



Experience With A Support Group Intervention Offered to Breast Cancer Women

Figen Erol Ursavaş¹, Özgül Karayurt²

¹Department of Nursing, Çankırı Karatekin University School of Health Sciences, Çankırı, Turkey

²Department of Nursing, İzmir Ekonomi University School of Health Sciences, İzmir, Turkey

ABSTRACT

Breast cancer is the most frequent cancer in Turkey and other countries. It is not sufficient for women with breast cancer to receive medical treatment protocols (i.e. surgery, chemotherapy, radiotherapy and hormone therapy) to overcome their disease. Breast cancer has biopsychosocial effects on the patients. Provision and maintenance of biopsychosocial wellbeing of the patients during and after the medical treatment process should be one of the primary treatment criteria. It is important for women with breast cancer to develop new strategies to adapt to the disease and treatment processes and to cope with their disease. Support groups and education are quite frequently utilized to achieve this adaptation and coping. Support group interventions allow the women to discuss, receive education and share their experiences. These opportunities guide the patients about how to manage their disease and help them fulfill their social support needs. Support groups are very important to promote physical and psychological health, expand social network and increase social support for breast cancer women. The aim of this review is to reveal experiences in the preparatory and implementation stages of a support group intervention designed for women diagnosed with breast cancer in the framework of a PhD dissertation.

Keywords: Experience, support group intervention, education, breast cancer

Introduction

Breast cancer is the type of cancer with the highest incidence rate in developing and developed countries globally as well as in Turkey (1, 2). According to the GLOBOCAN 2012 data, breast cancer constitutes 25% of all cancer cases globally and the incidence rates vary per country. While the incidence rate of breast cancer is 27 out of one hundred thousand in East Asia and Central Africa, this rate is reported to be 92 out of one hundred thousand in North America. The global five-year prevalence of breast cancer is reported to be 6.232.000 cases in total (1). While an increase is observed in global breast cancer incidence, it has been determined that breast cancer incidence started to decrease in developed countries such as France, Spain, USA, Canada, Australia and New Zealand (1). According to the 2016 data of the Ministry of Health in Turkey, breast cancer ranks the first with a rate of 45.9 out of one hundred thousand among age-standardized rates of the 10 cancers seen most frequently among women (2).

Breast cancer is a disease that influences people in biopsychosocial aspects. It is also recommended that patients are offered interventions that involve education and consulting in addition to medical treatment protocols as part of the therapeutic process. It is important for women with breast cancer to develop new coping methods to be able to adjust to the disease. Social support and education are interventions that are rather frequently used for this purpose (3-5). It has been identified that women diagnosed with breast cancer need support groups and education in order to cope with the crisis they experience (6, 7). Studies performed have determined that support group interventions help women cope with emotional problems such as anxiety, depression and despair, meets the need for information and support related to the disease, enhances emotional well-being and positively influences life satisfaction (8-11).

Support group intervention consists of educating people experiencing similar problems in a safe and comfortable environment about the disease and disease management and having them listen to one another and have discussions for ensuring emotional support (8). Support group intervention involves mutual discussion, education and sharing similar problems. The content of education consists of interventions about the way in which the disease and side effects of therapy will be managed. The goals of cancer support groups is to provide mutual discussion, education, direct help, make suggestions on the basis of personal experience, provide emotional support and develop

the emotion of belonging to a group. The support group and patients receive education and emotional support from the group members (peers) and group leader. Furthermore, support group intervention provides contribution for people to control their emotions, enhances their problem-solving skills and coping methods and facilitates compliance with the disease and treatment process (8, 12).

Cancer support groups provide a significant means that meets the social support requirements of cancer patients. The scope of social support for cancer patients is composed of family members (mother, father, sibling and children), close circle (relatives, friends) and health-care team (doctor, nurse, social service worker, psychologist). There are multiple social support elements in a cancer support group. While the group is composed of other cancer patients, who may be seen as friends as part of a close circle, a professional from the healthcare team assumes the role of the leader (12). It is recommended that support sessions last 60 min. to 90 min, are held with 6 to 20 participants, that 6 to 12 sessions are held and the frequency of meeting of support groups is determined on the basis of patient requirements and wishes (8, 12). The studies held show that sessions are held at different frequencies: every week, three days a week and once a month (4, 8, 13-15).

