BMJ Open

Imaginary decisions for life-sustaining treatment in families of older adults with cognitive impairment: a cross-sectional study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039470
Article Type:	Original research
Date Submitted by the Author:	16-Apr-2020
Complete List of Authors:	Youn, HyunChul; Soonchunhyang University Bucheon Hospital Lee, Suk-young ; Wonkwang University Jung, Han-yong ; Soonchunhyang University Bucheon Hospital Kim, Shin-Gyeom ; Soonchunhyang University Bucheon Hospital Jeong, Hyun-Ghang; Korea University College of Medicine and School of Medicine,
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MENTAL HEALTH, Adult palliative care < PALLIATIVE CARE, PUBLIC HEALTH, Adult psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Imaginary decisions for life-sustaining treatment in families of older adults with cognitive impairment: a cross-sectional study

HyunChul Youn,[1] Suk-young Lee,[2] Han-yong Jung,[1] Shin-Gyeom Kim,[1] Hyun-Ghang Jeong[3,4]

[1]Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic of Korea

[2]Division of Hemato-Oncology, Department of Internal Medicine, College of Medicine, Wonkwang University, Iksan, Republic of Korea

[3]Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine, Seoul, Republic of Korea

[4]Korea University Research Institute of Mental Health, Seoul, Republic of Korea

Correspondence to

Dr Hyun-Ghang Jeong;

Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine,

148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;

E-mail: jeonghg@korea.ac.kr

Word count: 3,003 words

ORCID iDs

HyunChul Youn https://orcid.org/0000-0002-6557-5628

Shin-Gyeom Kim https://orcid.org/0000-0001-8196-655X

Hyun-Ghang Jeong https://orcid.org/0000-0002-0318-5069

ABSTRACT

Objectives In South Korea, the Act on Decisions for Life-Sustaining Treatment was implemented on 4 February 2018. This study aimed to investigate the thoughts about life-sustaining treatment of family members of older adults with cognitive impairment and to assess the factors associated with withdrawal of life-sustaining treatment.

Design Cross-sectional study.

Setting Guro-gu center for dementia from 1 May 2018 to 31 December 2019.

Participants In total, 150 family members of older adults with cognitive impairment participated in this study. We classified our participants into two groups: individuals who want to maintain life-sustaining treatment (IMLT) and individuals who want to withdraw life-sustaining treatment (IWLT).

Outcome measures The questionnaire consisted of self-report items with some instructions, demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales. The psychosocial scales included the Generalized Anxiety Disorder-7, Patient Health Questionnaire-9, Connor–Davidson Resilience Scale, and Multidimensional Scale of Perceived Social Support.

Results There were twice as many participants in the IWLT group than there were in the IMLT. In making this decision, the IWLT group focused more on physical and mental distress. Additionally, 32.7% of participants responded that terminal status was an optimal time for this decision, but more participants want to decide it earlier. Participants with higher levels of education/depression/anxiety and lower levels of perceived family support tended to fall in the IWLT group.

Conclusions Our findings can help assess issues regarding advance directives and life-sustaining treatment in individuals who have cared for chronic and deteriorating patients as well as in individuals with cognitive impairment.

Keywords: Life-sustaining treatment, Advance directives, Education, Depression, Anxiety

Strengths and limitations of this study

- This study enrolled the "current" and "potential future" legal guardians of individuals with cognitive impairment.
- The effects of psychosocial factors including depression, anxiety, resilience, and perceived social support on decision for life-sustaining treatment were investigated.
- This study did not include the severity or diagnosis of cognitive impairment, which can be associated with degree of distress as a family member.

INTRODUCTION

According to the constitutional right to self-determination, judging one's own life is part of one's dignity and worth as a human being.[1] In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.[1] Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.[2] At this time, the Patient Self-Determination Act was first formalized in United States.[3] In South Korea, the Act on the Determination of Life-Life Care for Patients in the Hospice and Relaxation Medicine and the Deathly Hallows Process was finally passed by the National Assembly on 8 January 2016 and was implemented on 4 February 2018.[1] Under this act, advance directives can be prepared in South Korea for terminal states where decision-making is impossible. Advance directives are defined as "any statement given in advance of decisional incapacity directing the provision of life-sustaining treatment in incapacitated states".[2]

Between February 2018 and September 2019, a total of 378,350 people registered their advance directives with the National Agency for Management of Life-Sustaining Treatment.[4] Of these people, 859 individuals discontinued life-sustaining treatment according to their advance directives.[4] However, until now, many more people judged their own life at the terminal stage. Furthermore, the discontinuation of life-sustaining treatment of many people was determined by their family members. The National Agency for Management of Life-Sustaining Treatment [4] reported that the former numbered 21,479 and the latter 22,758 over the same time period.

Previous studies showed that a majority of people do not want aggressive treatment at the last moment of life.[3 5-8] Accordingly, advance directives are especially important because individuals who did not sign advance directives tend to receive aggressive life-sustaining

treatment until the last moment of their lives regardless of their own intention.[9] Older adults with cognitive impairment may face difficulty in deciding whether to receive life-sustaining treatment or not, considering their judgement and executive function. Though many statistics have not been collected, we speculated that the last moment of many older adults with cognitive impairment might be determined by their family members. Until now, there have been few studies of advance directives or preferences for life-sustaining treatment in older adults with cognitive impairment or their family members. In this study, we focused on the thoughts regarding life-sustaining treatment of family members of older adults with cognitive impairment. Considering the influence of family members on the life of older adults with cognitive impairment,[10 11] our survey may help assess issues for advance directives and life-sustaining treatment in older adults with cognitive impairment.

In addition, family members of older adults with cognitive impairment can feel psychological distress, including depression and anxiety.[12-14] Medical illness that may be related to fatal conditions can also be comorbid with negative mood.[15-18] That is, one can experience depression or anxiety at the moment one signs one's own advance directives or decides whether to receive life-sustaining treatment or not. Therefore, we additionally focused on the possibility that negative mood affects the decision for life-sustaining treatment.

The aim of this study is to investigate the thoughts regarding life-sustaining treatment of family members of older adults with cognitive impairment and to assess the factors, especially negative mood, associated with withdrawal of life-sustaining treatment.

METHODS

Participants and procedure

A total of 152 family members of older adults with cognitive impairment were recruited via the Guro-gu center for dementia from 1 May 2018 to 31 December 2019. Participants with a history of serious disease such as cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study. After some instructions were provided, participants filled out a survey on the spot. It took about 20 to 30 minutes to complete the questionnaires. Participants answered the questions anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on life-sustaining treatment) and were, therefore, excluded. The necessary ethical permissions were received from the Institutional Review Board at Korea University Guro Hospital prior to the initiation of the research (2018GR0151). Before completing the questionnaires, participants were informed about the study protocol and gave their written informed consent.

Measures

All questionnaires were in self-report format. The questionnaire consisted of three parts. The first part contained items assessing the following demographic characteristics: age, gender, education, marital status, housing status, occupational status, religion, and monthly income.

In the second part, participants answered questions regarding their thoughts on life-sustaining treatment. We provided a description of the terms used in the questionnaire before the second part to avoid confusion. According to the answer of the question "Do you want to receive life-sustaining treatment?" we classified our participants into two groups: individuals who want to maintain life-sustaining treatment (IMLT) and individuals who want to withdraw life-sustaining treatment (IWLT). We adopted "cancer" as the example to help participants understand life-sustaining treatment better, because many South Koreans regard cancer as most worrying disease.[19]

The third part included the psychosocial items. We adopted the Generalized Anxiety Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression, respectively.[20] A higher score on these scales indicates a higher possibility of having anxiety or depressive symptoms. These scales have been translated into Korean, and their reliability and validity have been confirmed.[21 22] The Connor–Davidson Resilience Scale (CD-RISC) was used to assess the degree of resilience.[23] This scale contains 25 items scored in a five-point response format, and the total score ranges from zero to 100, where higher scores reflect greater resilience. We used the Korean version of the CD-RISC, which has been found to be reliable and valid.[24] We included the Multidimensional Scale of Perceived Social Support (MSPSS) to evaluate the perceived social support of family, friends, and significant others.[25] The MSPSS contains four items that are rated on a seven-point scale ranging from *very strongly disagree* [1] to *very strongly agree*.[7] We adopted the Korean version of MSPSS.[26]

Statistical analysis

Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous variables and percentages for categorical variables). Differences between IMLT and IWLT groups in basic characteristics, thoughts on life-sustaining treatment, and psychosocial scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used independent *t*-tests for continuous variables and χ^2 tests or Fisher's exact test for categorical variables.

RESULTS

Among the 150 participants, the IMLT and IWLT groups comprised 50 and 100 participants,

respectively. Table 1 shows the basic characteristics of the IMLT and IWLT groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female. The participants with college-level education or higher were significantly more numerous in the IWLT group than the IMLT group.

Table 1 Basic characteristics of IMLT and IWLT groups

	Total (n=150)	IMLT (n=50)	IWLT (n=100)	P value*
Age, years	45.38 ± 14.71	45.48 ± 14.16	45.33 ± 15.04	0.953
Gender				1.000
Male	66 (44.0)	22 (44.0)	44 (44.0)	
Female	84 (56.0)	28 (56.0)	56 (56.0)	
Education				0.014†
≤High school graduate	49 (32.7)	23 (46.0)	26 (26.0)	
≥College	101 (67.3)	27 (54.0)	74 (74.0)	
Marital status				0.507
Married (living with spouse)	100 (66.7)	35 (70.0)	65 (65.0)	
Living together without being married	7 (4.7)	3 (6.0)	4 (4.0)	
Unmarried	36 (24.0)	10 (20.0)	26 (26.0)	
Divorce/Separation	1 (0.7)	1 (2.0)	0 (0.0)	
Separation by death	6 (4.0)	1 (2.0)	5 (5.0)	
Housing status				0.874
Live alone	16 (10.7)	4 (8.0)	12 (12.0)	
Live with family	130 (86.7)	45 (90.0)	85 (85.0)	
Others	3 (2.0)	1 (2.0)	2 (2.0)	
Occupational status				0.124
Unemployed	17 (11.3)	6 (12.0)	11 (11.0)	
Stay-at-home spouse	28 (18.7)	7 (14.0)	21 (21.0)	
Student	5 (3.3)	0 (0.0)	5 (5.0)	
Self-employed	16 (10.7)	9 (18.0)	7 (7.0)	
Office worker	61 (40.7)	18 (36.0)	43 (43.0)	
Others	23 (15.3)	10 (20.0)	13 (13.0)	
Religion				0.079
Having religion	87 (58.0)	26 (52.0)	37 (37.0)	
No religion	63 (42.0)	24 (48.0)	63 (63.0)	
Monthly income (million won)				0.778
<100	17 (11.3)	4 (8.0)	13 (13.0)	
100-299	53 (35.3)	16 (32.0)	37 (37.0)	
300-499	50 (33.3)	17 (34.0)	33 (33.0)	
500-699	15 (10.0)	6 (12.0)	9 (9.0)	
≥700	9 (6.0)	4 (8.0)	5 (5.0)	

The data is presented as mean ± standard deviation or number (%).

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†p<0.05.

IMLT, individuals who want to maintain life-sustaining treatment; IWLT, individuals who want to withdraw life-sustaining treatment.

We compared the thoughts on life-sustaining treatment of the IMLT and IWLT groups (Table 2). The IMLT group focused more on the chance of survival, while the IWLT group was more concerned about physical and mental distress. In addition, the IWLT group agreed with assisted suicide more than the IMLT group.

Table 2 Thoughts on life-sustaining treatment of IMLT and IWLT groups

	Total (n=150)	IMLT (n=50)	IWLT (n=100)	P value*
Most important issue in deciding whether to receive life-sustaining treatment or not	Chance of survival (81 (54.0%))	Chance of survival (38 (76.0%))	Chance of survival (43 (43.0%))	0.001†
	Physical distress (29 (19.3%))	Physical distress (3 (6.0%))	Physical distress (26 (26.0%))	
	Mental distress (13 (8.7%))	Religious belief (3 (6.0%))	Mental distress (12 (12.0%))	
	Terminal state (49 (32.7%))	Immediately after diagnosis of metastatic cancer (19 (38.0%))	Terminal state (37 (37.0%))	0.458
Optimal timing to decide whether to receive life-sustaining treatment or not	Immediately after diagnosis of metastatic cancer (42 (28.0%))	Immediately after diagnosis of any cancer regardless of stage (13 (26.0%))	Immediately after diagnosis of any cancer regardless of stage (24 (24.0%))	
	Immediately after diagnosis of any cancer regardless of stage (37 (24.7%))	Terminal state (12 (24.0%))	Immediately after diagnosis of metastatic cancer (23 (23.0%))	
Pros and cons on assisted suicide under the disease conditions of severe distress and no hope of recovery	Agreement (111 (74.0%))	Agreement (32 (64.0%))	Agreement (79 (79.0%))	0.048‡

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†p<0.01.

‡p<0.05.

IMLT, individuals who want to maintain life-sustaining treatment; IWLT, individuals who want to withdraw life-sustaining treatment.

The IMLT and IWLT groups also showed differences in some psychosocial scale scores. GAD-7 and PHQ-9 scores were higher in the IWLT group than the IMLT group, whereas the IMLT group showed significantly higher MSPSS-family scores. These results are shown in Table 3.

Table 3 Comparison of GAD-7, PHQ-9, CD-RISC, and MSPSS scores between the IMLT and IWLT groups

	Total (n=150)	IMLT (n=50)	IWLT (n=100)	P value*
GAD-7	4.14 ± 4.47	3.12 ± 3.20	4.65 ± 4.92	0.024†
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048†
CD-RISC	65.33 ± 17.58	67.76 ± 17.71	64.09 ± 17.48	0.237
MSPSS				
Family	23.01 ± 4.88	24.34 ± 4.04	22.32 ± 5.15	0.011†
Friend	20.17 ± 5.01	20.60 ± 4.26	19.95 ± 5.37	0.457
Others	21.61 ± 5.82	22.76 ± 5.28	21.02 ± 6.02	0.086
Total	64.99 ± 13.07	67.70 ± 11.92	63.57 ± 13.47	0.070

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†$p<0.05$.

