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Research Article

Change in the Preference for Place of Death among Community Residents through the Intervention of an End-of-Life Care Seminar

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Abstract

Purpose: In this study, we examined the change in the preference for place of death among community residents after an end-of-life care (EOLC) seminar intervention.

Methods: The survey items included background conditions, degree of apprehension about the seminar contents, their preferred place of death, and requests for EOLC.

Results: The results indicated that preference for death at home was characteristic of individuals who lived with a family, spouse, and/or grandchild, and individuals who endorsed "living their lives without regret." Before the seminar, more participants who lacked confidence in their own health preferred to die in the hospital; However, after the seminar, a greater number of these participants reported that they preferred to die in a nursing home.

Conclusion: Both before and after the seminar, "home" was the most frequently selected preferred place of death. The second highest preference was "hospital" before the seminar, and "nursing home" after they attended the seminar. These findings clarify the changes in community residents' preferred place to die following the EOLC seminar.

Keywords: End-of-Life Care (EOLC), community residents, decision-making, preference for place of death

Introduction

The world's population is rapidly aging. According to the Global Health Observatory (GHO) data published by the World Health Organization (WHO) in 2016, the longest life expectancy in the world was found in the Japanese population, with a mean of 83.7 years in 2015 [1]. For more than 20 years, since the first statistical data on this subject were published, Japan has been among the countries with the highest longevity. Owing to these social conditions, the importance of end-of-life care (EOLC) has been increasing.

Research suggests that advanced care planning (ACP) improves the quality of EOLC, increases the satisfaction of elderly and their families, and alleviates stress, anxiety, and depression in family members [2]. Furthermore, a systematic review of ACP in EOLC [3] suggests that it is important to consider the end-of-life as a part of life, and that it is imperative to discuss end-of-life decisions with important family and friends. Often, individuals at the end of their lives wish to stay with their loved ones as opposed to staying in a hospital. EOLC reduces hospitalizations and medical costs, as well as improves efficiency.

In Japan, most people wish to die naturally at home. Despite this, hospital deaths are common. According to a survey of outpatients by Matsushita et al. [4] the "wish to die at home" was observed in 64% of outpatients, while only 24% had a "wish to die in the hospital." In addition, 80% of outpatients reported a "wish to die naturally," 9.3% reported having a "wish to receive life-sustaining care" However, another study revealed that the percentage of residents who "wish to die at home" has been decreasing in rural areas, particularly in the younger generation and among local residents with a smaller number of family members [5].

Nevertheless, only a small percentage of outpatients leave a written documentation of their wishes pertaining to EOLC. Shimada et al. [6] conducted a survey on communications about wishes/preferences concerning EOLC prior to an imminent situation. It was reported that 10% of outpatients had both engaged in verbal communication and written records of their wishes pertaining to EOLC, and that most of these people had a designated guardian to make these decisions by proxy. In the study, outpatients who avoided facing their death did not have written records documenting their EOLC wishes. Araki, Horiuchi, and Asano (2010) [7] reported in their survey of local residents that wishes pertaining to EOLC are often verbally conveyed to a spouse or child, and that people in poor health were more likely to have such communication pertaining to their wishes. Furthermore, men, people free of illness not receiving hospital care, and people in good health, tended to choose their home as the place to spend the end-of-life period. From the above, it is evident people have various EOLC needs.

Guidelines for EOLC and decision-making have been established worldwide [8-10]. Cardona-Morrell et al. [11] in a systematic review of 17 effective decision aid interventions for EOLC, found that most people who received these interventions were patients, including elderly nursing home residents. As for the decision-making format in such interventions, most utilized validated tools or indicators and a multidisciplinary team or dedicated staff, along with video, audio, print, and computerized materials and surrogate involvement [11]. These interventions were found to lead to multiple improvements, including increased knowledge, reduced decision-making conflict, and increased decision concordance.

In Japan, an effective method of understanding the EOLC needs of the elderly is the "life story method" [12]. Decision-making can also be promoted by encouraging individuals to visualize their lifestyles after moving from a hospital to the local community [13]. The number of older adults in Japan is growing rapidly. It is rapidly becoming a "super-aged society," and thus it is important to hold seminars for community residents to disseminate information on daily care during the end-of-life phase and the available welfare system/services. Such seminars might also be tailored to individuals' perceptions of their lives and residence.

