Effect of Implementing a Prechemotherapy Education Programme on Psychological Distress, Quality of Life, and Satisfaction of Egyptian Women Newly Diagnosed with Breast Cancer

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Abstract

Background: Many patients diagnosed with breast cancer receive chemotherapy. The need for education is especially elevated among these patients and their families. Oncology nurses are responsible for educating patients prior to the chemotherapy experience. Sufficient and appropriate information to patients and their families constitute a part of comprehensive cancer care.

Aim of the study: the aim of this study was to assess the effect of implementing a prechemotherapy education programme on psychological distress, quality of life, and satisfaction of Egyptian newly diagnosed breast cancer women and their carers.

Material and Methods:

Research design: Quasi-experimental, prospective study was used. Research setting: This study was conducted at outpatient’s chemotherapy clinic of the Oncology Center at Mansoura University Hospitals (OCMU), Egypt.

Subjects: A total of 63 eligible adult women newly diagnosed with breast cancer, with a confirmed diagnosis of breast cancer were approached to participate. Patients were randomized to the study group (n=32) and the control group (n=31).

Tools of the study: Three tools were used to collect data of the study: I: Psychological Distress Scale. II: European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 Questionnaire III: Patients’ Satisfaction Questionnaire.

Results: There were no significant differences at baseline between groups for any of the demographic and clinical characteristics. There were not statistically significant difference between the intervention and control groups regarding the data on HADS-A and HADS-D. Quality of Life data between intervention and control groups were similar and balanced between the intervention and control groups before the intervention and there were no significant differences after the intervention. Our study revealed that there were statistically significant differences between groups post intervention on satisfaction. The intervention group patients were markedly more satisfied with the information received than patients in the control group and reported significantly more satisfied with overall care.

Limitations: This study was conducted on patients attended to Oncology Centre – Mansoura University, hence might not representing all Egyptian patients. This study was conducted on a small sample and results may not be generalizable, larger studies should be considered. A more comprehensive study might offer further insights.

Nursing implications: The educational programme described in this study can be adapted to meet the education needs of almost any newly diagnosed patient with cancer who is about to begin chemotherapy. The educational programme also may be a useful guide to new oncology nurses who are developing their patient education skills.

Conclusion: Providing education to patients before the start of therapy prepares them for treatment and, in the long term, may improve coping strategies when dealing with the illness. This approach may assist patients in avoiding unnecessary side effects and lead to improved patient outcomes.

Recommendations: More studies on large samples are needed to examine the need for and benefits of an educational intervention before the start of chemotherapy to help patients develop an understanding of their therapy.

Keywords: Prechemotherapy education; Psychological distress; Quality of life; Satisfaction; Newly diagnosed; Breast cancer

Introduction

With the increasing incidence of breast cancer and moving trend of treatment to ambulatory settings, patient education
on coping with disease and treatment of side effects poses a challenge for oncology nurses. As a result, there is now clear evidence to suggest that the need for education is especially elevated among breast cancer patients and their families [1-4]. However, the general pattern that emerges from the literature is that large numbers of patients with breast cancer often report poor understanding and recall of what doctors tell them and, in addition, often express dissatisfaction with the quantity and quality of information they receive about aspects of their disease and treatment [4-6]. Poorly informed patients are less likely to comply with treatment and adhere to medical advice, or participate in the medical decision-making process [5,7-9]. They are also more likely to experience a high degree of uncertainty and anxiety, or seek scientifically unacceptable therapies, for example, from alternative healers [7,10].

Over the years, various methods for education intervention to breast cancer patients have been developed, including the use of written material, audiotapes, videotapes, telephone helplines, multimedia resources and the Internet [6,7,10–13]. Recent reviews of controlled clinical trials of information giving approaches have demonstrated that in the main, these methods are valued by patients and are effective in enhancing understanding, knowledge and recall, and promoting satisfaction with communication [6,10]. With regard to anxiety and depression, emotional distress outcomes in general, the evidence is equivocal, because a number of studies have shown positive effects, whereas others have shown no benefit [14-16]. Much less is known about the impact of information-giving approaches on quality of life (QoL) or functional ability [10]. To date, the evidence from the few controlled clinical trials that have been conducted is inconclusive, hence this issue merits further exploration [14].

