup>9, 20-22)</sup>. The selected variables were as follows: age, gender, duration of employment as a care worker, possession of certification in care work, knowledge of EOL care policies at present facility, participation in EOL care seminar at their facility, and participation in EOL care seminar outside of their facility. Communication skill in acceptance of others was measured using a part of the ENDCOREs which was based on the ENDCORE (encode, decode, control, and regulation) model<sup>22)</sup>. Communication skill in acceptance of others included four concepts: empathetic attitude, friendly attitude, acceptance of others opinion, and respect for others. The summed score of four items on a seven-point scale were calculated for each subject with a range from four to twenty-eight. A higher summed score indicates a high communication skill in acceptance of others.

To examine the effect of experience in EOL care for attitudes toward EOL care, we compared the change in attitudes toward EOL care over the three-time survey between the experienced in EOL care (EE) group and the inexperienced in EOL care (IE) group. Inexperienced in EOL care means having no experience of EOL care on the job. We also examined the effect of communication skill in acceptance of others on attitudes toward EOL care. Subjects were allocated to the high score communication (HSC) group and the low score communication (LSC) group. Moreover, we compared the selected factors influencing EOL care with experience in EOL care in 2012, 2013, and 2014.

The  $\chi^2$ -test, the Student's t-test, two-way repeated measure analysis of variance (two-way repeated measure ANOVA), and the Dunnett method for multiple comparison were used in the present study. Statistical analysis was performed using SPSS version 16.  $P < .05$  was considered the critical level of significance. The present study was approved by the Ethics Committee of Sapporo Medical University (approval number: 24-2-41).

### Results

Among 48 SNHs in the entirety of Sapporo, the directors of 19 SNHs (39.6%) agreed to participate in the study. Among 630 care workers in these SNHs, 253 subjects (40.2%) agreed to participate in the three-time survey by written informed consent. We obtained fulfilled questionnaire from 253, 199, and 189 subjects in 2012, 2013, and 2014, respectively. It was the same trend the summed score between two factors' score of FATCOD-B-J. Thus, we used summed score of FATCOD-B-J as attitudes toward EOL care.

In the end, 170 subjects participated in all three surveys. Their mean age (standard deviation) was 38.3 ( $\pm 10.5$ ) years, 123 subjects (72.4%) were female, and 124 care workers (72.9%) had experience in EOL care on the job at the survey in 2012.

Table 1 and Figure 1 were shown to examine the effect of experience in EOL care for attitudes toward EOL care. Table 1 shows a comparison of the selected factors influencing EOL care between the EE and IE groups at the survey in 2012, 2013, and 2014. In the result, 124 subjects experienced EOL care. In the EE group, the mean number (standard deviation) of the experience of EOL care was 10.4 ( $\pm 15.0$ ) (data not shown). The EE group was more likely to be younger than the IE group ( $P = .04$ ). The EE group was more likely to have a longer duration of employment as a care workers ( $P < .001$ ) than the IE group. The EE group was observed to have a larger proportion of certified care workers than the IE group in 2012 ( $P < .001$ ) and in 2013 ( $P < .01$ ). However, it had ceased to be significantly different in 2014. The EE group was more likely to have knowledge of EOL care policies at present facility than the IE group in 2012 ( $P < .01$ ). The EE group was more likely to have participated EOL care seminar in their facility than the IE group in 2012 ( $P = .02$ ). The EE group was more likely to have better attitudes toward EOL

care than the IE group in 2014 ( $P < .01$ ). In 2012 and 2013, there were no differences between the two groups about attitudes toward EOL care. Notably, both groups hardly participated in external seminars. The total number of participants in external EOL care seminar during one year was only seven subjects (4.1%) in 2014.

Figure 1, the change in the mean score of attitudes toward EOL care among 170 subjects in 2012, 2013, and 2014. The mean scores of attitudes toward EOL care in the EE group were 23.17, 23.21, and 23.77 in 2012, 2013, and 2014, respectively. There were no statistically significant differences. The scores in the IE group were 22.37, 23.22, and 22.52 in 2012, 2013, and 2014, respectively. There were no statistically significant differences. The scores of attitudes toward EOL care in the EE group showed a significantly different pattern compared to the IE group ( $df = 2$ ,  $F = 3.35$ ,  $P < .05$ ).

