

# St. Luke's International University Repository

## St.Luke's College of Nursing 21st Century COE Program "Nursing for People-Centered Initiatives in Health Care and Health Promotion" Research Outcome Report for FY2005

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# **COE** People-Centered Care program



**St.Luke's College of Nursing  
21st Century COE Program**

"Nursing for People-Centered Initiatives in Health Care and Health Promotion"

**Research Outcome Report  
for FY2005**



**COE** People-Centered  
program



Care

## St. Luke's College of Nursing 21st Century COE Program

"Nursing for People-Centered Initiatives in Health Care and Health Promotion"

### Research Outcome Report for FY2005

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# Nursing for People-Centered Initiatives in Healthcare and Health Promotion:

What Has Been Seen as People-Centered Care and Future Issues



St. Luke's College of Nursing  
21st Century COE Program Leader

**Hiroko Komatsu**

With epoch-making advancements in science and information systems, the 21st century is an era in which individuals may lead their lives with their own unique lifestyles and create health conditions that are optimal to them. This possibility means that in order to protect and promote their health by themselves, individuals are required to understand a flood of information and make a number of choices in relation to their own life or way of living.

Nursing is a practical science that helps people make choices pertaining to how they live their lives. In other words, nursing serves a partnership role necessary for people to nurture their own good health, live better, and die with dignity.

Through the St. Luke's College of Nursing 21st Century Center of Excellence (COE) Program, we aim to build upon individual people's unique lifestyles and life experience, thereby realizing a society to promote health with the people's initiative. We seek to create providing innovative ways of nursing through partnership and collaboration with people. The program is called the Nursing for People-Centered Initiatives in Healthcare and Health Promotion: People-Centered Care.

With the leadership of the President of St. Luke's College of Nursing, the COE Leader and Steering Committee work together to ensure systematic coordination and control over research projects, while the Evaluation Committee, consisting of representatives of civil groups, financial circles, and the political arena, as well as international experts, present directions for continuous assessment and further development, thus promoting organizational momentum (Figure 1).

The program that was launched in 2003 as a five-year research project with research grants from the Ministry of Education, Culture, Sports, Science and Technology is now almost halfway complete.

The research programs of the COE, Nursing Practice Development Research for People-Centered Care, encompasses 11 projects (Figure 1). A community-based participatory research paradigm has been identified as the guide for analysis and development of all projects. People participate in the processes of planning, implementation, and evaluation. Four priority areas are being addressed: advanced medical technologies and nursing, coping with illness and nursing, stigma and nursing, and development of strategies for people-centered nursing service. Topics

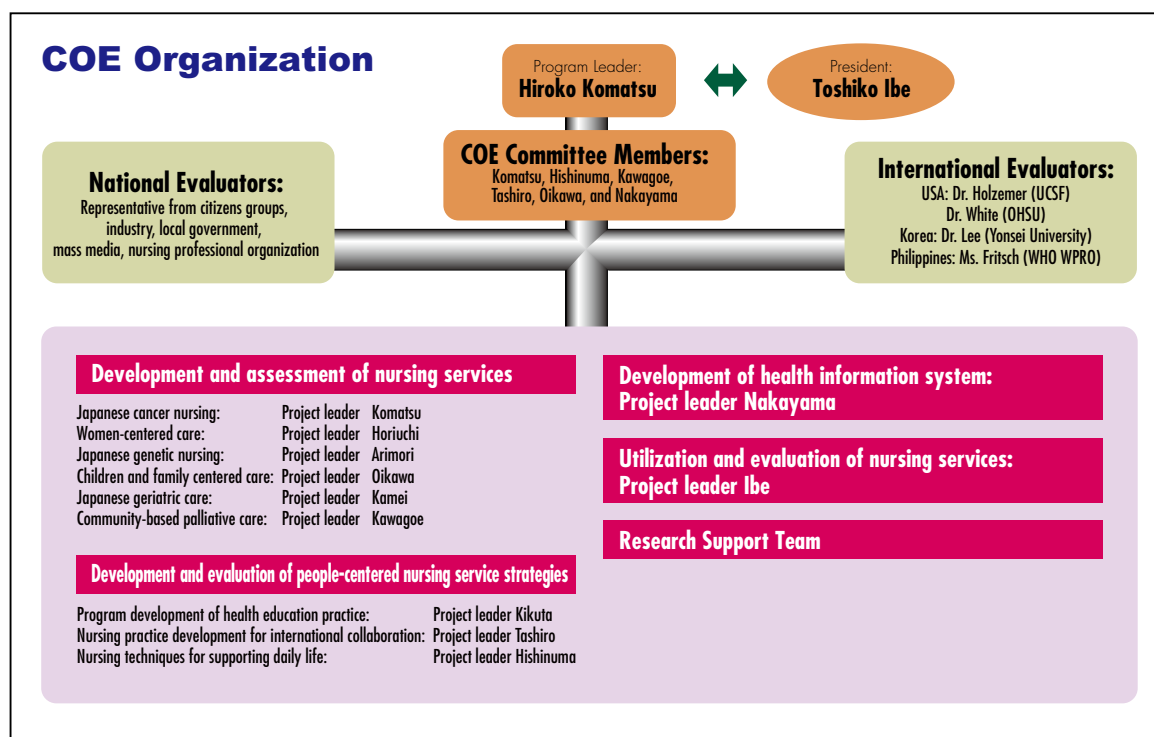


Figure 1

include Genetic Nursing in Japan, Japanese Cancer Nursing, and Women-Centered Care .

