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A Support Group for Breast Cancer Patients: Benefits and Risks

Mihaela LESE¹, Ioana LESE², Gabriela MILI³

Abstract

The aim of this study is to evaluate the results of the support group meetings organized for breast cancer patients. The period of time taken into account is one year. In the 23 meetings, there were 26 patients, 11 participating to only one meeting, while the highest rate of attendance was 19, for 2 patients. We are analyzing the number of patients who attended the support group sessions, the debated subjects, the group's structure and the patients' motivation. The profile of a frequent participant to the support group is represented by a lady with the age between 50 de 69 years old ($p=0.009$), married ($p=0.035$), with a medium level of education ($p=0.038$), for whom the magnitude of the operation ($p=0.056$), the time elapsed from the diagnosis ($p=0.65$), the information received from the treating physician ($p=0.31$) or the quality of the family support ($p=0.16$) did not influence the attendance.

Keywords: support group, breast cancer, meeting, benefits, risks.

Introduction

A support group is usually defined as a group of people with similar experiences and problems, able and willing to offer emotional and moral support for one another (APA, 2007). It is an informal group, outside the family, friends and professional community, which provides understanding, a place to show empathy and gives value to the participants' identity. It is actually a place where information can be exchanged, but at the same time, it is being led by an educated moderator

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(Open Directory Project, 1991). The therapeutic effect is based on the feeling of being part of a society's group of people, the chance to help one another (selflessness), the problem's globality (a frequent topic throughout society, mostly medical), the self-discovery and interpersonal learning opportunity, and most importantly, the hope and the answers given to each member's existential problems (Helgeson *et al.*, 2000).

There are, however, big individual differences regarding the reaction to the given support, mainly because the participants don't have the same needs when joining the group. Due to the fact that the studies available in our literature have followed with more interest the results' statistical significance, and not the effect upon each and every member of a group, these individual differences were not so much taken into account.

These support groups have become popular in the late seventies and the evaluation studies quickly followed, just a few years later. One of the most discussed studies belongs to Spiegel, dating back to 1989, ascertaining a longer survival of the metastatic breast cancer patients who participated in support group sessions in comparison to the ones that didn't take part to this kind of therapy (Spiegel *et al.*, 1989). Based on statistical data, the scientific community noticed that the value compared in this study was the arithmetic mean and not the median, the former being too much under the influence of extreme data (early death and the longest survival). Redoing the measurements and comparing once again, the two groups' survival rates didn't show any statistically significant results. The following studies couldn't prove the survival prolongation assigned to the support group participants, but they noticed an increase in self-esteem and in the quality of life (Spiegel *et al.*, 2007).

The patients taking part in the support groups benefit from one of these therapeutic concepts: (a) emotional support, by discussing the experienced emotions when finding the diagnosis and the treatment or waiting for the results etc.; (b) informational support, besides the aspects that the patients should already know from their treating physician; (c) social support and entertainment. The aim of our study is to evaluate the support group after a period of one year, to observe who and why have benefited by taking part in the sessions, and whether the meetings have had a good, bad or haven't had any influence at all upon the members.

Materials and Methods

This retrospective study analyzes the meetings of a support group designed for women with breast cancer by using the data of the Valens Foundation registry and an evaluation form assessing the participants' satisfaction. The patients included in this study had to have had a histopathologically confirmed breast cancer

diagnosis, an operation and an adjuvant treatment (chemotherapy and/or radiotherapy). The exclusion criteria comprised of patients with operations for benign breast tumors or with cancers with another localization. The data captured include demographics, education level and aspects regarding the disease and the treatment: the onset of the disease and the type of operation (breast-conserving surgery or radical mastectomy). Moreover, the support given by the family, the individual motivation for taking part in the support group's meetings and the main life goals of the patients (selflessness) were also noted. The evaluation form for the assessment of their satisfaction was given after receiving their consent to participate in this evaluation. The statistical data were processed with the SPSS program, 15.0 version for Windows, using the T, Mann-Whitney and χ^2 tests with statistical significance set at $p < 0.05$.

