



The effects of Dying Well Education Program on Korean women with breast cancer



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ABSTRACT

Background: Breast cancer patients fear the relapse of their disease and subsequent death the most. Dying Well Education Program, a death education program, was offered for breast cancer patients to help them to reflect on the meanings of life and death.

Purpose: This study evaluated the effects of a death education on fear of death, anxiety and depression, hope, and spiritual well-being among breast cancer patients.

Methods: Twenty-three women with breast cancer at a university hospital in South Korea who received Dying Well Education Program, once a week for 10 weeks, were compared with 25 participants in a control group who received the treatment as usual.

Results: Participants in the experimental group were satisfied with the program and showed a decreased level of fear of death, and increased levels of hope and spiritual well-being when compared to the control group. The anxiety and depression scores for both experimental and control groups were initially within normal ranges before the program and further decreased over time.

Conclusion: This study confirmed that a properly designed death education program could serve as a means of increasing breast cancer patients' hope and spiritual well-being.

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1. Introduction

Death represents the greatest threat to each individual's identity, and is often met with incredible fear and suffering by those facing it. These feelings not only pertain to one's own death, but also to that of loved ones (Goldsteen et al., 2006; Higginson & Costantini, 2008). Having a proper understanding of death enhances people's understanding of life: how to live, accept death, and value of one's existence (Madeira, Albuquerque, Santos, Mendes, & Roque, 2011; Shim & Hahm, 2011). Therefore, preparing individuals to overcome this fear of death can be done by helping them to understand the death properly.

Breast cancer shows one of the highest occurrence rates for cancers among women. Fortunately, recent developments in diagnostic techniques and treatment methods have greatly improved the survival rate. Even with the good prognosis compared to other types of cancer, patients suffer from fear of death during treatment just the same (Alifrangis et al., 2011; Yang, 2008). The results of previous studies have shown that the biggest fear among breast cancer patients is the relapse of their disease and the

subsequent death, and that with the extended survival period comes a similarly extended fear of relapse (van den Beuken-van Everdingen et al., 2008; van Laarhoven, Schilderman, Verhagen, Vissers, & Prins, 2011). An extended period of anxiety, fear of relapse, and depression threatens breast cancer patients' quality of lives. There is a great need of help, such as a death education program, for the patients in overcoming the negative feelings associated with death and in initiating the reflection on the positive meanings of life (Gonen et al., 2012; Tang, Chiou, Lin, Wang, & Liand, 2011).

Breast cancer mostly occurs in midlife, a period when people begin to see death in a new light after experiencing death second-handedly and realizing that they too have limited time to live. While the new perspective on existence might encourage people to live more meaningful lives; it might also bring negative outcomes such as depression. To better prepare individuals in their mid-life for their journey towards death, a death education program might be ideal (Burt, Shipman, Richardson, Ream, & Addington-Hall, 2010; Tang et al., 2011).

A death education program can help individuals, their spouses, and their other family members to prepare for their death, and to live more meaningful lives. These programs educate a wide variety of individuals, including health care providers, terminal cancer patients, and the family members of terminal cancer patients (Smith-Cumberland, 2006). In previous studies on death preparation programs, attitudes towards death became more positive following education, while death anxiety decreased in middle-aged adults, distress decreased in counselors, and empathy

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increased in social work students (Cacciatore, Thieleman, Killian, & Tavasoli, 2015; Kang, 2011; Servaty-Seib & Tedrick Parikh, 2014)

The purpose of this study is to identify the effects of a death education program on the fear of death, anxiety, depression, hope, and spiritual well-being of female breast cancer patients in South Korea. In Korea, death education studies have been performed with the elderly, adults, or college students. Thus far, no study has investigated the effects of death education with cancer patients. Peaceful acceptance and preparation of death are not easy for patients at the progressed stages of cancer. Investigating positive effects of death education programs on cancer patients would be essential, especially if the education can help them to ease the fear, anxiety, and depression related to death and improve their quality of life by giving them better hope and spiritual well-being.

