

# BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email [info.bmjopen@bmj.com](mailto:info.bmjopen@bmj.com)

# BMJ Open

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

Journal:	<i>BMJ Open</i>
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

SCHOLARONE™  
Manuscripts



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.

1  
2  
3 **Imaginary decisions for life-sustaining treatment in families of older adults**  
4  
5  
6 **with cognitive impairment: a cross-sectional study**  
7  
8  
9

10  
11 **HyunChul Youn,<sup>1</sup> Suk-young Lee,<sup>2</sup> Han-yong Jung,<sup>1</sup> Shin-Gyeom Kim,<sup>1</sup> Hyun-Ghang**  
12  
13 **Jeong<sup>3,4</sup>**  
14  
15

16  
17  
18 <sup>1</sup>Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic  
19  
20 of Korea  
21

22 <sup>2</sup>Division of Hemato-Oncology, Department of Internal Medicine, College of Medicine,  
23  
24 Wonkwang University, Iksan, Republic of Korea  
25

26  
27 <sup>3</sup>Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
28  
29 Medicine, Seoul, Republic of Korea  
30

31 <sup>4</sup>Korea University Research Institute of Mental Health, Seoul, Republic of Korea  
32  
33

34  
35  
36 **Correspondence to**  
37

38 Dr Hyun-Ghang Jeong;  
39

40 Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
41  
42 Medicine,  
43

44  
45 148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;  
46

47 E-mail: jeonghg@korea.ac.kr  
48  
49

50  
51  
52 **Word count:** 3,003 words  
53  
54

55  
56  
57 **ORCID iDs**  
58  
59  
60

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>

For peer review only

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 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.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

For peer review only

## 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.<sup>1</sup> In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.<sup>1</sup> Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.<sup>2</sup> At this time, the Patient Self-Determination Act was first formalized in United States.<sup>3</sup> 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.<sup>1</sup> 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".<sup>2</sup>

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.<sup>4</sup> Of these people, 859 individuals discontinued life-sustaining treatment according to their advance directives.<sup>4</sup> 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<sup>4</sup> 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.<sup>3 5-8</sup> Accordingly, advance directives are especially important because individuals who did not sign advance directives tend to receive aggressive life-sustaining

1  
2  
3 treatment until the last moment of their lives regardless of their own intention.<sup>9</sup> Older adults  
4 with cognitive impairment may face difficulty in deciding whether to receive life-sustaining  
5 treatment or not, considering their judgement and executive function. Though many statistics  
6 have not been collected, we speculated that the last moment of many older adults with cognitive  
7 impairment might be determined by their family members. Until now, there have been few  
8 studies of advance directives or preferences for life-sustaining treatment in older adults with  
9 cognitive impairment or their family members. In this study, we focused on the thoughts  
10 regarding life-sustaining treatment of family members of older adults with cognitive  
11 impairment. Considering the influence of family members on the life of older adults with  
12 cognitive impairment,<sup>10 11</sup> our survey may help assess issues for advance directives and life-  
13 sustaining treatment in older adults with cognitive impairment.  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29

30 In addition, family members of older adults with cognitive impairment can feel  
31 psychological distress, including depression and anxiety.<sup>12-14</sup> Medical illness that may be  
32 related to fatal conditions can also be comorbid with negative mood.<sup>15-18</sup> That is, one can  
33 experience depression or anxiety at the moment one signs one's own advance directives or  
34 decides whether to receive life-sustaining treatment or not. Therefore, we additionally focused  
35 on the possibility that negative mood affects the decision for life-sustaining treatment.  
36  
37  
38  
39  
40  
41  
42  
43

44 The aim of this study is to investigate the thoughts regarding life-sustaining treatment of  
45 family members of older adults with cognitive impairment and to assess the factors, especially  
46 negative mood, associated with withdrawal of life-sustaining treatment.  
47  
48  
49  
50  
51  
52  
53  
54

## 55 **METHODS**

### 56 **Participants and procedure**

1  
2  
3 A total of 152 family members of older adults with cognitive impairment were recruited via  
4 the Guro-gu center for dementia from 1 May 2018 to 31 December 2019. Participants with a  
5 history of serious disease such as cancer, myocardial infarction, and cerebrovascular diseases  
6 were excluded from the study. After some instructions were provided, participants filled out a  
7 survey on the spot. It took about 20 to 30 minutes to complete the questionnaires. Participants  
8 answered the questions anonymously. Of the 152 initial participants, 2 had missing core  
9 questions (for thoughts on life-sustaining treatment) and were, therefore, excluded. The  
10 necessary ethical permissions were received from the Institutional Review Board at Korea  
11 University Guro Hospital prior to the initiation of the research (2018GR0151). Before  
12 completing the questionnaires, participants were informed about the study protocol and gave  
13 their written informed consent.  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31

## 32 **Measures**

33  
34  
35 All questionnaires were in self-report format. The questionnaire consisted of three parts. The  
36 first part contained items assessing the following demographic characteristics: age, gender,  
37 education, marital status, housing status, occupational status, religion, and monthly income.  
38  
39

40  
41  
42  
43 In the second part, participants answered questions regarding their thoughts on life-  
44 sustaining treatment. We provided a description of the terms used in the questionnaire before  
45 the second part to avoid confusion. According to the answer of the question “Do you want to  
46 receive life-sustaining treatment?” we classified our participants into two groups: individuals  
47 who want to maintain life-sustaining treatment (IMLT) and individuals who want to withdraw  
48 life-sustaining treatment (IWLTL). We adopted “cancer” as the example to help participants  
49 understand life-sustaining treatment better, because many South Koreans regard cancer as most  
50 worrying disease.<sup>19</sup>  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 The third part included the psychosocial items. We adopted the Generalized Anxiety  
4 Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression,  
5 respectively.<sup>20</sup> A higher score on these scales indicates a higher possibility of having anxiety  
6 or depressive symptoms. These scales have been translated into Korean, and their reliability  
7 and validity have been confirmed.<sup>21 22</sup> The Connor–Davidson Resilience Scale (CD-RISC) was  
8 used to assess the degree of resilience.<sup>23</sup> This scale contains 25 items scored in a five-point  
9 response format, and the total score ranges from zero to 100, where higher scores reflect greater  
10 resilience. We used the Korean version of the CD-RISC, which has been found to be reliable  
11 and valid.<sup>24</sup> We included the Multidimensional Scale of Perceived Social Support (MSPSS) to  
12 evaluate the perceived social support of family, friends, and significant others.<sup>25</sup> The MSPSS  
13 contains four items that are rated on a seven-point scale ranging from *very strongly disagree*<sup>1</sup>  
14 to *very strongly agree*.<sup>7</sup> We adopted the Korean version of MSPSS.<sup>26</sup>  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33

### 34 **Statistical analysis**

35  
36  
37 Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous  
38 variables and percentages for categorical variables). Differences between IMLT and IWLT  
39 groups in basic characteristics, thoughts on life-sustaining treatment, and psychosocial scales  
40 were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used  
41 independent *t*-tests for continuous variables and  $\chi^2$  tests or Fisher's exact test for categorical  
42 variables.  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54

## 55 **RESULTS**

56  
57  
58  
59 Among the 150 participants, the IMLT and IWLT groups comprised 50 and 100 participants,  
60

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 <sup>†</sup>
≤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 (%).

1  
2  
3 \*p value were calculated using the  $\chi^2$  test or Fisher's exact test and independent *t*-test.  
4

5 †p<0.05.  
6

7 IMLT, individuals who want to maintain life-sustaining treatment; IWLT, individuals who  
8 want to withdraw life-sustaining treatment.  
9  
10  
11  
12  
13  
14  
15  
16

17 We compared the thoughts on life-sustaining treatment of the IMLT and IWLT groups  
18 (Table 2). The IMLT group focused more on the chance of survival, while the IWLT group  
19 was more concerned about physical and mental distress. In addition, the IWLT group agreed  
20 with assisted suicide more than the IMLT group.  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 **Table 2** Thoughts on life-sustaining treatment of IMLT and IWLTL groups

	Total (n=150)	IMLT (n=50)	IWLTL (n=100)	P value*
Most important issue in deciding whether to receive life-sustaining treatment or not	Chance of survival (81 (54.0%)) Physical distress (29 (19.3%)) Mental distress (13 (8.7%)) Terminal state (49 (32.7%))	Chance of survival (38 (76.0%)) Physical distress (3 (6.0%)) Religious belief (3 (6.0%)) Immediately after diagnosis of metastatic cancer (19 (38.0%))	Chance of survival (43 (43.0%)) Physical distress (26 (26.0%)) Mental distress (12 (12.0%)) Terminal state (37 (37.0%))	0.001 <sup>†</sup>
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 (37 (24.7%))	Immediately after diagnosis of any cancer regardless of stage (13 (26.0%)) Terminal state (12 (24.0%))	Immediately after diagnosis of any cancer regardless of stage (24 (24.0%)) Immediately after diagnosis of metastatic cancer (23 (23.0%))	0.458
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 <sup>‡</sup>

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

3 <sup>†</sup>p<0.01.

4 <sup>‡</sup>p<0.05.

5 IMLT, individuals who want to maintain life-sustaining treatment; IWLTL, 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 <sup>†</sup>
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048 <sup>†</sup>
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 <sup>†</sup>
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  $\chi^2$  test or Fisher's exact test and independent *t*-test.

<sup>†</sup>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,



1  
2  
3 individuals who want to withdraw life-sustaining treatment.  
4  
5  
6  
7  
8  
9

## 10 **DISCUSSION**

11  
12  
13 In our study, there were twice as many participants in the IWLT group, compared to those  
14 in the IMLT group, who responded that they do not want to receive life-sustaining treatment.  
15  
16 Chance of survival was the most important issue in both groups in deciding whether or not  
17 to receive life-sustaining treatment, but the IWLT group focused more on physical and  
18 mental distress. Pros and cons on assisted suicide showed similar trends as preference for  
19 life-sustaining treatment. The timing preference order was terminal state, immediately after  
20 diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of  
21 stage in deciding whether to receive life-sustaining treatment. In addition, participants with  
22 higher education levels tended to be more common in the IWLT group. On the psychosocial  
23 scales, the IWLT group represented higher levels of depression/anxiety and lower level of  
24 perceived family support than the IMLT group.  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39

40 Most prior studies have reported that the majority of people do not want aggressive  
41 treatment in their terminal state.<sup>3 5-8</sup> Our results were consistent with these previous studies.  
42  
43 In addition, the IWLT group rated physical and mental distress highly in deciding their  
44 preference for life-sustaining treatment than the IMLT group in this study. According to  
45 previous reports, many people want hospice care and a more comfortable process of dying  
46 such as dying in their sleep.<sup>6 27 28</sup> Some studies have even shown that cancer pain was  
47 associated with a desire for hastened death.<sup>29 30</sup> Therefore, we speculate that avoidance of  
48 unwanted distress may account for the preference for withdrawal of life-sustaining treatment.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Furthermore, our results that a majority of participants, especially in the IWLT group, agreed  
4 with assisted suicide may be interpreted similarly. These findings may emphasize the  
5 importance of advance directives. A previous study reported a tendency to receive more life-  
6 sustaining treatment when patients' intention for life-sustaining treatment was unclear.<sup>9</sup>  
7 Accordingly, more publicity regarding actively participating in registering one's advance  
8 directives to National Agency for Management of Life-Sustaining Treatment may be needed  
9 to avoid unwanted life-sustaining treatment.  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19

20 In total, 32.7% of the participants in our study regarded terminal status as an optimal time  
21 to decide whether to receive life-sustaining treatment. However, more participants want to  
22 decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer  
23 regardless of stage. There have been few previous studies with this result. However, Keam  
24 et al.<sup>31</sup> mentioned that people may regard the decision for life-sustaining treatment as a will  
25 that embodies values about end-of life. We also believe that people may want to decide the  
26 last moment of their own life while they are relatively healthy and physically/mentally intact  
27 so as to preserve their dignity and worth as human beings.  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39

40 Among sociodemographic factors, education level was the factor that showed significant  
41 differences between the IMLT and IWLT groups. That is, participants with higher education  
42 levels tended to prefer withdrawal of life-sustaining treatment in this study. Some previous  
43 studies analyzed the association between education level and life-sustaining treatment, but  
44 the results were controversial.<sup>8 32 33</sup> On the other hand, various studies have reported that  
45 individuals with higher education levels had greater interest in advance directives and a  
46 stronger tendency to complete them beforehand.<sup>6 7 31</sup> However, there have been few  
47 comments on the causes of this association.<sup>6 7 31</sup> Though more studies are needed to clarify  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 our results, we speculate that a tendency toward introspection and accessibility of  
4 information may account for the association between education level and preference for life-  
5 sustaining treatment or advance directives. Our findings may emphasize the necessity of  
6 broader publicity and explanations of advance directives for life-sustaining treatment.  
7  
8  
9  
10  
11  
12

13 In addition, the IWLT group showed higher levels of depression and anxiety than the  
14 IMLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness,  
15 frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic  
16 problems including pain.<sup>34</sup> We believe that these symptoms can affect the decision for life-  
17 sustaining treatment. For example, as hopelessness is associated with suicide,<sup>35-37</sup> cancer  
18 patients who have feelings of hopelessness might wish to hasten death. In addition, previous  
19 studies reported that cancer pain was related to a desire for hastened death.<sup>29 30</sup> Therefore,  
20 we speculate that depressive patients with somatic problems such as pain aggravation might  
21 change their minds to select a peaceful death. Similar to our results, Wen et al.<sup>38</sup> reported  
22 that cancer patients with depressive symptoms were more likely to be in the comfort-  
23 preferring state in terms of preference for life-sustaining treatment. Our findings suggest that  
24 a consideration of depressive and anxiety symptoms may be needed in determining whether  
25 or not one receives life-sustaining treatment. Though many patients with severe physical  
26 illness suffer from depression and anxiety,<sup>15-18</sup> these symptoms can be attenuated by proper  
27 treatment.<sup>39-41</sup> That is, if individuals have depressive or anxiety symptoms when they  
28 complete their advance directives for life-sustaining treatment, delaying the timing of the  
29 decision may be recommended until after the proper treatment of depression or anxiety.  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
O'Mahony et al.<sup>42</sup> 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.