The series of COE International Relay Symposia provide a way to share information and exchange opinions on major interests and issues about people-centered care discovered over the course of research and practice (Table 1).

The third priority in addition to the research projects and International Relay Symposia is the development of a system to provide health information to make health resources created through people-centered care research and other activities available online, distributing and communicating their contents so that community people and professionals can have easy access to them. This system is available as Kango-net (<http://www.kango-net.jp>). It is open for

mutual communication with people, and drawing more than 20,000 hits per month at present. It has been featured in the media. One called it the “birth of a community website connecting citizens and nursing personnel” describing it as “a reliable and well-managed healthcare site in which users can understand optimal treatments or prophylaxes by keyword and receive health counseling with experts.” Kango-net presents classification “drawers” of health information, suggested ways for users to wisely make the most of health information, and access to additional information resources in an efficient manner. For example, users may search drawers labeled as “health-related multimedia,” “decision-making supports,” and “health risks,” from which they understand about health and illness in their daily lives and consider about how to make their own choices and manage their own health, by tracking down the information they need. In

Table 1 Topics of the St. Luke's College of Nursing 21st Century COE Program International Relay Symposia

1st	2004.7.17	Building a Community for Spending One's Last Days at Home
2nd	2004.10.3	Let's Talk about Healthcare! Patients are Part of the Team
3rd	2004.11.21	For Living a Life of Your Own Choice
4th	2005.10.29	Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care
5th	2005.11.27	Sharing Wisdom, Courage, and Experience: Women Supporting Each Other in Society

the future, Kango-net will expand to include enhanced learner-oriented health e-learning functions. Also it is planned to enhance Kango-net's international network by developing consumer health informatics that covers people-centered care in Japan, North America, and Asia.

In the course of these activities over the last two and half years, continued efforts have been made to understand what people-centered care should aim for, and be like, through the exchange of opinions among

research project members, at school-wide COE activity report meetings, and with people involved in COE research and activities. The results have been analyzed and used for the ongoing process to conceptualize people-centered care. Currently common concepts across the 11 projects reflect that people-centered care is built on the underlying concept of "consumer initiatives." Consumers are to be seen as beneficiaries of medical and health care as commercial products, in which experts incorporate new attitudes to healthcare, different from conventional ones. Examples of such stances include "the sense of deadlock in medical and health care in Japan may not be overcome without the increased involvement of lay expert" and "healthcare providers and people should openly communicate their own knowledge and skills as well as trust and respect." These should in turn lead to efficient feedback of implicit knowledge gained from people's innate experience encompassing birth, aging, illness, and death that is based on collaborative research with people. Thus benefiting the products (i.e. medical and health care) will better promote the collective health of the community as a whole. In other words, it is to produce a paradigm shift in healthcare from the concept of "product-out" to "market-in".