GAD-7, Generalized Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; CD-RISC, Connor–Davidson Resilience Scale; MSPSS, Multidimensional Scale of Perceived Social Support; IMLT, individuals who want to maintain life-sustaining treatment; IWLT,

individuals who want to withdraw life-sustaining treatment.

DISCUSSION

In our study, there were twice as many participants in the IWLT group, compared to those in the IMLT group, who responded that they do not want to receive life-sustaining treatment. Chance of survival was the most important issue in both groups in deciding whether or not to receive life-sustaining treatment, but the IWLT group focused more on physical and mental distress. Pros and cons on assisted suicide showed similar trends as preference for life-sustaining treatment. The timing preference order was terminal state, immediately after diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in deciding whether to receive life-sustaining treatment. In addition, participants with higher education levels tended to be more common in the IWLT group. On the psychosocial scales, the IWLT group represented higher levels of depression/anxiety and lower level of perceived family support than the IMLT group.

Most prior studies have reported that the majority of people do not want aggressive treatment in their terminal state.[3 5-8] Our results were consistent with these previous studies. In addition, the IWLT group rated physical and mental distress highly in deciding their preference for life-sustaining treatment than the IMLT group in this study. According to previous reports, many people want hospice care and a more comfortable process of dying such as dying in their sleep.[6 27 28] Some studies have even shown that cancer pain was associated with a desire for hastened death.[29 30] Therefore, we speculate that avoidance of unwanted distress may account for the preference for withdrawal of life-sustaining treatment.

Furthermore, our results that a majority of participants, especially in the IWLT group, agreed with assisted suicide may be interpreted similarly. These findings may emphasize the importance of advance directives. A previous study reported a tendency to receive more life-sustaining treatment when patients' intention for life-sustaining treatment was unclear.[9] Accordingly, more publicity regarding actively participating in registering one's advance directives to National Agency for Management of Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.

In total, 32.7% of the participants in our study regarded terminal status as an optimal time to decide whether to receive life-sustaining treatment. However, more participants want to decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer regardless of stage. There have been few previous studies with this result. However, Keam et al. [31] mentioned that people may regard the decision for life-sustaining treatment as a will that embodies values about end-of life. We also believe that people may want to decide the last moment of their own life while they are relatively healthy and physically/mentally intact so as to preserve their dignity and worth as human beings.

Among sociodemographic factors, education level was the factor that showed significant differences between the IMLT and IWLT groups. That is, participants with higher education levels tended to prefer withdrawal of life-sustaining treatment in this study. Some previous studies analyzed the association between education level and life-sustaining treatment, but the results were controversial.[8 32 33] On the other hand, various studies have reported that individuals with higher education levels had greater interest in advance directives and a stronger tendency to complete them beforehand.[6 7 31] However, there have been few comments on the causes of this association.[6 7 31] Though more studies are needed to clarify

our results, we speculate that a tendency toward introspection and accessibility of information may account for the association between education level and preference for life-sustaining treatment or advance directives. Our findings may emphasize the necessity of broader publicity and explanations of advance directives for life-sustaining treatment.

In addition, the IWLT group showed higher levels of depression and anxiety than the IMLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness, frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic problems including pain.[34] We believe that these symptoms can affect the decision for life-sustaining treatment. For example, as hopelessness is associated with suicide,[35-37] cancer patients who have feelings of hopelessness might wish to hasten death. In addition, previous studies reported that cancer pain was related to a desire for hastened death.[29 30] Therefore, we speculate that depressive patients with somatic problems such as pain aggravation might change their minds to select a peaceful death. Similar to our results, Wen et al. [38] reported that cancer patients with depressive symptoms were more likely to be in the comfort-preferring state in terms of preference for life-sustaining treatment. Our findings suggest that a consideration of depressive and anxiety symptoms may be needed in determining whether or not one receives life-sustaining treatment. Though many patients with severe physical illness suffer from depression and anxiety,[15-18] these symptoms can be attenuated by proper treatment.[39-41] That is, if individuals have depressive or anxiety symptoms when they complete their advance directives for life-sustaining treatment, delaying the timing of the decision may be recommended until after the proper treatment of depression or anxiety. O'Mahony et al. [42] showed that improvements in depression moderated the severity of the desire for hastened death in patients with cancer pain. Our recommendation is consistent with this previous report.

Furthermore, participants who felt relatively well-supported by their family members tended to prefer to maintain life-sustaining treatment. However, the results of other studies differ from ours, though a consensus does not have been previously reached. Kim and Shin [43] reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al. [44] also reported that patients who were single, divorced, or bereaved were significantly more likely to reverse life-sustaining treatment decisions to a higher intensity of life-sustaining treatment. As our findings were opposite to these previous studies, consideration of the characteristics of our participants may be needed to understand our results. Our participants were family members of patients in a center for dementia. Therefore, distress as a family member might be reflected in the answers on MSPSS-family items. That is, the participants who perceived a lower level of family support might be likely to suffer from distress as a family member, and consequently might have a greater tendency to prefer peaceful death. We believe that the influences of family support in deciding whether one receives life-sustaining treatment vary depending on the participants and settings of each study. Uhlmann and Pearlman [45] even showed that family relationships and preference for life-sustaining treatment were not significantly associated in chronically ill, elderly outpatients. Further studies including a greater variety of participants can clarify the association between family support and life-sustaining treatment.

In this study, we investigated the preference for life-sustaining treatment and factors associated with the decision in family members of individuals with cognitive impairment. The thoughts regarding life-sustaining treatment of our participants were generally consistent with previous reports on life-sustaining treatment. However, our results showed the possibility that distress as a family member of individuals with cognitive impairment

might be reflected in the preference for life-sustaining treatment. In particular, depressive and anxiety symptoms may have an effect on this issue. According to our findings, it may be essential to address negative mood such as depression or anxiety when signing one's own advance directives or deciding whether one receives life-sustaining treatment, particularly in individuals in a distressed situation. That is, if necessary, adequate intervention can be applied to individuals with negative moods during their decision-making process on life-sustaining treatment.

As mentioned in the Introduction, there have been few studies of preferences for life-sustaining treatment in individuals with cognitive impairment. Our participants, the family members, may be the "current" and "potential future" legal guardians of individuals with cognitive impairment. Therefore, our results may provide data to assess issues of advance directives and life-sustaining treatment in individuals with cognitive impairment. Furthermore, our findings might also serve as a reference for this issue for family members of patients with other chronic and deteriorating diseases considering the courses of patients in center for dementia. However, there may be some disagreement between patients and their family members on preferences for life-sustaining treatment. Abdul-Razzak et al. [46] also reported an appreciable disagreement between hospitalized patients and family members on this issue. We believe that future studies including patients with cognitive impairment can advance our results.

There are some limitations to this study. First, our study has a relatively small number of participants. This may limit the generalizability of our results. Second, we only included the family members of patients in a center for dementia. That is, this study does not have comparison subjects such as patients with cognitive impairment. Though our results were

generally consistent with previous studies, direct comparison between patients and their family members may be needed to clarify our results. In addition, further studies including various other groups such as the general public, physicians, and cancer patients may represent more informative results. Third, we did not investigate the severity or diagnosis of cognitive impairment, which can be associated with degree of distress as a family member. Inclusion of these factors may help assess the associations between preference for life-sustaining treatment and distress as a family member. Fourth, our study used a cross-sectional design. However, the preference for life-sustaining treatment can change over time. Gallo et al. [47] also reported that periodic reassessment for planning end-of-life care was needed in their 12-year follow-up study. Finally, our questionnaire consisted of only self-report items. Though we provided descriptions of the meanings of the terms, using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

CONCLUSION

This study showed the thoughts and associated factors regarding life-sustaining treatment of family members of older adults with cognitive impairment. Our participants tended to want to withdraw life-sustaining treatment and to agree with assisted suicide. In deciding the withdrawal of life-sustaining treatment, chance of survival and physical/mental distress were the important issues. Thirty-two point seven percent of participants responded that terminal status was an optimal time to decide whether to receive life-sustaining treatment. However, many more participants want to decide this issue earlier. Among sociodemographic and psychosocial factors, higher levels of education, depression, and anxiety and lower levels of

family support were associated with the decision to withdraw life-sustaining treatment. Our findings can help assess issues of advance directives and life-sustaining treatment in individuals who have cared for chronic and deteriorating patients as well as in individuals with cognitive impairment.

Contributors HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK contributed to interpretation. All authors critically revised the manuscript and gave final approval.

Funding This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.

Disclaimer The funders had no role in planning or conducting the study.

Competing interests The authors declare no conflicts of interest.

Patient and public involvement Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Patient consent for publication Not required.

Data availability statement The data that support the findings of this study are available on request from the corresponding author.

REFERENCES

1. Kim JS. Some improvements of act on decisions on life-sustaining treatment for patients. *Law Rev* 2019;19:357-80.
2. Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. *Health Psychol* 2005;24:S63-70.
3. Garrido MM, Balboni TA, Maciejewski PK, *et al.* Quality of life and cost of care at the end of life: The role of advance directives. *J Pain Symptom Manage* 2015;49:828-35.
4. National Agency for Management of Life-Sustaining Treatment. Present performance status of withdrawal of life-sustaining treatment. 2019. https://www.lst.go.kr/comm/monthlyStatistics.do (accessed 31 Oct 2019).
5. Kim J, Heo S, Hong SW, *et al.* Correlates of advance directive treatment preferences among community-dwelling older people with chronic diseases. *Int J Older People Nurs* 2019;14:e12229.
6. Lee MO, Park J, Park EY, *et al.* The Korean-advance directive model and factors associated with its completion among patients with hematologic disorders. *J Hosp Palliat Nurs* 2019;21:E10-e6.
7. Hoe DF, Enguidanos S. So help me, god: Religiosity and end-of-life choices in a nationally representative sample. *J Palliat Med* 2020;23:563-7.
8. Yun YH, Han KH, Park S, *et al.* Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients. *CMAJ* 2011;183:E673-9.
9. Pasman HR, Kaspers PJ, Deeg DJ, *et al.* Preferences and actual treatment of older adults at the end of life. A mortality follow-back study. *J Am Geriatr Soc* 2013;61:1722-9.

10. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009;11:217-28.
11. Sousa MF, Santos RL, Arcoverde C*, et al.* Quality of life in dementia: the role of non-cognitive factors in the ratings of people with dementia and family caregivers. *Int Psychogeriatr* 2013;25:1097-105.
12. Garand L, Dew MA, Eazor LR*, et al.* Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry* 2005;20:512-22.
13. Garand L, Lingler JH, Deardorf KE*, et al.* Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Dis Assoc Disord* 2012;26:159-65.
14. Teri L. Behavior and caregiver burden: behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Dis Assoc Disord* 1997;11 Suppl 4:S35-8.
15. Thom R, Silbersweig DA, Boland RJ. Major depressive disorder in medical illness: A review of assessment, prevalence, and treatment options. *Psychosom Med* 2019;81:246-55.
16. Spiegel D. Cancer and depression. *Br J Psychiatry Suppl* 1996:109-16.
17. Katon W, Lin EH, Kroenke K. The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *Gen Hosp Psychiatry* 2007;29:147-55.
18. Steffens DC, Helms MJ, Krishnan KR*, et al.* Cerebrovascular disease and depression symptoms in the cardiovascular health study. *Stroke* 1999;30:2159-66.
19. Health Insurance Review & Assessment Service. *Worrying diseases of the people*.

Wonju: Health Insurance Review & Assessment Service, 2016.

20. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-44.
21. Choi HS, Choi JH, Park KH*, et al.* Standardization of the Korean version of patient health questionnaire-9 as a screening instrument for major depressive disorder. *J Korean Acad Fam Med* 2007;28:114-9.
22. Seo JG, Cho YW, Lee SJ*, et al.* Validation of the generalized anxiety disorder-7 in people with epilepsy: a MEPSY study. *Epilepsy Behav* 2014;35:59-63.
23. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.
24. Jung YE, Min JA, Shin AY*, et al.* The Korean version of the Connor-Davidson Resilience Scale: an extended validation. *Stress Health* 2012;28:319-26.
25. Eker D, Arkar H. Perceived social support: psychometric properties of the MSPSS in normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr Epidemiol* 1995;30:121-6.
26. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the unemployed. *Korean J Soc Welf* 1999;37:241-69.
27. Kim S, Koh S, Park K*, et al.* End-of-life care decisions using a Korean advance directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.
28. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.
29. Chochinov HM, Wilson KG, Enns M*, et al.* Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.

30. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression. *Postgrad Med* 1989;85:263-6, 8, 70.

31. Keam B, Yun YH, Heo DS, *et al.* The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. *Support Care Cancer* 2013;21:1437-44.

32. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care interventions (active pain control, withdrawal of futile life-sustaining treatment, passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred cross-sectional survey of Korean patients with cancer, their family caregivers, physicians and the general Korean population. *BMJ Open* 2018;8:e020519.

33. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460-8.

34. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.

35. Minkoff K, Bergman E, Beck AT, *et al.* Hopelessness, depression, and attempted suicide. *Am J Psychiatry* 1973;130:455-9.

36. Beck AT, Brown G, Berchick RJ, *et al.* Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry* 1990;147:190-5.

37. Beck AT, Steer RA, Kovacs M, *et al.* Hopelessness and eventual suicide: a 10-year prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry* 1985;142:559-63.

38. Wen FH, Chen JS, Chou WC, *et al.* Factors predisposing terminally ill cancer patients'

preferences for distinct patterns/states of life-sustaining treatments over their last six months. *J Pain Symptom Manage* 2019;57:190-8.e2.