The provision of verbal information to patients supplemented with written material in the form of booklets, handouts, general cancer literature and specifically designed information packages, has long been the mainstay of information-giving approaches [1,6,17]. Research has shown that the majority of patients receiving written information express favorable attitudes towards it [5,18]. Written material is a relatively simple and cost-effective method to implement. The content can cover all important points, and it is also available to patients and significant others for future reference [5,19]. A large part of this material has been devoted to preparing patients for breast cancer treatment, and booklets have been used extensively [17,20,21]. Most commonly, such booklet contain a combination of sensory, procedural and practical information, and are given as an adjunct to information presented orally [5,21]. It has been shown that in order to be effective, preparatory information should be responsive to patients’ needs, be clear and easy to comprehend and be distributed before breast cancer treatment commences [5,20,21].

However, most of our knowledge in this area comes from Anglo-Saxon countries where preparatory information has long been a part of routine cancer care. In contrast, far less is known about the impact of such material on other societies and cultures, and this is among the issues that research on communication needs to pursue [10]. To our knowledge, only two randomized controlled trials have to date been conducted in a southern and eastern European context, one in Spain and one in Italy, and they both produced positive results. In the Spanish study [22], hospitalized breast cancer patients were given information booklets on surgical procedures 2–3 days before surgery and an additional booklet specific to adjuvant chemotherapy one month after surgery. Experimental group patients reported better adjustment in their working, domestic and sexual lives as time progressed compared with women who did not receive written information. The study from Italy [19] assessed the impact of oral, written and video information about chemotherapy on cancer patients who were about to start treatment. At follow-up, before the following cycle of chemotherapy, the results demonstrated that significantly more patients in the oral, written and video information group felt their QoL had improved as compared with those in the less intensive information groups. In addition, patients were positively disposed toward the provision of booklets and videotapes and reported high levels of utilization.

Treatment options and drug therapies can be confusing. Often, women newly diagnosed with breast cancer who undergo chemotherapy do not receive information from a nurse regarding their treatment until the day they begin treatment. Those patients expressed needs for information about their disease as well as personal, family, and social concerns. Most of women are unprepared for their illness and have little or no idea how to cope with their diagnosis. They may often are misled by false information regarding treatments and side effects, where nonscientific information on breast cancer treatment may be provided. They might be exposed to stories and false information about chemotherapy from relatives and/or neighbors. In addition to no standardized Prechemotherapy intervention has been developed to assist patients with breast cancer preparing for chemotherapy. Educating women regarding the type of chemotherapy they will receive, how often they will receive it and the side effects to expect physically and emotionally can provide them with a basic understanding of their health care before the start of chemotherapy and may improve their ability to cope with the illness. An educational intervention provided by nurses before the start of chemotherapy may assist women in increasing their knowledge of chemotherapy treatment, enhancing their ability to manage side effects and improving their coping strategies and their quality of lives. Patients can handle the side effects of chemotherapy physically and emotionally during treatment [23,24].

Material and Methods

Material

Design: Quasi-experimental, prospective study was used.

Setting: This study was conducted at outpatient’s chemotherapy clinic of the Oncology Center at Mansoura University Hospitals.
Research hypotheses: H1 Women newly diagnosed with breast cancer in the study group will have higher mean scores of knowledge about chemotherapy related information and consequently their levels of emotional distress will be reduced compared to control group.

H2 Women newly diagnosed with breast cancer in the study group will have higher mean scores of knowledge about chemotherapy-related information and consequently their QoL and satisfaction will be improved compared to control group.

H3 Women newly diagnosed with breast cancer in the intervention group will have a positive opinions towards the intervention compared to women treated conventionally

Subjects: A total of 65 eligible women newly diagnosed (within three weeks) with breast cancer, adults 18 years and older, able to speak, read, and write, have never received chemotherapy treatment previously, with a confirmed diagnosis of breast cancer scheduled to receive chemotherapy in the outpatient setting were approached to participate. Of these, two women (3.1%) refused to participate and gave oral consent. Patients with a history of breast cancer who had previously undergone chemotherapy, Patients who have communication barriers, patients with pre-existing major neurologic or psychiatric problems and patients who had vision impairments that could affect their ability to read were excluded from the study. The remaining 63 eligible patients were randomized to the study group (n=32) and to the control group (routine management) (n=31). Neither the oncology center nor the patients experienced financial burden as a result of participating in this study. All patients continued their usual medical treatment throughout the duration of the study.