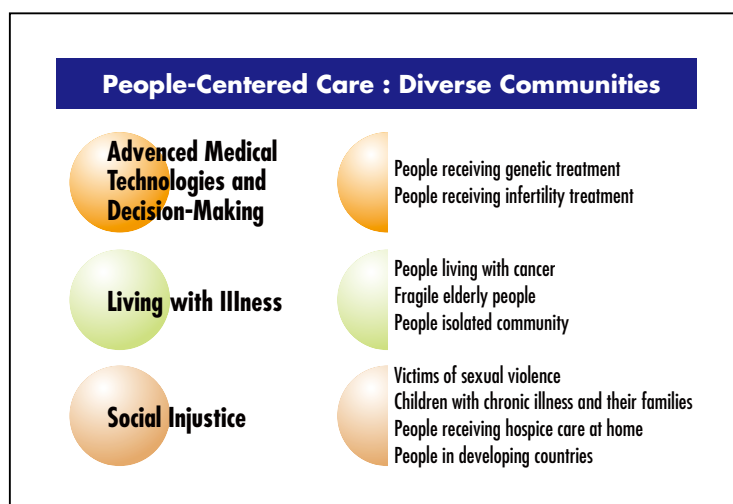


Figure 2

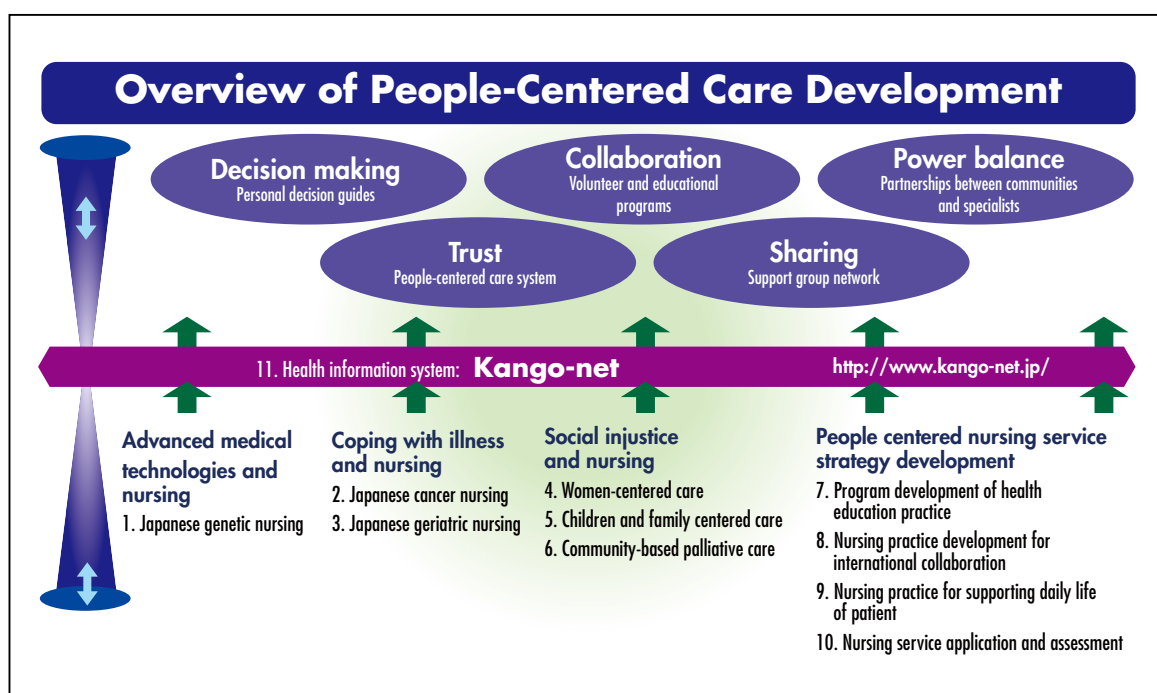


Figure 3

People-centered care may be considered to function as a system for collaboratively solving health problems based on partnerships with individuals, families and community (Figure 2). Its function is to produce a healthy community rich in voluntary commitment to choices as to health problems, the wise use of health information, and human wisdom, which should in turn foster the formation of a civil society rooted in the sense of safety and soundness.

In each research project, the collaborative activities of people are promoted so they might serve as role models, or a compass, for the healthy community.

Nursing services provided to the community with the help of public collaboration may be categorized into areas shown in Figure 3. They include personal decision guides, volunteer and educational programs for those who are involved in solving health problems as a volunteer or collaborator, partnerships between communities and specialists for the public and professionals to create power balance together, and people-centered care systems to foster trust and sharing.

As reference for the future work, Figure 4 presents what may become our model for “Nursing for People-Centered Initiatives in Health Care and Health Promotion” in two years' time. Each project is to form a model for changes or a base for practice of collaboration with people, designed to break the stagnation in the healthcare system that has been maintained by current medical institutions and fee systems. In Japanese Cancer Nursing, the author's research area, it is expected that systems for examining the ever-increasing number of patients with cancer may be shifted toward more patient-oriented ones, and that those who have experienced cancer might use their first-hand, compelling experience as a resource to initiate discussions and activities to enlighten cancer prevention activities. Should this happen, cancer prevention with minimum healthcare expenses and maximum attention to patients' needs may be realized. People-centered care is about developing a mechanisms to resolve health problems lying in the current healthcare with the help of people's collective wisdom, leading to a healthy community, and may be where nursing schools can make key contributions.

It is my utmost hope that we will be able to share wisdom, skills, courage, and trust with many people in order for a healthy community to become reality.