There are studies in the literature where the support intervention was applied for women with breast cancer and results were evaluated (4, 8, 11, 13). Similarly, a study was conducted where the influence of a support group intervention based on the Roy Adaptation Model (RAM) on sexual adaptation, body image and perceived support was examined at the Daytime Treatment Center of a University Hospital in Turkey in 2016. In a review, the experience gained in the study process was shared towards the aim of providing guidance for researchers who would conduct studies on "Support Group Intervention" in the future.

Support Group Intervention Preparatory Phase

The researchers developed an educational book aligned with the support group intervention program to meet the requirements of patients on the basis of RAM by benefiting from the literature. Regarding the research into and care by nurses, it is specified that a model should be used in order to ensure that nurses can focus on the nursing role and practice and to be able to provide systematic and effective care (16, 17). RAM was developed by Sister Callistra Roy in late 1960s and it was originally used in a license program in 1970. According to RAM, a highly developed model that is frequently used in defining the concepts of nursing, the purpose of nursing is to promote compliance and prolong the life expectancy (16). According to RAM, compliance in four adaptation model needs to be achieved. These adaptation systems are the following: physiologic mode, self-concept mode, role function mode and mutual interdependence mode. The content of the educational book was created on the basis of the adaptation modes of RAM.

The essential requirement in the physiologic mode is physiological integrity. The physiologic adaptation mode is composed of nine elements. The five essential elements are: oxygenation, diet, elimination, movement-resting and defense. Additionally, the four complex elements of liquid electrolyte, acid-base balance, neurological function and endocrine function are also in the scope of the physiological adaptation area (16-18). In the educational book to be used with the support group intervention, educational content for the areas of diet, elimination, movement-resting and defense has been formed.

The mode of Self-Concept was tackled in two dimensions being the physical self and personal self. Physical self is divided into two parts:

body image and emotions about the body. Emotions about the body include the person's body attitude about his/her own body and emotions about his/her sexuality (16-18). The educational book contains interventions targeted at diminishing the influence of the side effects of treatment methods on the body image and sexuality in order to intervene on the adaptation mode of the self-concept.

The underlying basis for the mode of role function is the assurance of social integrity. It focuses on the roles of an individual in the society (16-18). The educational book lays out interventions towards the aim of coping with the influence of the side effects of treatment methods on the mode of role function.

The mode of mutual interdependence is focused on the interaction of individuals within the framework of love, respect, gaining and showing appreciation. The fundamental purpose of this mode is relational integrity. In the mutual interdependence mode, the interactions of individuals with the individuals they deem important in their lives and support systems (16-18). To ensure adaptation in this mode, efforts were made to develop social aspects such as mutual love, respect, gaining and showing appreciation by means of the support group intervention.

Regarding the content of the educational book, opinions were received from six specialists in total: three members of faculty in the fields of general surgery, radiation oncology and medical oncology with specialization in breast cancer, one physical therapy specialist and one psychologist. The necessary changes were made as per the opinions of specialists and the educational book was finalized. The educational book includes the subjects explained during the support group trainings and is composed of 86 pages and 15 chapters in color print. The chapters of the book are as follows: 1) Breast cancer team, 2) Breast texture and breast cancer, 3) Breast cancer risk factors, 4) Signs and diagnose of breast cancer, 5) Breast self-exam, 6) Surgical treatment methods for breast cancer, 7) Side effects that may emerge following surgical treatment, 8) Breast reconstruction, 9) Breast cancer chemotherapy, 10) Radiotherapy for breast cancer, 11) Hormone therapy for breast cancer, 12) Target-oriented treatment for breast cancer, 13) Diet in breast cancer, 14) Breast cancer and sexuality, 15) Safe sexual intercourse (19). The educational books were handed out to patients that would join the group before the start of support group meetings.

