

## RESEARCH ARTICLE

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# A Self-Help Guided Psychoeducational Intervention for Indonesian Women with Breast Cancer Symptoms: Development and Pilot Feasibility Study

Hari Setyowibowo<sup>1,2\*</sup>, Aulia Iskandarsyah<sup>3</sup>, Sawitri S Sadarjoen<sup>3</sup>, Dharmayanti F Badudu<sup>4</sup>, Drajat R Suardi<sup>4</sup>, Jan Passchier<sup>2</sup>, Joke A M Hunfeld<sup>5</sup>, Marit Sijbrandij<sup>2</sup>

## Abstract

**Background:** Delay in the diagnosis of breast cancer (BC) may lead to an advanced stage of the disease and a poor prognosis. A psychoeducational intervention can be crucial in helping women with BC symptoms complete the examination procedures and reduce diagnosis delay of BC. **Objective:** To develop a psychoeducational intervention to reduce the delay of BC diagnosis among Indonesian women with BC symptoms. **Methods:** The development of the intervention included an inventory of crucial elements in developing psychoeducation through literature review as well as consultation with BC patients and healthcare providers. Additionally, we developed PERANTARA as the first pilot version of the self-help guided psychoeducational intervention. PERANTARA is an abbreviation for “Pengantar Perawatan Kesehatan Payadura”, which means an introduction to breast health treatment. The pilot feasibility study combined an expert review and a pilot testing in hospital settings. A semi-structured interview and the client satisfaction inventory were utilized to measure feasibility and acceptability of the intervention for Indonesian women with BC symptoms. **Results:** PERANTARA contained an oncologist’s explanation about BC and the BC survivors’ testimony to reduce the time to diagnosis. The pilot study results showed that most patients were satisfied with and trusted on PERANTARA. **Conclusion:** PERANTARA was feasible and acceptable for Indonesian patients with BC symptoms. The development framework suggested in this study can be applied to develop psychoeducational packages for other patients group, in particular, those interventional packages aimed at reducing diagnosis and treatment delays and non-adherence.

**Keywords:** Breast cancer- psychoeducation- time to diagnosis- oncology- Indonesia

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## Introduction

Breast cancer (BC) is the leading cause of cancer-related death among women, especially in low and middle-income countries (LMIC) (Torre et al., 2015; Torre et al., 2016). In Indonesia, During the last decade, it has been shown that BC continues to be the most commonly diagnosed cancer and leading cause of cancer-related death among women, with an incidence rate of 40.3 and a mortality rate of 16.6 per 100,000 people (Ferlay et al., 2012). According to Dharmais Cancer Hospital (National Cancer Center in Indonesia), BC incidence and its mortality rate ranked top from 2010 to 2015 in comparison with any other types of cancer, and its prevalence is going to increase annually (Ministry of Health Republic of Indonesia, 2016).

These reports on BC mortality rates are at odds with

those in many high-income countries (HICs) since BC mortality rate has decreased in high-income countries probably due to increase of early BC symptoms awareness (both in healthcare providers and patients), early detection and diagnosis, and also increase of effective treatments availability (Denny et al., 2017). However, the prognosis for women with BC in LMICs is still poor because of the delays in diagnosis, treatment, or even both (Price et al., 2012; Unger-Saldana, 2014). The reasons for diagnosis and treatment delays are multifactorial (Freitas and Weller, 2015). There are patient-related factors such as lack of BC knowledge, belief in traditional treatment, and a negative attitude toward cancer diagnosis and/or treatment (Norsa’adah et al., 2011; Iskandarsyah et al., 2014a; Iskandarsyah et al., 2014b; Maghous et al., 2016). In addition, there are administrative problems as

<sup>1</sup>Department of Educational Psychology, <sup>3</sup>Department of Clinical Psychology, Faculty of Psychology, Universitas Padjadjaran, Jatinangor, <sup>4</sup>Department of Surgical Oncology, Hasan Sadikin Hospital, Bandung, Indonesia, <sup>2</sup>Department of Clinical, Neuro- and Developmental Psychology, Faculty of Behavioural and Movement Sciences, VU University, Amsterdam, <sup>5</sup>Department of Psychiatry, section Medical Psychology, and Psychotherapy, Erasmus MC University Medical Center, Rotterdam, Netherlands.  
\*For Correspondence: h.setyowibowo@unpad.ac.id

well as miscommunication between patients and health care providers that may hinder the process of scheduling and obtaining the diagnostic tests (Caplan, 2014; Unger-Saldana, 2014; Freitas and Weller, 2015).

Time to diagnosis, the interval time between the first clinical consultation and the time that BC is diagnosed and confirmed by the doctor, is critical in BC management (Caplan et al., 1996; Barber et al., 2004; Redaniel et al., 2015; Abu-Helalah et al., 2016). In Indonesia, about 60-70% women with BC appear to be already in an advanced stage (stage III-IV) when starting their treatments (Ministry of Health of the Republic of Indonesia, 2016). Furthermore, there is a fact that around 67% of women with BC symptoms who visit a hospital to consult for their breast abnormalities, tend to not continue with a thorough examination to obtain a definitive diagnosis (Sander, 2011). Therefore, promoting breast cancer awareness and adequate medical help-seeking behavior is essential for women at risk of BC to facilitate early diagnosis and treatment process and to achieve better prognosis (Khan et al., 2015; Denny et al., 2017).

