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Association between subjective economic status and refusal of life-prolonging treatment : a cross-sectional study using content analysis with stratified random sampling

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Abstract

Introduction : Older adults tend to refuse life-prolonging treatment for various reasons, and it is important to respect their choice of treatment at the end-of-life stage. The present study examines the associations of subjective economic status and gender with reasons for refusal of life-prolonging treatment in older adults in general population.

Methods : In this cross-sectional study, using stratified random sampling, 1,595 older adults living in Koriyama City, Japan, as of 2016, completed self-administered questionnaires on subjective economic status and preference for life-prolonging treatment, with free-description regarding reasons for refusal. We analyzed the associations between the combination of subjective economic status and gender with frequently mentioned terms and their clusters regarding such reasons, using χ^2 test, content analysis, text mining and hierarchical cluster analysis.

Results : The combinations of subjective economic status and gender were significantly associated with clustered reasons for refusal of life-prolonging treatment ($p < 0.01$). The reasons frequently mentioned were : 'avoidance of unnecessary medical care' and 'dignity' in well-off females ; and 'financial burden on family' in poor males.

Conclusions : Our findings suggest that older adults who at first glance appear to be freely refusing life-prolonging treatment, may have their decision making restricted through economic constraints.

Key words : Older adult, Life-prolonging treatment, Subjective economic status, Quality of Life, Text mining

Introduction

Understanding decision-making by older adults about the refusal or acceptance of life-prolonging treatment (LPT) is important for medical professionals and their families. In recent years, the tendency to refuse LPT has spread widely through societies worldwide, and as a result, LPT tends to be refused by older adults, their families, and medical professionals^{1,2)}. Previous studies have revealed that older adults at the end-of-life (EOL) stage can

have a feeling of having lived a complete life, and are therefore tired of living. In addition, they wish to keep their dignity, minimize the burden they believe they put on their families, and avoid feelings isolation³⁻⁶⁾. These studies suggest that these are the reasons why older adults tend to reject LPT.

On the other hand, since refusal of LPT makes death certain, we must be extremely cautious about whether the decisions made by older adults are truly voluntary. Previous studies have shown that economic status is a social determinant when older

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adults make LPT decisions at the EOL stage ; they are more likely to accept treatment if it is low-cost⁷. Additionally, social inequality can result in feelings of social resentment and “denial of death” ; such feelings can enhance preference for LPT⁸. In addition, low income and low subjective economic status are associated with lower rates of LPT among older adults^{9,10}.

The above-mentioned reasons and social determinants, such as economic status regarding LPT, may be mutually associated. However, previous studies have not adequately defined these associations due to three limitations. First, the reasons why older adults refuse LPT were determined using the subjects’ answers to items prepared by researchers in advance^{1,4,5} ; thus, even if the subjects have more diverse reasons than the researchers expect, such reasons cannot be measured properly. Second, although a few studies have explored such reasons using qualitative methods, the subjects in these studies were comprised of individuals with certain characteristics, such as having cancer or being a resident of a nursing home^{11,12} ; as a result, the generalizability of such studies is considered to be narrow. Third, it has been reported that gender and economic status are determinants of LPT decision-making, but the extent of their influence on the decision-making is unknown^{13,14}. Therefore, we hypothesized that surveying reasons for refusal of LPT using open-ended questions in the general older adult population is necessary.

The purpose of the present study was to investigate the reasons for refusal of LPT according to gender and subjective economic status in the general older adult population by content analysis. We posit the following two hypotheses after taking into consideration the results of the above-mentioned previous studies : first, decision-making on LPT can vary depending on gender and subjective economic status. Second, individuals in difficult economic situations frequently use terms that are strongly related to their economic situation, while those without financial distress frequently use terms that are closely related to reasons other than economic circumstances.