Tools of the study: Three tools were used to collect data of the study:

I: Psychological Distress Scale

II: European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 Questionnaire

III: Patients' Satisfaction Questionnaire

Tool I: Hospital Anxiety and Depression Scale (HADS) [25] was used to assess psychological distress of newly diagnosed breast cancer women. It consists of 14 items rated on a four-point scale. There are seven items for anxiety (HADS-A) and seven for depression (HADS-D). Each subscale is scored from 0 to 21. In accordance with Zigmond and Snaith [2], scores of 0–7 represent a ‘non-case’ of anxiety and depression, 8–10 a ‘doubtful or borderline case’ and 11–21 a ‘definite case’.

Tool II: European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 questionnaire was used to assess the quality of life of women newly diagnosed with breast cancer. It consists of 30 items, relating to five functional scales (1-physical, 2-role, 3-cognitive, 4-emotional and 5-social function), three symptom scales (1-fatigue, 2-pain, and 3-nausea and vomiting), 6 single items assess other symptoms that measures (constipation, dyspnea, insomnia, loss of appetite, diarrhea, financial impact of the disease) and a global health status/QoL scale. The scoring of the EORTC QLQ-C30 items was performed according to the EORTC scoring manual. Statistical analysis was carried out using the Student t-test, with statistical significance set at the 5% level (P <0.05). In accordance with the procedures recommended by the EORTC, raw scores were linearly transformed to values between 0 and 100. For the functional and global QoL scales, higher values indicate a better level of function. For the symptom/single-item scales, higher scores reflect more symptoms.

Tool III: Patients' Satisfaction Questionnaire was used to assess the level of satisfaction with information provision and overall satisfaction with care on five-point items from 1 (very dissatisfied) to 5 (very satisfied). Patients' perceptions of having been informed were measured with a single five-point item from 1 (not at all) to 5 (very much): ‘Do you feel informed about your disease and treatment?’ Perceived quantity of information was assessed with a single five-point item from 1 (too little) to 5 (too much): ‘How much information have you been given about your disease and treatment?’ Perceived quality of information was measured with two items rated on a three-point scale (no, uncertain, yes): ‘The information you have been given so far about your disease and treatment has been, (a) clear, (b) detailed.’

Tool I and Tool II were used before and after implementing a Prechemotherapy education programme. Tool III was used only after implementing a Prechemotherapy education programme.

Methods and data collection

Official permission to conduct the study was obtained from the hospital administrative responsible authorities after explaining the aim and nature of the study.

Validity and Reliability: Five randomly selected patients, five experts in oncology and five caregivers gave feedback on content and structure of the educational manual and tool III, the principles for enhancing readability of written material were applied [5,21].

Women newly diagnosed with breast cancer were identified in an outpatient clinical setting after meeting with their oncologists to discuss treatment plans. Patients were invited by research assistant to take part in the study. Patients who accepted to participate were assured that their participation was entirely voluntary and informed of their rights as research subjects. Specific human rights which require protection during study include the right to self-determination, the right to privacy, and the right to autonomy and confidentiality

Each woman who was elected to have chemotherapy was approached at that time or by their mobile phone and asked to return for an educational meeting regarding her specific treatment. Eligible patients who agreed to participate were informed with the purposes and nature of the study and oral informed consent was obtained from all patients.

An educational intervention was scheduled at a convenient time and date before the start date of chemotherapy for each patient. Patients were encouraged to bring family members to the intervention. Patients who accepted to participate were
administered tool I and II prior to the first chemotherapy session by a researcher who offered assistance when needed, and checked the answers for omissions.

Baseline Sociodemographic data and disease-related information were collected for all patients from the treating physicians or from the hospital charts. After baseline data had been collected, patients were randomly assigned without stratification to either the study or control group in a 1:1 ratio. Prior to the study the research assistant underwent 2-hour training on content of the educational manual.

Pilot study

A pilot study was conducted in the previously mentioned setting. The researcher obtained formal permission from the concerned authority prior to the study. The study was conducted on 10 breast cancer patients who fulfilled the inclusion criteria for the selection of the sample. The purpose of the study was explained to the subjects and consents were obtained after assuring privacy and confidentiality. Baseline information was collected; and data was checked after intervention. The tools were found feasible and practical. No further changes were made in the tool after the pilot study and the researcher proceeded for the main study.