Decision-making in EOLC encompasses a rather broad range of concepts. In this study, we used the preferred place of death as an indicator of decision-making in EOLC. This is because it is considered an element of ACP, which is very important for people when discussing how they want to spend the end-of-life period [14].

The objective of the present study was to examine the change in the preference for place of death among community residents through the intervention of an EOLC seminar for local residents. We believe that this study will be useful for improving the effectiveness of ACP in EOLC for people living in Japan.

Methods

Subjects

The researchers received a request to hold EOLC lectures from an elderly group and agreed to fulfill this request at local salons and older-adult associations. Elderly volunteers were recruited to create the seminar flyer and advertise it around the community. People who read the flyer and understood the intended content of the seminar came. A questionnaire survey was conducted during the EOLC seminars. At the beginning of each seminar, we verbally

explained our intention to conduct a survey to all participants and asked only individuals who gave their consent to complete the survey. As a result, the following subjects were obtained.

The investigator hosted six EOLC seminars between May and December 2016. A total of 577 community residents attended these seminars. Among the, 522 consented to the survey, valid responses were obtained from 518.

Description of EOLC seminar

In the seminar, the following items were explained to the subjects via a handout: (1) a review of the subject's life story, (2) essential EOLC terms (e.g., EOLC, advance care planning, advance directive, do not attempt resuscitation orders), (3) projections of dying patterns, (4) the characteristics and availability of welfare systems/care services by place (hospital, nursing home, home, and others), (5) the process involved in moving from the hospital to the home at the end-of-life, and (6) the necessity and use of an "ending note." In addition, at the end of the seminar, all subjects participated in exercises designed to maintain their ability to eat through their mouth until death.

Survey procedure and content

The survey was conducted using a self-administered questionnaire. Written consent to participate in the survey was obtained in advance by the seminar host. At the beginning of the seminar, subjects were asked to participate in a survey after the seminar. At the end of the seminar, the questionnaire was distributed over a period of 10 minutes, and subjects were given an additional 30 minutes to stay and complete it. Completed questionnaires were placed into a designated collection box, and it was deemed that the consent of the subject was obtained.

The survey sections were as follows: (1) demographics, (2) subjects' perceptions of their lives, (3) preferred place of death (before and after the seminar), (4) degree of understanding of EOLC (understanding of care at home, hospital, nursing home, or others). For sections 1 to 4, the subjects were asked to answer multiple-choice items by placing a checkmark next to the applicable choice(s). Considering the potential burden imposed by the survey on the subjects, we administered the questionnaire only once (i.e., after the seminar).

Statistical analysis

A chi-square test was used to analyze the association between subjects' preferred place of death and other factors. All analyses were assessed using IBM SPSS Statistics 23 (IBM Corp., Armonk, NY).

Ethical considerations

The questionnaire was anonymous. The researcher fully informed the subjects about the survey both verbally and in writing. Consent was regarded as having been obtained if the subjects placed the questionnaire into the designated collection box, as noted above. The collection box was occluded so that nobody could look inside and was placed in a secluded area that offered privacy so that the subjects could voluntarily choose whether to submit the questionnaire or not without being coerced. This researcher informed the subjects that they would be able to participate in the seminar and would not be put at any disadvantage if they refused to participate in the survey. All data were kept by the principal investigator in a locked area. This study was conducted after obtaining approval (Receipt No. 160006) from the Medical Research Ethical Review Board for the researchers at Gunma University. We have no financial relationships to disclose.

Results

Demographic characteristics

The 518 subjects consisted of 161 men (31.1%) and 356 women (68.7%; Table 1). Their mean age was 71.8 years (SD=7.0). A large percentage of subjects were living with family (78.8%). Further, 457 subjects (88.2%) reported having somebody to talk to about their worries, and 339 subjects (65.4%) answered that they were confident about their health (Table 1).