A qualitative study on 50 Indonesian women with BC found that delay in seeking help and non-adherence to treatment were associated with lack of awareness and knowledge, patient's perception about cancer as a dangerous deadly disease, believing cancer is incurable, emotional burden, unmet information needs, and trust in traditional healers. One of the crucial findings signified that most women described BC as a deadly and incurable disease, trusting on information obtained from stories and BC experiences of their relatives and neighbors, or mass media sources (e.g., magazines, newspapers, and television) (Iskandarsyah et al., 2014a; Iskandarsyah et al., 2014b; Azhar et al., 2016). Consequently, interventions to reduce time to diagnosis are needed to encourage women with BC symptoms to receive medical treatment immediately to achieve a better prognosis.

A cross-sectional study on 70 women with BC in Indonesia discovered that many of patients (41-86%) were not satisfied with the amount of written information about BC that they received (Iskandarsyah et al., 2013). Therefore, the use of concise and understandable educational materials (e.g., leaflets, posters, flipcharts table, and visualized storytelling) may complement the verbal explanations usually provided by the health care providers at clinics. Furthermore, the implementation of educational materials may be an appropriate solution in overcoming the lack of resources (e.g., experts, time, and finance).

To the best of our knowledge, evidence-based guided self-help psychoeducational interventions to reduce time to diagnosis are still lacking in Indonesia. Therefore, we developed PERANTARA, a self-help psychoeducational program, aiming at reducing the time to diagnosis. In the current study, we described the development of PERANTARA. we also reported a pilot study on its feasibility and acceptability for women with BC symptoms residing in Indonesia .

## Materials and Methods

The development of PERANTARA consisted of three steps: 1) Inventory, 2) Intervention development, and 3) Pilot study See Figure 1, p 257.

### Inventory

A narrative literature review was conducted as an inventory step to ensure psychoeducation as a potential psychosocial intervention option for helping women with BC-related complaints, identify crucial elements for the intervention development, and to discover important issues or psychoeducation needs for women with BC symptoms. A narrative literature review is used to provide a comprehensive background to understand the current knowledge and highlight the importance of the new research (Cronin et al., 2008).

Furthermore, we conducted semi-structured interviews with women with BC (n= 27) and Focus Group Discussion (FGDs) with oncologists (n=5) and nurses (n=15) in the Hasan Sadikin Hospital Bandung. The patients' age ranged from 30 to 69 years old. Fifteen (56%) patients had completed elementary school or had lower level of education. Nineteen (70%) patients were housewives or unemployed. Twenty-five (93%) patients were married, and the remaining two patients were widows. Twenty-six (96%) patients had health insurance provided by the government for people with low income, which was less than 2 million rupiah a month. Both the interviews and FGDs addressed the following questions: (1) What would be a feasible way to tackle the reported diagnostic delay and adherence barriers? (2) Who should, can, and would you like to be involved in developing and implementing the interventions? (3) For which populations is it necessary to develop an intervention program?, and (4) What is a possible format of the intervention?

### Intervention development

For developing PERANTARA, we involved experts from the field of health psychology, health communication, oncology, and audiovisual design. Three BC survivors were engaged in providing suggestions for the content, format, and utilization of the intervention packages. The intervention development comprised of the following two main activities:

#### 1) Conducting FGD

FGDs with an oncologist, a health communication expert, two health psychology experts, and two BC survivors were held to review the intervention framework. The FGDs focused on the following issues: (1) The target population; (2) The person who delivers the contents; (3) The contents of the psychoeducation; (4) The delivery method; and (5) The delivery location.

#### 2) Developing PERANTARA

One of the authors (HS) organized a series of collaborative work to develop the first pilot version of the psychoeducation package. The process started by writing a script as a guide to develop PERANTARA. After that, he collaborated with the audiovisual communication

designers to prepare the printed material. The procedure included illustration drawing, layout making, lettering, and printing. In addition, he also cooperated with the audiovisual communication designer to develop the audiovisual storytelling. The process itself entailed video shooting, voice overtaking, music composing, animating motion graphic, and burning the DVD.

#### *Pilot study*

##### *Participant*

PERANTARA was pilot-tested on 13 patients to evaluate its feasibility for delivering in a controlled trial (Setyowibowo et al., 2017) and to gather preliminary information on its acceptability by patients. We recruited participants from Klinik Padjadjaran in Sumedang, West Java, Indonesia. The patients' age ranged from 18 to 61 years old. Eight (62%) patients were women with BC symptoms, and five (38%) patients were women with BC. Five (38%) patients had completed elementary school, six (42%) patients had completed high school, and two (15%) had completed college level. Eight (62%) patients were housewives or unemployed. Nine (69%) patients had income less than 2 million rupiahs a month. Eight (57%) patients had health insurance provided by the government for people with low income. One patient refused to fill out a questionnaire after providing with the package of interventions because she underwent BC treatment one day before data collection and felt tired to continue the study.