The place where the sessions would be held should offer the possibility to strengthen the interaction among group members. There should be a place known by group members which is easily accessible by everyone. It is necessary that the place selected be an area that is spacious enough and offer the possibility to sit on chairs and would not cause any communication issues among group members. Furthermore, it is necessary that people are seated in an arrangement to communicate comfortably with one another, have a table to be able to take notes and room temperature be adjusted well (20). In this context, support group sessions were held in a meeting hall in the chemotherapy unit known by everyone and easily accessible by everyone. In the meeting hall where the support group intervention was held, there was a large, round table and chairs around the table. The size, lighting and temperature of the room were convenient.

Making the Announcements and Determining the Participants for the Support Group Interventions

Registered women with breast cancer undergoing chemotherapy treatment at a daytime treatment center were called by phone and women

meeting the sample criteria were phoned and informed about the support group intervention and they were invited to participate in the support group meetings. Furthermore, information about the support group was also provided for women with breast cancer during the day by the nurse in charge and chemotherapy nurses and they were invited to the training. *Criteria for inclusion in the sample:* participants volunteering to take part in the study, being above the age of 18, being able to understand and speak Turkish, not having any hearing and speaking problems, being literate, having a sex partner, having been diagnosed with primary breast cancer, having undergone mastectomy or breast-conserving surgery.

Oncology nurses play an important role in meeting the education and support requirements of women diagnosed with breast cancer (7). The biggest concern following these meetings was related to ensuring the participation and continuing the attendance of patients. Regular participation in weekly meetings may be challenging as a function of the healthcare conditions of participants. Furthermore, patients participating in group meetings compare the progress of diseases with the other members of the group. Such factors may influence the participation of patients in meetings and their attendance (12). The sensitivity of nurses for the participation of women with breast cancer in support group meetings, their appreciation of support group meetings and encouragement they provided for women's participation have been facilitating factors in patient participation. Following the briefings and announcements made, the first session date was identified and patients were invited. The meetings were planned to be held on days when they would receive treatment. The patients had their blood analyses done in the mornings of these days and attended the meetings in the period of time they would wait for the results. This facilitated the assurance of attendance. Forty eight women agreed to present for the support group trainings. Four groups of twelve persons each were formed. Six people did not present to the training on the first day of education. The first meetings were held with 42 women in total who attended the support group trainings. Each and every woman participating in the meetings was very willing. In the consequent meetings, five people did not continue to attend the trainings for reasons such as pain, tiredness, unwillingness to hear anything about treatment, to be in the same environment with the same patient group and not answering the phone. Therefore, the group sizes were changed and four different support groups of 7-11 persons each were formed. One patient did not come to the meeting due to pain and another patient gave the following feedback: "I was actually not going to attend today's meeting since I had pain. My husband insisted that I go. I am happy that I came, it's very interesting. I currently have no pain even though I took medication. Since I focused my attention on you and my friends instead of myself, this feels very good for me." This feedback was very important in the sense that it showed the effectiveness of the support group. The patients' opinions about the frequency of support group meetings were received. In keeping with the participants' willingness to learn and to prevent having too long intervals in between, the frequency of sessions was set to be once a week.

At every support group meeting, patients were given cosmetics such as eyebrow eyeliner, eye shadow and sunscreen and small gifts such as vaginal lubricant and preservative. The fact that the majority of patients came to the meeting held the week after having used the make-up products also motivated the patients who had not yet use them to do so. A patient who was a retired teacher of painting said: "You have reminded us to perform self-grooming. We are back in touch with life again thanks to you." This statement was an indicator of the positive effect of the support group intervention on the body image.

Performance of the Support Group Intervention

Four sessions of the support group intervention applied on women with breast cancer were conducted by a consulting nurse and one session by a psychologist. The support group intervention was completed with four groups in five weeks with meetings of 90-120 min. once a week. In total, 20 support group meetings were held with four groups. The program applied in the support group intervention is shown in (Table 1).

The support group meetings were held in a seating arrangement where everyone could see one another at a round table in the daytime treatment center meeting hall of a university hospital. The lack of an authoritarian figure in this seating arrangement and the moderator of the session being in the same position as the patients provided relaxation for patients and encouraged them to share more (21). The written feedback received from patients such as "Gathering at a table was a very nice and positive practice." showed that the setting of the sessions was crucial and it positively influenced the individuals regarding participation and listening.