39. Smith HR. Depression in cancer patients: Pathogenesis, implications and treatment (Review). *Oncol Lett* 2015;9:1509-14.
40. Traeger L, Greer JA, Fernandez-Robles C*, et al.* Evidence-based treatment of anxiety in patients with cancer. *J Clin Oncol* 2012;30:1197-205.
41. Lyford J. Integrated care for cancer patients with depression is effective. *Pharm J* 2014. http://dx.doi.og/10.1211/PJ.2014.20066288.
42. O'Mahony S, Goulet J, Kornblith A*, et al.* Desire for hastened death, cancer pain and depression: report of a longitudinal observational study. *J Pain Symptom Manage* 2005;29:446-57.
43. Kim HS, Shin SR. The influence of social support among community dwelling elderly and their attitude towards the withdrawal of life-sustaining treatment: A mediating effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.
44. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and associated factors among older patients with terminal stage of cardiopulmonary disease. *J Korean Acad Nurs* 2019;49:329-39.
45. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.
46. Abdul-Razzak A, Heyland DK, Simon J*, et al.* Patient-family agreement on values and preferences for life-sustaining treatment: results of a multicentre observational study. *BMJ Support Palliat Care* 2019;9:e20.
47. Gallo JJ, Abshire M, Hwang S*, et al.* Advance directives, medical conditions, and preferences for end-of-life care among physicians: 12-year follow-up of the Johns

Hopkins precursors study. *J Pain Symptom Manage* 2019;57:556-65.

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1,3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6, 7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8, 9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8, 9
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	8
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	8
		(*e*) Describe any sensitivity analyses	9
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	11, 12, 13
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11, 12, 13
		(*b*) Report category boundaries when continuous variables were categorized	8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16, 17, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Preferences for life-sustaining treatment in individuals with family members with cognitive impairment: a cross-sectional study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039470.R1
Article Type:	Original research
Date Submitted by the Author:	08-Oct-2020
Complete List of Authors:	Youn, HyunChul; Soonchunhyang University Bucheon Hospital, Department of psychiatry Lee, Suk-young ; Wonkwang University Jung, Han-yong ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Kim, Shin-Gyeom ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Jeong, Hyun-Ghang; Korea University College of Medicine and School of Medicine,
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Palliative care, Patient-centred medicine
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MENTAL HEALTH, Adult palliative care < PALLIATIVE CARE, PUBLIC HEALTH, Adult psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Preferences for life-sustaining treatment in individuals with family members with cognitive impairment: a cross-sectional study

HyunChul Youn,[1] Suk-young Lee,[2] Han-yong Jung,[1] Shin-Gyeom Kim,[1] Hyun-Ghang Jeong[3,4]

[1]Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic of Korea

[2]Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine, Wonkwang University, Gunpo, Republic of Korea

[3]Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine, Seoul, Republic of Korea

[4]Korea University Research Institute of Mental Health, Seoul, Republic of Korea

Correspondence to

Dr Hyun-Ghang Jeong;

Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine,

148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;

E-mail: jeonghg@korea.ac.kr

Word count: 2,946 words

ORCID iDs

HyunChul Youn https://orcid.org/0000-0002-6557-5628

Shin-Gyeom Kim https://orcid.org/0000-0001-8196-655X

Hyun-Ghang Jeong https://orcid.org/0000-0002-0318-5069

ABSTRACT

Objectives In South Korea, the Act on Decisions for Life-Sustaining Treatment was implemented on 4 February 2018. This study aimed to investigate the thoughts on life-sustaining treatment of individuals with family members with cognitive impairment and to assess the factors associated with deciding to not receive life-sustaining treatment.

Design Cross-sectional study.

Setting Guro-gu center for dementia from 1 May 2018 to 31 December 2019.

Participants In total, 150 individuals with family members with cognitive impairment participated in this study. We classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT).

Outcome measures The questionnaire consisted of self-report items with some instructions, demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales. The psychosocial scales included the Generalized Anxiety Disorder-7 (GAD-7), Patient Health Questionnaire-9 (PHQ-9), Connor–Davidson Resilience Scale, and Multidimensional Scale of Perceived Social Support (MSPSS).

Results There were twice as many participants in the INLT group than there were in the IRLT. In making this decision, the INLT group focused more on physical and mental distress. Additionally, 32.7% of participants responded that terminal status was an optimal time for this decision, but more participants want to decide it earlier. The GAD-7 and PHQ-9 scores were significantly higher in the INLT group than in the IRLT group. However, the INLT group had significantly lower MSPSS family scores.

Conclusions Our findings can help in the future assessment of issues regarding advance directives and life-sustaining treatment in individuals who care for old or cognitively impaired patients.

Keywords: Life-sustaining treatment, Advance directives, Education, Depression, Anxiety

Strengths and limitations of this study

- This study enrolled individuals with family members with cognitive impairment.
- The effects of psychosocial factors including depression, anxiety, resilience, and perceived social support on decision for life-sustaining treatment were investigated.
- This study did not include the severity or diagnosis of cognitive impairment, which can be associated with degree of distress as a family member.

INTRODUCTION

According to the constitutional right to self-determination, judging one's own life is part of one's dignity and worth as a human being.[1] In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.[1] Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.[2] At this time, the Patient Self-Determination Act was first formalized in United States.[3] In South Korea, the Act on the Determination of Life-Life Care for Patients in the Hospice and Relaxation Medicine and the Deathly Hallows Process was finally passed by the National Assembly on 8 January 2016 and was implemented on 4 February 2018.[1] Under this act, advance directives can be prepared in South Korea for terminal states where decision-making is impossible. Advance directives are defined as "any statement given in advance of decisional incapacity directing the provision of life-sustaining treatment in incapacitated states".[2]

Between February 2018 and September 2019, a total of 378,350 people registered their advance directives with the National Agency for Management of Life-Sustaining Treatment.[4] Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.[4] However, until now, many more people judged their own life at the terminal stage. Furthermore, the discontinuation of life-sustaining treatment of many people was determined by their family members. The National Agency for Management of Life-Sustaining Treatment [4] reported that the former numbered 21,479 and the latter 22,758 over the same time period. Previous studies showed that a majority of people do not want aggressive treatment at the last moment of life.[3] [5-8] Accordingly, advance directives are especially important because individuals who did not sign advance directives tend to receive aggressive life-sustaining treatment until the last moment of their lives regardless of their own intention.[9]

In this study, we focused on the thoughts regarding life-sustaining treatment of individuals with family members with cognitive impairment. These individuals may be exposed to caregiver distress, which can include depression and anxiety.[10-12] We believe that our survey may help assess issues surrounding advance directives and life-sustaining treatment in caregivers living in an aging society. In addition, medical illnesses that may be related to fatal conditions can also be comorbid with negative mood.[13-16] That is, one can experience depression or anxiety at the moment one signs one's own advance directive or decides whether to receive life-sustaining treatment. This study may be additionally helpful in assessing the possibility that negative mood affects the decision regarding life-sustaining treatment.

The aim of this study was to investigate the thoughts regarding life-sustaining treatment of individuals with family members with cognitive impairment and to assess factors, especially negative mood, associated with not receiving life-sustaining treatment.

METHODS

Participants and procedure

A total of 152 individuals with family members with cognitive impairment were recruited via the Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited 170 family members, but 18 people declined to participate in this study because they were not interested in the issue of the research. Participants with a history of serious disease such as cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study. After some instructions were provided, participants filled out a survey on the spot. It took about 20 to 30 minutes to complete the questionnaires. Participants answered the questions anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on life-sustaining

treatment) and were, therefore, excluded. The necessary ethical permissions were received from the Institutional Review Board at Korea University Guro Hospital prior to the initiation of the research (2018GR0151). Before completing the questionnaires, participants were informed about the study protocol and gave their written informed consent.

Measures

All questionnaires were in self-report format. The questionnaire consisted of three parts. The first part contained items assessing the following demographic characteristics: age, gender, education, marital status, housing status, occupational status, religion, and monthly income.

In the second part, participants answered questions regarding their thoughts on life-sustaining treatment. We provided a description of the terms used in the questionnaire before the second part to avoid confusion (suppl 1). For example, "terminal state" is defined as a condition in which treatments for the purpose of life extension are not applicable to patients. According to the answer of the question "Do you want to receive life-sustaining treatment?" we classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT). We adopted "cancer" as the example to help participants understand life-sustaining treatment better, because many South Koreans regard cancer as most worrying disease.[17]

The third part included the psychosocial items. We adopted the Generalized Anxiety Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression, respectively.[18] A higher score on these scales indicates a higher possibility of having anxiety or depressive symptoms. These scales have been translated into Korean, and their reliability and validity have been confirmed.[19 20] The Connor–Davidson Resilience Scale (CD-RISC) was

used to assess the degree of resilience.[21] This scale contains 25 items scored in a five-point response format, and the total score ranges from zero to 100, where higher scores reflect greater resilience. We used the Korean version of the CD-RISC, which has been found to be reliable and valid.[22] We included the Multidimensional Scale of Perceived Social Support (MSPSS) to evaluate the perceived social support of family, friends, and significant others.[23] The MSPSS contains four items that are rated on a seven-point scale ranging from *very strongly disagree* [1] to *very strongly agree*.[7] We adopted the Korean version of MSPSS.[24]

Statistical analysis

Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous variables and percentages for categorical variables). Differences between the IRLT and INLT groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used independent *t*-tests for continuous variables and χ^2 tests or Fisher's exact test for categorical variables.

RESULTS

Among the 150 participants, the IRLT and INLT groups comprised 50 and 100 participants, respectively. Table 1 shows the basic characteristics of the IRLT and INLT groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female. The participants with college-level education or higher were significantly more numerous in the INLT group than in the IRLT group.

Table 1 Basic characteristics of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Age, years	45.38 ± 14.71	45.48 ± 14.16	45.33 ± 15.04	0.953
Gender				1.000
Male	66 (44.0)	22 (44.0)	44 (44.0)	
Female	84 (56.0)	28 (56.0)	56 (56.0)	
Education				0.014†
≤High school graduate	49 (32.7)	23 (46.0)	26 (26.0)	
≥College	101 (67.3)	27 (54.0)	74 (74.0)	
Marital status				0.507
Married (living with spouse)	100 (66.7)	35 (70.0)	65 (65.0)	
Living together without being married	7 (4.7)	3 (6.0)	4 (4.0)	
Unmarried	36 (24.0)	10 (20.0)	26 (26.0)	
Divorce/Separation	1 (0.7)	1 (2.0)	0 (0.0)	
Separation by death	6 (4.0)	1 (2.0)	5 (5.0)	
Housing status				0.874
Live alone	16 (10.7)	4 (8.0)	12 (12.0)	
Live with family	130 (86.7)	45 (90.0)	85 (85.0)	
Others	3 (2.0)	1 (2.0)	2 (2.0)	
Occupational status				0.124
Unemployed	17 (11.3)	6 (12.0)	11 (11.0)	
Stay-at-home spouse	28 (18.7)	7 (14.0)	21 (21.0)	
Student	5 (3.3)	0 (0.0)	5 (5.0)	
Self-employed	16 (10.7)	9 (18.0)	7 (7.0)	
Office worker	61 (40.7)	18 (36.0)	43 (43.0)	
Others	23 (15.3)	10 (20.0)	13 (13.0)	
Religion				0.079
Having religion	87 (58.0)	26 (52.0)	37 (37.0)	
No religion	63 (42.0)	24 (48.0)	63 (63.0)	
Monthly income (million won)				0.778
<100	17 (11.3)	4 (8.0)	13 (13.0)	
100-299	53 (35.3)	16 (32.0)	37 (37.0)	
300-499	50 (33.3)	17 (34.0)	33 (33.0)	
500-699	15 (10.0)	6 (12.0)	9 (9.0)	
≥700	9 (6.0)	4 (8.0)	5 (5.0)	

The data is presented as mean ± standard deviation or number (%).

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†$p<0.05$.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table 2). The IRLT group focused more on the chance of survival, while the INLT group was more concerned about physical and mental distress. In addition, the INLT group agreed with assisted suicide more than the IRLT group.

Table 2 Thoughts on life-sustaining treatment of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Most important issue in deciding whether to receive life-sustaining treatment or not	Chance of survival (81 (54.0%))	Chance of survival (38 (76.0%))	Chance of survival (43 (43.0%))	0.001†
	Physical distress (29 (19.3%))	Physical distress (3 (6.0%))	Physical distress (26 (26.0%))	
	Mental distress (13 (8.7%))	Religious belief (3 (6.0%))	Mental distress (12 (12.0%))	
	Other responses (religious belief, treatment cost)	Other responses (mental distress, treatment cost)	Other responses (religious belief, treatment cost)	
Optimal timing to decide whether to receive life-sustaining treatment (assuming a future terminal state)	Terminal state (49 (32.7%))	Immediately after diagnosis of metastatic cancer (19 (38.0%))	Terminal state (37 (37.0%))	0.458
	Immediately after diagnosis of metastatic cancer (42 (28.0%))	Immediately after diagnosis of any cancer regardless of stage (13 (26.0%))	Immediately after diagnosis of any cancer regardless of stage (24 (24.0%))	
	Immediately after diagnosis of any cancer regardless of stage (37 (24.7%))	Terminal state (12 (24.0%))	Immediately after diagnosis of metastatic cancer (23 (23.0%))	
	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	
Agreement on assisted suicide under the disease conditions of severe distress and no hope of recovery	Agreement (111 (74.0%))	Agreement (32 (64.0%))	Agreement (79 (79.0%))	0.048‡

*p value were calculated using the χ^2 test or Fisher's exact test.

†p<0.01.

‡p<0.05.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

The IRLT and INLT groups also showed differences in some psychosocial scale scores. The GAD-7 and PHQ-9 scores were higher in the INLT group than in the IRLT group, whereas the IRLT group showed significantly higher MSPSS-family scores. These results are shown in Table 3.