Table 1: Demographics of subjects (n=518)

Item		n	%
Sex	Male	161	31.1
	Female	356	68.7
	N/A	1	0.2
Age	<65 years	48	9.3
	≥ 65 and <75 years	290	56
	>75 years	158	30.5
	N/A	22	4.2
Living with family	Yes	408	78.8
	No	107	20.7
	N/A	3	0.6
Living with spouse	Yes	348	67.2
	No	170	32.8
	N/A	0	0
Living with child	Yes	196	37.8
	No	322	62.2
	N/A	0	0
Living with grandchild	Yes	70	13.5
	No	448	86.5
	N/A	0	0
Someone to talk to about worries	Yes	457	88.2
	No	33	6.4
	N/A	28	5.4
Confidence in health	Yes	339	65.4
	No	157	30.3
	N/A	22	4.2
N/A: Not Answered			

Subjects' perceptions of their lives

Three hundred sixty-five (70.5%) subjects reported that they were "living life to the fullest," and 355 (68.5%) reported having no regrets in life. Furthermore, 455 (87.8%) subjects answered that they made the utmost effort to live their lives, and 397 (76.6%) reported that they received help from other people. These results suggest that most subjects believed they had lived a good life (Table 2).

Table 2: Subjects' perceptions of their lives (n=518)

Item	Yes		No		N/A	
	n	%	n	%	n	%
Have you lived your life to the fullest?	365	70.5	84	16.2	69	13.3
Have you lived your life with regrets?	130	25.1	355	68.5	33	6.4
Did you make your utmost effort to live your life?	455	87.8	48	9.3	15	2.9
Did you receive help from other people?	397	76.6	95	18.3	26	5.0

Preferred place of death

Before the seminar, the subjects' preferred places of death were as follows: 318 subjects (61.4%) chose "home," 86 subjects (16.6%) chose "hospital," and 77 subjects (14.9%) chose "nursing home." After the seminar, the preferred places of death were as follows: 282 subjects (54.4%) chose "home," 68 subjects (13.1%) chose "hospital," and 110 subjects (21.2%) chose "nursing home." Thus, both before and after the seminar, the majority of subjects preferred to

die at "home." The second most common choices differed, however: before the seminar, the subjects chose "hospital," while after it, they chose "nursing home" (Table 3).

Table 3: Preferred place of death (n=518)

Item	Home		Hospital		Nursing home*		Others**		N/A	
	n	%	n	%	n	%	n	%	n	%
Before seminar	318	61.4	86	16.6	77	14.9	23	4.4	14	2.7
After seminar	282	54.4	68	13.1	110	21.2	20	3.9	38	7.3

*Nursing home (special elderly nursing home, long-term care health facility)

**Others (e.g., group home, private nursing home)

Understanding of care services available in each location

In the seminar, care services available at the following four locations were explained to the subjects: "home," "hospital," "nursing home," and "others." In the survey, subjects were asked if they had any understanding of the care services explained in the seminar. It was found that 450 (86.9%), 446 (86.1%), 443 (85.5%), and 440 (84.9%) subjects had an understanding of the kind of care available at the "hospital," "nursing home," "home," and "others" respectively. Furthermore, more than 80% of subjects had an understanding of available care at every location (Table 4).

Table 4: Understanding of care according to location (n=518)

Item	Understood		Did not understand		N/A	
	n	%	n	%	n	%
Home	443	85.5	38	7.3	37	7.1
Hospital	450	86.9	35	6.8	33	6.4
Nursing home	446	86.1	41	7.9	31	6.0
Other	440	84.9	43	8.3	35	6.8

Table 5: Factors related to preferred place of death after seminar

Item		Home		Hospital		Nursing home		Others		total	
		n	%	n	%	n	%	n	%	n	P-value
Living with spouse	Yes	208	63.2	37	11.2	74	22.5	10	3.0	329	0.004
	No	74	49.0	31	20.5	36	23.8	10	6.6	151	
Living with grandchild	Yes	50	78.1	7	10.9	7	10.9	0	0	64	0.005
	No	232	55.8	61	14.7	103	24.8	20	4.8	416	
Have you lived your life to the fullest?	Yes	213	61.7	43	12.5	79	22.9	10	2.9	345	0.003
	No	30	41.7	13	18.1	22	30.6	7	9.7	72	
Have you lived your life with regrets?	Yes	67	54.9	26	21.3	25	20.5	4	3.3	122	0.031
	No	198	60.4	35	10.7	79	24.1	16	4.9	328	
Understanding of care in hospital	Understood	238	56.9	66	15.8	99	23.7	15	3.6	418	0.006
	Did not understand	21	63.6	2	6.1	5	15.2	5	15.2	33	
Understanding of care in nursing home	Understood	238	57.3	60	14.5	102	24.6	15	3.6	415	0.016
	Did not understand	22	59.5	6	16.2	4	10.8	5	13.5	37	
Understanding of care at home	Understood	248	60.0	54	13.1	94	22.8	17	4.1	413	0.037
	Did not understand	13	37.1	9	25.7	10	28.6	3	8.6	35	