#### *Procedure*

Eligible patients were invited to the hospital, informed about the details of the study, and oral and written informed consent was obtained from each of them. Patients who agreed to participate filled out the socio-demographic and medical history form, read and watched the intervention package, filled out the questionnaire, and responded to the interview questions. This study was reviewed and approved by the Health Research Ethics Committee of Dr. Hasan Sadikin General Hospital Bandung (RSHS) on December 23rd, 2013 (Document No: LB.04.01/A05/EC/127/XII/2013).

#### *Instruments*

A standard socio-demographic form was distributed to collect patients' background data on ethnicity, age, marital status, religion, education level, employment status, income level, medical status, and insurance status. To assess feasibility and acceptability, we used the modified version of the Client Satisfaction Questionnaire (CSQ)-8 to fit the context of the use of the psychoeducation intervention (PERANTARA) in Indonesia. The original CSQ-8 has eight questions assessing the global client's satisfaction in a clinical setting (Larsen et al., 1979; Matsubara et al., 2013). The patients respond to those items using a 4-point Likert scale, and the total scores range from 8 to 32. Higher scores indicate greater satisfaction. We applied the forward- and back-translation method to modify the CSQ-8. First, we translated the questionnaire from English to Indonesian, and then we translated it back into English.

Afterward, we compared the original English version and the back-translation of the questionnaire to identify any discrepancies. After discussing any possible discrepancies, we achieved consensus and finalized the Indonesian version of the CSQ-8 that fitted the context of the use of PERANTARA. In this current study, the modified CSQ-8 achieved an acceptable reliability coefficient ( $\alpha=.80$ ).

We conducted open-ended interviews to obtain patients' feedbacks on the intervention packages. The interviewer addressed the following questions: (1) How do you feel about this intervention package? (2) What is your opinion about the testimonies/stories conveyed by the survivors and the explanations conveyed by the doctors in this intervention package? (3) What is your opinion about the presentation of this intervention package (fonts, language, and image)?

#### *Data-analysis*

The data from were analyzed qualitatively based on the Theoretical Thematic Analysis, a method for identifying, analyzing, and reporting patterns (themes) within data (Braun and Clarke, 2006). To analyze the qualitative data, we used a qualitative software program (NVIVO version 11.40). We first transcribed the interviews and FGDs. Two authors (HS and AI) created a coding directory independently (created nodes in NVIVO). After that, the nodes were compiled into main themes and presented in a coding matrix. The coding matrix was discussed until an agreement on the framework was achieved. Then, the verbatim material was coded and analyzed independently. Discussion meetings were organized to compare analyses, adapt the coding matrix and main themes, and analyze the data again before an agreement was met. Frequencies and percentages of participants mentioning a theme were calculated, and typical citations were noted. Descriptive statistics were used to describe participants and to summaries feedback on the intervention (using percentage).

## **Results**

#### *Inventory*

As shown in Table 1, we retrieved 13 papers reporting research on psychoeducational interventions for a population that had psycho-social problems related to BC. In the papers we reviewed, the interventions were targeted at women with BC instead of focusing on women who were still uncertain about whether they had BC or not. Several methods to deliver psychoeducational programs were applied, both the self-help using psychoeducational material (written materials, audiovisual materials) as well as group delivery of psychoeducation. The psychoeducational programs were meant to increase knowledge on BC, increase satisfaction with information of BC and the treatment, reduce cancer worry, increase quality of life in women affected by BC, increase risk perception, and improve adjustment to BC diagnosis. According to findings of these studies, psychoeducation can be a potential psychosocial intervention option to help women with BC-related complaints. In addition, printed material and audiovisual materials can be the alternative

Table 1. Overview of Studies Examining Educational Interventions in Women with BC Symptoms