Table 3 Comparison of GAD-7, PHQ-9, CD-RISC, and MSPSS scores between the IRLT and INLT groups

	Total (n=150)	**IRLT (n=50)**	**INLT (n=100)**	**P value***
GAD-7	4.14 ± 4.47	3.12 ± 3.20	4.65 ± 4.92	0.024†
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048†
CD-RISC	65.33 ± 17.58	67.76 ± 17.71	64.09 ± 17.48	0.237
MSPSS				
Family	23.01 ± 4.88	24.34 ± 4.04	22.32 ± 5.15	0.011†
Friend	20.17 ± 5.01	20.60 ± 4.26	19.95 ± 5.37	0.457
Others	21.61 ± 5.82	22.76 ± 5.28	21.02 ± 6.02	0.086
Total	64.99 ± 13.07	67.70 ± 11.92	63.57 ± 13.47	0.070

*p value were calculated using independent *t*-test.

†$p<0.05$.

GAD-7, Generalized Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; CD-RISC, Connor–Davidson Resilience Scale; MSPSS, Multidimensional Scale of Perceived Social Support; IRLT, individuals who wanted to receive life-sustaining treatment; INLT,

individuals who wanted to not receive life-sustaining treatment.

DISCUSSION

In our study, there were twice as many participants in the INLT group compared to those in the IRLT group, who responded that they do not want to receive life-sustaining treatment. Chance of survival was the most important issue in both groups in deciding whether or not to receive life-sustaining treatment, but the INLT group focused more on physical and mental distress. Agreement on assisted suicide showed similar trends as preference for life-sustaining treatment. The timing preference order was terminal state, immediately after diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in deciding whether to receive life-sustaining treatment. In addition, participants with higher education levels tended to be more common in the INLT group. On the psychosocial scales, the INLT group represented higher levels of depression/anxiety and lower level of perceived family support than the IRLT group.

Most prior studies have reported that the majority of people do not want aggressive treatment in their terminal state.[3 5-8] Our results were consistent with these previous studies. In addition, the INLT group rated physical and mental distress highly in deciding their preference for life-sustaining treatment than the IRLT group in this study. According to previous reports, many people want hospice care and a more comfortable process of dying such as dying in their sleep.[6 25 26] Some studies have even shown that cancer pain was associated with a desire for hastened death.[27 28] Therefore, we speculate that avoidance of unwanted distress may account for the preference for not receiving life-sustaining treatment.

Furthermore, our results that a majority of participants, especially in the INLT group, agreed with assisted suicide may be interpreted similarly. These findings may emphasize the importance of advance directives. A previous study reported a tendency to receive more life-sustaining treatment when patients' intention for life-sustaining treatment was unclear.[9] Accordingly, more publicity regarding actively participating in registering one's advance directives to National Agency for Management of Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.

In total, 32.7% of the participants in our study regarded terminal status as an optimal time to decide whether to receive life-sustaining treatment. However, more participants want to decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer regardless of stage. There have been few previous studies with this result. However, Keam et al. [29] mentioned that people may regard the decision for life-sustaining treatment as a will that embodies values about end-of life. We also believe that people may want to make decisions regarding the last moments of their own life, such as by signing advance directives, while they are relatively healthy and physically/mentally intact to preserve their dignity and worth as human beings. However, in determining whether to receive life-sustaining treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of stage," it may be important to take into account the possibility that patients are under stress at that time. We speculate that many participants might want to decide upon the last moments of their own life earlier than our existing options. For an example, many people would rather prefer to make their decision in a physically and mentally healthy state, uninfluenced by disease or pain. Although we asked the participants to write down other optimal timings directly, most participants opted for one of the existing options. Further studies are needed to clarify this issue.

Among sociodemographic factors, education level was the factor that showed significant differences between the IRLT and INLT groups. That is, participants with higher education levels tended to prefer to not receive life-sustaining treatment in this study. Some previous studies analyzed the association between education level and life-sustaining treatment, but the results were controversial.[8 30 31] On the other hand, various studies have reported that individuals with higher education levels had greater interest in advance directives and a stronger tendency to complete them beforehand.[6 7 29] However, there have been few comments on the causes of this association.[6 7 29] Though more studies are needed to clarify our results, we speculate that a tendency toward introspection and accessibility of information may account for the association between education level and preference for life-sustaining treatment or advance directives. Our findings may emphasize the necessity of broader publicity and explanations of advance directives for life-sustaining treatment.

In addition, the INLT group showed higher levels of depression and anxiety than the IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness, frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic problems including pain.[32] We believe that these symptoms can affect the decision for life-sustaining treatment. For example, as hopelessness is associated with suicide,[33-35] cancer patients who have feelings of hopelessness might wish to hasten death. In addition, previous studies reported that cancer pain was related to a desire for hastened death.[27 28] Therefore, we speculate that depressive patients with somatic problems such as pain aggravation might change their minds to select a peaceful death. Similar to our results, Wen et al. [36] reported that cancer patients with depressive symptoms were more likely to be in the comfort-preferring state in terms of preference for life-sustaining treatment. Our findings suggest that a consideration of depressive and anxiety symptoms may be needed in determining whether

or not one receives life-sustaining treatment. For example, clinicians may consider recommending the patient to delay making a decision on life-sustaining treatment if a patient's depressive or anxiety symptoms are believed to be temporary. According to the patient's condition, treatment for depression or anxiety symptoms may be provided to the patient before they make a decision. Our findings may be particularly meaningful because many patients with severe physical illness suffer from depression or anxiety.[13-16] Future research that can clarify any causal relationship may help verify and advance our results.

Furthermore, participants who felt relatively well-supported by their family members tended to prefer to receive life-sustaining treatment. However, the results of other studies differ from ours, though a consensus does not have been previously reached. Kim and Shin [37] reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al. [38] also reported that patients who were single, divorced, or bereaved were significantly more likely to reverse life-sustaining treatment decisions to a higher intensity of life-sustaining treatment. As our findings were opposite to these previous studies, consideration of the characteristics of our participants may be needed to understand our results. Our participants were family members of patients in a center for dementia. Therefore, distress as a family member might be reflected in the answers on MSPSS-family items. That is, the participants who perceived a lower level of family support might be likely to suffer from distress as a family member, and consequently might have a greater tendency to prefer peaceful death. We believe that the influences of family support in deciding whether one receives life-sustaining treatment vary depending on the participants and settings of each study. Uhlmann and Pearlman [39] even showed that family relationships and preference for life-sustaining treatment were not significantly associated in chronically ill, elderly outpatients. Further studies including a

greater variety of participants can clarify the association between family support and life-sustaining treatment.

In this study, we investigated the preference for life-sustaining treatment and factors associated with the decision in individuals with family members with cognitive impairment. The thoughts regarding life-sustaining treatment of our participants were generally consistent with previous reports on life-sustaining treatment. However, our results showed the possibility that distress as a family member of individuals with cognitive impairment might be reflected in the preference for life-sustaining treatment. In particular, depressive and anxiety symptoms may have an effect on this issue. According to our findings, if necessary, adequate interventions may be applied to individuals with negative mood during the decision-making process regarding life-sustaining treatment.

Our participants, the caregivers, were individuals with family members with cognitive impairment. Our results might serve as a reference for issues of advance directives and life-sustaining treatment for individuals who care for old or cognitively impaired patients. Furthermore, our findings may help design future studies on this issue in caregivers engaged in long-term care work for patients with chronic or deteriorating diseases.

There are some limitations to this study. First, our study has a relatively small number of participants. This may limit the generalizability of our results. Second, we only included individuals with family members with cognitive impairment. Further studies including various other groups such as the general public, caregivers of patients with other diseases, patients with cognitive impairment, physicians, and cancer patients may represent more informative results. Third, we did not investigate the severity or diagnosis of cognitive impairment, which can be associated with degree of distress as a family member. Inclusion

of these factors may help assess the associations between preference for life-sustaining treatment and distress as a family member. Fourth, our study used a cross-sectional design. However, the preference for life-sustaining treatment can change over time. Gallo et al. [40] also reported that periodic reassessment for planning end-of-life care was needed in their 12-year follow-up study. Fifth, absolute differences in the scores of scales between the two groups were relatively small, although statistically significant. For this reason, there may be limitations to the clinical significance of the results of this study. We believe that further study including patients with psychiatric problems, such as depression and anxiety, can help derive more clinical meaning. Sixth, this study presented specific options for each question regarding life-sustaining treatment. This may be convenient for the participant, but there is a possibility that the participant's intention was not sufficiently reflected. Finally, our questionnaire consisted of only self-report items. Though we provided descriptions of the meanings of the terms, using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

CONCLUSION

This study showed the thoughts and associated factors regarding life-sustaining treatment of individuals with family members with cognitive impairment. Our participants tended to want to not receive life-sustaining treatment and to agree with assisted suicide. In deciding to not receive life-sustaining treatment, chance of survival and physical/mental distress were the important issues. Thirty-two point seven percent of participants responded that terminal status was an optimal time to decide whether to receive life-sustaining treatment. However, many more participants want to decide this issue earlier. Among sociodemographic and

psychosocial factors, higher levels of education, depression, and anxiety and lower levels of family support were associated with the decision to not receive life-sustaining treatment. Our findings can help assess issues regarding advance directives and life-sustaining treatment in individuals who care for old or cognitively impaired patients.

Contributors HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK contributed to interpretation. All authors critically revised the manuscript and gave final approval.

Funding This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund. Grant number: N/A

Disclaimer The funders had no role in planning or conducting the study.

Competing interests The authors declare no conflicts of interest.

Patient and public involvement Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Patient consent for publication Not required.

Data availability statement The data that support the findings of this study are available on request from the corresponding author

REFERENCES

1. Kim JS. Some improvements of act on decisions on life-sustaining treatment for patients. *Law Rev* 2019;19:357-80.
2. Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. *Health Psychol* 2005;24:S63-70.
3. Garrido MM, Balboni TA, Maciejewski PK, *et al.* Quality of Life and Cost of Care at the End of Life: The Role of Advance Directives. *J Pain Symptom Manage* 2015;49:828-35.
4. National Agency for Management of Life-Sustaining Treatment. Present performance status of withdrawal of life-sustaining treatment. 2019. https://www.lst.go.kr/comm/monthlyStatistics.do (accessed 31 Oct 2019).
5. Kim J, Heo S, Hong SW, *et al.* Correlates of advance directive treatment preferences among community-dwelling older people with chronic diseases. *Int J Older People Nurs* 2019;14:e12229.
6. Lee MO, Park J, Park EY, *et al.* The Korean-advance directive model and factors associated with its completion among patients with hematologic disorders. *J Hosp Palliat Nurs* 2019;21:E10-e6.
7. Hoe DF, Enguidanos S. So help me, god: Religiosity and end-of-life choices in a nationally representative sample. *J Palliat Med* 2020;23:563-7.
8. Yun YH, Han KH, Park S, *et al.* Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients. *CMAJ* 2011;183:E673-9.
9. Pasman HR, Kaspers PJ, Deeg DJ, *et al.* Preferences and actual treatment of older adults at the end of life. A mortality follow-back study. *J Am Geriatr Soc*

2013;61:1722-9.

10. Garand L, Dew MA, Eazor LR, *et al.* Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry* 2005;20:512-22.
11. Garand L, Lingler JH, Deardorf KE, *et al.* Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Dis Assoc Disord* 2012;26:159-65.
12. Teri L. Behavior and caregiver burden: behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Dis Assoc Disord* 1997;11 Suppl 4:S35-8.
13. Thom R, Silbersweig DA, Boland RJ. Major Depressive Disorder in Medical Illness: A Review of Assessment, Prevalence, and Treatment Options. *Psychosom Med* 2019;81:246-55.
14. Spiegel D. Cancer and depression. *Br J Psychiatry Suppl* 1996:109-16.
15. Katon W, Lin EH, Kroenke K. The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *Gen Hosp Psychiatry* 2007;29:147-55.
16. Steffens DC, Helms MJ, Krishnan KR, *et al.* Cerebrovascular disease and depression symptoms in the cardiovascular health study. *Stroke* 1999;30:2159-66.
17. Health Insurance Review & Assessment Service. *Worrying diseases of the people* Wonju: Health Insurance Review & Assessment Service, 2016.
18. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-44.

19. Choi HS, Choi JH, Park KH, *et al.* Standardization of the Korean version of patient health questionnaire-9 as a screening instrument for major depressive disorder. *J Korean Acad Fam Med* 2007;28:114-9.

20. Seo JG, Cho YW, Lee SJ, *et al.* Validation of the generalized anxiety disorder-7 in people with epilepsy: a MEPSY study. *Epilepsy Behav* 2014;35:59-63.

21. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.

22. Jung YE, Min JA, Shin AY, *et al.* The Korean version of the Connor-Davidson Resilience Scale: an extended validation. *Stress Health* 2012;28:319-26.

23. Eker D, Arkar H. Perceived social support: psychometric properties of the MSPSS in normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr Epidemiol* 1995;30:121-6.

24. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the unemployed. *Korean J Soc Welf* 1999;37:241-69.

25. Kim S, Koh S, Park K, *et al.* End-of-life care decisions using a Korean advance directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.

26. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.

27. Chochinov HM, Wilson KG, Enns M, *et al.* Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.

28. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression. *Postgrad Med* 1989;85:263-6, 8, 70.

29. Keam B, Yun YH, Heo DS, *et al.* The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives.

Support Care Cancer 2013;21:1437-44.

30. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care interventions (active pain control, withdrawal of futile life-sustaining treatment, passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred cross-sectional survey of Korean patients with cancer, their family caregivers, physicians and the general Korean population. *BMJ Open* 2018;8:e020519.
31. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460-8.
32. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.
33. Minkoff K, Bergman E, Beck AT, *et al.* Hopelessness, depression, and attempted suicide. *Am J Psychiatry* 1973;130:455-9.
34. Beck AT, Brown G, Berchick RJ, *et al.* Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry* 1990;147:190-5.
35. Beck AT, Steer RA, Kovacs M, *et al.* Hopelessness and eventual suicide: a 10-year prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry* 1985;142:559-63.
36. Wen FH, Chen JS, Chou WC, *et al.* Factors Predisposing Terminally Ill Cancer Patients' Preferences for Distinct Patterns/States of Life-Sustaining Treatments Over Their Last Six Months. *J Pain Symptom Manage* 2019;57:190-8 e2.
37. Kim HS, Shin SR. The influence of social support among community dwelling elderly and their attitude towards the withdrawal of life-sustaining treatment: A mediating

effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.

38. Choi JJ, Kim SH, Kim SW. Reversals in Decisions about Life-Sustaining Treatment and Associated Factors among Older Patients with Terminal Stage of Cardiopulmonary Disease. *J Korean Acad Nurs* 2019;49:329.
39. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.
40. Gallo JJ, Abshire M, Hwang S, *et al.* Advance Directives, Medical Conditions, and Preferences for End-of-Life Care Among Physicians: 12-year Follow-Up of the Johns Hopkins Precursors Study. *J Pain Symptom Manage* 2019;57:556-65.

Verbatim translation of the scenario and description of the terms

* It is well known that about one-third of the population of South Korea will develop cancer during their lifetime. This questionnaire is conducted under the assumption that "if you have cancer (especially stage 4)".

* “Terminal state” is defined as a condition in which treatments for the purpose of life extension are not applicable to patients.

* “Life-sustaining treatment” is any treatment that serves to prolong life without reversing the underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in advance.

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1,3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6, 7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8, 9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8, 9
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	8
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	8
		(*e*) Describe any sensitivity analyses	9
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	11, 12, 13
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11, 12, 13
		(*b*) Report category boundaries when continuous variables were categorized	8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16, 17, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Preferences for life-sustaining treatment in Korean adults: a cross sectional study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039470.R2
Article Type:	Original research
Date Submitted by the Author:	24-Nov-2020
Complete List of Authors:	Youn, HyunChul; Soonchunhyang University Bucheon Hospital, Department of psychiatry Lee, Suk-young ; Wonkwang University Jung, Han-yong ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Kim, Shin-Gyeom ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Jeong, Hyun-Ghang; Korea University College of Medicine and School of Medicine,
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Palliative care, Patient-centred medicine
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MENTAL HEALTH, Adult palliative care < PALLIATIVE CARE, PUBLIC HEALTH, Adult psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Preferences for life-sustaining treatment in Korean adults: a cross sectional study

HyunChul Youn,[1] Suk-young Lee,[2] Han-yong Jung,[1] Shin-Gyeom Kim,[1] Hyun-Ghang Jeong[3,4]

[1]Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic of Korea

[2]Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine, Wonkwang University, Gunpo, Republic of Korea

[3]Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine, Seoul, Republic of Korea

[4]Korea University Research Institute of Mental Health, Seoul, Republic of Korea

Correspondence to

Dr Hyun-Ghang Jeong;

Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine,

148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;

E-mail: jeonghg@korea.ac.kr

Word count: 2,772 words

ORCID iDs

HyunChul Youn https://orcid.org/0000-0002-6557-5628

Shin-Gyeom Kim https://orcid.org/0000-0001-8196-655X

Hyun-Ghang Jeong https://orcid.org/0000-0002-0318-5069

ABSTRACT

Objectives Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, and left ventricular assist devices. This study aimed to investigate the thoughts on life-sustaining treatment of Koreans and to assess the factors associated with deciding to not receive life-sustaining treatment.

Design Cross-sectional study.

Setting Guro-gu center for dementia from 1 May 2018 to 31 December 2019.

Participants In total, 150 individuals participated in this study.

Outcome measures The questionnaire consisted of self-report items with some instructions, demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales. The preferences of the participants were investigated on the assumption that they develop cancer. The psychosocial scales included the Generalized Anxiety Disorder-7 (GAD-7), Patient Health Questionnaire-9 (PHQ-9), Connor–Davidson Resilience Scale, and Multidimensional Scale of Perceived Social Support (MSPSS).

Results We classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT). There were twice as many participants in the INLT group than there were in the IRLT. In making this decision, the INLT group focused more on physical and mental distress. Additionally, 32.7% of participants responded that terminal status was an optimal time for this decision, but more participants want to decide it earlier. The GAD-7 and PHQ-9 scores were significantly higher in the INLT group than in the IRLT group. However, the INLT group had significantly lower MSPSS family scores.

Conclusions Our findings can help assess issues regarding advance directives and life-sustaining treatment, and will be a reference for designing future studies on this issue.

Keywords: Life-sustaining treatment, Advance directives, Education, Depression, Anxiety

Strengths and limitations of this study

▶ This study enrolled Korean individuals for assessing issues regarding advance directives and life-sustaining treatment.

▶ We adopted cross-sectional design, and the questionnaire consisted of demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales.

▶ The effects of psychosocial factors including depression, anxiety, resilience, and perceived social support on decision for life-sustaining treatment were investigated.

▶ Our participants tended to want to not receive life-sustaining treatment, and higher levels of education, depression, and anxiety and lower levels of family support were associated with the decision to not receive life-sustaining treatment.

▶ Our questionnaire consisted of only self-report items, but using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

INTRODUCTION

According to the constitutional right to self-determination, judging one's own life is part of one's dignity and worth as a human being.[1] In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.[1] Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.[2] At this time, the Patient Self-Determination Act was first formalized in United States.[3] In South Korea, the Act on the Determination of Life-Life Care for Patients in the Hospice and Relaxation Medicine and the Deathly Hallows Process was finally passed by the National Assembly on 8 January 2016 and was implemented on 4 February 2018.[1] Under this act, advance directives can be prepared in South Korea for terminal states where decision-making is impossible. Advance directives are defined as "any statement given in advance of decisional incapacity directing the provision of life-sustaining treatment in incapacitated states".[2]

Between February 2018 and September 2019, a total of 378,350 people registered their advance directives with the National Agency for Management of Life-Sustaining Treatment.[4] Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.[4] However, until now, the majority chose to make the decision only at the very end of their lives. Furthermore, the discontinuation of life-sustaining treatment of many people was determined by their family members. The National Agency for Management of Life-Sustaining Treatment [4] reported that the former numbered 21,479 and the latter 22,758 over the same time period. Previous studies showed that a majority of people do not want aggressive treatment at the last moment of life.[3] [5-8] Accordingly, advance directives are especially important because individuals who did not sign advance directives tend to receive aggressive life-sustaining treatment until the last moment of their lives regardless of their own

intention.[9]

In this study, we focused on the thoughts regarding life-sustaining treatment of Korean individuals. We believe that our survey may help assess issues surrounding advance directives and life-sustaining treatment in individuals in the early stages of implementation of the advance directives system. In addition, medical illnesses that may be related to fatal conditions can also be comorbid with negative mood.[10-13] That is, one can experience depression or anxiety at the moment one signs one's own advance directive or decides whether to receive life-sustaining treatment. This study may be additionally helpful in assessing the possibility that negative mood affects the decision regarding life-sustaining treatment.

The aim of this study was to investigate the thoughts regarding life-sustaining treatment of Koreans and to assess factors, especially negative mood, associated with not receiving life-sustaining treatment.

METHODS

Participants and procedure

A total of 152 Korean individuals were participated in this study. We recruited family members of visitors in Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited 170 individuals, but 18 people declined to participate in this study because they were not interested in the issue of the research. Participants with a history of serious disease such as cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study. After some instructions were provided, participants filled out a survey on the spot. It took about 20 to 30 minutes to complete the questionnaires. Participants answered the questions anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on

life-sustaining treatment) and were, therefore, excluded. The necessary ethical permissions were received from the Institutional Review Board at Korea University Guro Hospital prior to the initiation of the research (2018GR0151). Before completing the questionnaires, participants were informed about the study protocol and gave their written informed consent.

Measures

All questionnaires were in self-report format. The questionnaire consisted of three parts. The first part contained items assessing the following demographic characteristics: age, gender, education, marital status, housing status, occupational status, religion, and monthly income.

In the second part, participants answered questions regarding their thoughts on life-sustaining treatment. We provided a description of the terms used in the questionnaire before the second part to avoid confusion (suppl 1). For example, "terminal state" is defined as a condition in which treatments for the purpose of life extension are not applicable to patients. We adopted "cancer" as the example to help participants understand life-sustaining treatment better, because many South Koreans regard cancer as most worrying disease.[14]

The third part included the psychosocial items. We adopted the Generalized Anxiety Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression, respectively.[15] A higher score on these scales indicates a higher possibility of having anxiety or depressive symptoms. These scales have been translated into Korean, and their reliability and validity have been confirmed.[16 17] The Connor–Davidson Resilience Scale (CD-RISC) was used to assess the degree of resilience.[18] This scale contains 25 items scored in a five-point response format, and the total score ranges from zero to 100, where higher scores reflect greater resilience. We used the Korean version of the CD-RISC, which has been found to be reliable and valid.[19] We included the Multidimensional Scale of Perceived Social Support (MSPSS) to

evaluate the perceived social support of family, friends, and significant others.[20] The MSPSS contains four items that are rated on a seven-point scale ranging from *very strongly disagree* [1] to *very strongly agree*.[7] We adopted the Korean version of MSPSS.[21]

Statistical analysis

Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous variables and percentages for categorical variables). Differences between the IRLT and INLT groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used independent *t*-tests for continuous variables and χ^2 tests or Fisher's exact test for categorical variables.

RESULTS

According to the answer of the question "Do you want to receive life-sustaining treatment?" we classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT). Among the 150 participants, the IRLT and INLT groups comprised 50 and 100 participants, respectively. Table 1 shows the basic characteristics of the IRLT and INLT groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female. The participants with college-level education or higher were significantly more numerous in the INLT group than in the IRLT group.

Table 1 Basic characteristics of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Age, years	45.38 ± 14.71	45.48 ± 14.16	45.33 ± 15.04	0.953
Gender				1.000
Male	66 (44.0)	22 (44.0)	44 (44.0)	
Female	84 (56.0)	28 (56.0)	56 (56.0)	
Education				0.014†
≤High school graduate	49 (32.7)	23 (46.0)	26 (26.0)	
≥College	101 (67.3)	27 (54.0)	74 (74.0)	
Marital status				0.507
Married (living with spouse)	100 (66.7)	35 (70.0)	65 (65.0)	
Living together without being married	7 (4.7)	3 (6.0)	4 (4.0)	
Unmarried	36 (24.0)	10 (20.0)	26 (26.0)	
Divorce/Separation	1 (0.7)	1 (2.0)	0 (0.0)	
Separation by death	6 (4.0)	1 (2.0)	5 (5.0)	
Housing status				0.874
Live alone	16 (10.7)	4 (8.0)	12 (12.0)	
Live with family	130 (86.7)	45 (90.0)	85 (85.0)	
Others	3 (2.0)	1 (2.0)	2 (2.0)	
Occupational status				0.124
Unemployed	17 (11.3)	6 (12.0)	11 (11.0)	
Stay-at-home spouse	28 (18.7)	7 (14.0)	21 (21.0)	
Student	5 (3.3)	0 (0.0)	5 (5.0)	
Self-employed	16 (10.7)	9 (18.0)	7 (7.0)	
Office worker	61 (40.7)	18 (36.0)	43 (43.0)	
Others	23 (15.3)	10 (20.0)	13 (13.0)	
Religion				0.079
Having religion	87 (58.0)	26 (52.0)	37 (37.0)	
No religion	63 (42.0)	24 (48.0)	63 (63.0)	
Monthly income (million won)				0.778
<100	17 (11.3)	4 (8.0)	13 (13.0)	
100-299	53 (35.3)	16 (32.0)	37 (37.0)	
300-499	50 (33.3)	17 (34.0)	33 (33.0)	
500-699	15 (10.0)	6 (12.0)	9 (9.0)	
≥700	9 (6.0)	4 (8.0)	5 (5.0)	

The data is presented as mean ± standard deviation or number (%).

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†$p<0.05$.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table 2). The IRLT group focused more on the chance of survival, while the INLT group was more concerned about physical and mental distress.

Table 2 Thoughts on life-sustaining treatment of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Most important issue in deciding whether to receive life-sustaining treatment or not	Chance of survival (81 (54.0%))	Chance of survival (38 (76.0%))	Chance of survival (43 (43.0%))	0.001†
	Physical distress (29 (19.3%))	Physical distress (3 (6.0%))	Physical distress (26 (26.0%))	
	Mental distress (13 (8.7%))	Religious belief (3 (6.0%))	Mental distress (12 (12.0%))	
	Other responses (religious belief, treatment cost)	Other responses (mental distress, treatment cost)	Other responses (religious belief, treatment cost)	
Optimal timing to decide whether to receive life-sustaining treatment (assuming a future terminal state)	Terminal state (49 (32.7%))	Immediately after diagnosis of metastatic cancer (19 (38.0%))	Terminal state (37 (37.0%))	0.458
	Immediately after diagnosis of metastatic cancer (42 (28.0%))	Immediately after diagnosis of any cancer regardless of stage (13 (26.0%))	Immediately after diagnosis of any cancer regardless of stage (24 (24.0%))	
	Immediately after diagnosis of any cancer regardless of stage (37 (24.7%))	Terminal state (12 (24.0%))	Immediately after diagnosis of metastatic cancer (23 (23.0%))	
	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	

*p value were calculated using the χ^2 test or Fisher's exact test.

†p<0.01.

‡p<0.05.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

The IRLT and INLT groups also showed differences in some psychosocial scale scores. The GAD-7 and PHQ-9 scores were higher in the INLT group than in the IRLT group, whereas the IRLT group showed significantly higher MSPSS-family scores. These results are shown in Table 3.