1  
2  
3 Furthermore, participants who felt relatively well-supported by their family members  
4 tended to prefer to maintain life-sustaining treatment. However, the results of other studies  
5 differ from ours, though a consensus does not have been previously reached. Kim and Shin  
6  
7  
8  
9  
10<sup>43</sup> reported that perceived family support was related to the preference for withdrawal of life-  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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<sup>43</sup> reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al.<sup>44</sup> 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<sup>45</sup> 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

1  
2  
3 might be reflected in the preference for life-sustaining treatment. In particular, depressive  
4 and anxiety symptoms may have an effect on this issue. According to our findings, it may  
5 be essential to address negative mood such as depression or anxiety when signing one's own  
6 advance directives or deciding whether one receives life-sustaining treatment, particularly  
7 in individuals in a distressed situation. That is, if necessary, adequate intervention can be  
8 applied to individuals with negative moods during their decision-making process on life-  
9 sustaining treatment.  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19

20 As mentioned in the Introduction, there have been few studies of preferences for life-  
21 sustaining treatment in individuals with cognitive impairment. Our participants, the family  
22 members, may be the "current" and "potential future" legal guardians of individuals with  
23 cognitive impairment. Therefore, our results may provide data to assess issues of advance  
24 directives and life-sustaining treatment in individuals with cognitive impairment.  
25 Furthermore, our findings might also serve as a reference for this issue for family members  
26 of patients with other chronic and deteriorating diseases considering the courses of patients  
27 in center for dementia. However, there may be some disagreement between patients and  
28 their family members on preferences for life-sustaining treatment. Abdul-Razzak et al.<sup>46</sup>  
29 also reported an appreciable disagreement between hospitalized patients and family  
30 members on this issue. We believe that future studies including patients with cognitive  
31 impairment can advance our results.  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48

49 There are some limitations to this study. First, our study has a relatively small number of  
50 participants. This may limit the generalizability of our results. Second, we only included the  
51 family members of patients in a center for dementia. That is, this study does not have  
52 comparison subjects such as patients with cognitive impairment. Though our results were  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 generally consistent with previous studies, direct comparison between patients and their  
4 family members may be needed to clarify our results. In addition, further studies including  
5 various other groups such as the general public, physicians, and cancer patients may  
6 represent more informative results. Third, we did not investigate the severity or diagnosis of  
7 cognitive impairment, which can be associated with degree of distress as a family member.  
8 Inclusion of these factors may help assess the associations between preference for life-  
9 sustaining treatment and distress as a family member. Fourth, our study used a cross-  
10 sectional design. However, the preference for life-sustaining treatment can change over time.  
11 Gallo et al.<sup>47</sup> also reported that periodic reassessment for planning end-of-life care was  
12 needed in their 12-year follow-up study. Finally, our questionnaire consisted of only self-  
13 report items. Though we provided descriptions of the meanings of the terms, using various  
14 methods such as clinician-report scales and interviews can help avoid misunderstandings of  
15 the terms and ensure a more effective survey.

## 37 CONCLUSION

38  
39  
40  
41 This study showed the thoughts and associated factors regarding life-sustaining treatment of  
42 family members of older adults with cognitive impairment. Our participants tended to want  
43 to withdraw life-sustaining treatment and to agree with assisted suicide. In deciding the  
44 withdrawal of life-sustaining treatment, chance of survival and physical/mental distress were  
45 the important issues. Thirty-two point seven percent of participants responded that terminal  
46 status was an optimal time to decide whether to receive life-sustaining treatment. However,  
47 many more participants want to decide this issue earlier. Among sociodemographic and  
48 psychosocial factors, higher levels of education, depression, and anxiety and lower levels of

1  
2  
3 family support were associated with the decision to withdraw life-sustaining treatment. Our  
4  
5 findings can help assess issues of advance directives and life-sustaining treatment in  
6  
7 individuals who have cared for chronic and deteriorating patients as well as in individuals  
8  
9 with cognitive impairment.  
10  
11  
12  
13  
14

15 **Contributors** HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed  
16  
17 to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK  
18  
19 contributed to interpretation. All authors critically revised the manuscript and gave final  
20  
21 approval.  
22  
23  
24  
25  
26

27 **Funding** This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.  
28  
29  
30  
31

32 **Disclaimer** The funders had no role in planning or conducting the study.  
33  
34  
35

36 **Competing interests** The authors declare no conflicts of interest.  
37  
38  
39  
40

41 **Patient and public involvement** Patients or the public were not involved in the design, or  
42  
43 conduct, or reporting, or dissemination plans of our research.  
44  
45  
46  
47

48 **Patient consent for publication** Not required.  
49  
50  
51

52 **Data availability statement** The data that support the findings of this study are available  
53  
54 on request from the corresponding author.  
55  
56  
57  
58  
59  
60

## 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. Pasma 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.



- 1  
2  
3 10. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin*  
4  
5 *Neurosci* 2009;11:217-28.  
6  
7
- 8 11. Sousa MF, Santos RL, Arcoverde C, *et al.* Quality of life in dementia: the role of non-  
9  
10 cognitive factors in the ratings of people with dementia and family caregivers. *Int*  
11  
12 *Psychogeriatr* 2013;25:1097-105.  
13  
14
- 15 12. Garand L, Dew MA, Eazor LR, *et al.* Caregiving burden and psychiatric morbidity in  
16  
17 spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry*  
18  
19 2005;20:512-22.  
20  
21
- 22 13. Garand L, Lingler JH, Deardorf KE, *et al.* Anticipatory grief in new family caregivers  
23  
24 of persons with mild cognitive impairment and dementia. *Alzheimer Dis Assoc Disord*  
25  
26 2012;26:159-65.  
27  
28
- 29 14. Teri L. Behavior and caregiver burden: behavioral problems in patients with Alzheimer  
30  
31 disease and its association with caregiver distress. *Alzheimer Dis Assoc Disord* 1997;11  
32  
33 Suppl 4:S35-8.  
34  
35
- 36 15. Thom R, Silbersweig DA, Boland RJ. Major depressive disorder in medical illness: A  
37  
38 review of assessment, prevalence, and treatment options. *Psychosom Med*  
39  
40 2019;81:246-55.  
41  
42
- 43 16. Spiegel D. Cancer and depression. *Br J Psychiatry Suppl* 1996:109-16.  
44  
45
- 46 17. Katon W, Lin EH, Kroenke K. The association of depression and anxiety with medical  
47  
48 symptom burden in patients with chronic medical illness. *Gen Hosp Psychiatry*  
49  
50 2007;29:147-55.  
51  
52
- 53 18. Steffens DC, Helms MJ, Krishnan KR, *et al.* Cerebrovascular disease and depression  
54  
55 symptoms in the cardiovascular health study. *Stroke* 1999;30:2159-66.  
56  
57
- 58 19. Health Insurance Review & Assessment Service. *Worrying diseases of the people.*  
59  
60

- 1  
2  
3 Wonju: Health Insurance Review & Assessment Service, 2016.  
4  
5  
6 20. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of  
7  
8 PRIME-MD: the PHQ primary care study. *Primary Care Evaluation of Mental*  
9  
10 *Disorders. Patient Health Questionnaire. JAMA* 1999;282:1737-44.  
11  
12 21. Choi HS, Choi JH, Park KH, *et al.* Standardization of the Korean version of patient  
13  
14 health questionnaire-9 as a screening instrument for major depressive disorder. *J*  
15  
16 *Korean Acad Fam Med* 2007;28:114-9.  
17  
18 22. Seo JG, Cho YW, Lee SJ, *et al.* Validation of the generalized anxiety disorder-7 in  
19  
20 people with epilepsy: a MEPSY study. *Epilepsy Behav* 2014;35:59-63.  
21  
22 23. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-  
23  
24 Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.  
25  
26 24. Jung YE, Min JA, Shin AY, *et al.* The Korean version of the Connor-Davidson  
27  
28 Resilience Scale: an extended validation. *Stress Health* 2012;28:319-26.  
29  
30 25. Eker D, Arkar H. Perceived social support: psychometric properties of the MSPSS in  
31  
32 normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr*  
33  
34 *Epidemiol* 1995;30:121-6.  
35  
36 26. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the  
37  
38 unemployed. *Korean J Soc Welf* 1999;37:241-69.  
39  
40 27. Kim S, Koh S, Park K, *et al.* End-of-life care decisions using a Korean advance  
41  
42 directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.  
43  
44 28. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among  
45  
46 community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.  
47  
48 29. Chochinov HM, Wilson KG, Enns M, *et al.* Desire for death in the terminally ill. *Am J*  
49  
50 *Psychiatry* 1995;152:1185-91.  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 30. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression.  
4  
5 *Postgrad Med* 1989;85:263-6, 8, 70.  
6  
7
- 8 31. Keam B, Yun YH, Heo DS, *et al.* The attitudes of Korean cancer patients, family  
9  
10 caregivers, oncologists, and members of the general public toward advance directives.  
11  
12 *Support Care Cancer* 2013;21:1437-44.  
13  
14
- 15 32. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care  
16  
17 interventions (active pain control, withdrawal of futile life-sustaining treatment,  
18  
19 passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred  
20  
21 cross-sectional survey of Korean patients with cancer, their family caregivers,  
22  
23 physicians and the general Korean population. *BMJ Open* 2018;8:e020519.  
24  
25
- 26 33. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia  
27  
28 and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*  
29  
30 2000;284:2460-8.  
31  
32
- 33 34. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*  
34  
35 *sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.  
36  
37
- 38 35. Minkoff K, Bergman E, Beck AT, *et al.* Hopelessness, depression, and attempted  
39  
40 suicide. *Am J Psychiatry* 1973;130:455-9.  
41  
42
- 43 36. Beck AT, Brown G, Berchick RJ, *et al.* Relationship between hopelessness and  
44  
45 ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry*  
46  
47 1990;147:190-5.  
48  
49
- 50 37. Beck AT, Steer RA, Kovacs M, *et al.* Hopelessness and eventual suicide: a 10-year  
51  
52 prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry*  
53  
54 1985;142:559-63.  
55  
56
- 57 38. Wen FH, Chen JS, Chou WC, *et al.* Factors predisposing terminally ill cancer patients'

- 1  
2  
3 preferences for distinct patterns/states of life-sustaining treatments over their last six  
4 months. *J Pain Symptom Manage* 2019;57:190-8.e2.  
5  
6  
7  
8 39. Smith HR. Depression in cancer patients: Pathogenesis, implications and treatment  
9 (Review). *Oncol Lett* 2015;9:1509-14.  
10  
11  
12 40. Traeger L, Greer JA, Fernandez-Robles C, *et al*. Evidence-based treatment of anxiety  
13 in patients with cancer. *J Clin Oncol* 2012;30:1197-205.  
14  
15  
16 41. Lyford J. Integrated care for cancer patients with depression is effective. *Pharm J* 2014.  
17 <http://dx.doi.org/10.1211/PJ.2014.20066288>.  
18  
19  
20 42. O'Mahony S, Goulet J, Kornblith A, *et al*. Desire for hastened death, cancer pain and  
21 depression: report of a longitudinal observational study. *J Pain Symptom Manage*  
22 2005;29:446-57.  
23  
24  
25 43. Kim HS, Shin SR. The influence of social support among community dwelling elderly  
26 and their attitude towards the withdrawal of life-sustaining treatment: A mediating  
27 effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.  
28  
29  
30 44. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and  
31 associated factors among older patients with terminal stage of cardiopulmonary disease.  
32 *J Korean Acad Nurs* 2019;49:329-39.  
33  
34  
35 45. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-  
36 sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.  
37  
38  
39 46. Abdul-Razzak A, Heyland DK, Simon J, *et al*. Patient-family agreement on values and  
40 preferences for life-sustaining treatment: results of a multicentre observational study.  
41 *BMJ Support Palliat Care* 2019;9:e20.  
42  
43  
44 47. Gallo JJ, Abshire M, Hwang S, *et al*. Advance directives, medical conditions, and  
45 preferences for end-of-life care among physicians: 12-year follow-up of the Johns  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

For peer review only

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

Section/Topic	Item #	Recommendation	Reported on page #
<b>Title and abstract</b>	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
<b>Introduction</b>			
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
<b>Methods</b>			
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
<b>Results</b>			

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	-
<b>Discussion</b>			
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
<b>Other information</b>			
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](http://www.strobe-statement.org).

# BMJ Open

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

Journal:	<i>BMJ Open</i>
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,
<b>Primary Subject Heading</b>:	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

SCHOLARONE™  
Manuscripts





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.