No	Study	Participants	Location	Interventions	Design	Outcome Measures	Results
1	Fukui, et al. 2000	BC patients (N=46)	Japan	Intervention Group: Facilitator-assisted (Group psycho-education, 1.5 hours weekly for 6 weeks) Control Group: the wait-list, no contact with the therapists until the intervention began.	RCT	The Profile of Mood States (POMS) The Mental Adjustment to Cancer (MAC) scale The Hospital Anxiety and Depression Scale (HADS)	In the group psychoeducation group: significant reductions in of POMS total mood disturbance scores ( $p=.003$ ), and increases in the POMS vigor scores ( $p=.002$ ) and MAC fighting spirit scores ( $p=.003$ ) post-intervention. No other differences between groups.
2	Jahraus, et al. 2002	BC patients (N=79)	Canada	1. Intervention Group: Self-help (Interactive video) 2. Control group: Facilitator-assisted (Individual and Group)	Pre-Posttest, no control group	The Toronto Informational Needs Questionnaire-Breast Cancer (TINQ-BC) Information-seeking activities: The Informational Styles Questionnaire (ISQ)	The patient education program significantly increased the perceived knowledge adequacy scores: disease subscale ( $p = <.01$ ), investigative subscale ( $p = <.01$ ), treatments subscale ( $p = <.01$ ), physical functioning ( $p = .01$ ), psychosocial functioning ( $p = .01$ ). No other differences between groups.
3	Appleton, et al. 2004	Women who had received BC genetic risk counselling (N=163)	United Kingdom	Intervention Groups: Group 1: Scientific and psychosocial written self-help information related to familial risk of breast cancer Group 2: Scientific written self-help information related to familial risk of breast cancer 3. Control Group: standard care only	RCT	Cancer Worry Scale (CWS) Objective knowledge of breast cancer risk-related topics Impact of Event Scale (IES) Perceived risk Perceived control	There was a significant decrease in cancer worry ,i.e. a significant decrease in scores on the CWS from baseline to postintervention for Group 1 ( $z = 2.133$ , $p = .033$ ) and Group 3 ( $z = -2.449$ , $p = .014$ ). The total number of correct responses on the objective knowledge of BC significantly improved between baseline and postintervention for both Group 1 and Group 2 ( $z = -4.605$ , $p = .000$ ; $z = -5.090$ , $p = .000$ ).
4	William, et al. 2004	BC patients (N=70)	United States	Intervention Group: Self-help (Audiotapes and written information) Control Group: Information about BC as usual	RCT	The Self-care diary (SCD) The Spielberger State-Trait Anxiety Instrument (STA)	The self-help education intervention increased the use of recommended self-care behaviors for anxiety on the first SCD ( $p < .05$ ).
5	Stanton, et al. 2005	BC patients (N= 558)	United States	1.Self-help standard written psychoeducation and peer-modeling videotape (VID) 2. Self-help standard written psychoeducation and peer-modeling videotape and two sessions with a trained cancer educator, and informational Workbook (EDU) 3. Self-help standard written psychoeducation Control)	RCT	The four-item Short Form-36 (SF-36; subscales: Vitality, Physical Component Summary and Mental Component Summary). The Impact of Events Scale (IES-R) The Center for Epidemiologic Studies-Depression Scale (CES-D) The Posttraumatic Growth Inventory (PTGI) Perceived Preparedness for Re-entry Scale	VID produced significant improvement in Vitality subscale of SF-36 at 6 months relative to CTL ( $p = .018$ ). No other differences between group.
6	Vallance, et.al. 2007	BC Survivors (N=377)	Canada	Intervention group: Self-help 1. Print Material (PM) Group: written material. 2. Pedometer (PED) Group: Step Pedometer 3. Combination (COM) Group: written material and Step Pedometer CG: Standard recommendation to perform physical activities (PA), no additional intervention materials.	RCT	The leisure score index (LSI) The Functional Assessment of Cancer Therapy-Breast (FACT-B) scale	The BC specific materials and pedometer significantly improved the Quality of Life ( $p = .003$ ). No other differences between group.
7	Burgess, et al. 2009	Women at risk of developing BC (N=292)	United Kingdom	Core intervention: Self-help psychoeducation booklet) Boosted intervention: Self-help psychoeducation booklet followed by interview)	Within-group before-and-after evaluation, no control group	Knowledge of BC symptoms, knowledge of risk, confidence to detect a change, and disclosure to someone close. The Lerman Breast Cancer Worry Scale	At 1-month postintervention, both psychoeducational interventions increased the mean number of BC symptoms identified ( $p=.001$ ) in the core intervention group ( $p=.001$ ) and in the boosted intervention group ( $p=.001$ ). No other differences between groups.

Table 1. Continued

No	Study	Participants	Location	Interventions	Design	Outcome Measures	Results
8	Capozzo, et al. 2010	BC patients (N=29);	Italy	Facilitator-assisted (Group Psychoeducation)	Pre-Posttest, no control group	The Mini-Mental Adjustment to Cancer scale (Mini-MAC)	Reduction in anxious preoccupation subscale of Mini-MAC ( $p = .003$ ). No significant changes on other subscales.
9	Dastan and Buzlu. 2012	BC patients (N=76)	Turkey	Intervention groups: 1. Facilitator-assisted (Group psycho-education) 2. Self-help (Audiovisual information) Control group: usual care	Pre-Post Test control group design	The Mental Adjustment to Cancer Scale (MACS)	At 6 months, group psychoeducation increased MACS subscales "fighting spirit," ( $p = .000$ ), and decreased "helplessness/hopelessness" ( $p = .000$ ), "anxious preoccupation" ( $p = .000$ ) and "fatalism" ( $p = 0.000$ ).
10	Komatsu, et al. 2012	BC patients (N= 82)	Japan	Intervention groups: 1.Self-help kit (written information and video) 2.Facilitator-assisted (Professional-led support groups) Control group: usual care	Pre-Post Test control group design	The Center for Epidemiologic Studies-Depression Scale (CES-D) The Spielberger State-Trait Anxiety Inventory (STAII) Quality of Life (SF-36)	Reduction in mental subscale score of SF-36 between the intervention and the control groups over the study period, but the effect size was small ( $F = 7.48, p = .008, \eta^2 = .004$ ). No other differences between groups.
11	Sherman, et al. 2012	BC patients (N = 249)	United States	Intervention groups: 1.Self-help (Videotapes); 2.Facilitator/Counselor assisted (Telephone Counseling) Control group: usual care	RCT	The Profile of Adaptation to Life Clinical Scale (PAL-C) The Self-Report Health Scale (SRHS) The Psychosocial Adjustment to Illness Scale (PAIS) The Breast Cancer Treatment Response Inventory (BCTR)	Improvement within the telephone counselling group in PAL-C psychological well-being from baseline to adjuvant therapy, followed by a decrease from the adjuvant therapy phase to the ongoing recovery phase ( $p = .002$ ). Higher side effect distress subscale of the BCTR in intervention groups ( $p = .012$ ) from post-surgery to ongoing recovery. No other differences between groups.
12	Jones, et al. 2013	BC patients (N = 442)	Canada	Intervention group: Getting back on track (GBOT) Class Control group: Getting back on track (GBOT) Book.	RCT, no inactive control	1 The Knowledge Regarding Re-Entry Transition (a questionnaire specifically developed to cover the contents of GBOT curriculum) 2. The Perceived Preparedness for Re-Entry Scale (Stanton, et al. 2005) 3. The Self-Efficacy for Managing Chronic Disease Scale 4. The Profile of Mood States Scale-Short Form (POMS-SF) 5. The Medical Outcomes Study (MOS)-Health Distress Scale	Group psychoeducational intervention significantly enhanced ( $p < .0001$ ) the knowledge regarding the re-entry transition period and their feelings of preparedness for the re-entry phase ( $p < .0001$ ). No other differences between groups.
13	Ram, et al. 2013	BC patients (N = 34)	Malaysia	Facilitator assisted (Group psycho-education)	A cluster non-randomized trial	The WHO-five Well-being Index (1998 version)	The group psychoeducation improved the proportion of patients in the state of adequate well-being ( $p < .05$ ) and reduced the proportion of depressed patients ( $p < .05$ ).