Table 3 Comparison of GAD-7, PHQ-9, CD-RISC, and MSPSS scores between the IRLT and INLT groups

	Total (n=150)	**IRLT (n=50)**	**INLT (n=100)**	**P value***
GAD-7	4.14 ± 4.47	3.12 ± 3.20	4.65 ± 4.92	0.024†
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048†
CD-RISC	65.33 ± 17.58	67.76 ± 17.71	64.09 ± 17.48	0.237
MSPSS				
Family	23.01 ± 4.88	24.34 ± 4.04	22.32 ± 5.15	0.011†
Friend	20.17 ± 5.01	20.60 ± 4.26	19.95 ± 5.37	0.457
Others	21.61 ± 5.82	22.76 ± 5.28	21.02 ± 6.02	0.086
Total	64.99 ± 13.07	67.70 ± 11.92	63.57 ± 13.47	0.070

*p value were calculated using independent *t*-test.

†$p<0.05$.

GAD-7, Generalized Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; CD-RISC, Connor–Davidson Resilience Scale; MSPSS, Multidimensional Scale of Perceived Social Support; IRLT, individuals who wanted to receive life-sustaining treatment; INLT,

individuals who wanted to not receive life-sustaining treatment.

DISCUSSION

In our study, there were twice as many participants in the INLT group compared to those in the IRLT group, who responded that they do not want to receive life-sustaining treatment. Chance of survival was the most important issue in both groups in deciding whether or not to receive life-sustaining treatment, but the INLT group focused more on physical and mental distress. The timing preference order was terminal state, immediately after diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in deciding whether to receive life-sustaining treatment. In addition, participants with higher education levels tended to be more common in the INLT group. On the psychosocial scales, the INLT group represented higher levels of depression/anxiety and lower level of perceived family support than the IRLT group.

Most prior studies have reported that the majority of people do not want aggressive treatment in their terminal state.[3 5-8] Our results were consistent with these previous studies. In addition, the INLT group rated physical and mental distress highly in deciding their preference for life-sustaining treatment than the IRLT group in this study. According to previous reports, many people want hospice care and a more comfortable process of dying such as dying in their sleep.[6 22 23] Some studies have even shown that cancer pain was associated with a desire for hastened death.[24 25] Therefore, we speculate that avoidance of unwanted distress may account for the preference for not receiving life-sustaining treatment. These findings may emphasize the importance of advance directives. A previous study

reported a tendency to receive more life-sustaining treatment when patients' intention for life-sustaining treatment was unclear.[9] Accordingly, more publicity regarding actively participating in registering one's advance directives to National Agency for Management of Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.

In total, 32.7% of the participants in our study regarded terminal status as an optimal time to decide whether to receive life-sustaining treatment. However, more participants want to decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer regardless of stage. There have been few previous studies with this result. However, Keam et al. [26] mentioned that people may regard the decision for life-sustaining treatment as a will that embodies values about end-of life. We also believe that people may want to make decisions regarding the last moments of their own life, such as by signing advance directives, while they are relatively healthy and physically/mentally intact to preserve their dignity and worth as human beings. However, in determining whether to receive life-sustaining treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of stage," it may be important to take into account the possibility that patients are under stress at that time. We speculate that many participants might want to decide upon the last moments of their own life earlier than our existing options. For an example, many people would rather prefer to make their decision in a physically and mentally healthy state, uninfluenced by disease or pain. Although we asked the participants to write down other optimal timings directly, most participants opted for one of the existing options. Further studies are needed to clarify this issue.

Among sociodemographic factors, education level was the factor that showed significant differences between the IRLT and INLT groups. That is, participants with higher education

levels tended to prefer to not receive life-sustaining treatment in this study. Some previous studies analyzed the association between education level and life-sustaining treatment, but the results were controversial.[8 27 28] On the other hand, various studies have reported that individuals with higher education levels had greater interest in advance directives and a stronger tendency to complete them beforehand.[6 7 26] However, there have been few comments on the causes of this association.[6 7 26] Though more studies are needed to clarify our results, we speculate that a tendency toward introspection and accessibility of information may account for the association between education level and preference for life-sustaining treatment or advance directives. Our findings may emphasize the necessity of broader publicity and explanations of advance directives for life-sustaining treatment.

In addition, the INLT group showed higher levels of depression and anxiety than the IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness, frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic problems including pain.[29] We believe that these symptoms can affect the decision for life-sustaining treatment. For example, as hopelessness is associated with suicide,[30-32] cancer patients who have feelings of hopelessness might wish to hasten death. In addition, previous studies reported that cancer pain was related to a desire for hastened death.[24 25] Therefore, we speculate that depressive patients with somatic problems such as pain aggravation might change their minds to select a peaceful death. Similar to our results, Wen et al. [33] reported that cancer patients with depressive symptoms were more likely to be in the comfort-preferring state in terms of preference for life-sustaining treatment. Our findings suggest that a consideration of depressive and anxiety symptoms may be needed in determining whether or not one receives life-sustaining treatment. For example, clinicians may consider recommending the patient to delay making a decision on life-sustaining treatment if a

patient's depressive or anxiety symptoms are believed to be temporary. According to the patient's condition, treatment for depression or anxiety symptoms may be provided to the patient before they make a decision. Our findings may be particularly meaningful because many patients with severe physical illness suffer from depression or anxiety.[10-13] Future research that can clarify any causal relationship may help verify and advance our results.

Furthermore, participants who felt relatively well-supported by their family members tended to prefer to receive life-sustaining treatment. However, the results of other studies differ from ours, though a consensus does not have been previously reached. Kim and Shin [34] reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al. [35] also reported that patients who were single, divorced, or bereaved were significantly more likely to reverse life-sustaining treatment decisions to a higher intensity of life-sustaining treatment. As our findings were opposite to these previous studies, consideration of the characteristics of our participants may be needed to understand our results. Our participants were family members of patients in a center for dementia. Therefore, distress as a family member might be reflected in the answers on MSPSS-family items. That is, the participants who perceived a lower level of family support might be likely to suffer from distress as a family member, and consequently might have a greater tendency to prefer peaceful death. We believe that the influences of family support in deciding whether one receives life-sustaining treatment vary depending on the participants and settings of each study. Uhlmann and Pearlman [36] even showed that family relationships and preference for life-sustaining treatment were not significantly associated in chronically ill, elderly outpatients. Further studies including a greater variety of participants can clarify the association between family support and life-sustaining treatment.

In this study, we investigated the preference for life-sustaining treatment and factors associated with the decision in Koreans. The thoughts regarding life-sustaining treatment of our participants were generally consistent with previous reports on life-sustaining treatment. Depressive and anxiety symptoms may have an effect on this issue. According to our findings, if necessary, adequate interventions may be applied to individuals with negative mood during the decision-making process regarding life-sustaining treatment.

There are some limitations to this study. First, our study has a relatively small number of participants. This may limit the generalizability of our results. Second, our participants are the family members of visitors in Guro-gu center for dementia. Therefore, specific characteristics of our participants such as caregiver distress can affect our results. Though these may be more helpful to a specific group such as individuals with family members with cognitive impairment, further studies including various other groups such as the general public, caregivers of patients with other diseases, patients with cognitive impairment, physicians, and cancer patients may represent more informative results. Third, our study used a cross-sectional design. However, the preference for life-sustaining treatment can change over time. Gallo et al. [37] also reported that periodic reassessment for planning end-of-life care was needed in their 12-year follow-up study. Fourth, absolute differences in the scores of scales between the two groups were relatively small, although statistically significant. For this reason, there may be limitations to the clinical significance of the results of this study. We believe that further study including patients with psychiatric problems, such as depression and anxiety, can help derive more clinical meaning. Fifth, this study presented specific options for each question regarding life-sustaining treatment. This may be convenient for the participant, but there is a possibility that the participant's intention was not sufficiently reflected. Finally, our questionnaire consisted of only self-report items.

Though we provided descriptions of the meanings of the terms, using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

CONCLUSION

This study showed the thoughts and associated factors regarding life-sustaining treatment of Korean individuals. Our participants tended to want to not receive life-sustaining treatment. In deciding to not receive life-sustaining treatment, chance of survival and physical/mental distress were the important issues. Thirty-two point seven percent of participants responded that terminal status was an optimal time to decide whether to receive life-sustaining treatment. However, many more participants want to decide this issue earlier. Among sociodemographic and psychosocial factors, higher levels of education, depression, and anxiety and lower levels of family support were associated with the decision to not receive life-sustaining treatment. Our findings can help assess issues regarding advance directives and life-sustaining treatment, and will be a reference for designing future studies on this issue.

Contributors HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK contributed to interpretation. All authors critically revised the manuscript and gave final approval.

Funding This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.

Disclaimer The funders had no role in planning or conducting the study.

Competing interests The authors declare no conflicts of interest.

Patient and public involvement Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Patient consent for publication Not required.

Data availability statement The data that support the findings of this study are available on request from the corresponding author.

REFERENCES

1. Kim JS. Some improvements of act on decisions on life-sustaining treatment for patients. *Law Rev* 2019;19:357-80.
2. Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. *Health Psychol* 2005;24:S63-70.
3. Garrido MM, Balboni TA, Maciejewski PK, *et al.* Quality of life and cost of care at the end of life: The role of advance directives. *J Pain Symptom Manage* 2015;49:828-35.
4. National Agency for Management of Life-Sustaining Treatment. Present performance status of withdrawal of life-sustaining treatment. 2019. https://www.lst.go.kr/comm/monthlyStatistics.do (accessed 31 Oct 2019).
5. Kim J, Heo S, Hong SW, *et al.* Correlates of advance directive treatment preferences among community-dwelling older people with chronic diseases. *Int J Older People Nurs* 2019;14:e12229.
6. Lee MO, Park J, Park EY, *et al.* The Korean-advance directive model and factors associated with its completion among patients with hematologic disorders. *J Hosp Palliat Nurs* 2019;21:E10-e6.
7. Hoe DF, Enguidanos S. So help me, god: Religiosity and end-of-life choices in a nationally representative sample. *J Palliat Med* 2020;23:563-7.
8. Yun YH, Han KH, Park S, *et al.* Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients. *CMAJ* 2011;183:E673-9.
9. Pasman HR, Kaspers PJ, Deeg DJ, *et al.* Preferences and actual treatment of older adults at the end of life. A mortality follow-back study. *J Am Geriatr Soc* 2013;61:1722-9.

10. Thom R, Silbersweig DA, Boland RJ. Major depressive disorder in medical illness: A review of assessment, prevalence, and treatment options. *Psychosom Med* 2019;81:246-55.
11. Spiegel D. Cancer and depression. *Br J Psychiatry Suppl* 1996:109-16.
12. Katon W, Lin EH, Kroenke K. The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *Gen Hosp Psychiatry* 2007;29:147-55.
13. Steffens DC, Helms MJ, Krishnan KR*, et al.* Cerebrovascular disease and depression symptoms in the cardiovascular health study. *Stroke* 1999;30:2159-66.
14. Health Insurance Review & Assessment Service. *Worrying diseases of the people*. Wonju: Health Insurance Review & Assessment Service, 2016.
15. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-44.
16. Choi HS, Choi JH, Park KH*, et al.* Standardization of the Korean version of patient health questionnaire-9 as a screening instrument for major depressive disorder. *J Korean Acad Fam Med* 2007;28:114-9.
17. Seo JG, Cho YW, Lee SJ*, et al.* Validation of the generalized anxiety disorder-7 in people with epilepsy: a MEPSY study. *Epilepsy Behav* 2014;35:59-63.
18. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.
19. Jung YE, Min JA, Shin AY*, et al.* The Korean version of the Connor-Davidson Resilience Scale: an extended validation. *Stress Health* 2012;28:319-26.
20. Eker D, Arkar H. Perceived social support: psychometric properties of the MSPSS in

normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr Epidemiol* 1995;30:121-6.

21. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the unemployed. *Korean J Soc Welf* 1999;37:241-69.
22. Kim S, Koh S, Park K*, et al.* End-of-life care decisions using a Korean advance directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.
23. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.
24. Chochinov HM, Wilson KG, Enns M*, et al.* Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
25. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression. *Postgrad Med* 1989;85:263-6, 8, 70.
26. Keam B, Yun YH, Heo DS*, et al.* The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. *Support Care Cancer* 2013;21:1437-44.
27. Yun YH, Kim KN, Sim JA*, et al.* Comparison of attitudes towards five end-of-life care interventions (active pain control, withdrawal of futile life-sustaining treatment, passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred cross-sectional survey of Korean patients with cancer, their family caregivers, physicians and the general Korean population. *BMJ Open* 2018;8:e020519.
28. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460-8.
29. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*

sciences/clinical psychiatry. Philadelphia, PA: Wolters Kluwer, 2015.

30. Minkoff K, Bergman E, Beck AT*, et al.* Hopelessness, depression, and attempted suicide. *Am J Psychiatry* 1973;130:455-9.
31. Beck AT, Brown G, Berchick RJ*, et al.* Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry* 1990;147:190-5.
32. Beck AT, Steer RA, Kovacs M*, et al.* Hopelessness and eventual suicide: a 10-year prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry* 1985;142:559-63.
33. Wen FH, Chen JS, Chou WC*, et al.* Factors predisposing terminally ill cancer patients' preferences for distinct patterns/states of life-sustaining treatments over their last six months. *J Pain Symptom Manage* 2019;57:190-8.e2.
34. Kim HS, Shin SR. The influence of social support among community dwelling elderly and their attitude towards the withdrawal of life-sustaining treatment: A mediating effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.
35. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and associated factors among older patients with terminal stage of cardiopulmonary disease. *J Korean Acad Nurs* 2019;49:329-39.
36. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.
37. Gallo JJ, Abshire M, Hwang S*, et al.* Advance directives, medical conditions, and preferences for end-of-life care among physicians: 12-year follow-up of the Johns Hopkins precursors study. *J Pain Symptom Manage* 2019;57:556-65.

Verbatim translation of the scenario and description of the terms

* It is well known that about one-third of the population of South Korea will develop cancer during their lifetime. This questionnaire is conducted under the assumption that "if you have cancer (especially stage 4)".