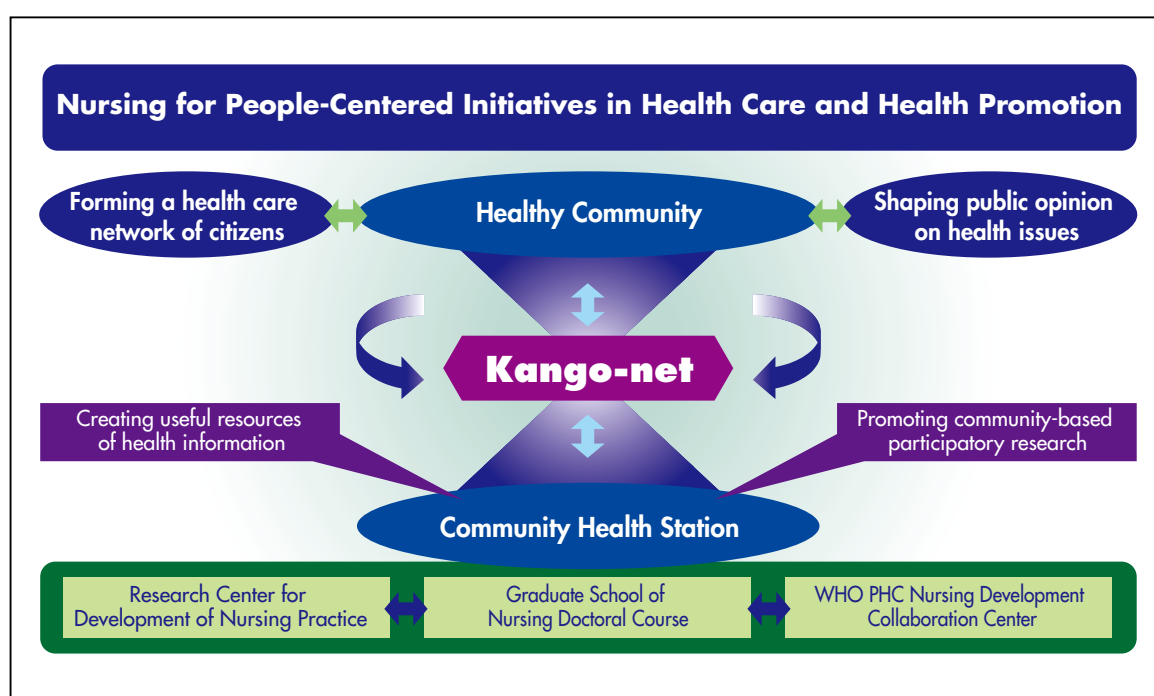


Figure 4



# Nursing Practice Development Research for People-Centered Care

1

## Creation and Dissemination of Genetic Nursing in Japan



Project Leader

**Naoko Arimori**

Project Members

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Project Participants

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Human genome decoding can be credited as one of the greatest scientific breakthroughs in the 21st century. It is not always certain, however, that knowing your own genetic information is equivalent to your individual happiness, which must be determined according to personal values in life.

We are now able to know the condition of a child before birth (prenatal diagnosis) as well as detect several hereditary diseases before the manifestation of any symptoms (pre-symptomatic testing). Before making a decision to undergo prenatal diagnosis, it is necessary to consider the limits of these tests and what range of people the results will affect. It is the role of nursing to support such difficult decisions while valuing the Japanese people's spirit of "harmony".

Health is determined by interactions between genes and the environment. From a broad perspective, genetic elements play a role in lifestyle-related diseases, and thus genetic medicine should be the concern of every individual. Diseases and disorders are part of the genetic makeup of human beings. Science seems to show us an alternative perspective: how to improve our lives with the genes we received hereditarily. Specific support for people at all life stages and health level at home and in social life is also the role of nursing service.

In our project, we hope to deliberate the issue of "helping people lead lives which began with the genes inherited from parents in a way which best suits them" together with all stakeholders, from children to adults, in families, schools, and the communities.

## RESEARCH PROGRESS AND OUTCOME

### Development of Decision Aid Regarding Genetic Medicine

We launched the "Decision Aid" website. In this website, we are disseminating the Japanese translation of the Ottawa Personal Decision Aids, developed by the Ottawa Health Research Institute. It presents five steps for decision making are discussed to allow patients to pursue a lifestyle of their own choice. Also introduced on the same page are the results of the study on intervention for supporting decision-making for prenatal diagnosis and the "yardsticks" used for evaluating these results (obstacles in making decisions).

In addition to medicine-related decision making, this guide can be used in decisions on the pursuit of further education or starting a new professional career, etc. We hope that the guide would be used by as many as possible so that it can grow more advanced and sophisticated.



### Dissemination of Genetic Education in Society

As part of the Genetic Nursing in Japan project, a successful Genetic Education Forum was held at our college. Participants (about 40 clinical staff, nursing students, and nursing teachers) exceeded the number of participants initially expected. In the morning session, lecturers of the Nagasaki University School

of Health Sciences gave a mock class on genetic education. The lecturers hold a class “Genetic Science Course: Enjoying Learning About Genes” where they teach genes to elementary school children in Nagasaki who have applied to take the course voluntarily. As the difficult topic of genes was taught through games, the participants were seen to be very drawn into the class. In the afternoon session, those involved in genetic education gave presentations introducing their activities, providing opportunities to deliberate the ideal methods of genetic education.



### Learning about Life and Ripple Effects

Working with the Tokyo Branch Chuo Ward Section of the Japanese Midwives' Association, we have been and are supporting a project called “Learning about Life” run by midwives for grade five elementary school children from two schools in Tokyo. As part of project activities, we have published a book with the aim of conveying to as many children as possible the message on the birth of life, and that life did not just start with us, but is something passed down over generations, from our grandfathers and grandmothers, to our fathers and mothers. Working together with Poplar Publishing Co., Ltd., a Tokyo-based publisher which has published many children's books, we invited stories related to the birth of life from the public and selected 33 from the roughly 300 stories that were sent in.