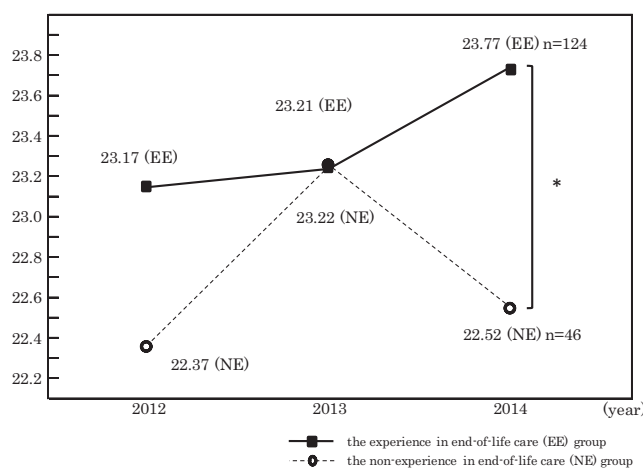
Table 2 and Figure 2 were shown to examine the effect of communication skill in acceptance of others on attitudes toward EOL care. Table 2 shows comparison of the same influencing factors in Table 1 between the HSC and LSC groups at the survey in 2012, 2013, and 2014. The HSC group was more likely to be younger than the LSC group ( $P = .04$ ). The HSC group was more likely to have a shorter duration of employment as care worker ( $P < .05$ ) than the LSC group. The HSC group was observed to have a larger proportion of certified care workers than the LSC group in 2014 ( $P = .02$ ). The HSC group was more likely to have better attitudes toward EOL care than the LSC group in 2012 ( $P < .01$ ), 2013 ( $P < .001$ ), and 2014 ( $P < .01$ ).

Figure 2 shows the change in the mean score of attitudes toward EOL care among 170 subjects in 2012, 2013, and 2014. Using the median value of the communication score, 77 subjects were allocated to the HSC group ( $\geq 20$ ) and 93 subjects were placed in the LSC group ( $\leq 19$ ). The mean scores of attitudes toward EOL care in the HSC group were 23.69, 24.03, and 24.10 in 2012, 2013, and 2014, respectively. There were no statistically significant differences. The mean scores of attitudes toward EOL care in the LSC group were 22.34, 22.54, and 22.87 in 2012, 2013, and 2014, respectively. There were no statistically significant differences. The score of attitudes toward EOL care in the HSC group did not show a significantly different pattern when compared to

**Table 1.** Comparison of the experience in end-of-life care (EE) group and the non-experience in end-of-life care (NE) group of 170 subjects participated in 2012, 2013, and 2014

Item	Content	year at survey	Total N = 170	EE group n = 124	NE group n = 46	P -value
Age	mean ± SD † (year)	2012	38.3 ± 10.5	37.3 ± 10.2	41.0 ± 10.9	0.04
Gender (female)	number (%)	2012	123 (72.4)	90 (72.6)	33 (71.7)	1.00
Duration of employment as a care worker	mean ± SD (year)	2012	8.0 ± 5.8	8.9 ± 6.1	5.4 ± 4.0	< 0.001
Certified care worker (yes)	number (%)	2012	139 (81.8)	110 (88.7)	29 (63.0)	< 0.001
	number (%)	2013	144 (84.7)	112 (90.3)	32 (69.6)	< 0.01
	number (%)	2014	153 (90.0)	115 (92.7)	38 (82.6)	0.08
Knowledge of EOL ‡ care policies at present facility (yes)	number (%)	2012	109 (64.1)	89 (71.8)	20 (43.5)	< 0.01
	number (%)	2013	126 (74.1)	94 (76.4)	32 (71.1)	0.55
	number (%)	2014	122 (71.8)	91 (73.4)	31 (67.4)	0.45
Participation in EOL care seminar at their facility (during a previous year/yes)	mean ± SD (number)	2012	1.0 ± 1.7	1.2 ± 1.9	0.5 ± 0.6	0.02
	number (%)	2013	74 (43.5)	53 (42.7)	21 (45.7)	0.73
	number (%)	2014	45 (26.5)	30 (24.2)	15 (32.6)	0.33
Participation in EOL care seminar outside of their facility (during a previous year/yes)	mean ± SD (number)	2012	0.2 ± 0.6	0.2 ± 0.6	0.2 ± 0.6	0.61
	number (%)	2013	16 (9.4)	11 (8.9)	5 (10.9)	0.77
	number (%)	2014	7 (4.1)	5 (4.0)	2 (4.3)	1.00

† SD: standard deviation.. ‡ EOL: end-of-life.