Association between preferred place of death and each factor

Table 5 shows that the results of the chi-square test used for analyzing the factors associated with preferred place of death. Only the significant factors are presented in the table. Significantly more subjects who lived with a spouse or a grandchild, felt that they were living their life to the fullest, had no regrets about their life, and had an understanding of care at home reported that their preferred place of death was "home" ($p<0.05$). Furthermore, more subjects who did not live with a spouse, had regrets in their life, and had an understanding of care at the hospital or home selected "hospital" as their preferred place ($p<0.05$). Those who live with their grandchild had significantly fewer people who chose to die in "nursing home" than those who did not live with their grandchild ($p<0.01$).

Association between preferred place of death and confidence in own health

Before and after the seminar, this study found a change in the relationship between preferred place of death and subjects' confidence in their health, as shown in Table 6. Before the seminar, among the subjects who selected "home," those who were confident about their health were significantly more (69.9%; $p<0.001$) than those who were not confident. After the seminar, among the subjects who selected "home," those who were confident about their health were still significantly more (63.6%; $p<0.05$) than those who were not confident.

Table 6: Changes in preferred place of death before and after the seminar according to confidence in health

Item		Home		Hospital		Nursing home		Others		total	
		n	%	n	%	n	%	n	%	n	P-value
Before seminar	Confident	230	69.9	45	13.7	43	13.1	11	3.3	329	<0.001
	Not confident	76	49.4	37	24.0	30	19.5	11	7.1	154	
After seminar	Confident	204	63.6	42	13.1	64	19.9	11	3.4	321	0.028
	Not confident	67	48.6	24	17.4	40	29.0	7	5.1	138	

Prior to the seminar, significantly a greater number of subjects who were not confident about their health selected "hospital" (24.0%; $p<0.001$) than those who were confident. Further, the number of subjects without confidence in their health who selected "nursing home" increased significantly after the seminar (29.0%; $p<0.05$) compared to the number of subjects with confidence.

Discussion

Age of community residents

In the present study, the mean age of subjects was 71.8 years; individuals of this age are referred to as "early-phase elderly." In 2025, most of these individuals will be considered "late-phase elderly," and individuals in this age group typically require medical care. Moreover, many of the households in this study comprised a husband and wife, which means that the number of elderly adults aged 65 years or older taking care of other older adults is likely to rise in the future. The life expectancy in Japan has been increasing for both men and women, and the difference in healthy life expectancy is about 9 years for men and 13 years in women, suggesting that many people in the end-of-life phase will require some type of EOLC. Thus, the subjects were assumed to be interested in EOLC for themselves.

Preferred place of death

Both before and after the seminar, "home" was the most frequently preferred place of death. The second highest preference was "hospital" before the seminar, and "nursing home" after the seminar. Similarly, subjects who lacked confidence in their own health more often selected "hospital" before the seminar, whereas after the seminar, they selected "nursing home" more often. Therefore, it seems that subjects' perceived health status influenced their decision-making about EOLC. Araki et al. [7] also reported that subjects with poor health tend to choose "hospital" as their preferred place to spend the end-of-life phase. The reason for the change from hospital to nursing home is perhaps

because, during the seminar, subjects were told that they can receive EOLC in the nursing home. The nursing home aligned better with their desire to maintain their preferred lifestyle rather than to receive life-prolonging treatment, which was also reported after the seminar. In Japan, an integrated community care system has been promoted, wherein EOLC is made available not only to hospital patients but also to nursing home residents. In addition, the residents of private residential homes and private nursing homes can receive EOLC from third-party service providers. Being aware of these options might influence people's decision-making.

