Development of a Self-Care Agency Model for Breast Cancer Patients Receiving Chemotherapy

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Abstract

This research was designed to develop a self-care agency model for nursing staff to assist patients undergoing systemic chemotherapy, to establish their own system of self-care. The main objective was to improve the patients’ attitudes toward their disease and treatment which would result in improved quality of life as a desirable end point. Twenty breast-cancer patients who were treated at the Oncology Outpatient Clinic were chosen for this study. Qualitative data pertaining to the patients’ needs and concerns, factors influencing self-care behavior, process of self-care agency development, and helping methods for developing self-care agency were obtained by an in-depth interview and participant observation. These instruments were used to obtain data serially, prior to treatment, and then monthly for three consecutive months. Results of the study indicated that breast-cancer patients undergoing systemic chemotherapy desired information regarding their disease status, treatment received, and potential side effects. They were also concerned about self-image, time consumed for visits to clinics, weight gain, treatment expense, sexual relationship, and side effects from chemotherapy. Factors which influenced patient self-care included: attitude toward the disease and type of treatment, culture and personal beliefs, personal health habits, family support, and their own initial performance status. The process of self-care development by the patients consisted of two stages. The initial stage required a decision-making process after all the information was made available. The second stage is the action-taking step, which is dictated by time and experience. The latter can develop from their own trial and error process as well as previous experiences provided by other patients. However, the optimal self-care system will be met only when the patients have received advice provided by the health-care profession.

Keywords: Breast cancer, self-care agency model, systemic chemotherapy, quality of life, attitude toward disease and treatment.

Introduction

Cancer is a life threatening disease. It has become an important health issue in many countries and all over the world. In Thailand, cancer is the third cause of death next to coronary heart disease and accident (Health Care Information Unit 1993). Breast cancer is an important female cancer. There is an increasing trend of the rate of breast cancer in Thai women which in 1992 stood at one in sixteen (Jariyalertsak 1994). Breast-cancer patients need chemotherapy treatment (Thongprasert 1993). The treatment for these patients are arranged at the Outpatient Medical Clinic. Thus side effects of chemotherapy occur at the patients’ home. Patients need to learn to do self-care action to meet their demands, prevent complication, and adjust life pattern and behavior for their illness.

At present, there is no specific nursing system to care for breast-cancer patients receiving chemotherapy. For the development of self-care agency for these patients, health-care team needs to understand about patients’ life style, attitude of patients toward their
disease and treatment, coping mechanism and their decision making. Then the team would cooperate with the patients and their family to develop their self-care agency to meet their demands, illness, and life style. In the present investigation, the researcher studied the model of self-care agency development for these patients, using methodology of action research to create the nursing system for outpatient clinic.

**Conceptual Framework**

The research was based on theoretical and research methodology framework. The theoretical framework employed Orem's General Theory of Nursing which indicated that an individual has potential and uniqueness. The main concept of nursing is holistic care. It is believed that an individual is composed of bio-psycho-social and spiritual being, integrated into one dimension of the individual's life (Hanucharurnkul 1993). Illness can disturb both the body and the mind. Individual may feel loss of morale, depression, hopelessness, and unable to control situation. These emotions will increase stress, effect on immune system, and induce the growth of cancer cells (Simonton and Simonton 1980). Thus, the development of self-care agency for breast-cancer patients receiving chemotherapy needs to understand about patients' perception, beliefs, attitude toward their disease and treatment because these will be the data base for attitude improvement to reduce the patients' stress, and improve the function of immune system to inhibit the growth of cancer cells (Hanucharurnkul et al. 1995).

Quality of life is related to individual health. Illness of individuals would have effect on their quality of life. Therefore, self-care is essential for individuals' health and well-being. For sick persons, measurement of the quality of life is more appropriate than health evaluation. So, the quality-of-life measurement is the method that evaluates the patients' self-care agency development.

The concept was based on action research whose objectives were practice improvement and theory development. Such action research believes that theory is related to practice (Boonchan 1994). The research was arranged into a spiral with five steps, namely: planning, acting, observing, reflecting, and re-planning.

In planning the project operation, the following four disciplines were taken into consideration:

- Breast cancer, chemotherapy treatment and its side effects
- Self-care and self-care promotion in breast-cancer patients receiving chemotherapy
- Attitude toward disease and treatment of breast-cancer patients, and
- Quality of life in breast-cancer patients.

It was revealed that breast-cancer patients undergoing chemotherapy treatment had increased therapeutic self-care demands. They need to develop their self-care agency sufficiently and continuously to meet their demands. Furthermore, it was shown that factors influencing self-care behavior, individual self-care agency, and positive attitude toward disease and its treatment would improve the patients' self-care agency.

**Assumption**

This research was based on the assumption that self-care agency of breast-cancer patients receiving chemotherapy can be developed by the appropriate method.