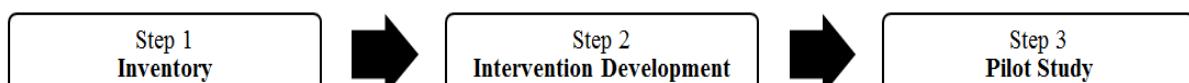
BC, Breast cancer; RCT, Randomize control trials

delivery methods, especially when resources to deliver individual or group psychoeducation are limited (money, facilities, experts).

After consulting with women with BC and healthcare providers, we found seven themes, including (1) Target Population; (2) Content; (3) Delivery Method; (4)

Delivery Agent; (5) Time Frame of Delivery; (6) Location; and (7) Possible barriers. The primary results per theme are described below.

1) Target population. Most of the BC patients (23 patients, 82.5%) recommended that the psychoeducational program should also be given to their caregivers (spouse,



Activities:  
1.1 Literature Review  
1.2 Interview (n= 27 patients)  
1.3 FGDs (n = 15 Healthcare Providers)

Activities:  
2.1 FGDs (n = 4 Experts and 2 BC Survivors)  
2.2 Developing the first pilot version (n=4 experts and 2 BC Survivors)

Activities:  
3.1 Interview (n = 13 patients)

Figure 1. Intervention Development Framework

family, or their significant other). The healthcare providers (oncologists and nurses) also agreed that the psychoeducational program should be targeted at the caregivers too.

2) The content of the intervention. The patients stated that they needed to get more information from the experts regarding (a) breast cancer and its treatment (27 patients, 100%), (b) coping strategies and spirituality (25 patients, 92.6%), (c) nutrition and diet (16 patients, 59.3%), and (d) healthcare facilities and financial support (9 patients, 33.3%). The healthcare providers mentioned that patients needed to have sufficient understanding of their illness, so that these patients would immediately call for medical help and comply with the examination/diagnostic and treatment procedures.

3) Delivery method. Many participants (20 patients, 74.1%) believed that the delivery method should be interactive as well as informative using group discussion or individual consultation. Some of the patients (n= 14, 51.9%) suggested that psychoeducation materials, written

and audiovisual, could be used as supplementary tools as long as they contained expert explanations and displayed visually attractive pictures but not too frightening ones. Several patients (n=7, 25.9%) suggested using the internet, even though they realized that some patients would need other people to help them in accessing the information on the internet.

4) Delivery agent (Facilitator). Both patients and healthcare providers agreed that healthcare provider should be delivery agents (facilitator). They mentioned that this might be a task of an oncologist (16 patients, 59.3%) and a nurse or a midwife (15 patients, 55.6%). Despite the fact that most of the patients understood that their oncologist or doctor had limited time to deliver the intervention, they still considered the oncologist as the key delivery agent.

5) The time frame of delivery. Both healthcare providers and patients recommended using this program when they were visiting the healthcare institution, at the first breast symptom before breast cancer diagnosis (19