2. Methods

2.1. Participants

The content and method of the study were approved by the Institute of Bioethics at The Catholic University of Korea. The participants were South Korean women between 40 and 65 years old who were receiving outpatient follow-up care after breast surgeries at Seoul St. Mary's Hospital at The Catholic University of Korea. The eligibility criteria included patients with: no evidence of recurrent or progressive disease; the completion of chemotherapy and/or radiotherapy with or without current hormone therapy use; no mental disease or systemic disease. None of the participants were taking any psychiatric drugs. All participants understood the purpose of the study and gave their written informed consents to participate. The sample size was calculated using the G*Power 3.1.2 program with an effect size of 0.3, statistical power of 0.8, and a significance threshold of 0.05, giving us a required sample size of 18 in each group for a repeated measures analysis of variance (Faul, Erdfelder, Buchner, & Lang, 2009). With the dropout rate, twenty-five participants were recruited for each group. The subjects were recruited from the breast cancer center of a tertiary general hospital, and randomly assigned to the control and experimental groups via a lottery. All subjects in the experimental group were required to participate in at least 8 sessions of the 10-week long Dying Well Education, a death education program.

The total number of participants was 48, with 23 in the experimental group and 25 in the control group after two participants from the experimental group dropped out: one due to a personal reason and another recurrence of the cancer.

2.2. Study procedures

Data collection was conducted from April 29, 2011 to July 15, 2011. Before the start of the death education program, both groups participated in the pre-program survey using questionnaires about fear of death, anxiety, depression, hope, and spiritual well-being. The death education program was conducted only for the experimental group. The post-program survey, conducted on the last day of the program, was given to measure the same characteristics and the perceptions as the pre-program survey. The control group received the same training as the experimental group after the completion of data collection to extend them the same potential benefits of the program. There was no significant difference in the general characteristics and pre-program survey results between the control and experimental groups (Table 1). Once all of the data had been collected, all participants received a small gift.

2.3. Measures

2.3.1. Dying Well Education Program

The death education program that we developed was based on the ADDIE model, which consisted of five steps: Analysis, Design, Development, Implementation, and Evaluation (Fig. 1) (Seels & Richey, 1994).

The program consisted of ten, two-hour long sessions over 10 weeks of time. The length of the program was based on the results of previous studies

Table 1
Homogeneity test of characteristics and research variables.

Groups Characteristics	Exp. (n = 23)	Cont. (n = 25)	t/χ^2	p
	N (%) or Mean \pm SD	N (%) or Mean \pm SD		
Age (years)	54.0 \pm 4.9	56.0 \pm 5.1	1.36	.181
Religion ^a				
Yes (Catholicism, Christianity, Buddhism)	21 (91.3)	24 (96.0)		.601
No	2 (8.7)	1 (4.0)		
Education				
\geq High school	10 (43.5)	16 (64.0)	2.03	.154
\leq College	13 (56.5)	9 (36.0)		
Family income (10,000 won)	400.0 \pm 144.8	356.1 \pm 215.5	.80	.429
Physical symptom (score)	19.0 \pm 9.8	15.4 \pm 12.7	1.09	.290
Health state (score)	6.5 \pm 1.9	7.3 \pm 1.7	1.54	.131
Duration of diagnosis (months)	75.6 \pm 46.4	79.8 \pm 60.3	.27	.790
Stage ^a				
I	10 (43.5)	11 (44.0)		.712
II	11 (47.8)	10 (40.0)		
III	2 (8.7)	4 (16.0)		
Fear of death	97.61 \pm 9.97	92.87 \pm 7.40	1.83	.074
Anxiety	7.65 \pm 3.13	6.08 \pm 3.11	.86	.088
Depression	5.43 \pm 2.90	5.04 \pm 3.37	1.75	.667
Hope	38.43 \pm 4.05	37.36 \pm 4.60	.43	.397
Spiritual well-being	36.74 \pm 7.61	36.56 \pm 5.65	.09	.926

Exp.: experimental group. Cont.: control group.

^a Fisher's exact test.

(Cui, Shen, Ma, & Zhao, 2011; Kawagoe & Kawagoe, 2000; Smith-Cumberland, 2006; Wynne, 2013; Yoo, 2008), which argued that those who were under 60 years prefer ten death education program sessions and people who are 60 and over prefer a six session long program (Yang, 2009).

Each week participants were either given a short lecture or watched a video clip on a given theme and discussed their thoughts and feelings afterwards. Previous study argued that death education programs were more effective when implemented through conversations and discussions based on case studies rather than long lectures (Kang, 2011; Wynne, 2013). Small groups of six or seven were formed to encourage more conversations and discussions.

The death education program allowed participants to focus on their understanding of themselves through self-reflection and provided them with the opportunity to consider the realistic obstacles that each of them faces. Also, the program readies participants for the acceptance of death by writing a will, planning for their funerals, and mentally preparing participants. The specific educational content was shown in Fig. 2.