Results

The free of charge support group organized for the women with breast cancer between August 11th 2012 and August 31st 2013 has had a number of 23 meetings with a total of 26 patients. The group is open, there are no rules for the participation and the meetings take place twice a month at the Valens Foundation headquarters. The attendance throughout the period taken into account was variable: there were patients that took part in only one meeting, while 2 patients have attended 19 meetings (Figure 1).

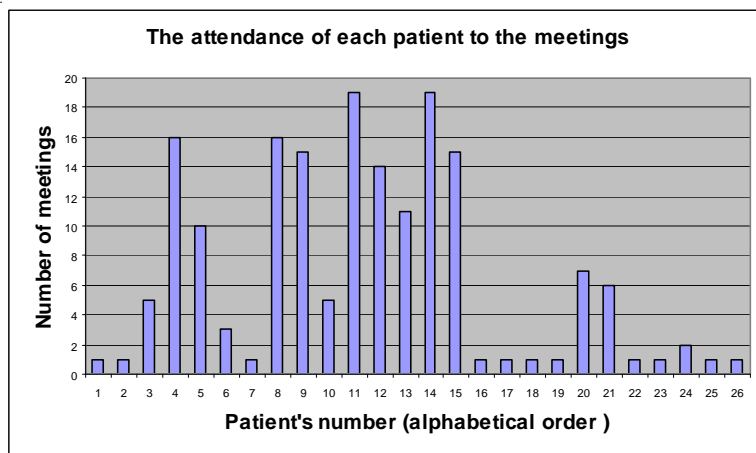


Figure 1. The attendance of each patient to the support group meetings

The demographics, education level, type of surgery and period between diagnosis and the patient’s first meeting are shown in Table 1.

Table 1. *The support group attendance according to demographics and the disease’s details (26 patients, 174 attendances)*

Variables	Parameters	Number of patients	Number of meetings	P
Age	40 – 49 years	2	11	0,009
	50-59 years	10	47	
	60-69 years	8	70	
	70-79 years	6	46	
Marital Status	married	18	124	0,035
	divorced	4	45	
	widow	4	5	
Education level	Elementary school	2	2	0,038
	Highschool	16	99	
	University	8	73	
Type of surgery	Modified radical mastectomy	11	42	0,056
	Sectorectomy	15	132	
Time elapsed from diagnosis	1 year	6	46	0,65
	2 years	4	25	
	3 years	5	53	
	4 years	5	14	
	5 years	3	16	
	Over 5 years	3	20	

The type of surgery (breast-conserving surgery or radical mastectomy), as well as the time elapsed from the diagnosis didn’t correlate in a significant way with the number of attendances. Similar results were observed by correlating the presence at the meetings with the type of family support, the information’s quality received from the professionals, the motivation for taking part in the support group or the patients’ selflessness (Table 2).

The evaluation form regarding the participants’ satisfaction was filled out by 13 patients: 12 patients having at least 7 attendances and one being at her first meeting. 11 patients considered the discussed subjects very helpful in answering many questions about breast cancer. The reason for taking part in these meetings was different: 10 patients came to meet people with the same problems, 12 patients were interested in the subjects that were being discussed, 10 patients were helped to understand and to overcome some problems that appeared along with the disease and other 7 ladies considered that it was a good opportunity to get out of their house and socialize.

Table 2. The support group attendance according to needs and objectives (26 patients, 174 attendances)

Variables	Parameters	Number of patients	Attendances	P
Family support	Significant	22	155	0,16
	Insignificant	4	19	
Information's quality	Significant	14	91	0,31
	Insignificant	12	83	
Motivation	Emotional support	6	53	0,16
	Medical information	10	63	
	Time well spent	10	68	
Important life goals	To help my family	7	51	0,09
	To be at peace with myself	12	50	
	To have an easy life	7	73	

Regarding the anxiety and the depression, 10 patients thought that these feelings were reduced after the meetings, while 2 denied being anxious or depressed. The spirituality meeting was considered by all 12 patients very useful.

To the question “Which theme did you enjoy most?”, 4 patients placed the healthy nutrition on the first place, one considered music therapy the best, 4 ladies were impressed by the positive attitude subject, 2 stated that all the subjects were useful and one patient especially appreciated the meeting about the breast tumors’ way of developing.