## Supporting the Health of Working Women

Aiming to develop a care system for supporting working women to lead healthy lives proactively and comfortably by focusing on the health issues unique to women, such as psychological, physical, and sex-related issues, we launched the “Project for Supporting the Health of Working Women.” As the first step, we started studies aiming to clarify needs related to information retrieval, such as how women gather and make use of information required for them to lead healthy lives. Based on the opinions obtained, we placed our proposed care system for supporting working women on our website to collect comments from our women readers.



自立を目指し、夢の実現を目指す。... 社会に出て活躍する女性が多くなりました。毎日を忙しく、張り合いを持って働くことはとても楽しい。でも、ふとしたことで体調を崩してしまったり、忙しすぎて月経が来なくなったりします。『そういえば、私の母、光采がなくな。』と不安になってしまふことがあると思います。特に女性は、職場での役割だけでなく家庭においても多くの役割を担っていき、心身ともにストレスや健康問題を抱えやすいといわれます。働く女性の健康づくりを、事業所が積極的に推進していくことが重要ですが、女性自身が生涯にわたる自らの健康を守るために、自分から積極的に取り組むことも非常に大切だと考えています。

助産師を中心とした私達は、心やからだ、性の問題など女性特有の健康問題に焦点をあてて、働く女性の皆さんが自ら積極的に健康づくりを行っていただけることを支援するケアシステムの開発を目指し、「働く女性の健康支援プロジェクト」を立ち上げました。その第一段階として、皆さんが健康づくりに必要な情報をどのように集めて、どのように利用しているのかなど情報探索に関するニーズを明らかにすることを目的とした研究を始めました。

## EVALUATION

From the beginning to the last fiscal year, the focus of our activities was placed on disseminating information from the nursing perspective to the community (such as implementing “Learning about Life” classes at elementary schools, providing information on prenatal genetic risk assessment, compiling a guidebook for medical staff, distributing a calendar on Down's Syndrome, and compiling the translated Ottawa Personal Decision Aids) and on searching for concepts which can form the core of people-centered care (supporting decision-making by the International Relay Symposium). During the first two year we gave priority to creating networks and partnerships to serve as the basis of community-based participatory research (CBPR), without which we could not have gone onto the next step (coalition).

Into the third year of the project, we have started efforts to meet partners who “share the same language” for letting the community know more about nursing, and other research studies (publication of book “Learning about Life,” Project to Support the Health of Working Women). In the future, we hope to evaluate the process of this project from CBPR and carry out evaluation of the project results to determine how much it has contributed in providing health support to the community.

## *Japanese Cancer Nursing Development of a Care Provisioning System for a Multidisciplinary Approach to Cancer Nursing*



Project Leader

### **Hiroko Komatsu**

Projects Members:

Kumi Suzuki, Noriko Matoba, Kazuhiro Nakayama,  
Yoshie Murakami, Naoko Matsuzaki, Miwa Tomita,  
Wakako Ichikawa, Naoko Hayashi

Project Participants:

Hideo Anbo, Hiroko Muraoka, Sadako Sakai, Mika Nomura

### **Towards a new health care system centered on patients as a primary focus**

Technologies of cancer diagnosis and treatment are advancing at a surprising pace, resulting in the continual development of new treatments with increasing rate of cure. Various types of support from health professionals is therefore essential for patients to be able to select the appropriate treatment and approach from the different treatment options available to them. The teaming-up of medical personnel from different fields of specialty such as doctors, nurses, and pharmacists to share their knowledge and experience with patients enables them to receive treatments that are best suited and satisfactory to them. In living with cancer, the patient, and not the health caregiver, is at the helm of decision-making about treatment options.

This project aims to develop a care system model for patient-centered multidisciplinary approach to cancer nursing taking into account the cancer medical care situation in Japan. Specifically, the following tasks are carried out in this project based on partnership

between patients receiving breast cancer treatment, their families, and the medical specialists providing breast cancer medical care: (1) Propose the importance of partnership between women who have to live with breast cancer and medical specialists, and examine realistic approaches to cancer treatment; (2) Based on realistic partnership, propose a care providing system model which enables patients to control and use information and resources required for them to live with treatments and cancer, and continue making and carrying out decisions with which are they satisfied; and (3) Build new care providing system models based on partnership, and review their practicability and suitability.

## **RESEARCH PROGRESS AND OUTCOME**

### **Current Situation of Team-Based Treatment for Breast Cancer in Japan**

To investigate the foundation for realizing a patient-centered cancer care system in this country, we analyzed opinions from both medical care providers and cancer patients on the tangible aspects (medical fees and staffing) and intangible issues (consultation and communication between medical specialists) of patient-centered cancer care available, and the problems that need to be resolved. The results showed that under the current system in Japan, the doctor in charge of the patient bears overall responsibility throughout the treatment process of the patient, and this doctor and the nurses under the doctor's supervision are basically the only the medical care providers who understand or keep track of patients. They attend to any required communication and care adjustments with other medical care providers from related medical departments within the very restricted human and physical environment of the outpatient department. To investigate this situation in further detail on a national



level focusing especially on breast cancer medical care, we conducted a nationwide questionnaire survey on how the multidisciplinary approach to cancer nursing as a patient-centered cancer medical system is being developed in Japan, and the problems that need to be resolved. With the cooperation of hospitals authorized by The Japanese Breast Cancer Society, we analyzed data from 249 hospitals, 1,652 doctors and nurses, and 1,950 patients. The results showed that multidisciplinary conferences are being held only at one-fourth of these hospitals, indicating the need for more information sharing between medical professionals.