1  
2  
3 **Preferences for life-sustaining treatment in individuals with family**  
4  
5  
6 **members with cognitive impairment: a cross-sectional study**  
7  
8  
9

10  
11 **HyunChul Youn,<sup>1</sup> Suk-young Lee,<sup>2</sup> Han-yong Jung,<sup>1</sup> Shin-Gyeom Kim,<sup>1</sup> Hyun-Ghang**  
12  
13 **Jeong<sup>3,4</sup>**  
14  
15

16  
17  
18 <sup>1</sup>Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic  
19  
20 of Korea  
21

22 <sup>2</sup>Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine,  
23  
24 Wonkwang University, Gunpo, Republic of Korea  
25

26  
27 <sup>3</sup>Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
28  
29 Medicine, Seoul, Republic of Korea  
30

31 <sup>4</sup>Korea University Research Institute of Mental Health, Seoul, Republic of Korea  
32  
33

34  
35  
36 **Correspondence to**  
37

38 Dr Hyun-Ghang Jeong;  
39

40 Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
41  
42 Medicine,  
43

44  
45 148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;  
46

47 E-mail: jeonghg@korea.ac.kr  
48  
49

50  
51  
52 **Word count:** 2,946 words  
53  
54

55  
56  
57 **ORCID iDs**  
58  
59  
60

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>

For peer review only

## 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.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

For peer review only

## 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.<sup>1</sup> In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.<sup>1</sup> Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.<sup>2</sup> At this time, the Patient Self-Determination Act was first formalized in United States.<sup>3</sup> 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.<sup>1</sup> 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".<sup>2</sup>

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.<sup>4</sup> Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.<sup>4</sup> 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<sup>4</sup> 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.<sup>3 5-8</sup> 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.<sup>9</sup>

1  
2  
3 In this study, we focused on the thoughts regarding life-sustaining treatment of individuals  
4 with family members with cognitive impairment. These individuals may be exposed to  
5 caregiver distress, which can include depression and anxiety.<sup>10-12</sup> We believe that our survey  
6 may help assess issues surrounding advance directives and life-sustaining treatment in  
7 caregivers living in an aging society. In addition, medical illnesses that may be related to fatal  
8 conditions can also be comorbid with negative mood.<sup>13-16</sup> That is, one can experience  
9 depression or anxiety at the moment one signs one's own advance directive or decides whether  
10 to receive life-sustaining treatment. This study may be additionally helpful in assessing the  
11 possibility that negative mood affects the decision regarding life-sustaining treatment.  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24

25 The aim of this study was to investigate the thoughts regarding life-sustaining treatment of  
26 individuals with family members with cognitive impairment and to assess factors, especially  
27 negative mood, associated with not receiving life-sustaining treatment.  
28  
29  
30  
31  
32  
33  
34  
35

## 36 **METHODS**

### 37 **Participants and procedure**

38  
39  
40 A total of 152 individuals with family members with cognitive impairment were recruited via  
41 the Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited 170 family  
42 members, but 18 people declined to participate in this study because they were not interested  
43 in the issue of the research. Participants with a history of serious disease such as cancer,  
44 myocardial infarction, and cerebrovascular diseases were excluded from the study. After some  
45 instructions were provided, participants filled out a survey on the spot. It took about 20 to 30  
46 minutes to complete the questionnaires. Participants answered the questions anonymously. Of  
47 the 152 initial participants, 2 had missing core questions (for thoughts on life-sustaining  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 treatment) and were, therefore, excluded. The necessary ethical permissions were received  
4  
5 from the Institutional Review Board at Korea University Guro Hospital prior to the initiation  
6  
7 of the research (2018GR0151). Before completing the questionnaires, participants were  
8  
9 informed about the study protocol and gave their written informed consent.  
10  
11  
12  
13  
14  
15

## 16 **Measures**

17  
18  
19 All questionnaires were in self-report format. The questionnaire consisted of three parts. The  
20  
21 first part contained items assessing the following demographic characteristics: age, gender,  
22  
23 education, marital status, housing status, occupational status, religion, and monthly income.  
24  
25  
26

27 In the second part, participants answered questions regarding their thoughts on life-  
28  
29 sustaining treatment. We provided a description of the terms used in the questionnaire before  
30  
31 the second part to avoid confusion (suppl 1). For example, “terminal state” is defined as a  
32  
33 condition in which treatments for the purpose of life extension are not applicable to patients.  
34  
35 According to the answer of the question “Do you want to receive life-sustaining treatment?”  
36  
37 we classified our participants into two groups: individuals who wanted to receive life-  
38  
39 sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining  
40  
41 treatment (INLT). We adopted “cancer” as the example to help participants understand life-  
42  
43 sustaining treatment better, because many South Koreans regard cancer as most worrying  
44  
45 disease.<sup>17</sup>  
46  
47  
48  
49

50 The third part included the psychosocial items. We adopted the Generalized Anxiety  
51  
52 Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression,  
53  
54 respectively.<sup>18</sup> A higher score on these scales indicates a higher possibility of having anxiety  
55  
56 or depressive symptoms. These scales have been translated into Korean, and their reliability  
57  
58 and validity have been confirmed.<sup>19 20</sup> The Connor–Davidson Resilience Scale (CD-RISC) was  
59  
60

1  
2  
3 used to assess the degree of resilience.<sup>21</sup> This scale contains 25 items scored in a five-point  
4 response format, and the total score ranges from zero to 100, where higher scores reflect greater  
5 resilience. We used the Korean version of the CD-RISC, which has been found to be reliable  
6 and valid.<sup>22</sup> We included the Multidimensional Scale of Perceived Social Support (MSPSS) to  
7 evaluate the perceived social support of family, friends, and significant others.<sup>23</sup> The MSPSS  
8 contains four items that are rated on a seven-point scale ranging from *very strongly disagree*<sup>1</sup>  
9 to *very strongly agree*.<sup>7</sup> We adopted the Korean version of MSPSS.<sup>24</sup>  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22

### 23 **Statistical analysis**

24  
25  
26 Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous  
27 variables and percentages for categorical variables). Differences between the IRLT and INLT  
28 groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial  
29 scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used  
30 independent *t*-tests for continuous variables and  $\chi^2$  tests or Fisher's exact test for categorical  
31 variables.  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 44 **RESULTS**

45  
46  
47 Among the 150 participants, the IRLT and INLT groups comprised 50 and 100 participants,  
48 respectively. Table 1 shows the basic characteristics of the IRLT and INLT groups. The mean  
49 age of participants was 45.38 (SD = 14.71) years, and 56.0% were female. The participants  
50 with college-level education or higher were significantly more numerous in the INLT group  
51 than in the IRLT group.  
52  
53  
54  
55  
56  
57  
58  
59  
60

**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 <sup>†</sup>
≤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  $\chi^2$  test or Fisher's exact test and independent *t*-test.

<sup>†</sup>p<0.05.

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

1  
2  
3  
4  
5  
6 We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table  
7  
8  
9 2). The IRLT group focused more on the chance of survival, while the INLT group was more  
10  
11 concerned about physical and mental distress. In addition, the INLT group agreed with assisted  
12  
13 suicide more than the IRLT group.  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

1 **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%)) Physical distress (29 (19.3%)) Mental distress (13 (8.7%)) Other responses (religious belief, treatment cost)	Chance of survival (38 (76.0%)) Physical distress (3 (6.0%)) Religious belief (3 (6.0%)) Other responses (mental distress, treatment cost)	Chance of survival (43 (43.0%)) Physical distress (26 (26.0%)) Mental distress (12 (12.0%)) Other responses (religious belief, treatment cost)	0.001 <sup>†</sup>
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 (42 (28.0%)) Immediately after diagnosis of any cancer regardless of stage (37 (24.7%)) Other responses (when to start chemotherapy, during chemotherapy)	Immediately after diagnosis of metastatic cancer (19 (38.0%)) Immediately after diagnosis of any cancer regardless of stage (13 (26.0%)) Terminal state (12 (24.0%)) Other responses (when to start chemotherapy, during chemotherapy)	Terminal state (37 (37.0%)) Immediately after diagnosis of any cancer regardless of stage (24 (24.0%)) Immediately after diagnosis of metastatic cancer (23 (23.0%)) Other responses (when to start chemotherapy, during chemotherapy)	0.458
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 <sup>‡</sup>

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

1  
2  
3 †p<0.01.  
4

5 ‡p<0.05.  
6

7  
8 IRLT, individuals who wanted to receive life-sustaining treatment; INLT, individuals who wanted to not receive life-sustaining treatment.  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46

For peer review only

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 <sup>†</sup>
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048 <sup>†</sup>
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 <sup>†</sup>
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.

<sup>†</sup>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,

1  
2  
3 individuals who wanted to not receive life-sustaining treatment.  
4  
5  
6  
7  
8

## 9 10 **DISCUSSION**

11  
12  
13 In our study, there were twice as many participants in the INLT group compared to those in  
14 the IRLT group, who responded that they do not want to receive life-sustaining treatment.  
15  
16 Chance of survival was the most important issue in both groups in deciding whether or not  
17 to receive life-sustaining treatment, but the INLT group focused more on physical and  
18 mental distress. Agreement on assisted suicide showed similar trends as preference for life-  
19 sustaining treatment. The timing preference order was terminal state, immediately after  
20 diagnosis of metastatic cancer, and immediately after diagnosis of any cancer regardless of  
21 stage in deciding whether to receive life-sustaining treatment. In addition, participants with  
22 higher education levels tended to be more common in the INLT group. On the psychosocial  
23 scales, the INLT group represented higher levels of depression/anxiety and lower level of  
24 perceived family support than the IRLT group.  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39

40 Most prior studies have reported that the majority of people do not want aggressive  
41 treatment in their terminal state.<sup>3 5-8</sup> Our results were consistent with these previous studies.  
42  
43 In addition, the INLT group rated physical and mental distress highly in deciding their  
44 preference for life-sustaining treatment than the IRLT group in this study. According to  
45 previous reports, many people want hospice care and a more comfortable process of dying  
46 such as dying in their sleep.<sup>6 25 26</sup> Some studies have even shown that cancer pain was  
47 associated with a desire for hastened death.<sup>27 28</sup> Therefore, we speculate that avoidance of  
48 unwanted distress may account for the preference for not receiving life-sustaining treatment.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 Furthermore, our results that a majority of participants, especially in the INLT group, agreed  
4 with assisted suicide may be interpreted similarly. These findings may emphasize the  
5 importance of advance directives. A previous study reported a tendency to receive more life-  
6 sustaining treatment when patients' intention for life-sustaining treatment was unclear.<sup>9</sup>  
7 Accordingly, more publicity regarding actively participating in registering one's advance  
8 directives to National Agency for Management of Life-Sustaining Treatment may be needed  
9 to avoid unwanted life-sustaining treatment.  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19

20 In total, 32.7% of the participants in our study regarded terminal status as an optimal time  
21 to decide whether to receive life-sustaining treatment. However, more participants want to  
22 decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer  
23 regardless of stage. There have been few previous studies with this result. However, Keam  
24 et al.<sup>29</sup> mentioned that people may regard the decision for life-sustaining treatment as a will  
25 that embodies values about end-of life. We also believe that people may want to make  
26 decisions regarding the last moments of their own life, such as by signing advance directives,  
27 while they are relatively healthy and physically/mentally intact to preserve their dignity and  
28 worth as human beings. However, in determining whether to receive life-sustaining  
29 treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of  
30 stage," it may be important to take into account the possibility that patients are under stress  
31 at that time. We speculate that many participants might want to decide upon the last moments  
32 of their own life earlier than our existing options. For an example, many people would rather  
33 prefer to make their decision in a physically and mentally healthy state, uninfluenced by  
34 disease or pain. Although we asked the participants to write down other optimal timings  
35 directly, most participants opted for one of the existing options. Further studies are needed  
36 to clarify this issue.  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Among sociodemographic factors, education level was the factor that showed significant  
4 differences between the IRLT and INLT groups. That is, participants with higher education  
5 levels tended to prefer to not receive life-sustaining treatment in this study. Some previous  
6 studies analyzed the association between education level and life-sustaining treatment, but  
7 the results were controversial.<sup>8 30 31</sup> On the other hand, various studies have reported that  
8 individuals with higher education levels had greater interest in advance directives and a  
9 stronger tendency to complete them beforehand.<sup>6 7 29</sup> However, there have been few  
10 comments on the causes of this association.<sup>6 7 29</sup> Though more studies are needed to clarify  
11 our results, we speculate that a tendency toward introspection and accessibility of  
12 information may account for the association between education level and preference for life-  
13 sustaining treatment or advance directives. Our findings may emphasize the necessity of  
14 broader publicity and explanations of advance directives for life-sustaining treatment.  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31

32 In addition, the INLT group showed higher levels of depression and anxiety than the  
33 IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness,  
34 frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic  
35 problems including pain.<sup>32</sup> We believe that these symptoms can affect the decision for life-  
36 sustaining treatment. For example, as hopelessness is associated with suicide,<sup>33-35</sup> cancer  
37 patients who have feelings of hopelessness might wish to hasten death. In addition, previous  
38 studies reported that cancer pain was related to a desire for hastened death.<sup>27 28</sup> Therefore,  
39 we speculate that depressive patients with somatic problems such as pain aggravation might  
40 change their minds to select a peaceful death. Similar to our results, Wen et al.<sup>36</sup> reported  
41 that cancer patients with depressive symptoms were more likely to be in the comfort-  
42 preferring state in terms of preference for life-sustaining treatment. Our findings suggest that  
43 a consideration of depressive and anxiety symptoms may be needed in determining whether  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 or not one receives life-sustaining treatment. For example, clinicians may consider  
4 recommending the patient to delay making a decision on life-sustaining treatment if a  
5 patient's depressive or anxiety symptoms are believed to be temporary. According to the  
6 patient's condition, treatment for depression or anxiety symptoms may be provided to the  
7 patient before they make a decision. Our findings may be particularly meaningful because  
8 many patients with severe physical illness suffer from depression or anxiety.<sup>13-16</sup> Future  
9 research that can clarify any causal relationship may help verify and advance our results.