When asked about the subjects that should be discussed in the future, the support group patients had different opinions: hot flashes, spirituality once again, no sad things, practical and happy themes, the minimal blood work package, new available treatment for breast cancer and the possibilities to have them, the relationship between the patients and their families and 5 patients considered any theme to be interesting.

Discussions

The statistical analysis gives an overall image over one discussed problem, while the study of one small group of people like the support group can offer more detailed data (Kaplowitz *et* Hoehn., 2001). The interactions between the members reveal more useful information (Morgan, 1988), create a friendly environment in which the patients feel safer to express their spontaneous ideas and to discuss problems in order to find their solutions.

The support group for the breast cancer patients is an open group where there are no rules as far as the participation is concerned (Duggleby & Berry, 2005). Therefore, the attendance is a genuine indicator of the patients' benefits after taking part in the meetings.

The profile of a frequent participant to the support group is represented by a lady with the age between 50 de 69 years old ($p=0.009$), married ($p=0.035$), with a medium level of education ($p=0.038$), for whom the magnitude of the operation ($p=0.056$), the time elapsed from the diagnosis ($p=0.65$), the information received from the treating physician ($p=0.31$) or the quality of the family support ($p=0.16$) did not influence the attendance. The motivation was considered equal among the three types of therapy ($p=0.16$), while the emotional support, the medical information and the ways of spending their free time with the members of the support group were highly appreciated. The life goals suffered a drastic change for most of the ladies after the experience with the disease, the main focus being now their own person: an easier life and to reach reconciliation with themselves.

The duration of the meetings varied between 2 hours and 20 minutes and 3 hours and 40 minutes, and the themes comprised of a wide range of subjects: (a) breast cancer and new treatments; (b) types of food recommended in breast cancer and ayurvedic nutrition; (c) spirituality, music therapy, the change in body image; (d) death and the way we die, palliative care in terminally ill patients; (e) social interactions before and after the diagnosis; (f) the effect of praying and having a positive attitude; (g) lymphedema; (h) tomatoes, cabbage, cereals, spices etc.; (i) healthy ways of preserving the food; (j) Christmas play.

The reasons for not attending the support group anymore were also different. Patients who had their first contact with the support group during the session involving death and palliative care of the terminally ill patients didn't come again and ladies living in the countryside took part in no more than 3 meetings due to the distance. Patients having under their care old or ill relatives couldn't spare their time and one patient had an emotional crisis at the first and only meeting, therefore having anxiety to continue coming. Another lady with multiple metastases couldn't find among the group patients with such an advanced stage and decided not to come anymore since her questions remained with no answers. 4 patients undergoing chemotherapy attended only 3 meetings because they managed to get used to their disease and didn't consider useful the therapy provided by the group anymore. After 16 meetings, one patient suffered a traumatic experience with 2 deaths in her family, remaining unsatisfied with the medical system and the attention paid to the terminally ill patients. She decided not to come anymore and stated that "the theory that we discuss here is completely different than the practice".

Actually, the reason for taking part in this group is the need to cover some sort of deficiency, whether it is information or emotional support that is missing, or

they just want to have a way to spend their time. On one hand, patients with a very good family support don't have so good results after coming to the meetings because they are profoundly marked by the other patients' sufferings (Helgeson *et al.*, 2001). On the other hand, the informational support is considered more useful than the emotional support (Helgeson *et al.*, 1999). Besides the diagnosis and the treatment information, the practical advice received from one another is also highly appreciated (Radloff, 1977). In this way, patients, who until now didn't know so much about their disease and everything related to it, have the greatest benefits.

Conclusions

The support group is considered useful and the breast cancer patients take part in it because it is a homogenous and balanced group as far as their expectations are concerned. Most of the themes come from the patients' ideas. Besides the medical subjects, the daily life difficulties and the emotional and social aspects of the disease were also discussed, playing an important role in the patients' lives. After attending this group support, the patients feel stronger in their fight against breast cancer, more useful and helpful for their peers with the same problems, more confident and better informed. The innovation of this study is the evaluation of a support group for breast cancer patients, which, to our knowledge, is the first study of its kind published in Romania.

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