2.4. Instruments

2.4.1. The Fear of Death Scale (FODS)

FODS was developed by Collett and Lester (1969), and later revised by Lester and Abdel-Khalek (2003). The scale consists of twenty eight 5-point Likert scale items on the fear and anxiety related to one's own journey towards death, that of others, and observation of others' death. Item scores range from "very likely" (5 points) to "not at all" (1 point), with higher scores indicating greater degrees of fear and anxiety. The internal consistency reliability, determined by Cronbach's α , was 0.80 in the pre-program survey and 0.82 post-program.

2.4.2. The Hospital Anxiety and Depression Scale (HADS)

HADS was developed by Zigmond and Snaith (1983), used to assess participants' anxiety and depression levels. The scale consisted of 14 items and is measured using 4-point Likert scale, ranging from 0 to 3, where higher scores indicate greater severities of anxiety and depression. The same Cronbach's α value of 0.87 was observed before and after the program.

2.4.3. Hope

Hope was measured using a scale developed by Herth (1992). The scale comprises of 12 items, which are measured using a 4-point scale.

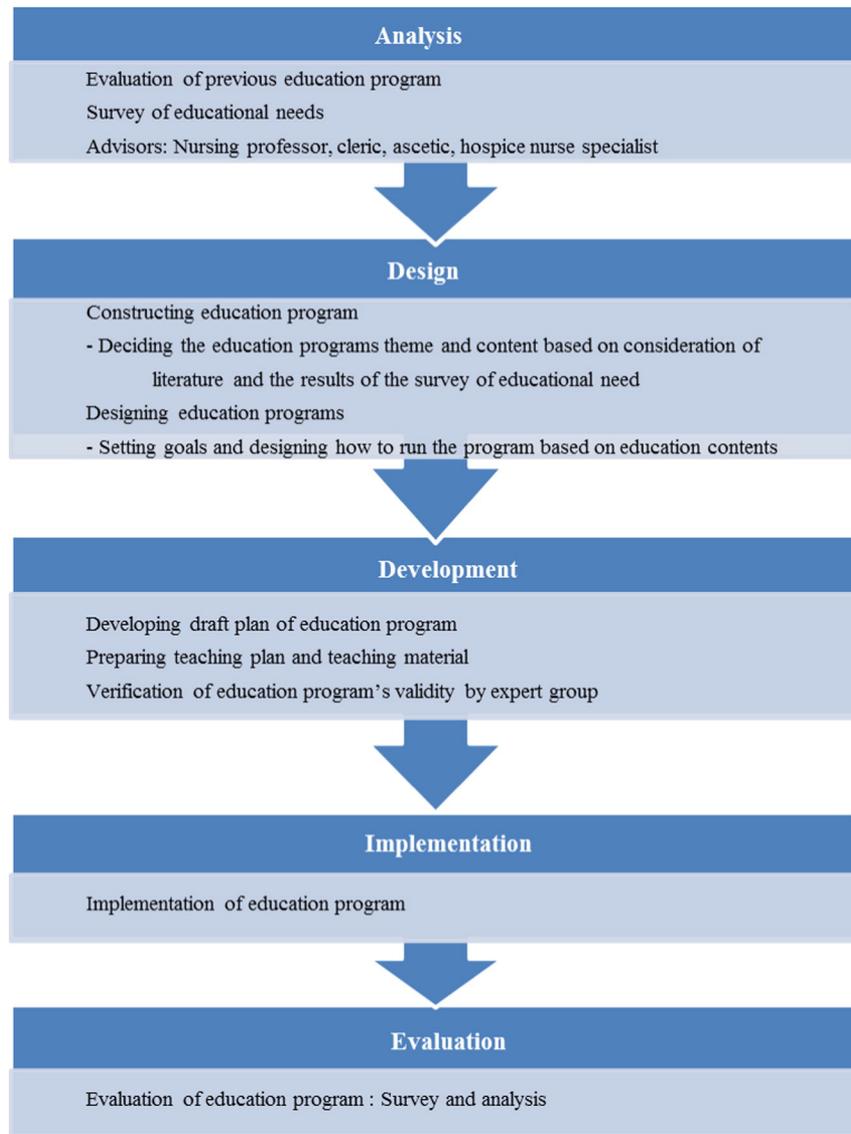


Fig. 1. Development process of the Dying Well Education Program.