10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20 Furthermore, participants who felt relatively well-supported by their family members  
21 tended to prefer to receive life-sustaining treatment. However, the results of other studies  
22 differ from ours, though a consensus does not have been previously reached. Kim and Shin  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
61  
62  
63  
64  
65  
66  
67  
68  
69  
70  
71  
72  
73  
74  
75  
76  
77  
78  
79  
80  
81  
82  
83  
84  
85  
86  
87  
88  
89  
90  
91  
92  
93  
94  
95  
96  
97  
98  
99  
100  
101  
102  
103  
104  
105  
106  
107  
108  
109  
110  
111  
112  
113  
114  
115  
116  
117  
118  
119  
120  
121  
122  
123  
124  
125  
126  
127  
128  
129  
130  
131  
132  
133  
134  
135  
136  
137  
138  
139  
140  
141  
142  
143  
144  
145  
146  
147  
148  
149  
150  
151  
152  
153  
154  
155  
156  
157  
158  
159  
160  
161  
162  
163  
164  
165  
166  
167  
168  
169  
170  
171  
172  
173  
174  
175  
176  
177  
178  
179  
180  
181  
182  
183  
184  
185  
186  
187  
188  
189  
190  
191  
192  
193  
194  
195  
196  
197  
198  
199  
200  
201  
202  
203  
204  
205  
206  
207  
208  
209  
210  
211  
212  
213  
214  
215  
216  
217  
218  
219  
220  
221  
222  
223  
224  
225  
226  
227  
228  
229  
230  
231  
232  
233  
234  
235  
236  
237  
238  
239  
240  
241  
242  
243  
244  
245  
246  
247  
248  
249  
250  
251  
252  
253  
254  
255  
256  
257  
258  
259  
260  
261  
262  
263  
264  
265  
266  
267  
268  
269  
270  
271  
272  
273  
274  
275  
276  
277  
278  
279  
280  
281  
282  
283  
284  
285  
286  
287  
288  
289  
290  
291  
292  
293  
294  
295  
296  
297  
298  
299  
300  
301  
302  
303  
304  
305  
306  
307  
308  
309  
310  
311  
312  
313  
314  
315  
316  
317  
318  
319  
320  
321  
322  
323  
324  
325  
326  
327  
328  
329  
330  
331  
332  
333  
334  
335  
336  
337  
338  
339  
340  
341  
342  
343  
344  
345  
346  
347  
348  
349  
350  
351  
352  
353  
354  
355  
356  
357  
358  
359  
360  
361  
362  
363  
364  
365  
366  
367  
368  
369  
370  
371  
372  
373  
374  
375  
376  
377  
378  
379  
380  
381  
382  
383  
384  
385  
386  
387  
388  
389  
390  
391  
392  
393  
394  
395  
396  
397  
398  
399  
400  
401  
402  
403  
404  
405  
406  
407  
408  
409  
410  
411  
412  
413  
414  
415  
416  
417  
418  
419  
420  
421  
422  
423  
424  
425  
426  
427  
428  
429  
430  
431  
432  
433  
434  
435  
436  
437  
438  
439  
440  
441  
442  
443  
444  
445  
446  
447  
448  
449  
450  
451  
452  
453  
454  
455  
456  
457  
458  
459  
460  
461  
462  
463  
464  
465  
466  
467  
468  
469  
470  
471  
472  
473  
474  
475  
476  
477  
478  
479  
480  
481  
482  
483  
484  
485  
486  
487  
488  
489  
490  
491  
492  
493  
494  
495  
496  
497  
498  
499  
500  
501  
502  
503  
504  
505  
506  
507  
508  
509  
510  
511  
512  
513  
514  
515  
516  
517  
518  
519  
520  
521  
522  
523  
524  
525  
526  
527  
528  
529  
530  
531  
532  
533  
534  
535  
536  
537  
538  
539  
540  
541  
542  
543  
544  
545  
546  
547  
548  
549  
550  
551  
552  
553  
554  
555  
556  
557  
558  
559  
560  
561  
562  
563  
564  
565  
566  
567  
568  
569  
570  
571  
572  
573  
574  
575  
576  
577  
578  
579  
580  
581  
582  
583  
584  
585  
586  
587  
588  
589  
590  
591  
592  
593  
594  
595  
596  
597  
598  
599  
600  
601  
602  
603  
604  
605  
606  
607  
608  
609  
610  
611  
612  
613  
614  
615  
616  
617  
618  
619  
620  
621  
622  
623  
624  
625  
626  
627  
628  
629  
630  
631  
632  
633  
634  
635  
636  
637  
638  
639  
640  
641  
642  
643  
644  
645  
646  
647  
648  
649  
650  
651  
652  
653  
654  
655  
656  
657  
658  
659  
660  
661  
662  
663  
664  
665  
666  
667  
668  
669  
670  
671  
672  
673  
674  
675  
676  
677  
678  
679  
680  
681  
682  
683  
684  
685  
686  
687  
688  
689  
690  
691  
692  
693  
694  
695  
696  
697  
698  
699  
700  
701  
702  
703  
704  
705  
706  
707  
708  
709  
710  
711  
712  
713  
714  
715  
716  
717  
718  
719  
720  
721  
722  
723  
724  
725  
726  
727  
728  
729  
730  
731  
732  
733  
734  
735  
736  
737  
738  
739  
740  
741  
742  
743  
744  
745  
746  
747  
748  
749  
750  
751  
752  
753  
754  
755  
756  
757  
758  
759  
760  
761  
762  
763  
764  
765  
766  
767  
768  
769  
770  
771  
772  
773  
774  
775  
776  
777  
778  
779  
780  
781  
782  
783  
784  
785  
786  
787  
788  
789  
790  
791  
792  
793  
794  
795  
796  
797  
798  
799  
800  
801  
802  
803  
804  
805  
806  
807  
808  
809  
810  
811  
812  
813  
814  
815  
816  
817  
818  
819  
820  
821  
822  
823  
824  
825  
826  
827  
828  
829  
830  
831  
832  
833  
834  
835  
836  
837  
838  
839  
840  
841  
842  
843  
844  
845  
846  
847  
848  
849  
850  
851  
852  
853  
854  
855  
856  
857  
858  
859  
860  
861  
862  
863  
864  
865  
866  
867  
868  
869  
870  
871  
872  
873  
874  
875  
876  
877  
878  
879  
880  
881  
882  
883  
884  
885  
886  
887  
888  
889  
890  
891  
892  
893  
894  
895  
896  
897  
898  
899  
900  
901  
902  
903  
904  
905  
906  
907  
908  
909  
910  
911  
912  
913  
914  
915  
916  
917  
918  
919  
920  
921  
922  
923  
924  
925  
926  
927  
928  
929  
930  
931  
932  
933  
934  
935  
936  
937  
938  
939  
940  
941  
942  
943  
944  
945  
946  
947  
948  
949  
950  
951  
952  
953  
954  
955  
956  
957  
958  
959  
960  
961  
962  
963  
964  
965  
966  
967  
968  
969  
970  
971  
972  
973  
974  
975  
976  
977  
978  
979  
980  
981  
982  
983  
984  
985  
986  
987  
988  
989  
990  
991  
992  
993  
994  
995  
996  
997  
998  
999  
1000

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<sup>37</sup> reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al.<sup>38</sup> 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<sup>39</sup> even showed that family relationships and preference for life-sustaining treatment were not significantly associated in chronically ill, elderly outpatients. Further studies including a

1  
2  
3 greater variety of participants can clarify the association between family support and life-  
4 sustaining treatment.  
5  
6

7  
8  
9 In this study, we investigated the preference for life-sustaining treatment and factors  
10 associated with the decision in individuals with family members with cognitive impairment.  
11 The thoughts regarding life-sustaining treatment of our participants were generally  
12 consistent with previous reports on life-sustaining treatment. However, our results showed  
13 the possibility that distress as a family member of individuals with cognitive impairment  
14 might be reflected in the preference for life-sustaining treatment. In particular, depressive  
15 and anxiety symptoms may have an effect on this issue. According to our findings, if  
16 necessary, adequate interventions may be applied to individuals with negative mood during  
17 the decision-making process regarding life-sustaining treatment.  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28

29  
30 Our participants, the caregivers, were individuals with family members with cognitive  
31 impairment. Our results might serve as a reference for issues of advance directives and life-  
32 sustaining treatment for individuals who care for old or cognitively impaired patients.  
33 Furthermore, our findings may help design future studies on this issue in caregivers engaged  
34 in long-term care work for patients with chronic or deteriorating diseases.  
35  
36  
37  
38  
39  
40

41  
42  
43 There are some limitations to this study. First, our study has a relatively small number of  
44 participants. This may limit the generalizability of our results. Second, we only included  
45 individuals with family members with cognitive impairment. Further studies including  
46 various other groups such as the general public, caregivers of patients with other diseases,  
47 patients with cognitive impairment, physicians, and cancer patients may represent more  
48 informative results. Third, we did not investigate the severity or diagnosis of cognitive  
49 impairment, which can be associated with degree of distress as a family member. Inclusion  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 of these factors may help assess the associations between preference for life-sustaining  
4 treatment and distress as a family member. Fourth, our study used a cross-sectional design.  
5  
6 However, the preference for life-sustaining treatment can change over time. Gallo et al.<sup>40</sup>  
7  
8 also reported that periodic reassessment for planning end-of-life care was needed in their  
9  
10 12-year follow-up study. Fifth, absolute differences in the scores of scales between the two  
11  
12 groups were relatively small, although statistically significant. For this reason, there may be  
13  
14 limitations to the clinical significance of the results of this study. We believe that further  
15  
16 study including patients with psychiatric problems, such as depression and anxiety, can help  
17  
18 derive more clinical meaning. Sixth, this study presented specific options for each question  
19  
20 regarding life-sustaining treatment. This may be convenient for the participant, but there is  
21  
22 a possibility that the participant's intention was not sufficiently reflected. Finally, our  
23  
24 questionnaire consisted of only self-report items. Though we provided descriptions of the  
25  
26 meanings of the terms, using various methods such as clinician-report scales and interviews  
27  
28 can help avoid misunderstandings of the terms and ensure a more effective survey.  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39

## 40 CONCLUSION

41  
42  
43 This study showed the thoughts and associated factors regarding life-sustaining treatment of  
44  
45 individuals with family members with cognitive impairment. Our participants tended to  
46  
47 want to not receive life-sustaining treatment and to agree with assisted suicide. In deciding  
48  
49 to not receive life-sustaining treatment, chance of survival and physical/mental distress were  
50  
51 the important issues. Thirty-two point seven percent of participants responded that terminal  
52  
53 status was an optimal time to decide whether to receive life-sustaining treatment. However,  
54  
55 many more participants want to decide this issue earlier. Among sociodemographic and  
56  
57  
58  
59  
60

1  
2  
3 psychosocial factors, higher levels of education, depression, and anxiety and lower levels of  
4 family support were associated with the decision to not receive life-sustaining treatment.  
5  
6 Our findings can help assess issues regarding advance directives and life-sustaining  
7  
8 treatment in individuals who care for old or cognitively impaired patients.  
9  
10  
11  
12  
13  
14

15 **Contributors** HCY, SYL and HGJ designed and drafted the manuscript. HCY contributed  
16 to acquisition of data. HCY and SYL analyzed and interpreted the data. HYJ and SGK  
17 contributed to interpretation. All authors critically revised the manuscript and gave final  
18 approval.  
19  
20  
21  
22  
23  
24  
25  
26

27 **Funding** This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.  
28  
29 Grant number: N/A  
30  
31  
32  
33

34 **Disclaimer** The funders had no role in planning or conducting the study.  
35  
36  
37  
38

39 **Competing interests** The authors declare no conflicts of interest.  
40  
41  
42

43 **Patient and public involvement** Patients or the public were not involved in the design, or  
44 conduct, or reporting, or dissemination plans of our research.  
45  
46  
47  
48  
49

50 **Patient consent for publication** Not required.  
51  
52  
53

54 **Data availability statement** The data that support the findings of this study are available  
55 on request from the corresponding author  
56  
57  
58  
59  
60

## 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.

- 1  
2  
3 *Support Care Cancer* 2013;21:1437-44.
- 4  
5  
6 30. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care  
7  
8 interventions (active pain control, withdrawal of futile life-sustaining treatment,  
9  
10 passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred  
11  
12 cross-sectional survey of Korean patients with cancer, their family caregivers,  
13  
14 physicians and the general Korean population. *BMJ Open* 2018;8:e020519.
- 15  
16  
17 31. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia  
18  
19 and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*  
20  
21 2000;284:2460-8.
- 22  
23  
24 32. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*  
25  
26 *sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.
- 27  
28  
29 33. Minkoff K, Bergman E, Beck AT, *et al.* Hopelessness, depression, and attempted  
30  
31 suicide. *Am J Psychiatry* 1973;130:455-9.
- 32  
33  
34 34. Beck AT, Brown G, Berchick RJ, *et al.* Relationship between hopelessness and  
35  
36 ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry*  
37  
38 1990;147:190-5.
- 39  
40  
41 35. Beck AT, Steer RA, Kovacs M, *et al.* Hopelessness and eventual suicide: a 10-year  
42  
43 prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry*  
44  
45 1985;142:559-63.
- 46  
47  
48 36. Wen FH, Chen JS, Chou WC, *et al.* Factors Predisposing Terminally Ill Cancer  
49  
50 Patients' Preferences for Distinct Patterns/States of Life-Sustaining Treatments Over  
51  
52 Their Last Six Months. *J Pain Symptom Manage* 2019;57:190-8 e2.
- 53  
54  
55 37. Kim HS, Shin SR. The influence of social support among community dwelling elderly  
56  
57 and their attitude towards the withdrawal of life-sustaining treatment: A mediating  
58  
59  
60

- 1  
2  
3 effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.  
4  
5  
6 38. Choi JJ, Kim SH, Kim SW. Reversals in Decisions about Life-Sustaining Treatment  
7 and Associated Factors among Older Patients with Terminal Stage of Cardiopulmonary  
8 Disease. *J Korean Acad Nurs* 2019;49:329.  
9  
10  
11  
12 39. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-  
13 sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.  
14  
15  
16  
17 40. Gallo JJ, Abshire M, Hwang S, *et al.* Advance Directives, Medical Conditions, and  
18 Preferences for End-of-Life Care Among Physicians: 12-year Follow-Up of the Johns  
19 Hopkins Precursors Study. *J Pain Symptom Manage* 2019;57:556-65.  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4 Verbatim translation of the scenario and description of the terms  
5  
6  
7  
8  
9

10 \* It is well known that about one-third of the population of South Korea will develop cancer  
11 during their lifetime. This questionnaire is conducted under the assumption that "if you have  
12 cancer (especially stage 4)".  
13  
14  
15  
16

17  
18  
19  
20  
21 \* "Terminal state" is defined as a condition in which treatments for the purpose of life extension  
22 are not applicable to patients.  
23  
24  
25

26  
27  
28  
29 \* "Life-sustaining treatment" is any treatment that serves to prolong life without reversing the  
30 underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical  
31 ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant  
32 legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in  
33 advance.  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

Section/Topic	Item #	Recommendation	Reported on page #
<b>Title and abstract</b>	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
<b>Introduction</b>			
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
<b>Methods</b>			
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
<b>Results</b>			

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	-
<b>Discussion</b>			
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
<b>Other information</b>			
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](http://www.strobe-statement.org).

# BMJ Open

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

Journal:	<i>BMJ Open</i>
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,
<b>Primary Subject Heading</b>:	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

SCHOLARONE™  
Manuscripts



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.