The consulting nurse shared the literature information about the subject using a visually enhanced power point presentation and shared it in a language understandable by patients without using medical terminology. Furthermore, the consulting nurse also answered the questions from the group and promoted active participation by group members and encouraged patients to share more. In this context, the patients shared their experience in line with the new information they acquired and found solutions to their problems by sharing their experience or learning from other participants' experience.

Support group intervention consists of educating people experiencing similar problems in a safe and comfortable environment about the disease and disease management and having them listen to one another and have discussions for ensuring emotional support (8). In Canada, it was determined that participants who participated in support groups expressed that support groups offered an excellent meeting atmosphere facilitating safe discussion/talk, ensuring the unknown to be recognized, making it easier to take decisions and inspiring hope (22). The written feedback received from patients such as "Since I gained new information, I also learned what I should do and should not do in this process. I have applied them and I continue to do so", "I feel safe here", "We're given the opportunity to talk and I really like this", "Knowing that we're not alone and hearing different suggestions about how to cope with problems have been useful", "I have been able to express and share everything related to my disease very comfortably. I have really enjoyed these." (Table 2) is important in the sense that it showed that the support group initiative achieved its goal.

Support group intervention helps patients to save themselves from being stigmatized as a cancer patient, develop sound communication with their loved ones and the treatment team and develop coping methods. Furthermore, receiving support from friends and supporting them, getting away from the thought of death, relieving or eliminating stress, depression and anxiety and reducing the feeling of despair are some of the positive effects that enhance the psychosocial adaptation of patients (12, 23). In this context, it is important that a support group initiative be accompanied by a consulting psychologist to ensure psychosocial well-being. The secondary sessions of the support group intervention were conducted by a consulting psychologist who worked for a long time with cancer patients. The psychologist tried to understand how patients met breast cancer and how they were influenced by it in the sec-

Table 1. Support group intervention program administered for women with breast cancer







Support group intervention	Educational subjects
1. Support group intervention (90 min)	<ol style="list-style-type: none"> 1. Introduction, Handing out the Educational books 2. Application of data collection tools 3. Sharing the expectations from the session 4. Sharing the educational program 5. Handing out the educational book prepared 6. Primary educational subjects <ul style="list-style-type: none"> • Incidence rate of breast cancer • Risk factors for breast cancer • Importance of diagnostics methods, diet and activity 7. Answering questions about the above-mentioned subjects and sharing experience 8. Receiving feedback and sharing the topic and date of the next session
2. Support group intervention (120 min)	<ol style="list-style-type: none"> 1. The subject of the second session was “coping with stress and offering psychological support.” This training was conducted by a consultant psychologist working with cancer patients. 2. Sharing the emotions, thoughts and experience about the subject of the session 3. Receiving feedback and sharing the topic and date of the next session 4. Handing out the key-holders with blue 'evil eye' beads prepared for the patients
3. Support group intervention (90 min)	<ol style="list-style-type: none"> 1. Subjects of the third training session <ul style="list-style-type: none"> • Suggestions to prevent and manage the side effects of chemotherapy and target-oriented therapy <ul style="list-style-type: none"> - Choosing a wig, hair loss, eyebrow and eyelash loss, skin changes, nausea, vomiting, changes in nails, vaginal dryness • Suggestions to prevent and manage the side effects of hormone therapy <ul style="list-style-type: none"> - Osteoporosis, vaginal dryness, hot flush, deep vein thrombosis 2. Answering questions about the above-mentioned subjects and sharing experience 3. Receiving feedback and sharing the topic and date of the next session 4. Offering eyebrow shadows, eyebrow eyeliners
4. Support group intervention (90 min)	<ol style="list-style-type: none"> 1. Subjects of the fourth training session <ul style="list-style-type: none"> • Suggestions to prevent and manage the side effects of surgical treatment <ul style="list-style-type: none"> - Breast prosthesis, correct choice of bra, breast reconstruction - Frozen shoulder syndrome and its prevention - Lymph edema and prevention • Suggestions to prevent and manage the side effects of radiotherapy <ul style="list-style-type: none"> - Preventing skin changes in the breast, wet-dry desquamation, edema in the breast, fatigue 2. Answering questions about the above-mentioned subjects and sharing experience 3. Receiving feedback, sharing the topic and date of the next training session 4. Handing out sunscreens to prevent sunburns
5. Support group intervention (90 min)	<ol style="list-style-type: none"> 1. Subjects of the fifth training session <ul style="list-style-type: none"> • Suggestions for improving sexual life • Safe sexual intercourse 2. Answering questions about the above-mentioned subjects and sharing experience 3. Receiving feedback 4. Filling in the evaluation forms on the support group intervention 5. Handing out vaginal lubricants and preservatives