Items are scored as follows, with higher scores indicating greater levels of hope: “very likely” (4 points), “most likely” (3 points), “generally not likely” (2 points), or “rarely likely” (1 point). The Cronbach's α was reported to be 0.89 in Herth's research. The Cronbach's α was 0.77 before the program and 0.86 after.

2.4.4. The Functional Assessment of Chronic-Illness Therapy-Spiritual Well-being (FACIT-Sp)

FACIT-Sp was developed by Peterman, Fitchett, Brady, Hernandez, and Cella (2002). This scale measures life meanings and peacefulness (8 items) and faithfulness (4 items). The questions assess general levels of strength and consolation breast cancer patients possess by looking at their perception on life meanings, harmony, peacefulness, and faith. Items are rated on a 5-point Likert scale, with higher scores indicating greater spiritual well-being. The scores range from 0 point to 4 points: “very much” (4 points), “quite a bit” (3 points), “somewhat” (2 points), “a little bit” (1 point), or “not at all” (0 point). The Cronbach's α was 0.90 before the program and 0.84 after.

2.4.5. The Dying Well Education Program Satisfaction Survey

Satisfaction survey was a questionnaire measured using a 10 cm visual analogue scale, with the leftmost side indicating “not at all satisfied” (0

points) and the rightmost indicating “very satisfied” (10 points). The contents of each session are also evaluated using a 5-point Likert scale: “very satisfied” (5 points), “satisfied” (4 points), “generally satisfied” (3 points), “not satisfied” (2 points), or “not at all satisfied” (1 point).

2.5. Statistical analysis

The data were analyzed using SAS for Windows (ver. 9.2). The homogeneity tests between the experimental and control groups were conducted using Chi-square and t-tests. The fear of death, anxiety and depression, hope, spiritual well-being in the experimental and control groups, before and after the experiment, were analyzed using repeated measures ANOVA and Bonferroni's multiple comparisons.

3. Results

3.1. Fear of death

Although the experimental group's fear of death score decreased from 97.61 to 93.17 after the program, the control group's score increased from 92.87 to 94.86 ($p = .018$) (Table 2).

Session	Theme	Contents	Methods
I	1	Orientation	<ul style="list-style-type: none"> • Self-introduction • Introduction to the program • Opening up <ul style="list-style-type: none"> • Group discussion and sharing
	2	Understanding the meaning of life and death	<ul style="list-style-type: none"> • The meaning of life • The meaning of death <ul style="list-style-type: none"> • Lecture
II	3	Mystery of life	<ul style="list-style-type: none"> • The birth of myself • Abortion, suicide and euthanasia <ul style="list-style-type: none"> • Video • Lecture • Group discussion and sharing
	4	The meaning of life	<ul style="list-style-type: none"> • Looking back on life • The value of life <ul style="list-style-type: none"> • Video • Lecture • Group discussion and sharing
III	5	The meaning of death	<ul style="list-style-type: none"> • Understanding hospice • A good death <ul style="list-style-type: none"> • Lecture • Group discussion and sharing
	6	Preparing for death	<ul style="list-style-type: none"> • Understanding the course of death <ul style="list-style-type: none"> • Video • Group discussion and sharing
	7	Experiencing death	<ul style="list-style-type: none"> • Writing a will • Preparing for my funeral <ul style="list-style-type: none"> • Taking a picture for my funeral • Group discussion and sharing
	8	Sorrow and loss	<ul style="list-style-type: none"> • Overcoming sorrow and loss <ul style="list-style-type: none"> • Video • Group discussion and sharing
IV	9	A life of fullness	<ul style="list-style-type: none"> • A life of sharing (Organ donation, body donation, voluntary service, etc) • Planning for a new life <ul style="list-style-type: none"> • Lecture • Making epitaph in a picture frame • Group discussion and sharing
	10	Review	<ul style="list-style-type: none"> • Sharing feelings with each other <ul style="list-style-type: none"> • Review sheet • Sharing

Fig. 2. Contents of the Dying Well Education Program.

3.2. Anxiety and depression

The experimental group's anxiety score decreased from 7.65 to 6.09 after the program, while the control group's score decreased from 6.08 to 5.50. The experimental group's depression score decreased from 5.43 to 4.43 after the program, while the control group's score increased from 5.04 to 5.09 ($p = .090$, $p = .051$) (Table 2).

3.3. Hope

The experimental group's hope score increased from 38.43 to 42.39 after the program, while the control group's score slightly decreased from 37.36 to 36.59 ($p = .041$) (Table 2).