**Fig. 1.** The change in the mean attitudes toward end-of-life care of the experience in end-of-life care group and the non-experience in end-of-life group in 2012, 2013, and 2014

\*  $p < .01$  Student t-test

the LSC group ( $df = 2$ ,  $F = 0.17$ ,  $P = .85$ ).

### Discussion

The attitudes toward EOL care of the EE group clearly showed different patterns from those of the IE group. In addition, the score of the EE group in 2014 were higher than those of the IE group. Although there were no statistically significant differences, the attitudes toward EOL care score of the EE group have increased year by year. According to

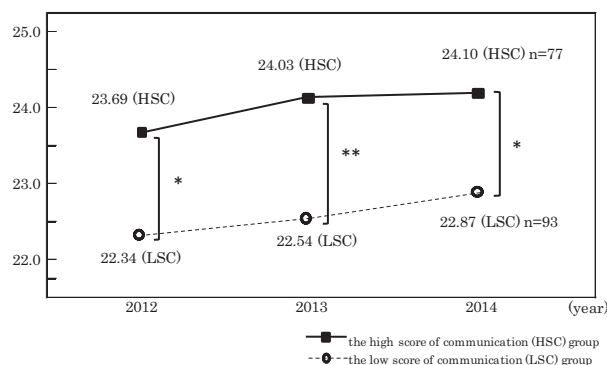
previous studies, nurses' positive attitude toward caring for dying patients related to the number of EOL care and opportunity to attend a seminar of EOL, the fact that lack of education and experience may contribute to the negative attitudes, and years of nursing experience related to educational training about death<sup>23-28</sup>). Characteristics of the EE group was that they had a long duration of employment and had a high rate of license holding. In addition, their awareness of the policy of their facilities

**Table 2.** Comparison of the high score of communication (HSC) group and the low score of communication (LSC) group of 170 subjects participated in 2012, 2013, and 2014

Item	Content	year at survey	HSC group n = 77	LSC group n = 93	P -value
Age	mean±SD <sup>†</sup> (year)	2012	36.5 ± 10.6	39.8 ± 10.2	0.04
Gender (female)	number (%)	2012	54 (70.1)	69 (74.2)	0.61
Duration of employment as a care worker	mean±SD (year)	2012	6.8 ± 4.3	8.9 ± 6.7	0.05
Certified care worker (yes)	number (%)	2012	65 (84.4)	74 (79.6)	0.43
	number (%)	2013	67 (87.0)	77 (82.8)	0.52
	number (%)	2014	74 (96.1)	79 (84.9)	0.02
Knowledge of EOL <sup>‡</sup> care policies at present facility (yes)	number (%)	2012	55 (71.4)	54 (58.1)	0.08
	number (%)	2013	54 (72.0)	72 (77.4)	0.48
	number (%)	2014	53 (68.8)	69 (74.2)	0.50
Participation in EOL care seminar at their facility (during a previous year/yes)	mean±SD (number)	2012	1.1 ± 2.0	0.9 ± 1.4	0.37
	number (%)	2013	28 (36.4)	46 (49.5)	0.09
	number (%)	2014	18 (23.4)	27 (29.0)	0.49
Participation in EOL care seminar outside of their facility (during a previous year/yes)	mean±SD (number)	2012	0.2 ± 0.6	0.2 ± 0.6	0.89
	number (%)	2013	6 (7.8)	10 (10.8)	0.60
	number (%)	2014	5 (6.5)	2 (2.2)	0.25

<sup>†</sup> SD: standard deviation.. <sup>‡</sup> EOL: end-of-life.

Communication skill in acceptance of others were divided the HSC group (ENDCOREs ≥ 20) and the LSC group (ENDCOREs ≤ 19).