Table 2. Opinions on satisfaction with the support group

Item	Responses from patients on the form
Help provided by the group process	<ul style="list-style-type: none"> - "I received the most accurate responses to the questions in my mind." - "It has been helpful to meet other people and share my experience." - "I have received sufficient answers to my questions." - "I have received sufficient and necessary information. I have learned very beneficial things about my disease process and it felt very good to communicate with the other patients." - "My perspective has changed. Now, I feel happy when I come to the hospital." - "I overcame my fears and I feel better." - "Knowing that we are not alone and hearing different recommendations about how we can cope with the problems." - "I realized that there were a lot of things I did not know about even though I am a healthcare professional."
The most likeable aspect of the group process	<ul style="list-style-type: none"> - "Communication among people in the group" - "Overcoming our deficiencies and learning what we did not know about" - "I really liked seeing that we were not alone at meetings and there were people ready to help" - "Sincerity" - "I was able to express very comfortably everything about my disease. I really enjoyed that." - "I felt that they were talking about me at the meetings. I thought there were people who understood me." - "The discussions and positive attitude of friends" - "The friendships we made" - "It was a really nice and positive practice to gather around a table." - "The group dynamic was really good. We received answers to all our questions." - "I am given the chance to speak, and I really like this." - "It has been a great source of morale for me to be together with friends who were fighting the same disease." - "I understood that we were not alone." - "The information shared was a real source of comfort for me." - "It was a sincere family atmosphere."
Different emotions inspired by the group process	<ul style="list-style-type: none"> - "I am happy that I joined this group. I feel safer." - "I feel more aware and cold-blooded." - "It is relaxing to see that I am not alone in having this problem." - "I feel that I am very relaxed and I have been able to express myself. My outlook on my disease has changed." - "I have learned what awaits me and what I should not do." - "I am happy as I leave every meeting." - "I have increased awareness; it is really nice that we can have these conversations without the relatives of patients with whom we have a lot of shared points." - "We shared our experience as people who experience the same problem. This gave us hope and ensured that we supported each other." - "I feel more comfortable. I have fewer worries about the disease." - "I feel safe here."
Changes in behaviours and habits after joining the group	<ul style="list-style-type: none"> - "I started to take better care of myself and do sports." - "Since I learned new information, I learned what I should and should not do in this process. I have applied them and I continue to do so." - "I no longer cry. I eat regularly. I take time for myself and this makes me happy." - "I am no longer pessimistic." - "I have a more positive outlook on my disease process." - "I have learned to share my emotions and thoughts instead of keeping them for myself." - "I started to smile more, my pessimism has disappeared."

- Suggestions for the future meetings
- "Such meetings should be held with every patient group."
 - "Shared events can be organized."
 - "I would like these meetings to continue on a continuous and regular manner. Because they have a very positive effect on me."
 - "It would be nice if the meetings are longer and shared activities such as trips are organized."
 - "It would be nice to give information to partners especially regarding sexual topics; there could at least be a booklet specific to them. Action must be taken especially to tackle the fears of partners. They abstain from sexual intercourse since they are afraid of passing germs to us and hurting us."
 - "The duration of meetings can be longer."
 - "Participation of fully recovered people in future meetings can inspire more hope in us."