3.4. Spiritual well-being

The experimental group's spiritual well-being score increased from 36.74 to 40.22 after the program, while the control group's score decreased from 36.56 to 36.45 ($p = .032$) (Table 2).

3.5. Dying Well Education Program Satisfaction Survey

Participants' overall sense of satisfaction with Dying Well Education Program was 9.1 out of 10. The sessions that participants were most satisfied with were writing a will, experiencing being in a casket, and visiting a charnel house, while they rated the lecture on understanding life and death to be the least satisfactory (Table 3).

4. Discussion

Human beings experience fear of death when confronted with life-threatening situations or when they start to realize the finite nature of their own existence (Yoo, 2008). The result of this study shows that breast cancer patients experienced a decrease in their fear of death after participating in the Dying Well Education Program, while those in the control group exhibited an increase. No known study investigated the effects of a death education program on breast cancer patients; therefore, it is difficult to compare our findings to an existing research's. However, death education programs were found to positively influence terminal patients under hospice care and the elderly (Kang, 2011). In a study conducted in Japan, 14 out of 15 terminal patients showed general acceptance of death after receiving four death education sessions (Kawagoe & Kawagoe, 2000). Researchers found a positive change in the attitude towards their own death and also a decreased level of fear on death. As with the current study, both cases suggest positive influences of death educations programs on individuals who need to confront and accept their own eventual death.

During the evaluation after education, we asked the following open question: "What have you gained through education?" The reasons that breast cancer patients participated in the present study were to overcome their fear of death and to search for methods to lessen the burden they would put on their family members during their progression towards death. Before participating in the death education program, most patients experienced a constant fear of death while going through the diagnosis and the treatment stages of their cancer. The death

Table 2
Changes in fear of death, anxiety and depression, hope, and spiritual well-being.

	Pre-intervention	Post-intervention	Source	F	p
	Mean ± SD	Mean ± SD			
Fear of death					
Exp.	97.61 ± 9.97 ^a	93.17 ± 10.62 ^a	G	1.09	.303
Cont.	92.87 ± 7.40	94.86 ± 9.51	T	1.08	.304
Anxiety			G*T interaction	6.07	.018
Exp.	7.65 ± 3.13	6.09 ± 1.81	G	3.05	.088
Cont.	6.08 ± 3.11	5.50 ± 2.39	T	6.09	.018
Depression			G*T interaction	3.01	.090
Exp.	5.43 ± 2.90	4.43 ± 2.19	G	.00	.974
Cont.	5.04 ± 3.37	5.09 ± 2.89	T	.88	.354
Hope			G*T interaction	4.03	.051
Exp.	38.43 ± 4.05	42.39 ± 9.12	G	5.72	.021
Cont.	37.36 ± 4.60	36.59 ± 5.17	T	2.32	.135
Spiritual well-being			G*T interaction	4.44	.041
Exp.	36.74 ± 7.61 ^b	40.22 ± 5.42 ^b	G	1.11	.298
Cont.	36.56 ± 5.65	36.45 ± 6.80	T	3.08	.086
			G*T interaction	4.94	.032

Exp.: experimental group (n = 23). Cont.: control group (n = 25). G: group. T: time. G*T: group * time.
^{a,b}: Significantly different from each other (Bonferroni adjusted p < 0.05).

education program helped them to face the possible recurrence of disease and subsequent death that they had feared for so long. Answering the program evaluation questions in the post-program survey, many claimed that they had found some extent of inner peace, as their thoughts on death became more tangible to them. Clearly, these breast cancer patients were helped to understand their feelings about death and develop greater insight on themselves.

The anxiety and depression scores for both experimental and control groups were initially within normal ranges before the program and further decreased over time. We found no influence of the program on those indexes. The average period of the time elapsed since the diagnosis was 75 months (6 years) and we suspect the length of time was sufficient for the participants to adapt to the conditions of their disease. In future studies, we would like to see the effect of death education program on anxiety and depression levels given varying lengths of post diagnosis periods.

Hope helps cancer patients search for a better way to live their lives despite their suffering, and even allows them to view death more positively (Chi, 2007; Tae, Heitkemper, & Kim, 2012). The analysis of the data revealed that participants in the experimental group showed an increment in terms of their perception of hope, while those in the control group showed a decrement in hope. Previous studies have argued that hope is related to religious beliefs or physical conditions (Schjolberg,

Dodd, Henriksen, & Rustoen, 2011). Most participants of this study were affiliated with a religion. The subjectively reported health status was 6 out of 10 in average, a score reflecting the patients' physical ability to cope with the sufferings from their disease. Thus, their hope before the program began was relatively high. In the program evaluation survey, many patients stated that the program had helped them realize that there was hope despite their difficult situations, and their faith to live and die well became stronger. We believe learning to face their own death in a controlled setting, for example in a session where they experiencing lying down in caskets, made the participants more thankful of what they still have in their lives and less anxious about actual death. Consequently, we conclude that a death education program has a positive effect on hope by allowing participants to accept death positively and to better their remaining future.