**Objectives**

The objectives of the present study were to study:

- The changing of attitude toward disease and treatment, and quality of life of the patients before and after development of self-care agency in breast-cancer patients receiving chemotherapy
- The factors influencing self-care behaviors of breast-cancer patients receiving chemotherapy
- The process of self-care agency development in breast-cancer patients receiving chemotherapy, and
- The model and methods useful in assisting the breast-cancer patients receiving chemotherapy to develop self-care agency.
Hypothesis

At the end of the program, breast-cancer patients receiving chemotherapy will develop more positive attitude towards disease and treatment and will have better quality of life than before entering the program.

Expected Outcomes

The expected outcomes of the study were:
- To arrive at the model of self-care agency development for breast-cancer patients receiving chemotherapy
- To develop a body of knowledge and nursing theory, both in descriptive and practice theory.

Research Methodology

Sample Selection

Subjects were purposely selected based on five inclusion criteria:
- Females, age between 20-60 years
- Aware of their own illness
- Diagnosed as having breast cancer and receiving chemotherapy in first course, or during Courses 1 to 3 (Thongprasert 1993)
- Have good consciousness, and understand Thai, and able to communicate in speaking, listening, writing, and reading, and
- Willing to join the research project.

Exclusion criteria were the followings:
- Have chronic diseases, such as heart disease, hypertension, and diabetes mellitus, etc.
- Have psychological disorders
- Used to be diagnosed to have cancer or recurrent breast cancer, and have undergone chemotherapy treatment.

Setting

This research was conducted at the Oncology Outpatient Clinic, Ramathibodi Hospital in Bangkok.

Instruments

Educational Materials or Booklets: The researcher has provided educational file consisting of booklets on the following topics:
- Breast-cancer patients with chemotherapy
- Chemotherapy for breast cancer
- Weight gain on breast-cancer patients receiving chemotherapy
- Self-care for breast-cancer patients after completed chemotherapy
- Self-care manual during chemotherapy
- Nutrition for cancer patients, and

Videotape: A 20-min videotape on “Self-Care During Chemotherapy”, created by the researcher from literature review, was also provided.

Assessment Tools: Assessment tools used in this study included the followings:
- Demographic data sheet to obtain information related to age, education level, marital status, position, stage of cancer, etc.
- Patients’ progressive notes to record date, times of follow up, body weight, medications, and side effects. This instrument used pattern of WHO Assessment Form with 12 items.
- Guideline for in-depth interview to obtain the patients’ concerns, factors influencing patients’ self-care behavior, perception of attitude toward disease, and treatment by using in-depth interview technique. The researcher used this guideline to ask for the process of patients’ self-care agency development and to meet the research objectives. In-depth interview technique and audio tape recording were used to collect the data.
- Questionnaire on attitude toward disease and treatment (ATT), translated from the Burns Cancer Belief Scale (Burns 1984). This is an Osgood Scale with 23 items for measurement that reflected the feelings and beliefs about cancer. Content validity was established through the five-person team of Ramathibodi Hospital’s nursing experts. Test of internal consistency reliability gave the value of alpha coefficient = 0.73.
- Questionnaire on cancer quality of life (QOL) developed from the one on HIV quality of life (Nanthachaiphan pers. comm.). This is a
linear analog scale, 100 mm in length, with 23 items. Content validity was established through the five-person team of Ramathibodi Hospital’s nursing experts. Test of internal consistency reliability gave the value of alpha coefficient = 0.85.

Research Implementation and Data Collection

All patients who fit the inclusion criteria were asked to participate in the study. In the first step the author made relationships with the patients and identified the objectives of the study. Then the examination steps were explained at the clinic. The subjects were asked to fill in the questionnaire form. These included demographic data, attitude toward disease and treatment, and quality of life. After that the participants were allowed to watch videotape in group and then started an in-depth interview one by one. For this step, the educational file was distributed to the participants in order to develop their self-care agency on individual basis. When the participants came for follow up, the researcher assessed chemotherapy side effects and assessed the ATT and QOL as well on a monthly basis for three consecutive months. At this moment the researcher collected qualitative data through an in-depth interview and audio tape recording, and worked together with the participants and their family to explore method of patients’ self-care agency development.

Data Analysis

The quantitative data were analyzed by SPSS PC program while the qualitative data were analyzed by content analysis technique.

Results and Discussion

Demographic Data

The 20 participants in this study were female breast-cancer patients undergoing chemotherapy at the Oncology Outpatient Clinic, Ramathibodi Hospital. The age of participants ranged from 35 to 58 years (mean = 47.75).

Side Effects

It was found that the most common side effect was hair loss, with the incidence of 75.57%. The second common side effect was nausea and vomiting, at 56.43%. The third common side effect was anorexia, at 45.71%.

Changing of Attitude towards Disease and Its Treatment

The data were analyzed by ‘One-Way Repeated Measure ANOVA’ method (Table 1). The results showed significant differences of ATT mean scores (p<.001). When compared pair of ATT mean scores with Neuman-Kuels test, it was revealed that there was a significant difference (p<.05). That means attitude toward disease and its treatment mean scores were slightly increased at the beginning until the end of the program.

Changing of QOL

The patient’s QOL mean scores before and after the completed self-care agency development at 1, 2, and 3 months were slightly increased. When compared QOL mean scores four times with One-way Repeated Measure ANOVA (Table 2), the results indicated that there were significant differences at p<.001. When compared the mean scores four times with Neuman-Kuels test, it was found that there were significant differences at p<.05.