1  
2  
3 **Preferences for life-sustaining treatment in Korean adults: a cross sectional**  
4  
5  
6 **study**  
7  
8  
9

10  
11 **HyunChul Youn,<sup>1</sup> Suk-young Lee,<sup>2</sup> Han-yong Jung,<sup>1</sup> Shin-Gyeom Kim,<sup>1</sup> Hyun-Ghang**  
12  
13 **Jeong<sup>3,4</sup>**  
14  
15

16  
17  
18 <sup>1</sup>Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic  
19  
20 of Korea  
21

22 <sup>2</sup>Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine,  
23  
24 Wonkwang University, Gunpo, Republic of Korea  
25

26  
27 <sup>3</sup>Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
28  
29 Medicine, Seoul, Republic of Korea  
30

31 <sup>4</sup>Korea University Research Institute of Mental Health, Seoul, Republic of Korea  
32  
33

34  
35  
36 **Correspondence to**  
37

38 Dr Hyun-Ghang Jeong;  
39

40 Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
41  
42 Medicine,  
43

44  
45 148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;  
46

47 E-mail: jeonghg@korea.ac.kr  
48  
49

50  
51  
52 **Word count:** 2,772 words  
53  
54

55  
56  
57 **ORCID iDs**  
58  
59  
60

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>

For peer review only

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 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.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

For peer review only

## 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.<sup>1</sup> In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.<sup>1</sup> Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.<sup>2</sup> At this time, the Patient Self-Determination Act was first formalized in United States.<sup>3</sup> 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.<sup>1</sup> 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".<sup>2</sup>

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.<sup>4</sup> Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.<sup>4</sup> 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<sup>4</sup> 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.<sup>3 5-8</sup> 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

1  
2  
3 intention.<sup>9</sup>  
4

5 In this study, we focused on the thoughts regarding life-sustaining treatment of Korean  
6 individuals. We believe that our survey may help assess issues surrounding advance directives  
7 and life-sustaining treatment in individuals in the early stages of implementation of the advance  
8 directives system. In addition, medical illnesses that may be related to fatal conditions can also  
9 be comorbid with negative mood.<sup>10-13</sup> That is, one can experience depression or anxiety at the  
10 moment one signs one's own advance directive or decides whether to receive life-sustaining  
11 treatment. This study may be additionally helpful in assessing the possibility that negative  
12 mood affects the decision regarding life-sustaining treatment.  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24

25 The aim of this study was to investigate the thoughts regarding life-sustaining treatment of  
26 Koreans and to assess factors, especially negative mood, associated with not receiving life-  
27 sustaining treatment.  
28  
29  
30  
31  
32  
33  
34  
35

## 36 **METHODS**

### 37 **Participants and procedure**

38  
39  
40 A total of 152 Korean individuals were participated in this study. We recruited family members  
41 of visitors in Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited  
42 170 individuals, but 18 people declined to participate in this study because they were not  
43 interested in the issue of the research. Participants with a history of serious disease such as  
44 cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study.  
45 After some instructions were provided, participants filled out a survey on the spot. It took about  
46 20 to 30 minutes to complete the questionnaires. Participants answered the questions  
47 anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 life-sustaining treatment) and were, therefore, excluded. The necessary ethical permissions  
4 were received from the Institutional Review Board at Korea University Guro Hospital prior to  
5 the initiation of the research (2018GR0151). Before completing the questionnaires, participants  
6 were informed about the study protocol and gave their written informed consent.  
7  
8  
9  
10  
11  
12  
13  
14  
15

## 16 **Measures**

17  
18  
19 All questionnaires were in self-report format. The questionnaire consisted of three parts. The  
20 first part contained items assessing the following demographic characteristics: age, gender,  
21 education, marital status, housing status, occupational status, religion, and monthly income.  
22  
23  
24  
25  
26

27 In the second part, participants answered questions regarding their thoughts on life-  
28 sustaining treatment. We provided a description of the terms used in the questionnaire before  
29 the second part to avoid confusion (suppl 1). For example, “terminal state” is defined as a  
30 condition in which treatments for the purpose of life extension are not applicable to patients.  
31 We adopted “cancer” as the example to help participants understand life-sustaining treatment  
32 better, because many South Koreans regard cancer as most worrying disease.<sup>14</sup>  
33  
34  
35  
36  
37  
38  
39

40 The third part included the psychosocial items. We adopted the Generalized Anxiety  
41 Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression,  
42 respectively.<sup>15</sup> A higher score on these scales indicates a higher possibility of having anxiety  
43 or depressive symptoms. These scales have been translated into Korean, and their reliability  
44 and validity have been confirmed.<sup>16 17</sup> The Connor–Davidson Resilience Scale (CD-RISC) was  
45 used to assess the degree of resilience.<sup>18</sup> This scale contains 25 items scored in a five-point  
46 response format, and the total score ranges from zero to 100, where higher scores reflect greater  
47 resilience. We used the Korean version of the CD-RISC, which has been found to be reliable  
48 and valid.<sup>19</sup> We included the Multidimensional Scale of Perceived Social Support (MSPSS) to  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 evaluate the perceived social support of family, friends, and significant others.<sup>20</sup> The MSPSS  
4 contains four items that are rated on a seven-point scale ranging from *very strongly disagree*<sup>1</sup>  
5  
6 to *very strongly agree*.<sup>7</sup> We adopted the Korean version of MSPSS.<sup>21</sup>  
7  
8  
9  
10  
11  
12

### 13 **Statistical analysis**

14  
15  
16 Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous  
17 variables and percentages for categorical variables). Differences between the IRLT and INLT  
18 groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial  
19 scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used  
20 independent *t*-tests for continuous variables and  $\chi^2$  tests or Fisher's exact test for categorical  
21 variables.  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34

## 35 **RESULTS**

36  
37  
38 According to the answer of the question "Do you want to receive life-sustaining treatment?"  
39 we classified our participants into two groups: individuals who wanted to receive life-  
40 sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining  
41 treatment (INLT). Among the 150 participants, the IRLT and INLT groups comprised 50 and  
42  
43 100 participants, respectively. Table 1 shows the basic characteristics of the IRLT and INLT  
44 groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female.  
45  
46  
47  
48 The participants with college-level education or higher were significantly more numerous in  
49 the INLT group than in the IRLT group.  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**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 <sup>†</sup>
≤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  $\chi^2$  test or Fisher's exact test and independent *t*-test.

<sup>†</sup>p<0.05.

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

1  
2  
3 We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table  
4  
5 2). The IRLT group focused more on the chance of survival, while the INLT group was more  
6  
7 concerned about physical and mental distress.  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

1 **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%)) Physical distress (29 (19.3%)) Mental distress (13 (8.7%)) Other responses (religious belief, treatment cost)	Chance of survival (38 (76.0%)) Physical distress (3 (6.0%)) Religious belief (3 (6.0%)) Other responses (mental distress, treatment cost)	Chance of survival (43 (43.0%)) Physical distress (26 (26.0%)) Mental distress (12 (12.0%)) Other responses (religious belief, treatment cost)	0.001 <sup>†</sup>
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 (42 (28.0%)) Immediately after diagnosis of any cancer regardless of stage (37 (24.7%)) Other responses (when to start chemotherapy, during chemotherapy)	Immediately after diagnosis of metastatic cancer (19 (38.0%)) Immediately after diagnosis of any cancer regardless of stage (13 (26.0%)) Terminal state (12 (24.0%)) Other responses (when to start chemotherapy, during chemotherapy)	Terminal state (37 (37.0%)) Immediately after diagnosis of any cancer regardless of stage (24 (24.0%)) Immediately after diagnosis of metastatic cancer (23 (23.0%)) Other responses (when to start chemotherapy, during chemotherapy)	0.458

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

3 <sup>†</sup>p<0.01.

4 <sup>‡</sup>p<0.05.

5 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 <sup>†</sup>
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048 <sup>†</sup>
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 <sup>†</sup>
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.

<sup>†</sup>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,

1  
2  
3 individuals who wanted to not receive life-sustaining treatment.  
4  
5  
6  
7  
8  
9

## 10 **DISCUSSION**

11  
12  
13 In our study, there were twice as many participants in the INLT group compared to those in  
14 the IRLT group, who responded that they do not want to receive life-sustaining treatment.  
15  
16 Chance of survival was the most important issue in both groups in deciding whether or not  
17 to receive life-sustaining treatment, but the INLT group focused more on physical and  
18 mental distress. The timing preference order was terminal state, immediately after diagnosis  
19 of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in  
20 deciding whether to receive life-sustaining treatment. In addition, participants with higher  
21 education levels tended to be more common in the INLT group. On the psychosocial scales,  
22 the INLT group represented higher levels of depression/anxiety and lower level of perceived  
23 family support than the IRLT group.  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36

37 Most prior studies have reported that the majority of people do not want aggressive  
38 treatment in their terminal state.<sup>3 5-8</sup> Our results were consistent with these previous studies.  
39  
40 In addition, the INLT group rated physical and mental distress highly in deciding their  
41 preference for life-sustaining treatment than the IRLT group in this study. According to  
42 previous reports, many people want hospice care and a more comfortable process of dying  
43 such as dying in their sleep.<sup>6 22 23</sup> Some studies have even shown that cancer pain was  
44 associated with a desire for hastened death.<sup>24 25</sup> Therefore, we speculate that avoidance of  
45 unwanted distress may account for the preference for not receiving life-sustaining treatment.  
46  
47 These findings may emphasize the importance of advance directives. A previous study  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 reported a tendency to receive more life-sustaining treatment when patients' intention for  
4 life-sustaining treatment was unclear.<sup>9</sup> Accordingly, more publicity regarding actively  
5 participating in registering one's advance directives to National Agency for Management of  
6 Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.  
7  
8  
9  
10  
11  
12

13 In total, 32.7% of the participants in our study regarded terminal status as an optimal time  
14 to decide whether to receive life-sustaining treatment. However, more participants want to  
15 decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer  
16 regardless of stage. There have been few previous studies with this result. However, Keam  
17 et al.<sup>26</sup> mentioned that people may regard the decision for life-sustaining treatment as a will  
18 that embodies values about end-of life. We also believe that people may want to make  
19 decisions regarding the last moments of their own life, such as by signing advance directives,  
20 while they are relatively healthy and physically/mentally intact to preserve their dignity and  
21 worth as human beings. However, in determining whether to receive life-sustaining  
22 treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of  
23 stage," it may be important to take into account the possibility that patients are under stress  
24 at that time. We speculate that many participants might want to decide upon the last moments  
25 of their own life earlier than our existing options. For an example, many people would rather  
26 prefer to make their decision in a physically and mentally healthy state, uninfluenced by  
27 disease or pain. Although we asked the participants to write down other optimal timings  
28 directly, most participants opted for one of the existing options. Further studies are needed  
29 to clarify this issue.  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52

53 Among sociodemographic factors, education level was the factor that showed significant  
54 differences between the IRLT and INLT groups. That is, participants with higher education  
55  
56  
57  
58  
59  
60

1  
2  
3 levels tended to prefer to not receive life-sustaining treatment in this study. Some previous  
4 studies analyzed the association between education level and life-sustaining treatment, but  
5 the results were controversial.<sup>8 27 28</sup> On the other hand, various studies have reported that  
6 individuals with higher education levels had greater interest in advance directives and a  
7 stronger tendency to complete them beforehand.<sup>6 7 26</sup> However, there have been few  
8 comments on the causes of this association.<sup>6 7 26</sup> Though more studies are needed to clarify  
9 our results, we speculate that a tendency toward introspection and accessibility of  
10 information may account for the association between education level and preference for life-  
11 sustaining treatment or advance directives. Our findings may emphasize the necessity of  
12 broader publicity and explanations of advance directives for life-sustaining treatment.  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26

27 In addition, the INLT group showed higher levels of depression and anxiety than the  
28 IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness,  
29 frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic  
30 problems including pain.<sup>29</sup> We believe that these symptoms can affect the decision for life-  
31 sustaining treatment. For example, as hopelessness is associated with suicide,<sup>30-32</sup> cancer  
32 patients who have feelings of hopelessness might wish to hasten death. In addition, previous  
33 studies reported that cancer pain was related to a desire for hastened death.<sup>24 25</sup> Therefore,  
34 we speculate that depressive patients with somatic problems such as pain aggravation might  
35 change their minds to select a peaceful death. Similar to our results, Wen et al.<sup>33</sup> reported  
36 that cancer patients with depressive symptoms were more likely to be in the comfort-  
37 preferring state in terms of preference for life-sustaining treatment. Our findings suggest that  
38 a consideration of depressive and anxiety symptoms may be needed in determining whether  
39 or not one receives life-sustaining treatment. For example, clinicians may consider  
40 recommending the patient to delay making a decision on life-sustaining treatment if a  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 patient's depressive or anxiety symptoms are believed to be temporary. According to the  
4 patient's condition, treatment for depression or anxiety symptoms may be provided to the  
5 patient before they make a decision. Our findings may be particularly meaningful because  
6 many patients with severe physical illness suffer from depression or anxiety.<sup>10-13</sup> Future  
7 research that can clarify any causal relationship may help verify and advance our results.  
8  
9