#### Comments of Women Receiving Team-Based Breast Cancer Care

We are still continuing our program to support women with breast cancer. This year, we held nine support group meetings, which were attended by more than 200 women. Based on the vision “sharing knowledge, courage, and spirit,” the circle of women living with breast cancer who support and understand each other is growing. The program agenda of each meeting takes into account the requests and needs of participants. With mini-lectures by participants when the occasion allows, the support group is transforming into a proactive one where the participants play the main role in the planning. We have also been preparing to set up a community station. This would allow collaboration between the support groups with resource persons so that participants of the support group are able to run the group as well as serving as the base for support group members to carry out their main activities. The working group has just been established. Support program participants are asked to submit proposals, requests, and ideas related to the patient-centered breast cancer medical system freely.

#### Extensive Discussion on Patient-centered, Team-Based Breast Cancer Care

In order to propose a new patient-centered medical system, it is important to take into account the views of the users (including patients and their families who may use the system). At the same time, the incorporation of Japanese medical care system characteristics should not be forgotten. For this, it is also indispensable to compare worldwide trends from a broad perspective and study the ideal medical care approaches required in Japan. We therefore selected “patient-centered, team-based breast cancer care” as the theme of this year’s COE International Relay Symposium. From the planning stage of the symposium, we had breast cancer patients participate to plan themes and methods

together. Some presenters were selected from breast cancer patients who volunteered to participate from the public. With these breast cancer patients at the helm, we discussed the goals of new breast cancer team medical care and how all those involved can cooperate from their respective positions.

#### Devising a Care Provisioning System Model for Multidisciplinary Approach to Cancer Nursing

Based on the results of the survey mentioned earlier, opinions exchanged at the International Relay Symposium, and comments made by participants of the breast cancer women support program, we are currently planning and discussing the establishment of a system aiming at multidisciplinary patient-centered breast cancer care. Based on the functions of multidisciplinary approach such as continuity, multiplicity, autonomy, and mutual dependency, the provisional main elements of the care system as of now are the development of information system tools for breast cancer patients and multidisciplinary medical professionals to share information, assignment of resource nurses to serve as partners so that patients are able to steer their treatment smoothly, and team conferences in which patient can participate. To attempt these goals in the actual clinical setting, we are currently making adjustments in the organization and environment among cooperating medical institutions.

### EVALUATION

It will be a milestone in cancer treatment if our patient-centered cancer care system is able to successfully incorporate the health needs of women who are the main players of the system, and be run in actual clinical settings with women participating proactively. In the installation, implementation, and evaluation process of the new system, we will set up a focus group for medical personnel and patients to carry out activities jointly, monitor results continuously, and conduct discussions together. As the next step, we will go into proposing a model which can be used and is useful from the viewpoint of patients and which will promote proactive involvement of patients in treatment.

We hope that through collaborative activities with all of these people, a network with resource persons promoting patient-centered cancer treatment system will be born, resulting in the proposal of policies initiating reforms to support patient-centered cancer treatment.



## Japanese Cancer Nursing Development of a Program Aiming to Recover Fitness of Cancer Survivors



Project Leader

**Akiko Tonosaki**

Project Members:

Keiko Takahashi, Fumiko Furukawa, Masami Sato,  
Satoko Imaizumi, Keisuke Koizumi

Many cancer survivors suffer prolonged continuation of symptoms such as easy fatigability and change in sleeping patterns due to reduced physical functions caused by the illness itself or treatment side effects. This as a consequence also causes many to suffer from various psychological reactions such as depression and anxiety. In order to relieve cancer survivors of such discomfort and enable them to return to a normal life as before treatment, we are working towards developing an exercise program to help cancer survivors to build up their health by themselves.

## RESEARCH PROGRESS AND OUTCOME

### Integration and Accumulation of Fundamental Data Related to the Development of Program for Recovery of Physical Fitness

- 1) Analysis of factors affecting patients' subjective views of their physical condition after hematopoietic cell transplant (hereafter referred to as transplant) and average number of steps

We analyzed the patient's subjective views of their physical condition assessed from number of steps, muscular strength of lower limbs, weariness and anxiety from the pre-transplantation period through one month after discharge from the hospital (Figure 1). As a result, it was confirmed that a reduced average steps during hospitalization amongst the 17 subjects surveyed correlated with delay in recovery of appetite,