Materials and methods

Study design and sample

The study population was the same as those in two previous studies^{15,16}. In the present cross-sectional study, a stratified random sampling method

was used to select potential participants aged 65 years or over, who as of 2016, were not certified as requiring nursing care, from the population of Koriyama City, Fukushima Prefecture, Japan. First, 78,821 older adults (33,958 males and 44,863 females) were extracted. Next, the potential subjects were stratified according to gender and 20 sub-regions, based on Koriyama City’s administrative boundaries. Gender and region distributions were then adjusted by sampling weights based on proportionate population sizes. Finally, 3,000 subjects were enrolled in the study ; 1,301 males (43.4%) and 1,699 females (56.6%). In January 2017, we distributed questionnaires to the participants, and a total of 2,206 participants answered and returned the questionnaires anonymously (response rate, 73.5%).

To avoid loss of accuracy of data, we excluded questionnaires that were answered by a person other than the participant ($n = 373$), and those that had been answered incompletely regarding subjective economic status and preference for LPT ($n = 304$). Thus, the number of participants analyzed in the present study was 1,595 in total ; 748 males (46.9%) and 847 females (53.1%), with an effective response rate of 53.1% (1,595/3,000).

Of the 1,595 participants, those who answered ‘probably/definitely yes’ ($n = 120$) and ‘undetermined’ ($n = 343$) to the question ‘Do you prefer LPT at the EOL stage?’ were excluded from further quantitative content analysis, while those who answered ‘no’ ($n = 1,132$) to said question were enrolled. Of these enrolled 1,132 participants, 898 (392 males, 43.7% ; and 506 females, 56.3%) who completely answered the open question about why they would refuse LPT were included in the quantitative content analysis, and their free descriptions were analyzed. The effective response rate of the quantitative content analysis was 79.3% (898/1,132).

Basic attributes

The basic attributes included age, gender, and subjective economic status. The degree of subjective economic status was assessed using a five-point scale (1, ‘very good’ ; 2, ‘good’ ; 3, ‘fair’ ; 4, ‘poor’ ; and 5, ‘very poor’).

Outcome

The following two outcomes were measured. First, each subject’s preference for LPT at the EOL stage was measured using the following question : ‘Do you prefer LPT at the EOL stage?’ (five-point scale : 1 = ‘definitely no’, 2 = ‘probably no’, 3 =

‘probably yes’, 4 = ‘definitely yes’, 5 = ‘undetermined’). Second, the reasons for refusing LPT was measured using a free description for the following open-ended question: ‘Please state the reason(s) why you would not like to undergo LPT’.

Analysis for preference of LPT and its related factors

Prior to analysis, age was classified into two categories: 65–74 years (‘early older adult’) and 75 years or older (‘late older adult’). Subjective economic status was dichotomized: poor included ‘very poor’ and ‘poor’, and well-off included ‘fair’, ‘good’ and ‘very good’. The five degrees of preference for LPT were classified into three categories: “prefer not” included ‘definitely not’ and ‘probably not’; “prefer” included ‘probably yes’ and ‘definitely yes’; and “undetermined” included ‘undetermined’. The subjects were divided into four groups according to the patterns of gender and dichotomized subjective economic status: poor males, well-off males, poor females, and well-off females.

Statistical analyses were performed using SPSS statistics version 26 (IBM Corp., Armonk, NY, USA), and the participants’ characteristics were summarized using descriptive statistics. The bivariate associations of preference for LPT with factors such as age and the above-mentioned four groups were examined using a χ^2 test, and then the statistical significance of the cells in the tables was analyzed using residual analysis.

Analysis for free description

To examine the lexical category and frequency of terms in the free description data of the above-mentioned groups, text mining was conducted. The subjected terms were comprised of nouns and adjectival nouns, which are a Japanese lexical category to explain the trait or state of something, and can be analyzed in the same way as nouns in English. Nouns and adjectival nouns were selected because they are both considered to be essential to constructing a basic sentence in Japanese. The free description data were preliminarily reviewed and then analyzed: we finally included the top 30–40% most frequently-used terms as our subjected terms for the analysis, as described in a previous study past¹⁷. Prior to clustering the terms extracted, among the terms obtained from the free descriptions, four were integrated, because they were judged to be easy to understand without losing their meaning: ‘money’, ‘parent’, ‘child’ and ‘end’.