Table 2. Intervention Blueprint

Title	Perantara: Pengantar Perawatan Kesehatan Payudara (Introduction To Breast Health Treatment)
Format	Table Flipchart
Language	Indonesia
Target Population	Female patients with breast cancer symptoms and newly diagnosed breast cancer. Demographic Status: middle to low level of education status, middle to low level of socio-economic status, live in the urban and rural area.
Behavior Objective	Reduce patient's delay and improve patient's adherence
Main Themes	
PERANTARA 1: Segera Periksa Ke Dokter (Immediately Consult The Doctor)	Profile: Oncologist and Breast cancer survivor Early Detection and Breast Cancer Symptoms Risk Factor of Breast Cancer: Diet, Hormone and reproduction factor, Radiation exposure, Genetic factor, Women with history of breast cancer or non-cancerous breast lumps. Breast Examination Procedures: Physical examination, Biopsy, Breast imaging, Receptor test. Support to diminish treatment delay, seeking help from significant person, especially family and husband.
PERANTARA 2: Patuhi Rekomendasi Dokter (Comply Doctor's Advice)	Breast cancer treatment and its effects: Surgery, Radiotherapy, Chemotherapy, Hormone therapy. Patuhi Rekomendasi Dokter (Comply Doctor's Advice) The choice of food, nutrition, and physical activity are recommended for breast cancer patients who are undergoing treatment.
Additional.	- Important list of address to gain support: informational, financial and emotional. - Personal notes: Complaints, questions asked, doctor's advices and other important notes - Calendar, to write down the scheduling of examination and treatment process
Title	Kisah Nyata Dua Perempuan Tangguh
Format	Audiovisual Story Telling - DVD
Language	Indonesia
Target Population	Female patients with breast cancer symptoms and newly diagnosed breast cancer. Demographic Status: middle to low level of education status, middle to low level of socio-economic status, live in the urban and rural area.
Behavior Objective	Reduce patient's delay and improve patient's adherence
Scene (Key Message)	Description
Introduction	Introduction: Survivor's Profile
Early Detection and Breast Cancer Symptoms	Breast Cancer Survivor's Testimony: - Early Detection - Breast Cancer Symptoms
Support to reduce patient's delay and increase adherence	Breast Cancer Survivor's Testimony: - Support to dealing with bad news - Support to reduce patient's delay - Support to increase adherence - Spirituality and Family Support

PERANTARA is abbreviation for PENGANTAR PERAWATAN KESEHATAN PAYUDARA, which means introduction to breast health treatment. The word PERANTARA is in Indonesian language that means mediator or facilitator. The PERANTARA will be delivered using printable and audiovisual materials. These materials will be given to the patient at hospital.

Table 3. Patients' Opinion

Theme	Sub Theme
Usability How do you feel after using the PERANTARA?	<b>Helpful.</b> Patients feel that PERANTARA is helpful because: improve their knowledge and awareness to continue the examination so that his complaint is promptly diagnosed and treated, and reduces anxiety and doubts to continue the examination and treatment. Patients feel that this intervention package is useful so they will recommend this package to others. <b>Motivating.</b> Patients feel motivated to use this package because it is attractive. Also, they also feel motivated to continue the examination and treatment after getting an explanation from the doctor and testimony from survivors in this package.
Source of Information What is your response to information provided by BC survivors and oncologists?	<b>Survivor.</b> Patients feel that the true story of the BC Survivors found in the PERANTARA stirred their feelings because the women who have been diagnosed with cancer still have high spirits to undergo the process of examination and treatment. Also, they also feel touched because it turns out BC Survivor can still live their lives every day without feeling isolated. Therefore, they suggested that the survivors' profiles could be added in the package. <b>Oncologist.</b> Oncologist's advice was helpful and easy to understand. Patients stated that information about the diagnosis of breast cancer and its treatment was helpful knowledge. Also, information on risk factors and preventive action is valuable.
Presentation What is your opinion regarding the presentation/display of the PERANTARA? Use past tense to present patients' opinions. I mean all you have written in the column named sub theme should be in past tense.	<b>Clarity.</b> The language and images that used make the information more understandable. Patients recommend that fonts in the bubbles be enlarged and critical statements written in bold fontss. <b>Attractiveness.</b> The images and colors used make the PERANTARA more interesting and not boring. Alternatively, patients suggest using photos.

patients, 70.4%), as well as during treatment (22 patients, 81.5%).

6) Location. Healthcare providers and some patients (14 patients, 51.9%) recommend nearby district hospitals as suitable locations for delivering psychoeducational programs.

7) Possible barriers. More than half of the patients (14 patients, 51.9%) considered their psychological conditions (anxiety, stress, fatigue) as potential barriers to engage in the intervention program. Some of the patients reported their financial problems (7 patients, 25.9%) and lack of

communication facilities (3 patients, 11.1%) as potential obstacles against engaging in the intervention program. Approximately a quarter of the patients (8 patients, 29.6%) considered some characteristics of the care provider (communication skills, a limited amount of expert time and consultation ) as possible challenges in the development and implementation of the intervention program. The care providers had a similar perspective toward these barriers. Moreover, they added that the educational / knowledge level of the patient was also important when developing and implementing an intervention program.

Table 4. Client's Satisfaction Inventory

Factors	Patient's Response				
Quality of the Materials	Poor	Fair (n=1, 8,3%)	Good (n=8, 66,7%)	Excellent (n=3, 25%)	
Kind of Information	No, definitely	No, not realy (n=1, 8,3%)	Yes, generaly (n= 5, 41,7%)	Yes, definitely (n=6, 50%)	
Met need	None of my needs have been met	Only a few of my needs have been met (n=2, 16,7%)	Most of my needs have been met (n=6. 50%)	Almost all my needs have been met (n=4, 33%)	
Recommend to a friend	No,definitely	No, I don't think so	Yes, I think so (n=2, 16,7%)	Yes, Definitely (n=10, 83,3%)	
Amount of help	Quite Dissatisfied	Mildly Dissatisfied	Mostly Satisfied (n=9, 75%)	Very Satisfied (n=3, 25%)	
Deal with problems	No, they seemed to make things worse	No, they really didn't help	Yes, they helped (n= 5, 41,7%)	Yes, they helped a great deal (n=7, 58,3%)	
Overall satisfaction	Quite Dissatisfied	Mildly Dissatisfied	Mostly Satisfied (n=8, 66,7%)	Very Satisfied (n=4, 33,3%)	
Continue using the materials	No, definitely	No, I don't think so	Yes, I think so (n=7, 58,3%)	Yes, Definitely (n=5, 41,7%)	