* “Terminal state” is defined as a condition in which treatments for the purpose of life extension are not applicable to patients.

* “Life-sustaining treatment” is any treatment that serves to prolong life without reversing the underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in advance.

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1,3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6, 7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8, 9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8, 9
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	8
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	8
		(*e*) Describe any sensitivity analyses	9
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	11, 12, 13
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11, 12, 13
		(*b*) Report category boundaries when continuous variables were categorized	8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16, 17, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Preferences for life-sustaining treatment in Korean adults: a cross sectional study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-039470.R3
Article Type:	Original research
Date Submitted by the Author:	30-Nov-2020
Complete List of Authors:	Youn, HyunChul; Soonchunhyang University Bucheon Hospital, Department of psychiatry Lee, Suk-young ; Wonkwang University Jung, Han-yong ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Kim, Shin-Gyeom ; Soonchunhyang University Bucheon Hospital, Department of psychiatry Jeong, Hyun-Ghang; Korea University College of Medicine and School of Medicine,
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Palliative care, Patient-centred medicine
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MENTAL HEALTH, Adult palliative care < PALLIATIVE CARE, PUBLIC HEALTH, Adult psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Preferences for life-sustaining treatment in Korean adults: a cross sectional study

HyunChul Youn,[1] Suk-young Lee,[2] Han-yong Jung,[1] Shin-Gyeom Kim,[1] Hyun-Ghang Jeong[3,4]

[1]Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic of Korea

[2]Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine, Wonkwang University, Gunpo, Republic of Korea

[3]Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine, Seoul, Republic of Korea

[4]Korea University Research Institute of Mental Health, Seoul, Republic of Korea

Correspondence to

Dr Hyun-Ghang Jeong;

Department of Psychiatry, Korea University Guro Hospital, Korea University College of Medicine,

148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;

E-mail: jeonghg@korea.ac.kr

Word count: 2,779 words

ORCID iDs

HyunChul Youn https://orcid.org/0000-0002-6557-5628

Shin-Gyeom Kim https://orcid.org/0000-0001-8196-655X

Hyun-Ghang Jeong https://orcid.org/0000-0002-0318-5069

ABSTRACT

Objectives Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, and left ventricular assist devices. This study aimed to investigate the thoughts on life-sustaining treatment of Koreans and to assess the factors associated with deciding to not receive life-sustaining treatment if they develop a terminal disease.

Design Cross-sectional study.

Setting Guro-gu center for dementia from 1 May 2018 to 31 December 2019.

Participants In total, 150 individuals participated in this study.

Outcome measures The questionnaire consisted of self-report items with some instructions, demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales. The preferences of the participants were investigated on the assumption that they develop terminal cancer. The psychosocial scales included the Generalized Anxiety Disorder-7 (GAD-7), Patient Health Questionnaire-9 (PHQ-9), Connor–Davidson Resilience Scale, and Multidimensional Scale of Perceived Social Support (MSPSS).

Results We classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT). There were twice as many participants in the INLT group than there were in the IRLT. In making this decision, the INLT group focused more on physical and mental distress. Additionally, 32.7% of participants responded that terminal status was an optimal time for this decision, but more participants want to decide it earlier. The GAD-7 and PHQ-9 scores were significantly higher in the INLT group than in the IRLT group. However, the INLT group had significantly lower MSPSS family scores.

Conclusions Our findings can help assess issues regarding advance directives and life-

sustaining treatment, and will be a reference for designing future studies on this issue.

Keywords: Life-sustaining treatment, Advance directives, Education, Depression, Anxiety

Strengths and limitations of this study

▶ This study enrolled Korean individuals for assessing issues regarding advance directives and life-sustaining treatment.

▶ We adopted cross-sectional design, and the questionnaire consisted of demographic characteristics, thoughts on life-sustaining treatment, and psychosocial scales.

▶ The effects of psychosocial factors including depression, anxiety, resilience, and perceived social support on decision for life-sustaining treatment were investigated.

▶ Our participants tended to want to not receive life-sustaining treatment, and higher levels of education, depression, and anxiety and lower levels of family support were associated with the decision to not receive life-sustaining treatment.

▶ Our questionnaire consisted of only self-report items, but using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

INTRODUCTION

According to the constitutional right to self-determination, judging one's own life is part of one's dignity and worth as a human being.[1] In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.[1] Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.[2] At this time, the Patient Self-Determination Act was first formalized in United States.[3] In South Korea, the Act on the Determination of Life-Life Care for Patients in the Hospice and Relaxation Medicine and the Deathly Hallows Process was finally passed by the National Assembly on 8 January 2016 and was implemented on 4 February 2018.[1] Under this act, advance directives can be prepared in South Korea for terminal states where decision-making is impossible. Advance directives are defined as "any statement given in advance of decisional incapacity directing the provision of life-sustaining treatment in incapacitated states".[2]

Between February 2018 and September 2019, a total of 378,350 people registered their advance directives with the National Agency for Management of Life-Sustaining Treatment.[4] Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.[4] However, until now, the majority chose to make the decision only at the very end of their lives. Furthermore, the discontinuation of life-sustaining treatment of many people was determined by their family members. The National Agency for Management of Life-Sustaining Treatment [4] reported that the former numbered 21,479 and the latter 22,758 over the same time period. Previous studies showed that a majority of people do not want aggressive treatment at the last moment of life.[3] [5-8] Accordingly, advance directives are especially important because individuals who did not sign advance directives tend to receive aggressive life-sustaining treatment until the last moment of their lives regardless of their own

intention.[9]

In this study, we focused on the thoughts regarding life-sustaining treatment of Korean individuals. We believe that our survey may help assess issues surrounding advance directives and life-sustaining treatment in individuals in the early stages of implementation of the advance directives system. In addition, medical illnesses that may be related to fatal conditions can also be comorbid with negative mood.[10-13] That is, one can experience depression or anxiety at the moment one signs one's own advance directive or decides whether to receive life-sustaining treatment. This study may be additionally helpful in assessing the possibility that negative mood affects the decision regarding life-sustaining treatment.

The aim of this study was to investigate the thoughts regarding life-sustaining treatment of Koreans and to assess factors, especially negative mood, associated with not receiving life-sustaining treatment if they develop a terminal disease.

METHODS

Participants and procedure

A total of 152 Korean individuals were participated in this study. We recruited family members of visitors in Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited 170 individuals, but 18 people declined to participate in this study because they were not interested in the issue of the research. Participants with a history of serious disease such as cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study. After some instructions were provided, participants filled out a survey on the spot. It took about 20 to 30 minutes to complete the questionnaires. Participants answered the questions anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on

life-sustaining treatment) and were, therefore, excluded. The necessary ethical permissions were received from the Institutional Review Board at Korea University Guro Hospital prior to the initiation of the research (2018GR0151). Before completing the questionnaires, participants were informed about the study protocol and gave their written informed consent.

Measures

All questionnaires were in self-report format. The questionnaire consisted of three parts. The first part contained items assessing the following demographic characteristics: age, gender, education, marital status, housing status, occupational status, religion, and monthly income.

In the second part, participants answered questions regarding their thoughts on life-sustaining treatment. We provided a description of the terms used in the questionnaire before the second part to avoid confusion (suppl 1). For example, "terminal state" is defined as a condition in which treatments for the purpose of life extension are not applicable to patients. We adopted "terminal cancer" as the example to help participants understand life-sustaining treatment better, because many South Koreans regard cancer as most worrying disease.[14]

The third part included the psychosocial items. We adopted the Generalized Anxiety Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression, respectively.[15] A higher score on these scales indicates a higher possibility of having anxiety or depressive symptoms. These scales have been translated into Korean, and their reliability and validity have been confirmed.[16 17] The Connor–Davidson Resilience Scale (CD-RISC) was used to assess the degree of resilience.[18] This scale contains 25 items scored in a five-point response format, and the total score ranges from zero to 100, where higher scores reflect greater resilience. We used the Korean version of the CD-RISC, which has been found to be reliable and valid.[19] We included the Multidimensional Scale of Perceived Social Support (MSPSS) to

evaluate the perceived social support of family, friends, and significant others.[20] The MSPSS contains four items that are rated on a seven-point scale ranging from *very strongly disagree* [1] to *very strongly agree*.[7] We adopted the Korean version of MSPSS.[21]

Statistical analysis

Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous variables and percentages for categorical variables). Differences between the IRLT and INLT groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used independent *t*-tests for continuous variables and χ^2 tests or Fisher's exact test for categorical variables.

RESULTS

According to the answer of the question "Do you want to receive life-sustaining treatment?" we classified our participants into two groups: individuals who wanted to receive life-sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining treatment (INLT). Among the 150 participants, the IRLT and INLT groups comprised 50 and 100 participants, respectively. Table 1 shows the basic characteristics of the IRLT and INLT groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female. The participants with college-level education or higher were significantly more numerous in the INLT group than in the IRLT group.

Table 1 Basic characteristics of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Age, years	45.38 ± 14.71	45.48 ± 14.16	45.33 ± 15.04	0.953
Gender				1.000
Male	66 (44.0)	22 (44.0)	44 (44.0)	
Female	84 (56.0)	28 (56.0)	56 (56.0)	
Education				0.014†
≤High school graduate	49 (32.7)	23 (46.0)	26 (26.0)	
≥College	101 (67.3)	27 (54.0)	74 (74.0)	
Marital status				0.507
Married (living with spouse)	100 (66.7)	35 (70.0)	65 (65.0)	
Living together without being married	7 (4.7)	3 (6.0)	4 (4.0)	
Unmarried	36 (24.0)	10 (20.0)	26 (26.0)	
Divorce/Separation	1 (0.7)	1 (2.0)	0 (0.0)	
Separation by death	6 (4.0)	1 (2.0)	5 (5.0)	
Housing status				0.874
Live alone	16 (10.7)	4 (8.0)	12 (12.0)	
Live with family	130 (86.7)	45 (90.0)	85 (85.0)	
Others	3 (2.0)	1 (2.0)	2 (2.0)	
Occupational status				0.124
Unemployed	17 (11.3)	6 (12.0)	11 (11.0)	
Stay-at-home spouse	28 (18.7)	7 (14.0)	21 (21.0)	
Student	5 (3.3)	0 (0.0)	5 (5.0)	
Self-employed	16 (10.7)	9 (18.0)	7 (7.0)	
Office worker	61 (40.7)	18 (36.0)	43 (43.0)	
Others	23 (15.3)	10 (20.0)	13 (13.0)	
Religion				0.079
Having religion	87 (58.0)	26 (52.0)	37 (37.0)	
No religion	63 (42.0)	24 (48.0)	63 (63.0)	
Monthly income (million won)				0.778
<100	17 (11.3)	4 (8.0)	13 (13.0)	
100-299	53 (35.3)	16 (32.0)	37 (37.0)	
300-499	50 (33.3)	17 (34.0)	33 (33.0)	
500-699	15 (10.0)	6 (12.0)	9 (9.0)	
≥700	9 (6.0)	4 (8.0)	5 (5.0)	

The data is presented as mean ± standard deviation or number (%).

*p value were calculated using the χ^2 test or Fisher's exact test and independent *t*-test.

†$p<0.05$.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table 2). The IRLT group focused more on the chance of survival, while the INLT group was more concerned about physical and mental distress.

Table 2 Thoughts on life-sustaining treatment of IRLT and INLT groups

	Total (n=150)	IRLT (n=50)	INLT (n=100)	P value*
Most important issue in deciding whether to receive life-sustaining treatment or not	Chance of survival (81 (54.0%))	Chance of survival (38 (76.0%))	Chance of survival (43 (43.0%))	0.001†
	Physical distress (29 (19.3%))	Physical distress (3 (6.0%))	Physical distress (26 (26.0%))	
	Mental distress (13 (8.7%))	Religious belief (3 (6.0%))	Mental distress (12 (12.0%))	
	Other responses (religious belief, treatment cost)	Other responses (mental distress, treatment cost)	Other responses (religious belief, treatment cost)	
Optimal timing to decide whether to receive life-sustaining treatment (assuming a future terminal state)	Terminal state (49 (32.7%))	Immediately after diagnosis of metastatic cancer (19 (38.0%))	Terminal state (37 (37.0%))	0.458
	Immediately after diagnosis of metastatic cancer (42 (28.0%))	Immediately after diagnosis of any cancer regardless of stage (13 (26.0%))	Immediately after diagnosis of any cancer regardless of stage (24 (24.0%))	
	Immediately after diagnosis of any cancer regardless of stage (37 (24.7%))	Terminal state (12 (24.0%))	Immediately after diagnosis of metastatic cancer (23 (23.0%))	
	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	Other responses (when to start chemotherapy, during chemotherapy)	

*p value were calculated using the χ^2 test or Fisher's exact test.

†p<0.01.

‡p<0.05.

IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.

The IRLT and INLT groups also showed differences in some psychosocial scale scores. The GAD-7 and PHQ-9 scores were higher in the INLT group than in the IRLT group, whereas the IRLT group showed significantly higher MSPSS-family scores. These results are shown in Table 3.

Table 3 Comparison of GAD-7, PHQ-9, CD-RISC, and MSPSS scores between the IRLT and INLT groups

	Total (n=150)	**IRLT (n=50)**	**INLT (n=100)**	**P value***
GAD-7	4.14 ± 4.47	3.12 ± 3.20	4.65 ± 4.92	0.024†
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048†
CD-RISC	65.33 ± 17.58	67.76 ± 17.71	64.09 ± 17.48	0.237
MSPSS				
Family	23.01 ± 4.88	24.34 ± 4.04	22.32 ± 5.15	0.011†
Friend	20.17 ± 5.01	20.60 ± 4.26	19.95 ± 5.37	0.457
Others	21.61 ± 5.82	22.76 ± 5.28	21.02 ± 6.02	0.086
Total	64.99 ± 13.07	67.70 ± 11.92	63.57 ± 13.47	0.070

*p value were calculated using independent *t*-test.