People with a higher level of spiritual well-being tend to show a positive attitude towards their lives even in difficult situations, and to feel greater harmony and inner peace (Matsui, Kanai, Kitagawa, & Hattori, 2013; Wynne, 2013). Spiritual well-being is used as a predictor in breast cancer patients' quality of life, and it aids in coping with a cancer diagnosis and its treatment process (Purnell, Andersen, & Wilmot, 2009). The analysis of pre and post program data indicates that the spiritual well-being of experimental group participants increased, while that of control group participants decreased. In the evaluation after completion of education, some patients commented that they wanted to seek comfort and consolation in God. Others expressed their willingness to make their lives more meaningful by volunteering and connecting more with their neighbors. The consolation and peace that religion provides should influence patients' physical and spiritual well-being positively (Salsman, Yost, West, & Cella, 2011). Some studies show that death education programs can reduce participants' hopelessness and sufferings in connection to death (McClain, Rosenfeld, & Breitbart, 2003). It is, however, difficult to make direct comparisons between our study and previous ones, because no studies have conducted a death preparation program specifically for breast cancer patients or investigated patients' spiritual well-being. Nevertheless, in our study, while the effect of death education is not quantifiable and the long-term effects of the program on breast cancer patients have yet to be found, this research shows a positive influence of death education program on breast cancer patients' spiritual well-being.

Participants' satisfaction with the death education program was positive in general. Participants were most satisfied with sessions where

Table 3
Satisfaction of program.

Contents	Scale (score ranges)	(N = 23)
		Mean ± SD
Overall quality of program ^a	10 cm VAS (0–10)	9.08 ± 0.83
Satisfaction of session topic ^b	5-point Likert scale	
Understanding the meaning of life and death	(1–5)	4.46 ± 0.58
Mystery of life	(1–5)	4.58 ± 0.50
Meaning of life	(1–5)	4.65 ± 0.56
Meaning of death	(1–5)	4.57 ± 0.57
Preparing for death	(1–5)	4.74 ± 0.45
Experiencing death	(1–5)	4.78 ± 0.42
Sorrow and loss	(1–5)	4.72 ± 0.46
Life of fullness	(1–5)	4.48 ± 0.58

VAS: visual analogue scale.

^a 0 (not at all satisfied)–10 (very satisfied).

^b 1 (not at all satisfied)–5 (very satisfied).

they wrote their wills and experienced being inside a casket and visiting a charnel house but were least satisfied with lectures on understanding life and death. Overall, they stated that the death education program was a good opportunity to learn and discuss their feelings and thoughts about death in a culture where death is an unpopular topic.

Until now, death is not an openly discussed topic in South Korea, and mentioning death to cancer patients and their family members could be regarded as an insensitive gesture depriving further hope from them (Higginson & Costantini, 2008). Also, breast cancer patients in South Korea tend not to share their feelings on death and avoid problems instead of facing them. Finally, breast cancer patients often feel more comfortable to share their physical and psychological pains with someone other than their own family members (Song et al., 2011). Considering the situations breast cancer patients are facing, this study suggests that a death education program could serve as a means to increase their hope and spiritual well-being. In addition, a death education program could provide an opportunity for patients to discuss death, which is traditionally avoided among cancer patients and their families but is necessary to support and console them more openly.

Our study included the following limitations: first, we could not follow up on the effects of the education program in the long-term. Second, we could not assess the effects of the education program in terms of objective, physiological indices. Finally, we were unable to customize the education program so that it considered individual subjects' characteristics, such as the subjects' death preparation, extent of fear about death, or expectations for the education program.

5. Conclusion

We concluded that a death education program is an effective method in reducing fear of death, inspiring hope, and promoting spiritual well-being of breast cancer patients. In addition, patients gained greater insights into the meaning of their lives, allowing themselves to hope despite their ambiguous futures. Therefore, a death education program is expected to enhance psychological and spiritual well-being of various cancer patients suffering from the fear of relapse and death as they go through treatments.

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