PERANTARA (self-help psychoeducation materials); Material 12 patients; Participant

Table 5. Final Script

**PERANTARA:**  
Segera Periksa Ke Dokter  
Format: Table Flipchart  
Language: Indonesia



**Target Population** Women with breast cancer symptoms (that can be presumed as related to breast cancer during the first visit to hospital). Demographic Status: middle to low level of education status, middle to low level of socio-economic status, live in the urban and rural area.

**Behavior Objective** Reduce patient's delay (Time to Diagnosis)

**Key Content**



**Part 1 Profile.**  
Oncologists. Breast Cancer Survivors

**Part 2. What's on My Breast.** A brief explanation of breast cancer symptoms for enabling the patients to have an accurate understanding and motivation to seek information/help from oncologists as a credible sources.

**Part 3. Why should immediately consult a Doctor?**

A stimulation to let the first breast examinations immediately be followed by a biopsy so that the disease can be diagnosed and treated early; and a brief explanation of breast examination procedure to raise the patient's awareness on their symptoms and willingness to follow the procedure.

**Part 4. You are not alone.** Information showing that many people are around who care; Recommendation to seek support from significant persons and institutions.

**Personal Notes.** Providing facilities (space) for patients to record some important things, for example: complaints, questions asked, doctor's advices and other important notes

**Title** KISAH NYATA DUA PEREMPUAN TANGGUH

**Format** Audiovisual Story Telling - DVD

**Language** Indonesia

**Target Population** Female patients with breast cancer symptoms (that can be presumed as related to breast cancer during the first visit to a hospital). Demographic Status: middle to low level of education status, middle to low level of socio-economic status, live in the urban and rural area.

**Behavior Objective** Reduce patient's delay (Time to Diagnosis)

**Short Description** The testimony of two survivors of breast cancer who shared their stories about their conditions, promoting active coping and seeking social support, and give recommendation to patients to consult a doctor immediately when they discover abnormalities in their breast.

Table 5. Continued

Scene (Key Message)
1) Introduction. Sample script: “This is a true story of the struggles of two tough women, ever since they discovered any abnormalities in their breasts, until successfully through various challenges during the treatment process. Now, they are still actively working for the community and beloved family.”
2) Reduce delay. Sample script: “If we find the things that are suspicious, or anything different than usual, consult with a doctor or other health professionals, to assure what the problem is...” “Do not be too scared first because not all lumps are cancer. The important thing is consult to the doctor immediately to know the examination procedures.”
3) Coping with psychosocial issues. Sample script: “...When you go through the process of examination and treatment, probably will emerge feeling sad and lonely. You do not have to worry too much, because you are not alone. Many care about you! Ask your husband, family or friends to accompany you. Share stories, feelings and expectations need to be done...” “...My message to the family, especially to her husband, the emotional support to a spouse or who are undergoing examination or treatment of breast cancer is very important. Without the support of the husband, their spirit will fall.”
4) Contacts Important list of address to gain support: informational, financial and emotional.

### *Intervention Development*

The process of developing PERANTARA begins with FGDs involving an oncologist, health psychologists, a health communication expert, and BC survivors. The following were the results of the FGDs:

1) Who was the target population? The panel recommended patients as the target population of the psychoeducational intervention. Depending on the specific behavioral objective, interventions were delivered to the patient during her first visit to the hospital after finding BC symptoms, after BC diagnosis, or during treatment. Moreover, the caregiver was also considered to receive psychoeducation because the caregiver's support would influence a patient's health behavior.

2) Who should deliver the content? Potential psychoeducational intervention agents included oncologists, nurses, midwives, psychologists, social workers, or BC survivors. The oncologist was considered more credible due to his medical background, while the BC survivor was regarded more acceptable because of her experiences.

3) What were the contents? The psychoeducational program should provide both a simple scientific and medical explanation of BC symptoms and psychosocial support in order to stimulate the patients to immediately undergo the examination (diagnostic). This would enhance quick diagnose and treatment of the disease.

4) How to deliver the content? The selection of the delivery method was chosen according to demographic characteristics of the target population (middle-low education level, middle-low social, and economic status). Further, the limited availability of healthcare professionals and consultation time within the hospital was regarded. Therefore, the intervention was self-help, and support by practitioners was limited. Furthermore, the panel also

recommended the use of attractive printed and audiovisual materials.

5) Where to deliver the program? Some locations were considered as potential places to deliver the psychoeducational package, including hospital, first line health services, and community activity center.