In addition to the analysis using the subjected terms directly, we summarized the terms by cluster-

ing them in order to more deeply examine the meaning of the participants’ reasons for refusal of LPT. Hierarchical cluster analysis using Jaccard index and Ward’s method was employed for such clustering by using KH Coder (version 3. Alpha. 17K)¹⁸, a software program for Japanese language which has a language morphological analysis system. Using the hierarchical cluster analysis, seven clusters were extracted, each of which was inductively named from the terms included. The word frequency was deemed to correspond with the degree of interest, and the total frequencies of the terms in each cluster were calculated. Then, a χ^2 test was conducted to examine the associations of said clusters with combinations of subjective economic status and gender, using residual analysis to confirm the statistical significance of the cells in the tables.

Ethics statement

This study was approved by the Ethics Committee of Fukushima Medical University (Application No. 29,047).

Results

The characteristics of the participants are shown in Table 1. In total, the mean age was 73.9 years (SD: 6.9, range: 65–93), and the numbers of early and late older adult subjects were 922 (57.8%) and 673 (74.9%), respectively. The most common answer for subjective economic status was ‘fair’ (63.1%) and that preference for LPT was ‘definitely no’ (49.3%).

Bivariate analysis indicated that preference for LPT was significantly associated with combination of gender and subjective economic status, as shown in Table 2 ($p < 0.001$). Residual analysis revealed that, among the participants who answered ‘preferred’ for LPT, the number of well-off males was significantly high (10.5%), whereas the number of well-off females was significantly low (4.7%). Among the participants who answered ‘undetermined,’ the number of well-off females was significantly low (18.4%). Regarding those who answered ‘non-preferred’, the number of well-off males was significantly low (65.9%), whereas the number of well-off females was significantly high (76.9%).

For the quantitative content analysis, a total of 445 subjected terms were used, and their appearance frequency in total was 2,893. Of these subjected terms, 50 that each had an appearance frequency of 10 or more times (top 34.4% terms) were

Table 1. Characteristics ($N = 1,595$)

Variables	n (%)
Age \pm SD, years	73.88 \pm 6.91
Early older adult	922 (57.8)
Late older adult	673 (42.2)
Gender	
Male	748 (45.3)
Female	847 (54.7)
Subjective economic status	
Very good	9 (0.7)
Good	75 (4.7)
Fair	1,012 (63.1)
Poor	370 (23.0)
Very poor	129 (8.5)
Preference for life prolonging treatment	
Definitely no	790 (49.3)
Probably no	342 (21.3)
Probably yes	74 (4.6)
Definitely yes	46 (2.9)
Undetermined	343 (21.4)

extracted, and hierarchical cluster analysis was conducted to summarize those terms on the basis of their co-occurrence tendencies as shown in Table 3.

The 50 terms were categorized into the following seven clusters: 'age and future', which included 'age' and 'future'; "dignity and humanity," which included 'naturally', 'death', 'quiet', 'prolonging life', 'excessive', 'tenure of life', 'human being', 'living', 'health', 'life', 'meaning', 'LPT', 'need', 'vegetative state', 'status', 'awareness', 'anxiety' and 'will'; 'financial burden on family', which included 'annoyance', 'child', 'money', 'family and 'burden'; 'difficulty of nursing care', which included 'nursing care', 'parents', 'myself' and 'hard'; "loss of independence," which included 'around', 'people', 'longevi-

ty', 'spry', 'bedridden' and 'care'; 'mental and physical health', which included 'relative', 'old age', 'treatment', 'illness', 'lifetime', 'end', 'the person', 'distress', 'state', 'body' and 'unwelcome'; and 'avoidance of unnecessary medical care', which included 'expectancy', 'recovery', 'medicine' and 'wasteful'.

The names of the clusters were determined through discussions among the authors about which concepts would be representative of the words in the clusters. The following four clusters are named after all or approximately the top two words in terms of frequency: 'age and future', 'financial burden on family', 'difficulty of nursing care' and 'avoidance of unnecessary medical care'. 'Dignity and humanity' includes 'naturally', 'awareness', 'meaning', 'human being', 'vegetative state', so we decided that the reason is to live and die naturally with dignity and humanity intact. 'Loss of independence' was determined by focusing on 'longevity', 'bedridden', and 'care' as reasons to avoid being bedridden and cared for over a long time. 'Mental and physical health' was determined by focusing on 'treatment', 'distress', 'body', 'illness', and 'unwelcome' as reasons for refusing LPT with impaired mental and physical health.