10  
11  
12  
13  
14  
15  
16 Furthermore, participants who felt relatively well-supported by their family members  
17 tended to prefer to receive life-sustaining treatment. However, the results of other studies  
18 differ from ours, though a consensus does not have been previously reached. Kim and Shin  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
61  
62  
63  
64  
65  
66  
67  
68  
69  
70  
71  
72  
73  
74  
75  
76  
77  
78  
79  
80  
81  
82  
83  
84  
85  
86  
87  
88  
89  
90  
91  
92  
93  
94  
95  
96  
97  
98  
99  
100  
101  
102  
103  
104  
105  
106  
107  
108  
109  
110  
111  
112  
113  
114  
115  
116  
117  
118  
119  
120  
121  
122  
123  
124  
125  
126  
127  
128  
129  
130  
131  
132  
133  
134  
135  
136  
137  
138  
139  
140  
141  
142  
143  
144  
145  
146  
147  
148  
149  
150  
151  
152  
153  
154  
155  
156  
157  
158  
159  
160  
161  
162  
163  
164  
165  
166  
167  
168  
169  
170  
171  
172  
173  
174  
175  
176  
177  
178  
179  
180  
181  
182  
183  
184  
185  
186  
187  
188  
189  
190  
191  
192  
193  
194  
195  
196  
197  
198  
199  
200  
201  
202  
203  
204  
205  
206  
207  
208  
209  
210  
211  
212  
213  
214  
215  
216  
217  
218  
219  
220  
221  
222  
223  
224  
225  
226  
227  
228  
229  
230  
231  
232  
233  
234  
235  
236  
237  
238  
239  
240  
241  
242  
243  
244  
245  
246  
247  
248  
249  
250  
251  
252  
253  
254  
255  
256  
257  
258  
259  
260  
261  
262  
263  
264  
265  
266  
267  
268  
269  
270  
271  
272  
273  
274  
275  
276  
277  
278  
279  
280  
281  
282  
283  
284  
285  
286  
287  
288  
289  
290  
291  
292  
293  
294  
295  
296  
297  
298  
299  
300  
301  
302  
303  
304  
305  
306  
307  
308  
309  
310  
311  
312  
313  
314  
315  
316  
317  
318  
319  
320  
321  
322  
323  
324  
325  
326  
327  
328  
329  
330  
331  
332  
333  
334  
335  
336  
337  
338  
339  
340  
341  
342  
343  
344  
345  
346  
347  
348  
349  
350  
351  
352  
353  
354  
355  
356  
357  
358  
359  
360  
361  
362  
363  
364  
365  
366  
367  
368  
369  
370  
371  
372  
373  
374  
375  
376  
377  
378  
379  
380  
381  
382  
383  
384  
385  
386  
387  
388  
389  
390  
391  
392  
393  
394  
395  
396  
397  
398  
399  
400  
401  
402  
403  
404  
405  
406  
407  
408  
409  
410  
411  
412  
413  
414  
415  
416  
417  
418  
419  
420  
421  
422  
423  
424  
425  
426  
427  
428  
429  
430  
431  
432  
433  
434  
435  
436  
437  
438  
439  
440  
441  
442  
443  
444  
445  
446  
447  
448  
449  
450  
451  
452  
453  
454  
455  
456  
457  
458  
459  
460  
461  
462  
463  
464  
465  
466  
467  
468  
469  
470  
471  
472  
473  
474  
475  
476  
477  
478  
479  
480  
481  
482  
483  
484  
485  
486  
487  
488  
489  
490  
491  
492  
493  
494  
495  
496  
497  
498  
499  
500  
501  
502  
503  
504  
505  
506  
507  
508  
509  
510  
511  
512  
513  
514  
515  
516  
517  
518  
519  
520  
521  
522  
523  
524  
525  
526  
527  
528  
529  
530  
531  
532  
533  
534  
535  
536  
537  
538  
539  
540  
541  
542  
543  
544  
545  
546  
547  
548  
549  
550  
551  
552  
553  
554  
555  
556  
557  
558  
559  
560  
561  
562  
563  
564  
565  
566  
567  
568  
569  
570  
571  
572  
573  
574  
575  
576  
577  
578  
579  
580  
581  
582  
583  
584  
585  
586  
587  
588  
589  
590  
591  
592  
593  
594  
595  
596  
597  
598  
599  
600  
601  
602  
603  
604  
605  
606  
607  
608  
609  
610  
611  
612  
613  
614  
615  
616  
617  
618  
619  
620  
621  
622  
623  
624  
625  
626  
627  
628  
629  
630  
631  
632  
633  
634  
635  
636  
637  
638  
639  
640  
641  
642  
643  
644  
645  
646  
647  
648  
649  
650  
651  
652  
653  
654  
655  
656  
657  
658  
659  
660  
661  
662  
663  
664  
665  
666  
667  
668  
669  
670  
671  
672  
673  
674  
675  
676  
677  
678  
679  
680  
681  
682  
683  
684  
685  
686  
687  
688  
689  
690  
691  
692  
693  
694  
695  
696  
697  
698  
699  
700  
701  
702  
703  
704  
705  
706  
707  
708  
709  
710  
711  
712  
713  
714  
715  
716  
717  
718  
719  
720  
721  
722  
723  
724  
725  
726  
727  
728  
729  
730  
731  
732  
733  
734  
735  
736  
737  
738  
739  
740  
741  
742  
743  
744  
745  
746  
747  
748  
749  
750  
751  
752  
753  
754  
755  
756  
757  
758  
759  
760  
761  
762  
763  
764  
765  
766  
767  
768  
769  
770  
771  
772  
773  
774  
775  
776  
777  
778  
779  
780  
781  
782  
783  
784  
785  
786  
787  
788  
789  
790  
791  
792  
793  
794  
795  
796  
797  
798  
799  
800  
801  
802  
803  
804  
805  
806  
807  
808  
809  
810  
811  
812  
813  
814  
815  
816  
817  
818  
819  
820  
821  
822  
823  
824  
825  
826  
827  
828  
829  
830  
831  
832  
833  
834  
835  
836  
837  
838  
839  
840  
841  
842  
843  
844  
845  
846  
847  
848  
849  
850  
851  
852  
853  
854  
855  
856  
857  
858  
859  
860  
861  
862  
863  
864  
865  
866  
867  
868  
869  
870  
871  
872  
873  
874  
875  
876  
877  
878  
879  
880  
881  
882  
883  
884  
885  
886  
887  
888  
889  
890  
891  
892  
893  
894  
895  
896  
897  
898  
899  
900  
901  
902  
903  
904  
905  
906  
907  
908  
909  
910  
911  
912  
913  
914  
915  
916  
917  
918  
919  
920  
921  
922  
923  
924  
925  
926  
927  
928  
929  
930  
931  
932  
933  
934  
935  
936  
937  
938  
939  
940  
941  
942  
943  
944  
945  
946  
947  
948  
949  
950  
951  
952  
953  
954  
955  
956  
957  
958  
959  
960  
961  
962  
963  
964  
965  
966  
967  
968  
969  
970  
971  
972  
973  
974  
975  
976  
977  
978  
979  
980  
981  
982  
983  
984  
985  
986  
987  
988  
989  
990  
991  
992  
993  
994  
995  
996  
997  
998  
999  
1000

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<sup>34</sup> reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al.<sup>35</sup> 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<sup>36</sup> 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.

1  
2  
3 In this study, we investigated the preference for life-sustaining treatment and factors  
4 associated with the decision in Koreans. The thoughts regarding life-sustaining treatment of  
5 our participants were generally consistent with previous reports on life-sustaining treatment.  
6  
7 Depressive and anxiety symptoms may have an effect on this issue. According to our  
8 findings, if necessary, adequate interventions may be applied to individuals with negative  
9 mood during the decision-making process regarding life-sustaining treatment.  
10  
11  
12  
13  
14  
15  
16  
17

18 There are some limitations to this study. First, our study has a relatively small number of  
19 participants. This may limit the generalizability of our results. Second, our participants are  
20 the family members of visitors in Guro-gu center for dementia. Therefore, specific  
21 characteristics of our participants such as caregiver distress can affect our results. Though  
22 these may be more helpful to a specific group such as individuals with family members with  
23 cognitive impairment, further studies including various other groups such as the general  
24 public, caregivers of patients with other diseases, patients with cognitive impairment,  
25 physicians, and cancer patients may represent more informative results. Third, our study  
26 used a cross-sectional design. However, the preference for life-sustaining treatment can  
27 change over time. Gallo et al.<sup>37</sup> also reported that periodic reassessment for planning end-  
28 of-life care was needed in their 12-year follow-up study. Fourth, absolute differences in the  
29 scores of scales between the two groups were relatively small, although statistically  
30 significant. For this reason, there may be limitations to the clinical significance of the results  
31 of this study. We believe that further study including patients with psychiatric problems,  
32 such as depression and anxiety, can help derive more clinical meaning. Fifth, this study  
33 presented specific options for each question regarding life-sustaining treatment. This may  
34 be convenient for the participant, but there is a possibility that the participant's intention was  
35 not sufficiently reflected. Finally, our questionnaire consisted of only self-report items.  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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.

1  
2  
3 **Funding** This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.  
4  
5  
6  
7

8 **Disclaimer** The funders had no role in planning or conducting the study.  
9  
10  
11

12 **Competing interests** The authors declare no conflicts of interest.  
13  
14  
15  
16

17 **Patient and public involvement** Patients or the public were not involved in the design, or  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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. Pasma 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

- 1  
2  
3 normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr*  
4 *Epidemiol* 1995;30:121-6.  
5  
6  
7  
8 21. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the  
9 unemployed. *Korean J Soc Welf* 1999;37:241-69.  
10  
11  
12 22. Kim S, Koh S, Park K, *et al.* End-of-life care decisions using a Korean advance  
13 directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.  
14  
15  
16 23. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among  
17 community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.  
18  
19  
20 24. Chochinov HM, Wilson KG, Enns M, *et al.* Desire for death in the terminally ill. *Am J*  
21 *Psychiatry* 1995;152:1185-91.  
22  
23  
24 25. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression.  
25  
26 *Postgrad Med* 1989;85:263-6, 8, 70.  
27  
28  
29 26. Keam B, Yun YH, Heo DS, *et al.* The attitudes of Korean cancer patients, family  
30 caregivers, oncologists, and members of the general public toward advance directives.  
31  
32 *Support Care Cancer* 2013;21:1437-44.  
33  
34  
35 27. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care  
36 interventions (active pain control, withdrawal of futile life-sustaining treatment,  
37 passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred  
38 cross-sectional survey of Korean patients with cancer, their family caregivers,  
39 physicians and the general Korean population. *BMJ Open* 2018;8:e020519.  
40  
41  
42 28. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia  
43 and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*  
44 2000;284:2460-8.  
45  
46  
47 29. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 *sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.  
4  
5  
6 30. Minkoff K, Bergman E, Beck AT, *et al*. Hopelessness, depression, and attempted  
7  
8 suicide. *Am J Psychiatry* 1973;130:455-9.  
9  
10  
11 31. Beck AT, Brown G, Berchick RJ, *et al*. Relationship between hopelessness and  
12  
13 ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry*  
14  
15 1990;147:190-5.  
16  
17 32. Beck AT, Steer RA, Kovacs M, *et al*. Hopelessness and eventual suicide: a 10-year  
18  
19 prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry*  
20  
21 1985;142:559-63.  
22  
23  
24 33. Wen FH, Chen JS, Chou WC, *et al*. Factors predisposing terminally ill cancer patients'  
25  
26 preferences for distinct patterns/states of life-sustaining treatments over their last six  
27  
28 months. *J Pain Symptom Manage* 2019;57:190-8.e2.  
29  
30  
31 34. Kim HS, Shin SR. The influence of social support among community dwelling elderly  
32  
33 and their attitude towards the withdrawal of life-sustaining treatment: A mediating  
34  
35 effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.  
36  
37  
38 35. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and  
39  
40 associated factors among older patients with terminal stage of cardiopulmonary disease.  
41  
42 *J Korean Acad Nurs* 2019;49:329-39.  
43  
44  
45 36. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-  
46  
47 sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.  
48  
49  
50 37. Gallo JJ, Abshire M, Hwang S, *et al*. Advance directives, medical conditions, and  
51  
52 preferences for end-of-life care among physicians: 12-year follow-up of the Johns  
53  
54 Hopkins precursors study. *J Pain Symptom Manage* 2019;57:556-65.  
55  
56  
57  
58  
59  
60



1  
2  
3  
4 Verbatim translation of the scenario and description of the terms  
5  
6  
7  
8  
9

10 \* It is well known that about one-third of the population of South Korea will develop cancer  
11 during their lifetime. This questionnaire is conducted under the assumption that "if you have  
12 cancer (especially stage 4)".  
13  
14  
15  
16

17  
18  
19  
20  
21 \* "Terminal state" is defined as a condition in which treatments for the purpose of life extension  
22 are not applicable to patients.  
23  
24  
25

26  
27  
28  
29 \* "Life-sustaining treatment" is any treatment that serves to prolong life without reversing the  
30 underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical  
31 ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant  
32 legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in  
33 advance.  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

Section/Topic	Item #	Recommendation	Reported on page #
<b>Title and abstract</b>	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
<b>Introduction</b>			
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
<b>Methods</b>			
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
<b>Results</b>			

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	-
<b>Discussion</b>			
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
<b>Other information</b>			
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](http://www.strobe-statement.org).

# BMJ Open

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

Journal:	<i>BMJ Open</i>
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,
<b>Primary Subject Heading</b>:	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

SCHOLARONE™  
Manuscripts



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.