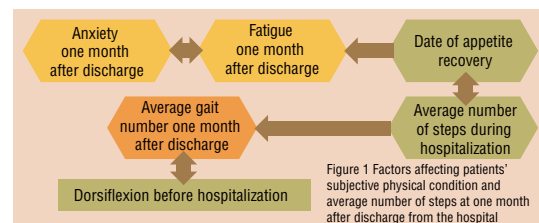


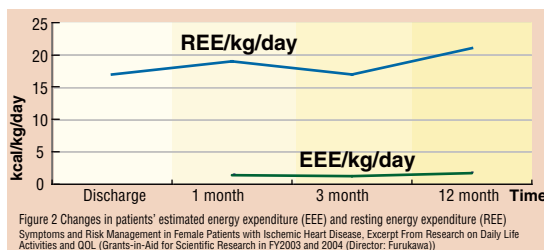
Figure 1 Factors affecting patients' subjective physical condition and average number of steps at one month after discharge from the hospital

and this delay heightens fatigue one month after discharge from the hospital. It was also found that weakness of the dorsiflexion of ankle joints before hospitalization results in an inadequate average steps after hospitalization. These findings suggest that insufficient steps causes reduced muscular strength of the ankle joints, reduced physical balance, an increased sense of burden in walking and physical weakness, and increased feeling of tiredness. Delayed food intake was also a major factor contributing to fatigue. Analysis of each subject showed that male subjects with a step number of more than 2,000 on average during hospitalization in particular were able to smoothly increase their physical activity after hospitalization, indicating the importance of aiming at a step number of 2,000 per day at least, and continuing training of low intensity physical exercise to maintain and enhance the muscular strength of ankle joints, even when not in good physical condition for recovery of walking ability.

(Akiko Tonosaki: Analysis of Factors Affecting Patients' Subjective View of Their Physical Strength after Hematopoietic Cell Transplant, 20th Japanese Society of Cancer Nursing Conference Proceedings, 2006)

- 2) Relation of onset factors in female patients with ischemic heart disease as seen from daily physical activity levels

Most ischemic heart disease in women occurs a few years after menopause. Due to reduced metabolic function from aging, improvement of lifestyle habit is indispensable for preventing recurrence; in particular, exercise is the key to preventing recurrence. However, currently objective physical activity level after discharge from the hospital is not adequately tracked. For this reason, we conducted a study on 12 subjects (average age: 66.3 years) to measure their estimated energy expenditure (EEE) using a pedometer with accelerometer and resting energy expenditure (REE) using a simple calorie meter at four times for one year from discharge from hospital, and analyzed the findings (Figure 2). As a result, although the cardio functional level of the subjects was found to have improved even in the first year after discharge from hospitalization, both EEE and REE continued to be low. The study also provided objective details on the actual situation of localization of lifestyle activities and sedentary lifestyle. The habit of leading a sedentary lifestyle is thought



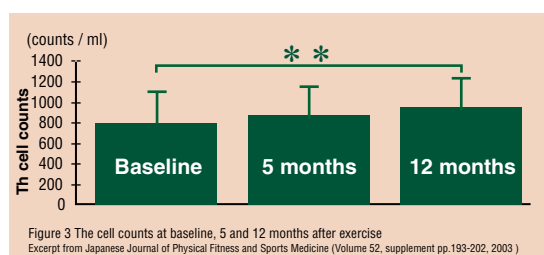
to cause a vicious cycle of physical reserve, delayed recovery, and recurrence. Thus, individual support methods to prevent the habit of sedentary state are therefore important.

(Fumiko Furukawa: Symptoms and Risk Management in Female Patients with Ischemic Heart Disease, Excerpt From Research on Daily Life Activities and QOL, Grants-in-Aid for Scientific Research in FY2003 and 2004 (Director: Furukawa))

### 3) Effects of continuous exercise on immunity function of elderly persons

Our immunity function is known to deteriorate with age, decreasing our resistance to infections. It is, however, also known that continuous moderate exercise increases this immunity function. We therefore conducted a review on whether continuous exercise can help improve declining immunity function. Subjects consisted of 27 elderly persons who were not exercising habitually. They were placed on a continuous twice-a-week exercise program for more than one year. As a result of the continued exercise, the count of various cells of the lymphocyte subset of peripheral blood Th, etc. improved significantly twelve months after the start of exercise (Figure 3). In another investigation on the secretion speed of saliva secretion IgA antibodies with 20 elderly persons, the secretion speed rose significantly from the nineteenth month after the start of training, indicating that the preventive function against oral infections improves with continuous exercise. These results indicate that continuation of exercise for more than one year may improve overall and local immunity function.

(Keisuke Koizumi: Journal of Master's Program in Health and Physical Education, University of Tsukuba, 2001, and Japanese Journal of Physical Fitness and Sports Medicine, Volume 52, supplement pp.193-202, 2003)



## Hints Obtained from Summary of Fundamental Data of Above and Results of Searching for Literature on "Development of Program Aiming to Recover Fitness of Cancer Survivors"

An attitude for exercise after cancer treatment is influenced by the person's primary exercise ability, impact of illness and treatment on exercise functions, interest and enthusiasm towards exercise, and physical and economic environment. The setting of a program suited to the individual is therefore very important in terms of exercise effects and continuity. Our program, focusing on the recovery of cancer survivor fitness, aims to maintain patients' physical ability, to enable them to recover quickly from fatigue and move onto the next activity promptly, and as a result enable patients to return to the lifestyle led prior to illness (the program's final goal). From the data described in 1) and from recent literature on exercise in cancer patients, the importance of the following elements has been clarified.