The χ^2 test results indicate that the frequency of clusters which cited reasons for refusal of LPT varied by combination of gender and subjective economic status as shown in Table 4 ($p < 0.001$). Residual analysis revealed that the frequency of the terms in the 'financial burden on family' cluster was significantly high among the poor male and poor female participants (16.9%, 16.9%, respectively). However, among the poor females, those of 'dignity and humanity' and 'avoidance of unnecessary medical care' were significantly low (10.9% and 6.5%, re-

Table 2. Bivariate analysis of the associations of preference for receiving life-prolonging treatment with combination of gender and subjective economic status

Variables	Preference for LPT			p -value
	Prefer	Undetermined	Prefer Not	
Combinations of gender and subjective economic status				< 0.001*
Poor male	27 (10.0)	60 (22.2)	183 (67.8)	
Poor female	14 (6.1)	56 (24.5)	159 (69.4)	
Well-off male	50 (10.5)†	113 (23.6)	315 (65.9)‡	
Well-off female	29 (4.7)‡	114 (18.4)‡	475 (76.9)†	

n (%)

All categorical variables were examined using a χ^2 test.

*Indicates statistical significance.

†Indicates adjusted standardized residual > 1.96.

‡Indicates adjusted standardized residual < -1.96.

Table 3. Extracted 50 terms with 10 or more appearance

Cluster	Terms	All	Subjects groups			
			Poor male	Poor female	Well-off Male	Well-off female
Age and future	Age	11	1 (0.1)	1 (0.1)	3 (0.3)	6 (0.5)
	Future	10	2 (0.2)	4 (0.4)	0 (0.0)	4 (0.4)
Dignity and humanity	Naturally	106	12 (0.1)	12 (0.1)	22 (0.2)	60 (0.6)
	Life-prolonging Treatment	89	12 (0.1)	9 (0.1)	28 (0.3)	40 (0.4)
	Tenure of life	54	10 (0.2)	3 (0.1)	26 (0.5)	15 (0.3)
	Prolonging life	40	10 (0.3)	3 (0.1)	12 (0.3)	15 (0.4)
	Awareness	33	3 (0.1)	6 (0.2)	7 (0.2)	17 (0.5)
	Status	32	5 (0.2)	2 (0.1)	8 (0.3)	17 (0.5)
	Need	31	4 (0.1)	2 (0.1)	10 (0.3)	15 (0.5)
	Meaning	26	7 (0.3)	7 (0.3)	7 (0.3)	5 (0.2)
	Life	24	4 (0.2)	7 (0.3)	4 (0.2)	9 (0.4)
	Death	22	4 (0.2)	1 (0.0)	4 (0.2)	13 (0.6)
	Biosis	18	3 (0.2)	3 (0.2)	2 (0.1)	10 (0.6)
	Excessive	18	1 (0.1)	3 (0.2)	5 (0.3)	9 (0.5)
	Anxiety	15	1 (0.1)	0 (0.0)	5 (0.3)	9 (0.6)
	Health	14	2 (0.1)	2 (0.1)	4 (0.3)	6 (0.4)
	Human being	14	1 (0.1)	1 (0.1)	7 (0.5)	5 (0.4)
Vegetative state	13	3 (0.2)	0 (0.0)	6 (0.5)	4 (0.3)	
Quiet	10	0 (0.0)	1 (0.1)	1 (0.1)	8 (0.8)	
Will	10	1 (0.1)	0 (0.0)	1 (0.1)	8 (0.8)	
Financial burden on family	Family	289	43 (0.1)	44 (0.2)	77 (0.3)	125 (0.4)
	Burden	210	42 (0.2)	31 (0.1)	53 (0.3)	84 (0.4)
	Annoyance	208	31 (0.1)	36 (0.2)	45 (0.2)	96 (0.5)
	Money	79	21 (0.3)	19 (0.2)	13 (0.2)	26 (0.3)
	Child	67	7 (0.1)	14 (0.2)	13 (0.2)	33 (0.5)
Difficulty of nursing care	Myself	109	21 (0.2)	13 (0.1)	25 (0.2)	50 (0.5)
	Hard	35	5 (0.1)	7 (0.2)	5 (0.1)	18 (0.5)
	Nursing care	30	7 (0.2)	3 (0.1)	7 (0.2)	13 (0.4)
	Parents	19	2 (0.1)	2 (0.1)	2 (0.1)	13 (0.7)
Loss of independence	Around	43	5 (0.1)	5 (0.1)	8 (0.2)	25 (0.6)
	People	39	5 (0.1)	5 (0.1)	9 (0.2)	20 (0.5)
	Longevity	31	4 (0.1)	4 (0.1)	8 (0.3)	15 (0.5)
	Bedridden	18	1 (0.1)	3 (0.2)	5 (0.3)	9 (0.5)
	Spry	14	1 (0.1)	4 (0.3)	0 (0.0)	9 (0.6)
	Care	11	0 (0.0)	1 (0.1)	2 (0.2)	8 (0.7)
Mental and physical health	Treatment	50	5 (0.1)	8 (0.2)	11 (0.2)	26 (0.5)
	The person	21	1 (0.0)	3 (0.1)	5 (0.2)	12 (0.6)
	Lifetime	15	4 (0.3)	1 (0.1)	4 (0.3)	6 (0.4)
	Distress	14	1 (0.1)	0 (0.0)	7 (0.5)	6 (0.4)
	End	14	1 (0.1)	3 (0.2)	2 (0.1)	8 (0.6)
	Relative	12	5 (0.4)	2 (0.2)	2 (0.2)	3 (0.3)
	Body	10	0 (0.0)	4 (0.4)	2 (0.2)	4 (0.4)
	Illness	10	0 (0.0)	3 (0.3)	2 (0.2)	5 (0.5)
	Old age	10	1 (0.1)	0 (0.0)	4 (0.4)	5 (0.5)
	State	10	0 (0.0)	0 (0.0)	0 (0.0)	10 (1.0)
Unwelcome	10	1 (0.1)	2 (0.2)	1 (0.1)	6 (0.6)	
Avoidance of unnecessary medical care	Medicine	29	4 (0.1)	2 (0.1)	12 (0.4)	11 (0.4)
	Wasteful	24	3 (0.1)	2 (0.1)	11 (0.5)	8 (0.3)
	Expectancy	23	2 (0.1)	2 (0.1)	9 (0.4)	10 (0.4)
	Recovery	16	0 (0.0)	0 (0.0)	11 (0.7)	5 (0.3)