Description of prechemotherapy education intervention

The education intervention was a structured 30 minute one-on-one session performed solely by the research assistant, with a short time allotted for questions. Thirty minutes was determined to be an appropriate timeframe as educational interventions in the literature ranged from 20 minutes to one hour. All pre-chemotherapy education sessions were scheduled between 1 and 7 days before first treatment, in a private room away from the treatment area. Sessions focused on eliciting and responding to patient-identified concerns/fears, delivery of tailored evidence-based messages about chemotherapy side-effects, and discussion and coaching of relevant self-care strategies to manage side-effects and psychological distress. The researcher was available on call for any questions or issues raised by nurses when implementing the program, and follow up was conducted to confirm patients’ knowledge. The Education Intervention consisted of:

1. Preparing patients for potentially threatening procedures, tailoring to the specific needs of individuals, emphasizing evidence-based self-care, and psychosocial support.
2. Patients also received a brief orientation to the chemotherapy area and an introduction to available staff members.
3. Understanding Chemotherapy.
4. Verbal explanation and presentation of the information about chemotherapy included in the booklet, section by section.
5. Encouraging the patients to ask questions and express their concerns.
6. Provision of patients with the booklet to take away and read at home.

After completing the baseline questionnaires, each patient allocated to the study group attended the educational intervention session given by the research assistant with experience caring for breast cancer patients. The session lasted approximately 30 min. The research assistant was instructed not to provide and explain any additional information other than that included in the manual. Questions that could not be addressed by the research assistant were referred back to the treating oncologists or to the researchers. At the end of the session, patients were given the chemotherapy educational manual to take away and read at their leisure, and were immediately started on treatment.

Description of routine care

Patients in the control group receive routine care. Routine care consisted of verbal information covering common side-effects of chemotherapy provided on the first day of treatment either in the treatment or waiting area. No follow-up patient contacts were scheduled as part of routine care.

Patients of both groups were assessed through tool I and II by the same research assistant who had no knowledge of the patients’ group assignment before the following cycle of chemotherapy. At the end of the study, patients in the control group received the educational manual with verbal information about chemotherapy included in the manual.

At the end of the study, the study group also completed a short questionnaire to evaluate the usage and properties of the booklet. Patients were asked about the number of times they read all (or part) of the booklet, the number of people who read the booklet in addition to them, and whether they would recommend the booklet to other patients with cancer. In addition, two five-point items from 1 (not at all) to 5 (very much) asked the patients to indicate how useful the booklet was and whether it helped them to better remember medical instructions and advice. Finally, patients rated their overall satisfaction with the intervention on a five-point scale item from 1 (very dissatisfied) to 5 (very satisfied) with higher scores indicating higher satisfaction.

Description of the booklet

The booklet, entitled, Chemotherapy, the adverse effects of chemotherapy and how can you control them: Information for Patients and their Families. There were 30 (20×12 cm) pages altogether with illustrations. The patients’ booklets were written in simple Arabic language to help patients and their families understand more about chemotherapy, and answer most of their common questions, pointing out that booklet cannot substitute the discussion with the doctor and nurses. The content was designed to outline both the procedures and the sensations the patient would experience, as well as to present practical information about diet, precautions and self-care. There was also a section outlining positive coping modes such as seeking social support, expressing feelings and engaging in pleasant activities. The sections were headed:
‘Introduction’, ‘what is chemotherapy?’, ‘How is chemotherapy given?’, ‘How long does the therapy last?’, ‘What are the possible adverse effects of chemotherapy and how can you control them?’, ‘What can you do to feel better?’, ‘Some useful advice concerning your daily life during treatment’ and ‘Contact information’.

**Data analysis**

The primary outcome measure was satisfaction with information received and overall satisfaction with care. Secondary outcomes were QoL as measured by the QLQ-C30, emotional distress as measured by the HADS, perception of having been informed, and perceived quantity and quality of information. The perception of having been informed, the perceived quantity and quality of information, and patient’s satisfaction, were measured just at after program intervention.

Data were analyzed using SPSS for Windows (version 9.0; SPSS Inc., Chicago, IL, USA). Descriptive statistics, generated for all variables, included means, standard deviations of quantitative variables and percentages for categorical variables.

Between groups comparisons of means were achieved using the t-test for independent samples. Intra group comparisons were achieved by t-test for dependent samples. When normality of distribution was not satisfied, the non-parametric test of Mann–Whitney U-test was applied. Comparison of percentages was achieved using the Chi Square test. All tests were bilateral and the threshold of significance was fixed at the 5% level.