Table 3. Process of evaluating the support group meetings of the intervention group (n=37)

Process of support group meetings	 0	 1	 2	 3	 4	 5	Total
Emotions regarding the process	n=30 81.1%	n=6 16.2%	n=1 2.7%	-	-	-	n=37 100%
Duration of meetings	n=28 75.7%	n=5 13.5%	n=4 10.8%	-	-	-	n=37 100%
Clarity of information	n=35 94.6%	n=2 5.4%	-	-	-	-	n=37 100%
Skills of the moderator	n=35 94.6%	n=2 5.4%	-	-	-	-	n=37 100%
Opportunity to speak	n=31 83.8%	n=6 16.2%	-	-	-	-	n=37 100%
Interaction within the group	n=29 78.4%	n=7 18.9%	n=1 2.7%	-	-	-	n=37 100%
Meeting place	n=32 86.5%	n=3 8.1%	n=2 5.4%	-	-	-	n=37 100%

ondary sessions which mostly bore witness to emotional moments and lasted approximately 120 min. The psychologist asked every patient to introduce oneself in turn and talk about how they encountered the diagnosis of breast cancer and how the diagnosis influenced them. There were some tears shed as emotions were expressed. A negative piece off experience explained by a member of the group may be intimidating or worrying for the other members (12). The therapeutic communication and psychological support offered by the psychologist were very comforting for the patients. It contributed to them coming to terms with the emotions they felt, feeling relaxed and accepting their disease. The written feedback given by participants such as "I am happy that I joined this group, now I feel safer", "We shared our experience as people having the same problem. This gave us hope and strength. We understood that we were not alone", "I feel more comfortable, I worry less about my disease", "I no longer cry, I take time for myself", "My pessimism has disappeared", "I have a more positive outlook on my disease process", "I started to laugh more, my pessimism has disappeared" (Table 2) suggests that education improves psychosocial well-being.

Finalization of the Support Group Intervention

In the last session of the support group initiative, visible differences could be discerned in the patients. In the first session, the patients

had come to the meetings in daily clothes such as lounge pants and were looking at each other with worried eyes while every patient was very chic and they had put on make-up in the last session. The worried looks had given way to sparkling gazes. Now, they were cracking jokes as they talked and they were happy as if they were friends who had long known each other. They remarked that they did not wish the sessions to come to an end, they were initially afraid as they came to the hospital but now they were happy since they knew they would see their friends, talk at sessions and learn subjects they did not know and were curious about.

To assess the satisfaction of patients with the support group, the support group meeting assessment for developed by Ordin and Karayurt (2016) was used (14). The patients stated that they were positively influenced by the support group initiative. The opinions of patients about their satisfaction with the support group are provided in Table 2 and (Table 3). After the support group meetings came to an end, the patients jointly agreed on dates and met in their houses or outside to maintain the support. Furthermore, they also established a communication network on social media and they continue to stay in touch and offer support to one another and celebrate each other on special days (festivities, religious holi-

days, Women's Day, etc.), thereby maintaining peer support. In line with the feedback received from patients, it can be concluded that the support group intervention increases the quality of relationships, relieves loneliness, positively influences life satisfaction and instigates positive changes in line with the studies performed (4, 8, 24)

Conclusion

In conclusion, the "Support Group Intervention" enabled women diagnosed with breast cancer to see that there are other women with breast cancer experiencing similar situations, they are not alone and can receive peer support. Furthermore, it also contributed to them gaining information from the correct resources regarding the disease and disease management. The fact that information, emotions and experience were shared in a group setting under the leadership of a consultant nurse and a psychologist created a proximity and togetherness among participants, thereby facilitating women to receive support from one another. Uncovering the challenges experienced by women, their needs, recommendations to one another and skills of coping with the disease during the support group intervention would contribute to the care provided for this patient group. It is thought that support group meetings would make it easier for patients to cope with the symptoms they experience, increase their quality of life and improve the patient care results if it is implemented as part of the nursing care. It is important to implement support group interventions in Turkey towards the aim of offering knowledge, consulting and psychosocial support to women diagnosed with breast cancer.

Suggestions

- Researchers who will implement a support group intervention in the future are recommended to select a place easily accessible by all the patients,
- Create a convenient environment for the patients (offering refreshments, gathering around one table and ensuring eye contact, having optimal room temperature and lighting),
- Ensure that the support group moderator is not an authoritarian figure, motivates patients to ask questions during the session and empower patients,
- Set the meeting days on the dates when they are to receive treatment in order to make it easier for patients to attend the sessions,
- Realize the support group sessions in future studies with participation of women who recovered from the disease and are currently in good health in order to have a positive influence on the morale and motivation of patients.

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