

Project Leader: Hiroko Komatsu

**[Purpose]**

The aim of this project is to develop a patient-centered cancer care system in which women with breast cancer actively participate in their own care. This system will help breast cancer patients fully understand their own treatment process, and learn how to communicate with various medical professionals and how to take good care of their own life and lifestyle.

**[Plan and Implementation Process]**

Step 1: Provide opportunities to form partnerships among patients receiving advanced breast cancer treatment, their families and healthcare/medical professionals providing care. (**Breast cancer support program**);

Step 2: Advocate the importance of forming partnerships among breast cancer patients, their families, and healthcare professionals, and suggest the current issues and future direction of a cancer care system which can be developed through treatment process in collaboration with patients and healthcare professionals. (**Symposium/core meetings**);

Step 3: Based on realistic ways of forming partnerships, propose a care provisioning system model for cancer patients to control and use information and resources required for living with treatment and cancer, make satisfactory decisions, and continue with the treatment (**Descriptive studies and core meetings**);

Step 4: Implement the new care provisioning system based on partnerships and review the practicality and validity of the system (Implementation of an evaluation study, introduction of new care practices).

**[Goal Attainment]**

**1. Research practice activities**

**1) Empowerment of Breast Cancer Patient Community (Breast Cancer Support Program)(Figure.1)**

Based on the theme “Sharing Knowledge, Courage, and Trust,” we regularly held our support program for women with breast cancer, and planned and implemented “Support Programs for Learning” in collaboration with core members of participants. We also planned to establish a branch of breast cancer support program in a cancer treatment institution, partnering with the core members. We will develop a prototype of a new medical system which offers peer support services to cancer patients who desire to talk and listen to peer patients. We also started studies toward launching a web-based support program and are currently considering the contents of health information to be included and how to manage the program.

**2) Development of a Multidisciplinary Approach to Breast Cancer for “Information Sharing between Patients and Medical Professionals”**

**A. Development of a prototype of a care provisioning system model (Figure2-8, Table1)**

We developed a prototype of a care provisioning system model with a focus on breast cancer. A project team was formed with members from S Hospital breast team and patients participating in breast cancer support program. The prototype model was carefully examined and refined by the project team. The care provisioning system model was then put to practical use as a multidisciplinary approach to breast cancer for “Information Sharing between Patients and Medical Professionals”. The system model includes the following three care programs:

- Strengthening the collaboration and partnership between team members, medical professionals and patients;
- Conducting efficient team conferences using breast cancer medical information sharing system;
- Using self-care booklets that give guidance to patients to actively participate in team medicine;

To design the breast cancer medical information sharing system as the main database to preserve electronic chart data for later use, we examined what kind of information and data should be shared among medical team members. This system includes conference sheets that support understanding the whole picture of patients, flow maps of treatment processes, and self care sheets that enable patients and medical professionals to exchange information on self care.

### **B. Clinical application and evaluation of the program**

We held a workshop on the theme of “Utilization of Medical Information Sharing Systems” and “The Role and Function of Resource Nurses” for introducing the program.

In order to evaluate the validity and effectiveness of the program, we conducted a quasi-experimental design study for breast cancer patient receiving pre-operation chemotherapy. Patients were assigned through satisfied allocation to either the experimental group, to which the developed program was clinically applied or the control group receiving standard care. Outcome measures included patient satisfaction, quality of life, chemotherapy completion rate, etc.

As a long-term follow-up of the outcome evaluation will be necessary; we requested the core members of the breast cancer support group to participate in the evaluation process.

A community for women with breast cancer has been changed from a support group to a support program on an outpatient basis and expanding in many ways.

## **2. Education of novice researchers**

<Project>	<Link with MS/PhD students>	<Educational intentions and commitment>	<Outcome>
Cancer	Proactive participation into a support program for breast-cancer patients	Acquisition of cancer communication competence Acquirement of high-level practical competence for community-based nursing	Obtainment of facilitator role
	Nomadic education in collaboration with the MD Anderson Cancer Center	Cultivation of internationally-minded, high-level practical competence for cancer nursing	Presentations at international academic conferences: 8 presentations Securing of research funds Research-backing from foundation for learning promotion: 6 person
	Conceptualization of people-centered care Participation in a working groups	Participatory learning pertinent to theory construction	Development of competence for promoting People-centered care

## **3. International collaborative research**

- ① Dr. Ueno cooperated on this research program as an International collaborating researcher. He participated in

the symposium "patient-centered breast cancer medicine" and clarified the differences between the health care system and the cultural background in the breast cancer team approach of Japan and the U.S.A. Furthermore, he was engaged in clinical application of the interdisciplinary approach for breast cancer using "sharing medical care information between patient and health care provider on electrical medical records system". He particularly focused on the reinforcement points of approach for the Japanese model after having clarified the strengths and weaknesses of the interdisciplinary approach in the U.S.A.

- ② We expanded the People-centered care for cancer patient to Asia country. We developed the East Asia Cancer Nursing Network (EACNN). The secretariat of EACNN is established at St. Luke's College of Nursing. The participating institutions are St. Luke's College of Nursing, Yonsei University (South Korea), Mahidol University (Thailand), Ramathibodi School of Nursing, Mahidol University (Thailand) and the National Yang-Ming University (Taiwan).

- ③ International collaboration research based on this network is the following:

Title: Suggestions for advanced Korean hospice based on analysis of hospice law, cost, and management systems in foreign countries.

Principal Investigator: Chung Yul Lee, Yonsei University College of Nursing

Co-Investigator: Hiroko Komatsu, St. Luke's College of Nursing

Yann-Fenn Chao, Yang Ming University

Weihua Zhang, Nell Hodgson Woodruff School of Nursing Emory University

#### **4. Future directions**

We are planning to expand the support program into virtual communities such as support programs on the web.

Issues currently under consideration are how to:

- disseminate our efforts as a model to the society (collaboration with mass media),
- generate policy recommendations based on our activities and research outcomes,
- raise funds and set up an organization for sustainable development of our activities, and
- pursue possibilities to work with other projects.