†$p<0.05$.

GAD-7, Generalized Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; CD-RISC, Connor–Davidson Resilience Scale; MSPSS, Multidimensional Scale of Perceived Social Support; IRLT, individuals who wanted to receive life-sustaining treatment; INLT,

individuals who wanted to not receive life-sustaining treatment.

DISCUSSION

In our study, there were twice as many participants in the INLT group compared to those in the IRLT group, who responded that they do not want to receive life-sustaining treatment. Chance of survival was the most important issue in both groups in deciding whether or not to receive life-sustaining treatment, but the INLT group focused more on physical and mental distress. The timing preference order was terminal state, immediately after diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in deciding whether to receive life-sustaining treatment. In addition, participants with higher education levels tended to be more common in the INLT group. On the psychosocial scales, the INLT group represented higher levels of depression/anxiety and lower level of perceived family support than the IRLT group.

Most prior studies have reported that the majority of people do not want aggressive treatment in their terminal state.[3 5-8] Our results were consistent with these previous studies. In addition, the INLT group rated physical and mental distress highly in deciding their preference for life-sustaining treatment than the IRLT group in this study. According to previous reports, many people want hospice care and a more comfortable process of dying such as dying in their sleep.[6 22 23] Some studies have even shown that cancer pain was associated with a desire for hastened death.[24 25] Therefore, we speculate that avoidance of unwanted distress may account for the preference for not receiving life-sustaining treatment. These findings may emphasize the importance of advance directives. A previous study

reported a tendency to receive more life-sustaining treatment when patients' intention for life-sustaining treatment was unclear.[9] Accordingly, more publicity regarding actively participating in registering one's advance directives to National Agency for Management of Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.

In total, 32.7% of the participants in our study regarded terminal status as an optimal time to decide whether to receive life-sustaining treatment. However, more participants want to decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer regardless of stage. There have been few previous studies with this result. However, Keam et al. [26] mentioned that people may regard the decision for life-sustaining treatment as a will that embodies values about end-of life. We also believe that people may want to make decisions regarding the last moments of their own life, such as by signing advance directives, while they are relatively healthy and physically/mentally intact to preserve their dignity and worth as human beings. However, in determining whether to receive life-sustaining treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of stage," it may be important to take into account the possibility that patients are under stress at that time. We speculate that many participants might want to decide upon the last moments of their own life earlier than our existing options. For an example, many people would rather prefer to make their decision in a physically and mentally healthy state, uninfluenced by disease or pain. Although we asked the participants to write down other optimal timings directly, most participants opted for one of the existing options. Further studies are needed to clarify this issue.

Among sociodemographic factors, education level was the factor that showed significant differences between the IRLT and INLT groups. That is, participants with higher education

levels tended to prefer to not receive life-sustaining treatment in this study. Some previous studies analyzed the association between education level and life-sustaining treatment, but the results were controversial.[8 27 28] On the other hand, various studies have reported that individuals with higher education levels had greater interest in advance directives and a stronger tendency to complete them beforehand.[6 7 26] However, there have been few comments on the causes of this association.[6 7 26] Though more studies are needed to clarify our results, we speculate that a tendency toward introspection and accessibility of information may account for the association between education level and preference for life-sustaining treatment or advance directives. Our findings may emphasize the necessity of broader publicity and explanations of advance directives for life-sustaining treatment.

In addition, the INLT group showed higher levels of depression and anxiety than the IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness, frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic problems including pain.[29] We believe that these symptoms can affect the decision for life-sustaining treatment. For example, as hopelessness is associated with suicide,[30-32] cancer patients who have feelings of hopelessness might wish to hasten death. In addition, previous studies reported that cancer pain was related to a desire for hastened death.[24 25] Therefore, we speculate that depressive patients with somatic problems such as pain aggravation might change their minds to select a peaceful death. Similar to our results, Wen et al. [33] reported that cancer patients with depressive symptoms were more likely to be in the comfort-preferring state in terms of preference for life-sustaining treatment. Our findings suggest that a consideration of depressive and anxiety symptoms may be needed in determining whether or not one receives life-sustaining treatment. For example, clinicians may consider recommending the patient to delay making a decision on life-sustaining treatment if a

patient's depressive or anxiety symptoms are believed to be temporary. According to the patient's condition, treatment for depression or anxiety symptoms may be provided to the patient before they make a decision. Our findings may be particularly meaningful because many patients with severe physical illness suffer from depression or anxiety.[10-13] Future research that can clarify any causal relationship may help verify and advance our results.

Furthermore, participants who felt relatively well-supported by their family members tended to prefer to receive life-sustaining treatment. However, the results of other studies differ from ours, though a consensus does not have been previously reached. Kim and Shin [34] reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al. [35] also reported that patients who were single, divorced, or bereaved were significantly more likely to reverse life-sustaining treatment decisions to a higher intensity of life-sustaining treatment. As our findings were opposite to these previous studies, consideration of the characteristics of our participants may be needed to understand our results. Our participants were family members of patients in a center for dementia. Therefore, distress as a family member might be reflected in the answers on MSPSS-family items. That is, the participants who perceived a lower level of family support might be likely to suffer from distress as a family member, and consequently might have a greater tendency to prefer peaceful death. We believe that the influences of family support in deciding whether one receives life-sustaining treatment vary depending on the participants and settings of each study. Uhlmann and Pearlman [36] even showed that family relationships and preference for life-sustaining treatment were not significantly associated in chronically ill, elderly outpatients. Further studies including a greater variety of participants can clarify the association between family support and life-sustaining treatment.

In this study, we investigated the preference for life-sustaining treatment and factors associated with the decision in Koreans. The thoughts regarding life-sustaining treatment of our participants were generally consistent with previous reports on life-sustaining treatment. Depressive and anxiety symptoms may have an effect on this issue. According to our findings, if necessary, adequate interventions may be applied to individuals with negative mood during the decision-making process regarding life-sustaining treatment.

There are some limitations to this study. First, our study has a relatively small number of participants. This may limit the generalizability of our results. Second, our participants are the family members of visitors in Guro-gu center for dementia. Therefore, specific characteristics of our participants such as caregiver distress can affect our results. Though these may be more helpful to a specific group such as individuals with family members with cognitive impairment, further studies including various other groups such as the general public, caregivers of patients with other diseases, patients with cognitive impairment, physicians, and cancer patients may represent more informative results. Third, our study used a cross-sectional design. However, the preference for life-sustaining treatment can change over time. Gallo et al. [37] also reported that periodic reassessment for planning end-of-life care was needed in their 12-year follow-up study. Fourth, absolute differences in the scores of scales between the two groups were relatively small, although statistically significant. For this reason, there may be limitations to the clinical significance of the results of this study. We believe that further study including patients with psychiatric problems, such as depression and anxiety, can help derive more clinical meaning. Fifth, this study presented specific options for each question regarding life-sustaining treatment. This may be convenient for the participant, but there is a possibility that the participant's intention was not sufficiently reflected. Finally, our questionnaire consisted of only self-report items.

Though we provided descriptions of the meanings of the terms, using various methods such as clinician-report scales and interviews can help avoid misunderstandings of the terms and ensure a more effective survey.

CONCLUSION

This study showed the thoughts and associated factors regarding life-sustaining treatment of Korean individuals. Our participants tended to want to not receive life-sustaining treatment. In deciding to not receive life-sustaining treatment, chance of survival and physical/mental distress were the important issues. Thirty-two point seven percent of participants responded that terminal status was an optimal time to decide whether to receive life-sustaining treatment. However, many more participants want to decide this issue earlier. Among sociodemographic and psychosocial factors, higher levels of education, depression, and anxiety and lower levels of family support were associated with the decision to not receive life-sustaining treatment. Our findings can help assess issues regarding advance directives and life-sustaining treatment, and will be a reference for designing future studies on this issue.

Contributors HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK contributed to interpretation. All authors critically revised the manuscript and gave final approval.

Funding This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.

Disclaimer The funders had no role in planning or conducting the study.

Competing interests The authors declare no conflicts of interest.

Patient and public involvement Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Patient consent for publication Not required.

Data availability statement The data that support the findings of this study are available on request from the corresponding author.

REFERENCES

1. Kim JS. Some improvements of act on decisions on life-sustaining treatment for patients. *Law Rev* 2019;19:357-80.
2. Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. *Health Psychol* 2005;24:S63-70.
3. Garrido MM, Balboni TA, Maciejewski PK, *et al.* Quality of life and cost of care at the end of life: The role of advance directives. *J Pain Symptom Manage* 2015;49:828-35.
4. National Agency for Management of Life-Sustaining Treatment. Present performance status of withdrawal of life-sustaining treatment. 2019. https://www.lst.go.kr/comm/monthlyStatistics.do (accessed 31 Oct 2019).
5. Kim J, Heo S, Hong SW, *et al.* Correlates of advance directive treatment preferences among community-dwelling older people with chronic diseases. *Int J Older People Nurs* 2019;14:e12229.
6. Lee MO, Park J, Park EY, *et al.* The Korean-advance directive model and factors associated with its completion among patients with hematologic disorders. *J Hosp Palliat Nurs* 2019;21:E10-e6.
7. Hoe DF, Enguidanos S. So help me, god: Religiosity and end-of-life choices in a nationally representative sample. *J Palliat Med* 2020;23:563-7.
8. Yun YH, Han KH, Park S, *et al.* Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients. *CMAJ* 2011;183:E673-9.
9. Pasman HR, Kaspers PJ, Deeg DJ, *et al.* Preferences and actual treatment of older adults at the end of life. A mortality follow-back study. *J Am Geriatr Soc* 2013;61:1722-9.

10. Thom R, Silbersweig DA, Boland RJ. Major depressive disorder in medical illness: A review of assessment, prevalence, and treatment options. *Psychosom Med* 2019;81:246-55.
11. Spiegel D. Cancer and depression. *Br J Psychiatry Suppl* 1996:109-16.
12. Katon W, Lin EH, Kroenke K. The association of depression and anxiety with medical symptom burden in patients with chronic medical illness. *Gen Hosp Psychiatry* 2007;29:147-55.
13. Steffens DC, Helms MJ, Krishnan KR*, et al.* Cerebrovascular disease and depression symptoms in the cardiovascular health study. *Stroke* 1999;30:2159-66.
14. Health Insurance Review & Assessment Service. *Worrying diseases of the people*. Wonju: Health Insurance Review & Assessment Service, 2016.
15. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-44.
16. Choi HS, Choi JH, Park KH*, et al.* Standardization of the Korean version of patient health questionnaire-9 as a screening instrument for major depressive disorder. *J Korean Acad Fam Med* 2007;28:114-9.
17. Seo JG, Cho YW, Lee SJ*, et al.* Validation of the generalized anxiety disorder-7 in people with epilepsy: a MEPSY study. *Epilepsy Behav* 2014;35:59-63.
18. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.
19. Jung YE, Min JA, Shin AY*, et al.* The Korean version of the Connor-Davidson Resilience Scale: an extended validation. *Stress Health* 2012;28:319-26.
20. Eker D, Arkar H. Perceived social support: psychometric properties of the MSPSS in

normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr Epidemiol* 1995;30:121-6.

21. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the unemployed. *Korean J Soc Welf* 1999;37:241-69.
22. Kim S, Koh S, Park K*, et al.* End-of-life care decisions using a Korean advance directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.
23. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.
24. Chochinov HM, Wilson KG, Enns M*, et al.* Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
25. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression. *Postgrad Med* 1989;85:263-6, 8, 70.
26. Keam B, Yun YH, Heo DS*, et al.* The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. *Support Care Cancer* 2013;21:1437-44.
27. Yun YH, Kim KN, Sim JA*, et al.* Comparison of attitudes towards five end-of-life care interventions (active pain control, withdrawal of futile life-sustaining treatment, passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred cross-sectional survey of Korean patients with cancer, their family caregivers, physicians and the general Korean population. *BMJ Open* 2018;8:e020519.
28. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460-8.
29. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*

sciences/clinical psychiatry. Philadelphia, PA: Wolters Kluwer, 2015.

30. Minkoff K, Bergman E, Beck AT*, et al.* Hopelessness, depression, and attempted suicide. *Am J Psychiatry* 1973;130:455-9.
31. Beck AT, Brown G, Berchick RJ*, et al.* Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry* 1990;147:190-5.
32. Beck AT, Steer RA, Kovacs M*, et al.* Hopelessness and eventual suicide: a 10-year prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry* 1985;142:559-63.
33. Wen FH, Chen JS, Chou WC*, et al.* Factors predisposing terminally ill cancer patients' preferences for distinct patterns/states of life-sustaining treatments over their last six months. *J Pain Symptom Manage* 2019;57:190-8.e2.
34. Kim HS, Shin SR. The influence of social support among community dwelling elderly and their attitude towards the withdrawal of life-sustaining treatment: A mediating effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.
35. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and associated factors among older patients with terminal stage of cardiopulmonary disease. *J Korean Acad Nurs* 2019;49:329-39.
36. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.
37. Gallo JJ, Abshire M, Hwang S*, et al.* Advance directives, medical conditions, and preferences for end-of-life care among physicians: 12-year follow-up of the Johns Hopkins precursors study. *J Pain Symptom Manage* 2019;57:556-65.

Verbatim translation of the scenario and description of the terms

* It is well known that about one-third of the population of South Korea will develop cancer during their lifetime. This questionnaire is conducted under the assumption that "if you have cancer (especially stage 4)".

* “Terminal state” is defined as a condition in which treatments for the purpose of life extension are not applicable to patients.

* “Life-sustaining treatment” is any treatment that serves to prolong life without reversing the underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in advance.

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1,3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6, 7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8, 9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8, 9
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	8
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	8
		(*e*) Describe any sensitivity analyses	9
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	11, 12, 13
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11, 12, 13
		(*b*) Report category boundaries when continuous variables were categorized	8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16, 17, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.