**Results**

A total of 65 eligible patients were approached to participate. Of these, two (3.1%) refused to participate and to give informed consent. The remaining 63 eligible patients were randomized to the intervention group (n=32) or to the control group (n=31). Univariate analyses revealed no significant differences at baseline between groups for any of the demographic and clinical characteristics, namely sex, age, educational level, disease extent or type of chemotherapy (Table 1). Likewise, the data on HADS-A and HADS-D at study entry were well balanced between the two arms. After the intervention, the HADS-A, a difference was not statistically significant between the study and control groups after implementing a Pre-chemotherapy education program for Non-cases (59.4% and 51.6%), and 53.1% - 59.4% between pre and post intervention group. Borderline cases were not statistically significant between the intervention and control groups after implementing a Pre-chemotherapy education program (15.6% and 19.4%), and also were not statistically significant within the intervention group (15.6% and 21.9%) respectively (Table 2).

Quality of Life data (EORTC QLQ-C30) between intervention and control groups were similar and balanced between the intervention and control groups before the intervention and there were no significant differences after the intervention (Table 3).

**Table 1 Baseline demographic and clinical characteristics of the study and control of patients, N= 63.**

| Characteristic               | Study Group N=32 | Group | Control Group N=31 | Group |
|-----------------------------|------------------|-------|--------------------|-------|
| All patients                | 33               | 100   | 32                 | 100   |
| Completed Study             | 32               | 96.9  | 31                 | 96.9  |
| Age                         |                  |       |                    |       |
| 20-30 Years                 | 5                | 15.6  | 5                  | 16.1  |
| 30-40 Years                 | 10               | 31.3  | 9                  | 29.0  |
| 40-50 Years                 | 13               | 40.6  | 12                 | 38.7  |
| 51-60 Years                 | 4                | 12.5  | 5                  | 16.1  |
| Level of education          |                  |       |                    |       |
| No Education (Read and Write)| 9               | 28.1  | 7                  | 22.6  |
| Primary School             | 2                | 6.3   | 4                  | 12.9  |
| Secondary School           | 16               | 50.0  | 13                 | 41.9  |
| College/University         | 5                | 15.6  | 7                  | 22.6  |
| Disease                    |                  |       |                    |       |
| Limited*                   | 15               | 46.9  | 14                 | 45.2  |
| Advanced*                  | 17               | 53.1  | 17                 | 54.8  |
| Treatment                  |                  |       |                    |       |
| Adjuvant*                  | 15               | 46.9  | 13                 | 41.9  |
| First-line’s               | 17               | 53.1  | 18                 | 58.1  |

There was no evidence for significant differences at baseline between groups for any of the demographic and clinical characteristics (P > 0.05)

*Limited or localized means that cancer remains in the place of origin and has not spread from that place

*Advanced (metastatic) breast cancer is cancer that has spread beyond the breast and underarm lymph nodes to other parts of the body.

*Adjuvant chemotherapy that is used to destroy suspected undetectable residual tumor after surgery or radiation treatment has eradicated all detectable tumor; effective in the treatment of breast and colon cancer.

*In first-line or neo adjuvant chemotherapy (preoperative treatment) initial chemotherapy is designed to shrink the primary tumor, thereby rendering local therapy (surgery or radiotherapy) less destructive or more effective. Neo adjuvant therapy aims to reduce the size or extent of the cancer before using radical treatment intervention, thus making procedures easier and more likely to succeed, and reducing the consequences of a more extensive treatment technique that
would be required if the tumor wasn’t reduced in size or extent.

Table 2 Psychosocial data of the study and control groups and comparison of HADS median change, N=63.

|                | Study group N= 32 | Control group N=31 | P-values |
|----------------|-------------------|--------------------|----------|
|                | Pre intervention  | Post interventions | Pre routine care | Post routine care |
| HADS-Anxiety   |                   |                    |                      |
| No.            | %                 | No.                | %                     | No.               | %               |
| Non-cases (0–7)| 17                | 53.1               | 19                    | 59.4              | 14              | 48.4           | 16              | 51.6           | 0.61          |
| Borderline (8–10)| 7                | 21.9               | 5                     | 15.6              | 7                | 22.6           | 6               | 19.4           |              |
| Definite cases (11–21)| 8            | 25.0               | 8                     | 25.0              | 9                | 29.0           | 9               | 29.0           |              |
| Median (range )| 7.0 (0-17)       |                    | 9.0 (0-19)            |                    |                  | 0.41           |
| HADS-Depression|                   |                    |                      |
| No.            | %                 | No.                | %                     | No.               | %               |
| Noncases (0–7)| 23                | 71.9               | 25                    | 78.1              | 21              | 67.7           | 22              | 70.9           | 0.35          |
| Borderline (8–10)| 3               | 9.4                | 2                     | 6.3               | 5                | 16.1           | 4               | 12.9           |              |
| Definite cases (11–21)| 6         | 18.9               | 5                     | 15.6              | 5                | 16.1           | 5               | 16.1           |              |
| Median (range )| 6.0 (0-17)       |                    | 6.0 (0-19)            |                    |                  | 0.46           |

Median changes were calculated by subtracting patients before values from after values and were examined by Mann–Whitney U-test.

