



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.

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