Based on these recommendations, the first author wrote a script (intervention blueprint) as guidance in developing an intervention package (PERANTARA). Critical elements in the intervention blueprint included title, format, language, target population, behavior objective, and main themes. (See Table 2. Intervention Blueprint). Based on this script, the PERANTARA package was developed with an audiovisual communication designer. The prototype was discussed with each of the research group members and, based on their feedback, the first pilot version of PERANTARA package was finalized.

### *Pilot Study*

#### *Qualitative Analysis*

As demonstrated in Table 3 (Patient's Opinion), patients stated that PERANTARA package was valuable and motivated them to undergo the medical procedure. Patients believed that the explanation given by the oncologist in PERANTARA was understandable and helpful. Furthermore, the patients stated that the narrative approach in presenting the information and utilization of a variety of images made PERANTARA clear and attractive

#### *Quantitative Analysis*

As shown in Table 4 (Client's Satisfaction Inventory), the large majority of patients (n=9; 75%) appeared to be satisfied with the help they had received from PERANTARA. According to patients, the quality of PERANTARA was good (n=8; 66,7%) and met their

needs (n=6; 50%). Furthermore, we found that patients obtained the information they needed (n=6; 50%) and PERANTARA helped them to cope with their problems more effectively (n=7; 58,3%). Moreover, patients stated that they were willing to continue using PERANTARA (n=7; 58,3%) and to recommend this intervention packages to a friend who would need similar help (n=10; 83,3%).

#### Finalization

Based on the results of the pilot study, we made some revisions in the content and presentation of PERANTARA (Setywibowo, 2017). These revisions were made following consultation with an oncologist, a health communication expert, a health psychology expert, and BC survivors. The revisions were:

1) The printed materials were adapted (adapted in a form of Table Flipchart (See Table 5). The content of table flipchart consisted of: (1) What's in my breast? a brief explanation of BC symptoms to enable patients to have an accurate understanding and motive them to seek help from oncologists as a reliable sources; (2) Why should I immediately consult a doctor? This part aimed to stimulate women to follow the examination procedure as soon as possible so that the disease can be diagnosed and treated as early as possible and to raise the patient's awareness on her symptoms; and (3) You are not alone: the recommendation to seek support from significant persons and institutions is provided.

2) Audiovisual materials . We added brief summaries of the key messages given in the printed materials. Besides, we also added a profile photo of an oncologist and BC survivors to increase the credibility of the information sources. See Table 5 (Final Script) for the final outline of PERANTARA.

## Discussion

In this study, we explained the process for the development of PERANTARA, a self-help psychoeducational material for Indonesian women with BC symptoms. Its development was an iterative process involving patients (women with BC symptoms, women with BC, and BC survivors), healthcare providers (nurses and oncologists), and a multi-disciplinary group (health psychologist, health communication, and audiovisual designer). First, we interviewed the patients since they were the potential target group for our intervention. Furthermore, we involved experts from various fields and BC survivors to review the intervention framework that we had designed based on the results gained in the inventory step. This was done since we had to consider the resources to develop and evaluate the intervention.

The PERANTARA development was based on data collected from previous studies investigating psychoeducational interventions in other populations. We found that using printed and audiovisual materials could be a potential option to deliver psychoeducation to women with BC-related complaints, especially when resources were limited in terms of money, facilities, and experts to provide face-to-face or group psychoeducation.

A strength of PERANTARA is the use of narrative

storytelling to educate and to persuade women with BC symptoms to immediately undergo the examination process so that the disease can be immediately diagnosed and treated. The use of narratives is emerging as a strategy to educate, persuade, and prompt health behavior change. Some previous studies reported that delivery of health information through the use of narratives was intrinsically persuasive (Kreuter et al., 2007; Kreuter et al., 2010; Dahlstrom, 2014) and more acceptable for patients with low and adequate health literacy (Moran et al., 2016) and populations that had a strong oral tradition (Hinyard and Kreuter, 2007), such as Indonesia. It is noteworthy to mention that PERANTARA contained information about both medical and psychosocial issues related to BC symptoms and diagnosis procedure. It aimed to reduce diagnostic delays and to support patients with BC symptoms. Evaluation of the content by a BC survivor, an oncologist, and a health psychologist confirmed that the information was relevant for women with BC symptoms.

A limitation of this study was that we included a small sample of women with BC and BC symptoms who may not represent the larger population of women with BC symptoms in Indonesia. Therefore, we recommend conducting a clinical trial in order to evaluate the efficacy of PERANTARA in reducing the time to diagnosis of Indonesian women from the moment they discover BC symptoms.

The results indicated that most of the women with BC and BC symptoms who participated in the pilot study had positive reactions toward the intervention package and were willing to recommend PERANTARA to new patients with BC (symptoms).

This study provided a useful framework to develop and pilot test a newly psychoeducational intervention. Given that the results of the ongoing crossover-controlled trial were positive, our intervention can be applied within standard oncological care in Indonesia. With some adaptation, the PERANTARA might also be suitable for women diagnosed with BC who had delayed their treatment. Moreover, the development process of PERANTARA, as described in this study, can be used as a future template to develop psychoeducational materials for other patient groups. Future studies are recommended to develop some psychoeducational interventions to help the caregiver of BC patients to cope with their psychosocial challenges.

#### Statement conflict of Interest

The authors declare that they have no competing interests.

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