HADS-D, Hospital Anxiety and Depression Scale-Depression; HADS-A and HADS-D at study entry were well balanced between the two groups.

Table 3 Quality of life between study group and control groups, N= 63.

|                   | Study group N= 32 | Control group N=31 | P- values |
|-------------------|-------------------|--------------------|----------|
|                   | Mean             | SD            | Mean     | SD            |                 |
| EORTC QLQ-C30 functioning scales |                   |                |          |               |                 |
| Global QoL / general health | 60.1          | 23.8          | 73.2     | 22.9          | 0.28           |
| Physical functioning | 80.1          | 23.3          | 79.2     | 25            | 0.6            |
| Role functioning   | 50.2            | 31.1          | 55       | 31.5          | 0.61           |
| Cognitive functioning | 69.1          | 17.2          | 81.7     | 22.7          | 0.6            |
| Emotional functioning | 52.6          | 23.9          | 58.6     | 24            | 0.43           |
| Social functioning | 72.7            | 22.6          | 69.6     | 27.7          | 0.42           |
| QLQ-C30 symptoms scales |                   |                |          |               |                 |
| Fatigue*           | 20.1            | 21.6          | 21.3     | 26.7          | 0.8            |
| Nausea/vomiting *  | 1.4             | 5.4           | 3.4      | 9.6           | 0.1            |
| Pain*              | 13.6            | 19.2          | 20.3     | 25.3          | 0.07           |
| Dyspnea*           | 13.9            | 20             | 16.4     | 25.5          | 0.51           |
| Sleep disturbance* | 26.7            | 30.3          | 23.3     | 24            | 0.22           |
| Appetite loss *    | 9.7             | 19.7          | 10       | 20.5          | 0.9            |
| Constipation*      | 18              | 29.0          | 21.9     | 30.5          | 0.41           |
Data on QLQ-C30 at study entry were well balanced between the two groups. All differences were not proved to be statistically significant (P>0.05) *Higher scores indicate more symptoms/difficulties.

SD: standard deviation; EORTC: European Organization for the Research and Treatment of Cancer; QoL: quality of life

Our study revealed that there were statistically significant differences between groups after implementing a Pre-chemotherapy education program on satisfaction. The study group patients were markedly more satisfied with the information received than patients in the control group and reported significantly more satisfied with overall care. In addition, they felt significantly better informed compared with patients allocated to the control group and reported having been provided with significantly more information relating to their disease and treatment. Likewise, patients provided with the manual evaluated the information received as being more clear and detailed than their control group counterparts (Table 4).

Table 4 Results of satisfaction between the study and control groups, N= 63.

| Potential range # | Study group N= 32 | Control group N=31 | P * values |
|------------------|-------------------|--------------------|------------|
|                  | Median | Observed range | Median  | Observed range |          |
| Satisfaction with information received | 1-5 | 5 | 3-5 | 3 | 1-5 | 0.000 |
| Overall satisfaction with care | 1-5 | 5 | 3-5 | 3 | 3-5 | 0.000 |
| Perceptions of having been informed | 1-5 | 5 | 3-5 | 4 | 1-5 | 0.000 |
| Perceived amount of information received | 1-5 | 4 | 3-5 | 3 | 1-5 | 0.000 |
| Perceived quality (I): information was clear | 1-3 | 3 | 2-3 | 2 | 1-3 | 0.004 |
| Perceived quality (II): information was detailed | 1-3 | 3 | 2-3 | 2 | 1-3 | 0.000 |

# Higher scores indicate more positive evaluations. * Mann-Whitney U-test.

In contrast, no reliable differences emerged in mean change scores (intervention group change versus control group change) on any of the QoL measures, with the exception of QLQ-C30 emotional functioning. In other words, intervention group patients experienced a statistically significant improvement in emotional functioning compared with control group patients (P=0.014). However, the mean difference between groups was <10 points, and hence it was not clinically meaningful (Table 5).