1  
2  
3 **Preferences for life-sustaining treatment in Korean adults: a cross sectional**  
4  
5  
6 **study**  
7  
8  
9

10  
11 **HyunChul Youn,<sup>1</sup> Suk-young Lee,<sup>2</sup> Han-yong Jung,<sup>1</sup> Shin-Gyeom Kim,<sup>1</sup> Hyun-Ghang**  
12  
13 **Jeong<sup>3,4</sup>**  
14  
15

16  
17  
18 <sup>1</sup>Department of Psychiatry, Soonchunhyang University Bucheon Hospital, Bucheon, Republic  
19  
20 of Korea  
21

22 <sup>2</sup>Division of Hemato-Oncology, Department of Internal Medicine, School of Medicine,  
23  
24 Wonkwang University, Gunpo, Republic of Korea  
25

26  
27 <sup>3</sup>Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
28  
29 Medicine, Seoul, Republic of Korea  
30

31 <sup>4</sup>Korea University Research Institute of Mental Health, Seoul, Republic of Korea  
32  
33

34  
35  
36 **Correspondence to**  
37

38 Dr Hyun-Ghang Jeong;  
39

40 Department of Psychiatry, Korea University Guro Hospital, Korea University College of  
41  
42 Medicine,  
43

44  
45 148 Gurodong-ro, Guro-gu, Seoul 08308, Republic of Korea;  
46

47 E-mail: jeonghg@korea.ac.kr  
48  
49

50  
51  
52 **Word count:** 2,779 words  
53  
54

55  
56  
57 **ORCID iDs**  
58  
59  
60

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>

For peer review only

## 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-



1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

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

For peer review only

## 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.<sup>1</sup> In this respect, there has been much discussion of the right to decide one's own life at the last moment of life.<sup>1</sup> Landmark legal decisions on severely injured individuals seeking relief from persistent vegetative states were made in the United States starting around 1990.<sup>2</sup> At this time, the Patient Self-Determination Act was first formalized in United States.<sup>3</sup> 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.<sup>1</sup> 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".<sup>2</sup>

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.<sup>4</sup> Of these people, 859 individuals died without life-sustaining treatment according to their advance directives.<sup>4</sup> 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<sup>4</sup> 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.<sup>3 5-8</sup> 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

1  
2  
3 intention.<sup>9</sup>  
4

5 In this study, we focused on the thoughts regarding life-sustaining treatment of Korean  
6 individuals. We believe that our survey may help assess issues surrounding advance directives  
7 and life-sustaining treatment in individuals in the early stages of implementation of the advance  
8 directives system. In addition, medical illnesses that may be related to fatal conditions can also  
9 be comorbid with negative mood.<sup>10-13</sup> That is, one can experience depression or anxiety at the  
10 moment one signs one's own advance directive or decides whether to receive life-sustaining  
11 treatment. This study may be additionally helpful in assessing the possibility that negative  
12 mood affects the decision regarding life-sustaining treatment.  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24

25 The aim of this study was to investigate the thoughts regarding life-sustaining treatment of  
26 Koreans and to assess factors, especially negative mood, associated with not receiving life-  
27 sustaining treatment if they develop a terminal disease.  
28  
29  
30  
31  
32  
33  
34  
35

## 36 **METHODS**

### 37 **Participants and procedure**

38  
39  
40 A total of 152 Korean individuals were participated in this study. We recruited family members  
41 of visitors in Guro-gu center for dementia from 1 May 2018 to 31 December 2019. We invited  
42 170 individuals, but 18 people declined to participate in this study because they were not  
43 interested in the issue of the research. Participants with a history of serious disease such as  
44 cancer, myocardial infarction, and cerebrovascular diseases were excluded from the study.  
45  
46 After some instructions were provided, participants filled out a survey on the spot. It took about  
47 20 to 30 minutes to complete the questionnaires. Participants answered the questions  
48 anonymously. Of the 152 initial participants, 2 had missing core questions (for thoughts on  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 life-sustaining treatment) and were, therefore, excluded. The necessary ethical permissions  
4 were received from the Institutional Review Board at Korea University Guro Hospital prior to  
5 the initiation of the research (2018GR0151). Before completing the questionnaires, participants  
6 were informed about the study protocol and gave their written informed consent.  
7  
8  
9  
10  
11  
12  
13  
14  
15

## 16 **Measures**

17  
18  
19 All questionnaires were in self-report format. The questionnaire consisted of three parts. The  
20 first part contained items assessing the following demographic characteristics: age, gender,  
21 education, marital status, housing status, occupational status, religion, and monthly income.  
22  
23  
24  
25  
26

27 In the second part, participants answered questions regarding their thoughts on life-  
28 sustaining treatment. We provided a description of the terms used in the questionnaire before  
29 the second part to avoid confusion (suppl 1). For example, “terminal state” is defined as a  
30 condition in which treatments for the purpose of life extension are not applicable to patients.  
31 We adopted “terminal cancer” as the example to help participants understand life-sustaining  
32 treatment better, because many South Koreans regard cancer as most worrying disease.<sup>14</sup>  
33  
34  
35  
36  
37  
38  
39

40 The third part included the psychosocial items. We adopted the Generalized Anxiety  
41 Disorder (GAD)-7 and Patient Health Questionnaire (PHQ)-9 to assess anxiety and depression,  
42 respectively.<sup>15</sup> A higher score on these scales indicates a higher possibility of having anxiety  
43 or depressive symptoms. These scales have been translated into Korean, and their reliability  
44 and validity have been confirmed.<sup>16 17</sup> The Connor–Davidson Resilience Scale (CD-RISC) was  
45 used to assess the degree of resilience.<sup>18</sup> This scale contains 25 items scored in a five-point  
46 response format, and the total score ranges from zero to 100, where higher scores reflect greater  
47 resilience. We used the Korean version of the CD-RISC, which has been found to be reliable  
48 and valid.<sup>19</sup> We included the Multidimensional Scale of Perceived Social Support (MSPSS) to  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 evaluate the perceived social support of family, friends, and significant others.<sup>20</sup> The MSPSS  
4 contains four items that are rated on a seven-point scale ranging from *very strongly disagree*<sup>1</sup>  
5  
6 to *very strongly agree*.<sup>7</sup> We adopted the Korean version of MSPSS.<sup>21</sup>  
7  
8  
9  
10  
11  
12

### 13 **Statistical analysis**

14  
15  
16 Descriptive statistics were calculated for all variables (i.e., means and SDs for continuous  
17 variables and percentages for categorical variables). Differences between the IRLT and INLT  
18 groups in terms of basic characteristics, thoughts on life-sustaining treatment, and psychosocial  
19 scales were analyzed using PASW Statistics 18.0 (SPSS Inc, Chicago, IL, USA). We used  
20 independent *t*-tests for continuous variables and  $\chi^2$  tests or Fisher's exact test for categorical  
21 variables.  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34

## 35 **RESULTS**

36  
37  
38 According to the answer of the question "Do you want to receive life-sustaining treatment?"  
39 we classified our participants into two groups: individuals who wanted to receive life-  
40 sustaining treatment (IRLT) and individuals who wanted to not receive life-sustaining  
41 treatment (INLT). Among the 150 participants, the IRLT and INLT groups comprised 50 and  
42  
43 100 participants, respectively. Table 1 shows the basic characteristics of the IRLT and INLT  
44 groups. The mean age of participants was 45.38 (SD = 14.71) years, and 56.0% were female.  
45  
46  
47  
48 The participants with college-level education or higher were significantly more numerous in  
49 the INLT group than in the IRLT group.  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**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 <sup>†</sup>
≤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  $\chi^2$  test or Fisher's exact test and independent *t*-test.

<sup>†</sup>p<0.05.

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

1  
2  
3 We compared the thoughts on life-sustaining treatment of the IRLT and INLT groups (Table  
4  
5 2). The IRLT group focused more on the chance of survival, while the INLT group was more  
6  
7 concerned about physical and mental distress.  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only



1 **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%)) Physical distress (29 (19.3%)) Mental distress (13 (8.7%)) Other responses (religious belief, treatment cost)	Chance of survival (38 (76.0%)) Physical distress (3 (6.0%)) Religious belief (3 (6.0%)) Other responses (mental distress, treatment cost)	Chance of survival (43 (43.0%)) Physical distress (26 (26.0%)) Mental distress (12 (12.0%)) Other responses (religious belief, treatment cost)	0.001 <sup>†</sup>
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 (42 (28.0%)) Immediately after diagnosis of any cancer regardless of stage (37 (24.7%)) Other responses (when to start chemotherapy, during chemotherapy)	Immediately after diagnosis of metastatic cancer (19 (38.0%)) Immediately after diagnosis of any cancer regardless of stage (13 (26.0%)) Terminal state (12 (24.0%)) Other responses (when to start chemotherapy, during chemotherapy)	Terminal state (37 (37.0%)) Immediately after diagnosis of any cancer regardless of stage (24 (24.0%)) Immediately after diagnosis of metastatic cancer (23 (23.0%)) Other responses (when to start chemotherapy, during chemotherapy)	0.458

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

3 <sup>†</sup>p<0.01.

4 <sup>‡</sup>p<0.05.

5 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 <sup>†</sup>
PHQ-9	4.99 ± 5.38	3.88 ± 4.25	5.56 ± 5.81	0.048 <sup>†</sup>
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 <sup>†</sup>
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.

<sup>†</sup>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,

1  
2  
3 individuals who wanted to not receive life-sustaining treatment.  
4  
5  
6  
7  
8  
9

## 10 **DISCUSSION**

11  
12  
13 In our study, there were twice as many participants in the INLT group compared to those in  
14 the IRLT group, who responded that they do not want to receive life-sustaining treatment.  
15  
16 Chance of survival was the most important issue in both groups in deciding whether or not  
17 to receive life-sustaining treatment, but the INLT group focused more on physical and  
18 mental distress. The timing preference order was terminal state, immediately after diagnosis  
19 of metastatic cancer, and immediately after diagnosis of any cancer regardless of stage in  
20 deciding whether to receive life-sustaining treatment. In addition, participants with higher  
21 education levels tended to be more common in the INLT group. On the psychosocial scales,  
22 the INLT group represented higher levels of depression/anxiety and lower level of perceived  
23 family support than the IRLT group.  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36

37 Most prior studies have reported that the majority of people do not want aggressive  
38 treatment in their terminal state.<sup>3 5-8</sup> Our results were consistent with these previous studies.  
39  
40 In addition, the INLT group rated physical and mental distress highly in deciding their  
41 preference for life-sustaining treatment than the IRLT group in this study. According to  
42 previous reports, many people want hospice care and a more comfortable process of dying  
43 such as dying in their sleep.<sup>6 22 23</sup> Some studies have even shown that cancer pain was  
44 associated with a desire for hastened death.<sup>24 25</sup> Therefore, we speculate that avoidance of  
45 unwanted distress may account for the preference for not receiving life-sustaining treatment.  
46  
47 These findings may emphasize the importance of advance directives. A previous study  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 reported a tendency to receive more life-sustaining treatment when patients' intention for  
4 life-sustaining treatment was unclear.<sup>9</sup> Accordingly, more publicity regarding actively  
5 participating in registering one's advance directives to National Agency for Management of  
6 Life-Sustaining Treatment may be needed to avoid unwanted life-sustaining treatment.  
7  
8  
9  
10  
11  
12

13 In total, 32.7% of the participants in our study regarded terminal status as an optimal time  
14 to decide whether to receive life-sustaining treatment. However, more participants want to  
15 decide it earlier, such as immediately after a diagnosis of metastatic cancer or any cancer  
16 regardless of stage. There have been few previous studies with this result. However, Keam  
17 et al.<sup>26</sup> mentioned that people may regard the decision for life-sustaining treatment as a will  
18 that embodies values about end-of life. We also believe that people may want to make  
19 decisions regarding the last moments of their own life, such as by signing advance directives,  
20 while they are relatively healthy and physically/mentally intact to preserve their dignity and  
21 worth as human beings. However, in determining whether to receive life-sustaining  
22 treatment at "immediately after a diagnosis of metastatic cancer or any cancer regardless of  
23 stage," it may be important to take into account the possibility that patients are under stress  
24 at that time. We speculate that many participants might want to decide upon the last moments  
25 of their own life earlier than our existing options. For an example, many people would rather  
26 prefer to make their decision in a physically and mentally healthy state, uninfluenced by  
27 disease or pain. Although we asked the participants to write down other optimal timings  
28 directly, most participants opted for one of the existing options. Further studies are needed  
29 to clarify this issue.  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52

53 Among sociodemographic factors, education level was the factor that showed significant  
54 differences between the IRLT and INLT groups. That is, participants with higher education  
55  
56  
57  
58  
59  
60

1  
2  
3 levels tended to prefer to not receive life-sustaining treatment in this study. Some previous  
4 studies analyzed the association between education level and life-sustaining treatment, but  
5 the results were controversial.<sup>8 27 28</sup> On the other hand, various studies have reported that  
6 individuals with higher education levels had greater interest in advance directives and a  
7 stronger tendency to complete them beforehand.<sup>6 7 26</sup> However, there have been few  
8 comments on the causes of this association.<sup>6 7 26</sup> Though more studies are needed to clarify  
9 our results, we speculate that a tendency toward introspection and accessibility of  
10 information may account for the association between education level and preference for life-  
11 sustaining treatment or advance directives. Our findings may emphasize the necessity of  
12 broader publicity and explanations of advance directives for life-sustaining treatment.  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26

27 In addition, the INLT group showed higher levels of depression and anxiety than the  
28 IRLT group. Depressive or anxiety symptoms can be related to hopelessness, worthlessness,  
29 frustration, fatigue, irritability, restlessness, feelings of guilt, loss of interest, and somatic  
30 problems including pain.<sup>29</sup> We believe that these symptoms can affect the decision for life-  
31 sustaining treatment. For example, as hopelessness is associated with suicide,<sup>30-32</sup> cancer  
32 patients who have feelings of hopelessness might wish to hasten death. In addition, previous  
33 studies reported that cancer pain was related to a desire for hastened death.<sup>24 25</sup> Therefore,  
34 we speculate that depressive patients with somatic problems such as pain aggravation might  
35 change their minds to select a peaceful death. Similar to our results, Wen et al.<sup>33</sup> reported  
36 that cancer patients with depressive symptoms were more likely to be in the comfort-  
37 preferring state in terms of preference for life-sustaining treatment. Our findings suggest that  
38 a consideration of depressive and anxiety symptoms may be needed in determining whether  
39 or not one receives life-sustaining treatment. For example, clinicians may consider  
40 recommending the patient to delay making a decision on life-sustaining treatment if a  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 patient's depressive or anxiety symptoms are believed to be temporary. According to the  
4 patient's condition, treatment for depression or anxiety symptoms may be provided to the  
5 patient before they make a decision. Our findings may be particularly meaningful because  
6 many patients with severe physical illness suffer from depression or anxiety.<sup>10-13</sup> Future  
7 research that can clarify any causal relationship may help verify and advance our results.  
8  
9