Association between preferred place of death and life perceptions

When the subjects were asked to review their lives, most reported that their lives had been good. The subjects who reported living their life to the fullest and having no regrets in their lives tended to select "home" as their preferred place of death. In contrast, subjects who reported having regrets tended to select "hospital." This suggests helping older adults to view their lives in a more positive way might change their wishes concerning their preferred place of death. This finding might relate to the notion of the "integration of the life," which is a developmental task in the later period of life. More specifically, in the seminar, the subjects were asked to review their life story and were introduced to the idea of an "ending note." In this way, the seminar gave the subjects an opportunity to look back on their lives and think about their EOLC. Ogusu [12] advocated for the importance of reviewing the life story at the end-of-life, as this helps elderly people in their decision-making. Reviewing their lives might give elderly adults greater confidence in their way of living and the care they choose to receive.

Importance of providing seminars for community residents on EOLC decision-making

At least 80% of subjects reported having an understanding of the care or services they could receive in each location studied. Through a seminar, it becomes possible to understand the EOLC provided at each preferred place of death. This understanding can lead to decision-making. The subjects also frequently selected as their preferred place of death those places whose services of care they understood. This might be related to the level of information that residents have and the expectations about the EOLC received in each location, as well as to the personnel who provide relevant information (i.e., healthcare workers and care providers). Health care personnel require a certain understanding of the care they are offering, and must convey that information in a satisfactory way if they are to influence residents' decision-making. To help with elderly people's decision-making, hospital nurses require knowledge of the care provided in a given nursing home or at home; conversely, nurses who conduct home visits or work in nursing homes require knowledge of the care provided in medical institutions. Further, both the recipients and providers of EOLC must have well-defined opinions on life and death.

Uchida et al. [15] have advocated for a multidisciplinary EOLC system in Japan in order to promptly respond to the care needs of recipients, which constantly change throughout the initiation, stable, and terminal phases of the end-of-life. Although most people still die in the hospital in Japan, healthcare workers should still verify the wishes of the patient, and appropriately move patients to a home or institution. EOLC in nursing homes requires networking by nurses, physicians, care staff, and family [16]. In this study, we believe that health and welfare workers should gain EOLC-related experience and knowledge in hospitals, nursing homes, nearby institutions located close to home, and homes. Such integrated knowledge and training can then be used both in the affiliated nursing homes and for community residents outside of these homes

According to research on end-of-life decision-making during unexpected emergency hospitalizations or admissions to a nursing home, the person requiring the hospitalization or admission is often incapable of making decisions. People who died in special elderly nursing homes have been shown to be of older age, have fewer hospitalizations, and have more experiences with conferences regarding the EOLC period. Further studies will be

necessary to determine what types of EOLC is needed specifically in special elderly nursing homes when it is difficult to confirm individuals' or families' intention regarding EOLC [17]. Thus, preparation for decision-making on EOLC should begin when individuals' ability to make decisions is still intact and the elderly person still resides in the local community. In other words, such preparation should begin prior to hospitalization or admission to an institution. To that end, promoting the EOLC seminars used in the present study is very meaningful.

Limitations and Suggestions for Further Research

One limitation of this study is that there was a bias in the gender ratio and health status of the subjects. Specifically, all had a sufficiently positive attitude and a good enough health status to participate in the seminar, and more than 60% of the subjects were women. Accordingly, the data cannot be simply generalized. Another limitation is that we administered the survey only once, after the seminar, because most subjects were elderly. In the future, EOLC seminars should be evaluated via randomized controlled trials that do their best to limit the burden on subjects. We surveyed community residents after EOLC seminars and found that most (nursing home residents) preferred to die at "home." Preferred place of death was correlated with whether the subject lived with their spouse, had lived life to the fullest, had regrets in life, had expectations about the care they could receive in each location, and had confidence in their health. Given that a significantly higher percentage of subjects who interpreted their life as good during the review of their life selected "home" as their preferred place to die, helping elderly people integrate their life story might assist in the process of decision-making. Moreover, to educate local residents about the EOLC they can receive in hospitals, nursing homes, and the home, we must disseminate information on EOLC. Nurses must also learn and understand the various forms of EOLC administered according to the setting and circumstances, from the outset.

Conclusion

Both before and after the seminar, "home" was the most frequently selected preferred place of death. The second highest preference was "hospital" before the seminar, and "nursing home" after it. Similarly, the subjects who lacked confidence in their own health more often selected "hospital" before the seminar, whereas after the seminar, they selected "nursing home" more often. It is important for community residents to understand ACP and EOLC.

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