Furthermore, the study also found a change of body weight of the subjects before entering and after completing the program. Fourteen of them had increased weight at the end of the program. The maximum weight gain was 9.1 kg, and the minimum weight gain was 1.1 kg. Only six subjects had weight loss. The maximum weight loss was 4.1 kg.

Qualitative Data

Four categories of qualitative data were found as follow:
Patients' Needs and Concerns: The study showed that the participants desired information related to their disease status, treatment received, and potential side effects. Moreover, it revealed the subjects' concerns on self-image, surgical wound, time consumed for visits to clinic, weight gain, treatment expense, sexual relationship, and chemotherapy side effects (hair loss, nausea, vomiting, mucositis, diarrhea, burning eye and lacrimation, neutropenia, and hot flash.)

Factors Influencing Self-Care Behavior: The following factors were found to influence self-care behavior:

- **Attitude toward disease and treatment:** Positive attitude of the patients towards disease and treatment is beneficial to the participants, as shown by the fact that those living with hopefulness would help them to cope with their illness. They would accept and fight with their illness for getting long life by providing own health care.

- **Culture and personal beliefs:** Although the participants selected medical treatment first, but most of them (80%) still believed in folk treatment. Only four of them selected only medical treatment. Personal beliefs, such as some prohibited food, might influence the patients' self-care behaviors.

- **Personal health habits:** The participants who were interested in their own health care would be active in doing self-care action and seeking health information.

- **Past experience:** Experiences about cancer from others would influence the patients' coping to their illness and patients' self-care behavior in treatment seeking.

- **Family system:** Most of their family members would support the participants to develop their self-care agency. The one who did not receive support from the family was tired and lack of morale. She thought that she would be a burden to others.

- **Social support:** Good social support would help the participants to cope with their illness.

- **Health state:** The patients' illness would have effect on their self-care agency development. Other illnesses, except chemotherapy side effects, would increase the patients' therapeutic self-care demands. If their self-care agency was not enough to meet their demands, they would have self-care deficits. There is a need to develop the agency of significant person for doing self-care action for them.

Process of Self-care Agency Development

The qualitative data showed that the process of self-care agency development for breast-cancer patients receiving chemotherapy would have effect on the increased sufficiency of self-care action, positive attitude toward disease and treatment, and good quality of life. The process had two phases (Orem 1995):

**Phase I:** Estimate type operations proceed to reflect understanding and judgment about the situation.

**Phase II:** Decision on what would be done, production of action and evaluation. The process required time, energy and effort. The participants discovered the appropriate actions by trial and error; using other experiences and resources.

The Self-care Agency Development Model

Educative-supportive nursing system was used to develop the patients' self-care agency. The present study found nine methods of helping the breast-cancer patients receiving chemotherapy:

- Providing supportive environment for the patients in developing self-care agency
  - Teaching
  - Creating the therapeutic relationship
  - Counseling
  - Guiding
  - Encouraging the patients to develop positive attitude
  - Supporting
  - Mobilizing resources, and
  - Acting as a patient's advocacy.
The research project demonstrated the feasibility and conceptual desirability to use QOL measures in the supportive care studies as a part of the establishment of patients’ self-care system and nursing intervention in this process. The final results confirmed the initial hypothesis that this interactive health-care system improved the patients’ attitude toward disease and treatment, and ultimately results in improvement of the quality of life.

Health-care team should recognize the patients’ needs and concerns. They should help the patients to decrease their concerns because reducing concerns will increase the patients’ self-care agency.

The study indicates the importance of advanced nursing curriculum that will help to develop skills and knowledge of the nurses to the expert level. Thus, it is necessary to promote nurses working in clinic to study at higher level to develop their skills in helping specific patient groups.

Acknowledgement

This paper is the result of the research conducted by the author under the supervision of Prof. Somchit Hanucharurnkul of the Department of Nursing, Ramathibodi Hospital, Mahidol University, Bangkok, Thailand. The author wishes to express her deep gratitude to both supervisors, without whose help and kind suggestions, this project would not be accomplished.

References

(All references are in Thai, except those marked with *)


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Table 1. Comparison of differences of attitude toward disease and treatment mean scores in the 1st, 2nd, 3rd, and 4th times with One-way Repeated Measure ANOVA (N=20)

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<th>Sources of Variation</th>
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<th>SS</th>
<th>MS</th>
<th>F</th>
<th>P</th>
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<td>16713.55</td>
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<td>Between interval</td>
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<td>25013.55</td>
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Means, standard deviation of ATT and differences of means score when compared with Newman Kuels Test are shown below:

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<td>139.70</td>
<td>14.39</td>
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</table>

* P < 0.05

Table 2. Comparison of differences of quality of life mean scores in the 1st, 2nd, 3rd, and 4th times with One-way Repeated Measure ANOVA (N=20)

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<th>Sources of Variation</th>
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<td>Total</td>
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Means, standard deviation of QOL and differences of mean score when compared with Newman Kuels Test are shown below:

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<td>6.16</td>
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* P <0.05