10  
11  
12  
13  
14  
15  
16 Furthermore, participants who felt relatively well-supported by their family members  
17 tended to prefer to receive life-sustaining treatment. However, the results of other studies  
18 differ from ours, though a consensus does not have been previously reached. Kim and Shin  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
61  
62  
63  
64  
65  
66  
67  
68  
69  
70  
71  
72  
73  
74  
75  
76  
77  
78  
79  
80  
81  
82  
83  
84  
85  
86  
87  
88  
89  
90  
91  
92  
93  
94  
95  
96  
97  
98  
99  
100  
101  
102  
103  
104  
105  
106  
107  
108  
109  
110  
111  
112  
113  
114  
115  
116  
117  
118  
119  
120  
121  
122  
123  
124  
125  
126  
127  
128  
129  
130  
131  
132  
133  
134  
135  
136  
137  
138  
139  
140  
141  
142  
143  
144  
145  
146  
147  
148  
149  
150  
151  
152  
153  
154  
155  
156  
157  
158  
159  
160  
161  
162  
163  
164  
165  
166  
167  
168  
169  
170  
171  
172  
173  
174  
175  
176  
177  
178  
179  
180  
181  
182  
183  
184  
185  
186  
187  
188  
189  
190  
191  
192  
193  
194  
195  
196  
197  
198  
199  
200  
201  
202  
203  
204  
205  
206  
207  
208  
209  
210  
211  
212  
213  
214  
215  
216  
217  
218  
219  
220  
221  
222  
223  
224  
225  
226  
227  
228  
229  
230  
231  
232  
233  
234  
235  
236  
237  
238  
239  
240  
241  
242  
243  
244  
245  
246  
247  
248  
249  
250  
251  
252  
253  
254  
255  
256  
257  
258  
259  
260  
261  
262  
263  
264  
265  
266  
267  
268  
269  
270  
271  
272  
273  
274  
275  
276  
277  
278  
279  
280  
281  
282  
283  
284  
285  
286  
287  
288  
289  
290  
291  
292  
293  
294  
295  
296  
297  
298  
299  
300  
301  
302  
303  
304  
305  
306  
307  
308  
309  
310  
311  
312  
313  
314  
315  
316  
317  
318  
319  
320  
321  
322  
323  
324  
325  
326  
327  
328  
329  
330  
331  
332  
333  
334  
335  
336  
337  
338  
339  
340  
341  
342  
343  
344  
345  
346  
347  
348  
349  
350  
351  
352  
353  
354  
355  
356  
357  
358  
359  
360  
361  
362  
363  
364  
365  
366  
367  
368  
369  
370  
371  
372  
373  
374  
375  
376  
377  
378  
379  
380  
381  
382  
383  
384  
385  
386  
387  
388  
389  
390  
391  
392  
393  
394  
395  
396  
397  
398  
399  
400  
401  
402  
403  
404  
405  
406  
407  
408  
409  
410  
411  
412  
413  
414  
415  
416  
417  
418  
419  
420  
421  
422  
423  
424  
425  
426  
427  
428  
429  
430  
431  
432  
433  
434  
435  
436  
437  
438  
439  
440  
441  
442  
443  
444  
445  
446  
447  
448  
449  
450  
451  
452  
453  
454  
455  
456  
457  
458  
459  
460  
461  
462  
463  
464  
465  
466  
467  
468  
469  
470  
471  
472  
473  
474  
475  
476  
477  
478  
479  
480  
481  
482  
483  
484  
485  
486  
487  
488  
489  
490  
491  
492  
493  
494  
495  
496  
497  
498  
499  
500  
501  
502  
503  
504  
505  
506  
507  
508  
509  
510  
511  
512  
513  
514  
515  
516  
517  
518  
519  
520  
521  
522  
523  
524  
525  
526  
527  
528  
529  
530  
531  
532  
533  
534  
535  
536  
537  
538  
539  
540  
541  
542  
543  
544  
545  
546  
547  
548  
549  
550  
551  
552  
553  
554  
555  
556  
557  
558  
559  
560  
561  
562  
563  
564  
565  
566  
567  
568  
569  
570  
571  
572  
573  
574  
575  
576  
577  
578  
579  
580  
581  
582  
583  
584  
585  
586  
587  
588  
589  
590  
591  
592  
593  
594  
595  
596  
597  
598  
599  
600  
601  
602  
603  
604  
605  
606  
607  
608  
609  
610  
611  
612  
613  
614  
615  
616  
617  
618  
619  
620  
621  
622  
623  
624  
625  
626  
627  
628  
629  
630  
631  
632  
633  
634  
635  
636  
637  
638  
639  
640  
641  
642  
643  
644  
645  
646  
647  
648  
649  
650  
651  
652  
653  
654  
655  
656  
657  
658  
659  
660  
661  
662  
663  
664  
665  
666  
667  
668  
669  
670  
671  
672  
673  
674  
675  
676  
677  
678  
679  
680  
681  
682  
683  
684  
685  
686  
687  
688  
689  
690  
691  
692  
693  
694  
695  
696  
697  
698  
699  
700  
701  
702  
703  
704  
705  
706  
707  
708  
709  
710  
711  
712  
713  
714  
715  
716  
717  
718  
719  
720  
721  
722  
723  
724  
725  
726  
727  
728  
729  
730  
731  
732  
733  
734  
735  
736  
737  
738  
739  
740  
741  
742  
743  
744  
745  
746  
747  
748  
749  
750  
751  
752  
753  
754  
755  
756  
757  
758  
759  
760  
761  
762  
763  
764  
765  
766  
767  
768  
769  
770  
771  
772  
773  
774  
775  
776  
777  
778  
779  
780  
781  
782  
783  
784  
785  
786  
787  
788  
789  
790  
791  
792  
793  
794  
795  
796  
797  
798  
799  
800  
801  
802  
803  
804  
805  
806  
807  
808  
809  
810  
811  
812  
813  
814  
815  
816  
817  
818  
819  
820  
821  
822  
823  
824  
825  
826  
827  
828  
829  
830  
831  
832  
833  
834  
835  
836  
837  
838  
839  
840  
841  
842  
843  
844  
845  
846  
847  
848  
849  
850  
851  
852  
853  
854  
855  
856  
857  
858  
859  
860  
861  
862  
863  
864  
865  
866  
867  
868  
869  
870  
871  
872  
873  
874  
875  
876  
877  
878  
879  
880  
881  
882  
883  
884  
885  
886  
887  
888  
889  
890  
891  
892  
893  
894  
895  
896  
897  
898  
899  
900  
901  
902  
903  
904  
905  
906  
907  
908  
909  
910  
911  
912  
913  
914  
915  
916  
917  
918  
919  
920  
921  
922  
923  
924  
925  
926  
927  
928  
929  
930  
931  
932  
933  
934  
935  
936  
937  
938  
939  
940  
941  
942  
943  
944  
945  
946  
947  
948  
949  
950  
951  
952  
953  
954  
955  
956  
957  
958  
959  
960  
961  
962  
963  
964  
965  
966  
967  
968  
969  
970  
971  
972  
973  
974  
975  
976  
977  
978  
979  
980  
981  
982  
983  
984  
985  
986  
987  
988  
989  
990  
991  
992  
993  
994  
995  
996  
997  
998  
999  
1000

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<sup>34</sup> reported that perceived family support was related to the preference for withdrawal of life-sustaining treatment in community dwelling elderlies. Choi et al.<sup>35</sup> 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<sup>36</sup> 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.

1  
2  
3 In this study, we investigated the preference for life-sustaining treatment and factors  
4 associated with the decision in Koreans. The thoughts regarding life-sustaining treatment of  
5 our participants were generally consistent with previous reports on life-sustaining treatment.  
6  
7 Depressive and anxiety symptoms may have an effect on this issue. According to our  
8 findings, if necessary, adequate interventions may be applied to individuals with negative  
9 mood during the decision-making process regarding life-sustaining treatment.  
10  
11  
12  
13  
14  
15  
16  
17

18 There are some limitations to this study. First, our study has a relatively small number of  
19 participants. This may limit the generalizability of our results. Second, our participants are  
20 the family members of visitors in Guro-gu center for dementia. Therefore, specific  
21 characteristics of our participants such as caregiver distress can affect our results. Though  
22 these may be more helpful to a specific group such as individuals with family members with  
23 cognitive impairment, further studies including various other groups such as the general  
24 public, caregivers of patients with other diseases, patients with cognitive impairment,  
25 physicians, and cancer patients may represent more informative results. Third, our study  
26 used a cross-sectional design. However, the preference for life-sustaining treatment can  
27 change over time. Gallo et al.<sup>37</sup> also reported that periodic reassessment for planning end-  
28 of-life care was needed in their 12-year follow-up study. Fourth, absolute differences in the  
29 scores of scales between the two groups were relatively small, although statistically  
30 significant. For this reason, there may be limitations to the clinical significance of the results  
31 of this study. We believe that further study including patients with psychiatric problems,  
32 such as depression and anxiety, can help derive more clinical meaning. Fifth, this study  
33 presented specific options for each question regarding life-sustaining treatment. This may  
34 be convenient for the participant, but there is a possibility that the participant's intention was  
35 not sufficiently reflected. Finally, our questionnaire consisted of only self-report items.  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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.



1  
2  
3 **Funding** This work was supported by the Choi Shin-Hai Neuropsychiatric Research Fund.  
4  
5  
6  
7

8 **Disclaimer** The funders had no role in planning or conducting the study.  
9  
10  
11

12 **Competing interests** The authors declare no conflicts of interest.  
13  
14  
15  
16

17 **Patient and public involvement** Patients or the public were not involved in the design, or  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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. Pasma 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

- 1  
2  
3 normal and pathological groups in a developing country. *Soc Psychiatry Psychiatr*  
4 *Epidemiol* 1995;30:121-6.  
5  
6  
7  
8 21. Shin JS, Lee YB. The effects of social supports on psychosocial well-being of the  
9 unemployed. *Korean J Soc Welf* 1999;37:241-69.  
10  
11  
12 22. Kim S, Koh S, Park K, *et al.* End-of-life care decisions using a Korean advance  
13 directive among cancer patient-caregiver dyads. *Palliat Support Care* 2017;15:77-87.  
14  
15  
16 23. Kim S, Hong SW, Kim J. Feasibility of the Korean-advance directives among  
17 community-dwelling elderly persons. *Holist Nurs Pract* 2017;31:234-42.  
18  
19  
20 24. Chochinov HM, Wilson KG, Enns M, *et al.* Desire for death in the terminally ill. *Am J*  
21 *Psychiatry* 1995;152:1185-91.  
22  
23  
24 25. Hahn MB, Jones MM, Carron H. Idiopathic pelvic pain. The relationship to depression.  
25 *Postgrad Med* 1989;85:263-6, 8, 70.  
26  
27  
28 26. Keam B, Yun YH, Heo DS, *et al.* The attitudes of Korean cancer patients, family  
29 caregivers, oncologists, and members of the general public toward advance directives.  
30 *Support Care Cancer* 2013;21:1437-44.  
31  
32  
33 27. Yun YH, Kim KN, Sim JA, *et al.* Comparison of attitudes towards five end-of-life care  
34 interventions (active pain control, withdrawal of futile life-sustaining treatment,  
35 passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred  
36 cross-sectional survey of Korean patients with cancer, their family caregivers,  
37 physicians and the general Korean population. *BMJ Open* 2018;8:e020519.  
38  
39  
40 28. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia  
41 and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*  
42 2000;284:2460-8.  
43  
44  
45 29. Sadock BJ, Sadock VA, Ruiz P. *Kaplan & Sadock's synopsis of psychiatry : Behavioral*  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 *sciences/clinical psychiatry*. Philadelphia, PA: Wolters Kluwer, 2015.  
4  
5  
6 30. Minkoff K, Bergman E, Beck AT, *et al*. Hopelessness, depression, and attempted  
7  
8 suicide. *Am J Psychiatry* 1973;130:455-9.  
9  
10 31. Beck AT, Brown G, Berchick RJ, *et al*. Relationship between hopelessness and  
11  
12 ultimate suicide: a replication with psychiatric outpatients. *Am J Psychiatry*  
13  
14 1990;147:190-5.  
15  
16 32. Beck AT, Steer RA, Kovacs M, *et al*. Hopelessness and eventual suicide: a 10-year  
17  
18 prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry*  
19  
20 1985;142:559-63.  
21  
22 33. Wen FH, Chen JS, Chou WC, *et al*. Factors predisposing terminally ill cancer patients'  
23  
24 preferences for distinct patterns/states of life-sustaining treatments over their last six  
25  
26 months. *J Pain Symptom Manage* 2019;57:190-8.e2.  
27  
28 34. Kim HS, Shin SR. The influence of social support among community dwelling elderly  
29  
30 and their attitude towards the withdrawal of life-sustaining treatment: A mediating  
31  
32 effect of self-esteem. *Korean J Adult Nurs* 2017;29:373-81.  
33  
34 35. Choi JJ, Kim SH, Kim SW. Reversals in decisions about life-sustaining treatment and  
35  
36 associated factors among older patients with terminal stage of cardiopulmonary disease.  
37  
38 *J Korean Acad Nurs* 2019;49:329-39.  
39  
40 36. Uhlmann RF, Pearlman RA. Perceived quality of life and preferences for life-  
41  
42 sustaining treatment in older adults. *Arch Intern Med* 1991;151:495-7.  
43  
44 37. Gallo JJ, Abshire M, Hwang S, *et al*. Advance directives, medical conditions, and  
45  
46 preferences for end-of-life care among physicians: 12-year follow-up of the Johns  
47  
48 Hopkins precursors study. *J Pain Symptom Manage* 2019;57:556-65.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4 Verbatim translation of the scenario and description of the terms  
5  
6  
7  
8  
9

10 \* It is well known that about one-third of the population of South Korea will develop cancer  
11 during their lifetime. This questionnaire is conducted under the assumption that "if you have  
12 cancer (especially stage 4)".  
13  
14  
15  
16

17  
18  
19  
20  
21 \* "Terminal state" is defined as a condition in which treatments for the purpose of life extension  
22 are not applicable to patients.  
23  
24  
25  
26

27  
28  
29 \* "Life-sustaining treatment" is any treatment that serves to prolong life without reversing the  
30 underlying medical conditions, and includes cardiopulmonary resuscitation, mechanical  
31 ventilation, hemodialysis, and left ventricular assist devices. With the recent passage of relevant  
32 legislation, it is becoming an issue to decide whether to receive life-sustaining treatment in  
33 advance.  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

Section/Topic	Item #	Recommendation	Reported on page #
<b>Title and abstract</b>	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
<b>Introduction</b>			
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
<b>Methods</b>			
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
<b>Results</b>			

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	-
<b>Discussion</b>			
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
<b>Other information</b>			
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](http://www.strobe-statement.org).