Table 4. The associations of subjective economic status-gender groups with clustered reasons for refusal of LPT

Variables	Combination of gender and subjective economic status				<i>p</i> -value
	Poor male	Poor female	Well-off male	Well-off female	
Age and future	3 (14.3)	5 (23.8)	3 (14.3)	10 (47.6)	< 0.001*
Dignity and humanity	83 (14.6)	62 (10.9) ‡	159 (27.9)	265 (46.6)	
Financial burden on family	144 (16.9) †	144 (16.9) †	201 (23.6)	364 (42.7) ‡	
Difficulty of nursing care	35 (18.1)	25 (13.0)	39 (20.2)	94 (48.7)	
Loss of independence	16 (10.3)	22 (14.1)	32 (20.5)	86 (55.1) †	
Mental and physical health	19 (10.8)	26 (14.8)	40 (22.7)	91 (51.7)	
Avoidance of unnecessary medical care	9 (9.8)	6 (6.5) ‡	43 (46.7) †	34 (37.0)	

Frequency (%)

*Indicates statistical significance.

†Indicates adjusted standardized residual > 1.96.

‡Indicates adjusted standardized residual < -1.96.

spectively). Among the well-off males, ‘avoidance of unnecessary medical care’ was significantly high (46.7%). Finally, among the well-off females, ‘financial burden on family’ was significantly low (42.7%) whereas ‘loss of independence’ was significantly high (55.1%).