**Fig. 2.** The change in the mean attitudes toward end-of-life care of the high score of communication group and the low score of communication group in 2012, 2013, and 2014

\*  $p < .01$ , \*\*  $p < .001$  Student t-test

regarding EOL. Although there was no significant difference, participated EOL care seminars was rare. It is said that the EE group had a learning personal foundation for EOL care. In the EE group, having learning personal foundation and EOL care experience promoted positive attitudes. In Japan, there is no standard EOL care education program for care workers. Previous study reported the effectiveness of palliative care in long-term care curriculum<sup>29</sup>. In the future study is necessary for the education system for care workers. Attitudes toward EOL care score of the

IE group were once raised and then lowered. As far as we know, there has been no similar study. There was no statistical change, however, it required further investigation because the IE group might lose their positive attitudes toward EOL care for some reason.

The HSC group's attitudes toward EOL care gradually improved. The LSC group's attitudes also gradually improved, similar to the HSC group. No significant difference in changes in the attitudes toward EOL care was recognized between the two groups. The HSC group was consistently higher in attitudes

toward EOL care than the LSC group. We believe that there are two reasons. In the present study, we measured that the communication skills were empathetic attitude, friendly attitude, acceptance of others' opinion, and respect for others. The HSC group was more likely to be younger and to have a shorter duration of employment as a care worker. The HSC group might be supported by other staff even if providing EOL care. In addition, the HSC group was observed to have a larger proportion of certified care workers. In the process of obtaining a license, they learned about death. Because the HSC group kept positive attitudes toward EOL care, communication skills were used a reliable indicator to evaluate the quality of EOL care<sup>30,31</sup>. Our present study also showed that communication skills indicated attitude toward EOL care. However, communication skills have multiple aspects. For example, Engelberg revealed that a communication skills questionnaire was constructed for general communication skills and communication about EOL care in hospice<sup>31</sup>. Furthermore, verification using a scale to measure communication skills specialized for EOL care.

In conclusion, experience in EOL and communication skill affected attitudes toward EOL care. However, each factor had a completely different influence on change in attitudes toward EOL care. The accumulation of EOL care experience prompted a positive change in attitudes toward EOL care. On the other hand, communication skill in acceptance of others had no effect on the change in attitudes toward EOL care.

Several limitations of the present study should be noted. Firstly, the response rate was not high. Future research should include a broader sample. Secondly, as our sampling for the study subjects was conducted only in Sapporo, our results cannot be confidently generalized for the whole of Japan. Finally, we did not research facilities' characteristics, number of EOL care, educational systems, residents' levels, or other related issues. Future efforts should be devoted to developing appropriate and effective training programs in EOL care.

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#### Disclosure statement

No potential conflicts of interest were disclosed.

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# 特別養護老人ホームにおける介護職の看取りに対する態度に影響を及ぼす要因：日本における縦断研究

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本研究の目的は、介護職の職業経験の長さおよび他者受容のコミュニケーションスキルが看取りに対する態度へ及ぼす影響を明らかにすることである。特別養護老人ホーム（以下、特養）の介護職に対して、2012年から2014年に自記式調査票を用いた郵送法調査を実施した。調査表は253人から回収し（回収率40.2%）、3回の調査すべてに回答した170人の調査票を分析した。対象者を2012年時点での職場における看取り経験群（EE: experienced end-of-life care group）と看取り未経験群（IE: inexperienced end-of-life care group）に分類し、EEとIEのFATCOD-B-Jの経年変化の比較を行った。コミュニケーションスキルは、対象者をENDCOREsの中央値を用いて高群（HSC: high score communication group）と低群（LSC: low score communication group）

に分類し、同様にFATCOD-B-Jの経年変化の比較を行った。統計解析は、繰り返しのある二元配置分散分析を用いた。2012年のベースライン時において、EEはIEに比べ、年齢が若く（ $P=.04$ ）、介護職としての経験が長かった（ $P<.001$ ）。また、施設内研修に参加した者の割合が多かった（ $P=.02$ ）。EEとIEの看取りに対する態度の変化のパターンは異なっていた（ $df=2$ ,  $F=3.35$ ,  $P<.05$ ）。HSCとLSCの看取りに対する態度の変化のパターンには差がなかった（ $df=2$ ,  $F=0.17$ ,  $P=.85$ ）。HSCはLSCと比べ、3回の調査すべてにおいてFATCOD-B-Jの点数が高かった。看取りの経験は看取りに対する態度が積極的に変化した。他者受容のコミュニケーションスキルの高さは看取りに対する態度の積極性に変化がみられなかった。