Table 5 Comparison of EORTC QLQ-C30 means change scores by study and control groups, N= 63.

| EORTC QLQ-C30          | Study group N= 32 | Control group N=31  | Mean difference | p-values |
|------------------------|-------------------|----------------------|-----------------|---------|
|                        | Mean change | SD     | Mean change | SD     |           |       |
| Global QoL              | 3.3        | 24.7   | -4.0      | 20.6   | 7.5       | 0.057 |
| Physical                | -1.9       | 29.9   | -2.2      | 27.6   | 0.3       | 0.95  |
| Role                    | 4.4        | 25.8   | -3.2      | 28.2   | 7.6       | 0.09  |
| Cognitive               | 4.7        | 17.4   | 0.2       | 17.6   | 4.5       | 0.12  |
| Emotional               | 12.1       | 21.5   | 3.0       | 22.3   | 9.1       | 0.014 |
| Social                 | -2.8       | 23.4   | -7.9      | 22.0   | 5.1       | 0.18  |
Fatigue | 4.4 | 22.1 | 12.5 | 29.0 | -8.1 | 0.06
Nausea/vomiting | 5.2 | 13.7 | 6.9 | 20.5 | -1.7 | 0.54
Pain | -1.9 | 24.5 | -2.8 | 27.2 | 0.9 | 0.83
Dyspnea | 1.4 | 19.9 | 0.9 | 23.7 | 0.5 | 0.89
Sleep disturbance | -4.2 | 26.9 | 0.0 | 20.2 | -4.2 | 0.29
Appetite loss | 5.2 | 22.9 | 9.3 | 28.6 | -4.1 | 0.34
Constipation | 7.0 | 33.7 | 3.7 | 36.1 | 3.3 | 0.56
Diarrhea | 1.4 | 18.2 | 2.8 | 24.2 | -1.4 | 0.70
Financial impact | 0.5 | 22.9 | -1.8 | 23.7 | 2.3 | 0.55

Mean changes were calculated by subtracting patients’ before and after and were examined by independent sample t-test.

Regarding the manual usage and evaluation, of the 32 intervention-group patients who completed the study all but one (96.9%) read the manual. Of these, 25 (80.6%) read the whole manual and six (19.4%) part of it. Patients read the manual an average of two times (48.4% read it once, 22.6% twice, 19.4% three times and 9.7% four or more times), and 22 patients (70.9%) had someone else read the manual in addition to themselves. The vast majority of patients (96.8%) reported that they would recommend the manual to other patients with breast cancer. They also rated the manual as quite a bit useful (16.1%) or very much useful (70.9%), and reported that it helped them quite a bit (16.1%) or very much (67.7%) to recall medical instructions and advice. Finally, patients were satisfied (12.9%) or highly satisfied (77.4%) overall with the manual (Table 6).

Table 6 Evaluation and usage of the patients to chemotherapy manual, N= 32.

| Characteristics | Study Group N=32 |
|----------------|------------------|
|                | No. | %    |
| Patients read the manual | 31  | 96.9 |
| Patients read the whole manual | 25  | 80.6 |
| Read the whole manual once | 15  | 48.4 |
| Read the whole manual twice | 7   | 22.6 |
| Read the whole manual three times | 6   | 19.4 |
| Read the whole manual four times or more | 3   | 9.7  |
| Patients read part of the manual | 6   | 19.4 |
| Someone else read the manual in addition to patients | 22  | 70.9 |
| Patients who recommend the manual to other breast cancer patient | 30  | 96.8 |
| Patients rated that the manual is as quite a bit useful | 5   | 16.1 |
| Patients rated that the manual is very much useful | 22  | 70.9 |
| Patients reported that it helped them quite a bit | 5   | 16.1 |
| Patients reported that it helped them very much recall medical instructions and advice for chemotherapy-related information | 21  | 67.7 |
| Patients were satisfied with the manual | 4   | 12.9 |
| Patients highly satisfied overall with the manual | 24  | 77.4 |

Discussion

This study revealed that patients in the intervention group who were provided with the educational intervention reported significantly higher rates of satisfaction with the information and with overall medical care than those allocated to the control group, felt significantly more and better informed, and perceived the information received as being clearer and detailed. The manual was read by almost all patients and to a great extent by significant others. The vast majority of patients were highly satisfied with the manual, reported that they would recommend it to other patients, and considered it as
being useful in general and helpful in refreshing their memories of chemotherapy-related information [26].