Discussion

In the present study, we investigated the associations between subjective economic status, gender and decision-making regarding the acceptance or refusal of LPT, and the reasons for refusing LPT in the general older adult population, positing two hypotheses. In regard to the first hypothesis, there were the association between subjective economic status and preference for LPT differed between genders. For the second hypothesis, we discovered that there were associations between the clustered reasons for LPT refusal and combinations of gender and subjective economic status. Importantly, our results suggest that older adults who at first glance appear to be freely refusing LPT may be restricted in decision making through economic constraints. Although it is important to respect the choices of older adults, particularly during the EOL stage, their families and attending medical professionals should consider the social and psychological factors behind said choices.

For the first hypothesis, we believe that the combination between gender and subjective economic status are associated with LPT preference. Consistent with the results of a previous study¹³, bivariate analysis showed that males preferred receiving LPT whereas females tended to refuse it among well-off older adults. These results are consistent with those of past studies, which pointed out that

older adult females are more likely than males to refuse LPT^{14,19}, and to have the wish to die sooner if terminally ill¹³. As for the result that this tendency was not observed among the poor older adults, given that high economic status is associated with high autonomy²⁰, the gender difference may be the result of thinking autonomically about LPT. In other words, although well-off subjective economic status allows for independent thinking for males and females, our analysis indicated that the resulting conclusions are different depending on gender.

In regard to our second hypothesis, the results of the quantitative content analysis showed that the reasons for refusing LPT varied depending on subjective economic status and gender. The older adults with poor economic status more frequently mentioned terms regarding ‘financial burden on family’ regardless of gender, and females with poor economic status less frequently mentioned terms related to ‘dignity and humanity’ and ‘avoidance of unnecessary medical care’. These results indicate that older adults who with a low economic status tend to focus on concerns about the financial burden on their families when considering LPT.

While previous study suggested that having a family, especially dependent children, is a factor that promotes LPT choice²¹, the older adults in this study did not prefer LPT due to economic concerns in despite the presence of family. The relationship between family presence and LPT choice may need to be explored further, in the context of economic status.

With regard to gender, the numbers of poor female participants who mentioned terms related to ‘financial burden on family’ was high frequently while ‘dignity and humanity’ and ‘avoidance of un-

necessary medical care' were significantly low, on the other hand, poor males just frequently mentioned about 'financial burden on family'. These categories may reflect personal values related to the EOL. These results that females did not focus on the personal topics are consistent with previous studies that reported females to be more strongly influenced by the presence of a spouse or family member in their LPT decisions than males^{13,14,19}; therefore, females may be more sensitive to what other people think and do not prioritize themselves when they are poor. Importantly, a no similar significant association was found in the well-off females, suggesting that the influence of a spouse and/or family on LPT decisions may be mediated by economic status in females. In general, when supporting poor older adults in decision-making at the EOL stage, it is important to address their economic anxiety first.

The present study has the following two limitations. First, the subjects were selected from a single city in Japan; future research should have more representative populations sampled from more areas than those used in the current study. Second, confounding factors were not entirely controlled in the present study. Previous studies reported that racial, social and cultural factors contribute to decision-making on treatment at the EOL stage^{8,22}. The decision process at the EOL stage is complex, and thus further investigation including other factors in addition to age and gender, such as educational background and religion, is required.

In conclusion, in addition to the findings from past studies, we found that the reasons for refusing LPT varied depending on subjective economic status and gender among older adults. When their subjective economic status is poor, it is difficult for older adults to consider future prospects and to have preemptive conversations about EOL^{13,23}. In light of these past studies, poor subjective economic status may make it difficult to think specifically about the future, including LPT, and may make older adults reluctant to collect and transmit information regarding their wishes on whether or not to undergo LPT. Therefore, we suggest that even older adults who apparently refuse LPT may want to live longer or, at least, fail to adequately consider the possibility of LPT. This is a new discovery made in the current study as a result of carefully-conducted quantitative analysis using qualitative data of free descriptions regarding EOL decisions. In addition for quantitative analysis by text mining using qualitative data, we used the technique of clustering words in the

current study, which allowed us to gain new insight into the thought processes of the people involved. For practical implications, our findings suggest that when assisting decision-making, relatives and medical experts should consider the social and psychological factors behind choices regarding LPT at the EOL stage by older adults.

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Disclosure

The authors declare that there are no conflicts of interest.

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