The present study was supported by McPherson et al., and Jefford and Tattersall in their single-center randomized trial study who mentioned that the provision of well-structured and adequate written information about cancer treatment is greatly appreciated by patients and exerts beneficial effects on a number of outcomes [6,10]. In Greece and other Mediterranean countries, the attitude of withholding detailed information from the patient is still dominant, although in recent years there has been a tendency towards increased openness, following the trends set in Anglo-Saxon and northern European societies [3,27,28]. Breast care nurse counselors in the United Kingdom provided support to patients before and after initial consultation with a surgeon. Patients in the intervention were found to have an increased understanding of treatments and significantly lower levels of anxiety compared to women treated conventionally.

Results of this study regarding HADS-A and HADS-D at study entry were well balanced between the two arms. After the intervention, the HADS-A, a difference was not statistically significant between the intervention and control groups after intervention for Non-cases, and between pre and post intervention group. Borderline cases were not statistically significant between the intervention and control groups after intervention, and also were not statistically significant within the intervention group. Quality of Life data (EORTC QLQ-C30) between intervention and control groups were similar and balanced before the intervention and there were no significant differences after the intervention.

The findings of this study may be related to many issues. The first is that the study operates and focused mainly at a cognitive level and there is almost no emphasis on affect. Perhaps, the provision solely of information without elements of counseling or psychotherapy may not have been sufficiently powerful to improve psychological well-being. Both cognition and affect are known to be important in medical communications, and this should be balanced. Strengthening the affective component of the intervention should have positive effects on mood, particularly for patients who are found on screening to experience severe levels of emotional distress [15]. The second issue relates to the short duration of our intervention. The one-time 30-min session during which the manual was presented and imparted to patients may have also been responsible for the lack of effects on distress and mainly QoL. In fact, a recent meta-analysis of controlled clinical trials suggested that psychosocial interventions, including psycho-education, should be planned for at least 12 weeks if reliable benefits to QoL are to emerge [29]. Thus, the effectiveness of multicomponent and more intensive, yet non-obstructive programs to the practice of oncology clinics needs to be addressed further.

Identification of patients’ information and emotional needs during the course of treatment has been the focus of much research. Disease, investigative tests, treatments, physical effects, and psychosocial effects were areas in which the highest emotional and information needs were identified by patients with breast cancer during the first cycle of chemotherapy. Patients newly diagnosed with cancer expressed needs for information about their disease as well as personal, family, and social concerns [30-32].

The present study showed that most of patients in the intervention-group read the whole manual. The vast majority of patients reported that they would recommend the manual to other patients with breast cancer. They also reported that it helped them very much and they were highly satisfied with the intervention. The findings of the current study was supported by McPherson et al., and Jefford M Tattersall in their single-center randomized trial study, they reported that the provision of well-structured and adequate written information about cancer treatment is greatly appreciated by patients and exerts beneficial effects on a number of outcomes [6,10]. Patients provided with the information booklet reported significantly higher rates of satisfaction with the information and overall with medical care than those allocated to the control group, felt significantly more and better informed, and perceived the information received as being clearer and detailed [33].

If nurses can arrange to meet with patients before the start of treatment, education about what to expect may lead to improved coping strategies. The type of educational intervention described in this article can be adapted to meet the education needs of almost any newly diagnosed patient with breast cancer who is about to begin chemotherapy. The educational intervention also may be a useful guide to new oncology nurses who are developing their patient education skills. The type of educational intervention described in this article can be adapted to meet the education needs of almost any newly diagnosed patient with breast cancer who is about to begin chemotherapy. The educational intervention also may be a useful guide to new oncology nurses who are developing their patient education skills.

Limitations

The major limitation of this study was that it only represented analysis of a small sample and results may not be generalizable Alternative intervention should be explored and larger studies should be considered. A more comprehensive study might offer further insights.

Nursing Implications

If nurses can arrange to meet with patients before the start of treatment, education about what to expect may lead to improved coping strategies. The type of educational strategy described in this article can be adapted to meet the education needs of almost any newly diagnosed patient with cancer who is about to begin chemotherapy. The educational intervention also may be a useful guide to new oncology nurses who are developing their patient education skills.
Conclusion and Recommendations

Nurses are patient educators who provide valuable information to patients with breast cancer undergoing treatment. Knowing what to anticipate during the course of chemotherapy and how to handle side effects is essential for all patients with breast cancer. Providing education to patients before the start of therapy prepares them for treatment and, in the long term, may improve coping strategies when dealing with the illness. This approach may assist outcomes. More studies on bigger samples are needed to examine the need for and benefits of an educational intervention before the start of chemotherapy to help patients develop an understanding of their therapy.

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