1) There is a risk of patients leading a sedentary lifestyle due to fear of disease even after one year from discharge from hospital. As this causes a vicious cycle of reduction in physical reserve, it is important to provide individual support to patients from an early stage after treatment so that patients form the habit of continuing physical activities of low to high impact. This is considered to help enhance immunity function, overcome increased susceptibility to infections, and prevent recurrence.

2) Most of the time, the effects of exercise become visible after having continued for more than one year. Instead of rapidly exercising at high impact, it is ideal to start from low impact exercise and gradually increase exercise level as the patient's physical functions recover. It is therefore important to set up a support system which can provide recommendations to patients on exercise methods than can be continued for more than one year, and follow-up on patients through regular phone calls and email to enhance exercise adherence, thereby reassuring the patients that they (the cancer survivors) are being cared for by, are connected to, and at anytime able to seek advice from their caregivers.

## EVALUATION

Future course: As described above, we have set down a future course of our research on what to incorporate in our program. For the next fiscal year, we are already planning to visit pioneering programs in the U.S. that are applying the above methods, and use the information obtained to develop Japanese programs.

## Development of Japanese Geriatric Care



Project Leader

**Tomoko Kamei**

### Project Members:

Fumiko Kajii, Tsuyako Yamada, Wakako Kushiro, Kaori Nakayama, Chiaki Ando, Tomoko Sugimoto

This fiscal year members coming from backgrounds such as social worker, former nurse at home care support centers, rehabilitation nurse, etc. were included to expand the research team to one that can respond to public needs. The regional needs of the elderly and their families were identified, foundations for CBPR (Community-Based Participatory Research) were established, and models were developed.

The research results can be browsed at the “Kango-net” website, presented by St. Luke’s College of Nursing: (<http://www.kango-net.jp/project/04/index.html>)

## Japanese Interdisciplinary Team Approach: Establishment of Education Center for the Elderly and Professionals

### 1. Dissemination of information

We oversaw the editing and publication of the local community PR newsletter “St. Luke’s SilverPress-Iki-Iki-Net” with the help of the elderly and care-giving organizations to the elderly in the community (Photo 1). We also distributed reliable information on care for the elderly and a the newsletter to the public through community meetings held in Chuo-ku. The information was evaluated as being significant. Pamphlets and booklets on care for the elderly were also distributed in at Luke-Navi. In addition, we continued to provide information for patients with chronic respiratory failure



Photo 1. PR News letter



Photo 2. Website for elderly with dementia and Alzheimer's, and caregivers

Photo 3. Information magazine

on the web, updating and adding to the contents as required. Strong public needs for such information could be seen from the enquiries received from readers.

We also launched a new website for the elderly with dementia & Alzheimer’s disease and their families (Photo 2). This website provides information such as a dementia checklist, a column on nursing experiences sent in from the public, as well as tools for evaluating the quality of care for the elderly with dementia.

### 2. Educational program for the elderly, their families and caregivers in the community

Based on the results of a survey on the risks of dehydration in the elderly at home during their visits to hospitals, we clarified the risks and symptoms of dehydration in vulnerable elderly patients according to their health level, and the ideal preventive nursing methods. We also provided an educational program for the community, elderly patients, and caregivers on the prevention and early detection of dehydration in vulnerable elderly patients receiving home care in a periodic booklet, “Information Magazine Supporting the Independence and Nursing of Elderly Patients: Anshin Support” (Photo 3).

### 3. Educational program for students aiming to work in an interdisciplinary team

The educational program for students pursuing careers as health, medical and welfare professionals is ongoing. The program consists of lectures, multi-disciplinary case studies, hands-on activities-challenge program, etc. We also developed evaluation tools, and are continuing follow-up surveys prior to participation, after three months, after six months, and after 12

months. The results confirmed that participation in the program is effective for the value and recognition of the interdisciplinary team approach, self-contribution, and skills. It was also confirmed that participants continue to exchange information and counsel each other after the program ends, demonstrating that the program helps establish a community for resolving issues on care for the elderly at home. We will continue to accumulate data on participants.

#### 4. Identifying community needs and establishing foundations for CBPR

We conducted a needs survey by visiting the community chairperson near the college, welfare commissioners, Minseijin, home care support centers, etc. As a result, we were able to identify specific needs related to the provision of general and technical information on care for the elderly in the community, mini-care programs on prevention of falls, etc. Based on this, we launched programs for public-participated exercise classes for preventing falls and fractures according to public needs and outreach-type nursing courses. We have also started a local fundamental network, recommending the establishment of outreach programs based on community needs.

In November, we held a class on the prevention of falls and fractures for the elderly in the community (Photo 4) and obtained information on specific requests



Photo 4. A class on the prevention of falls and fractures for the elderly

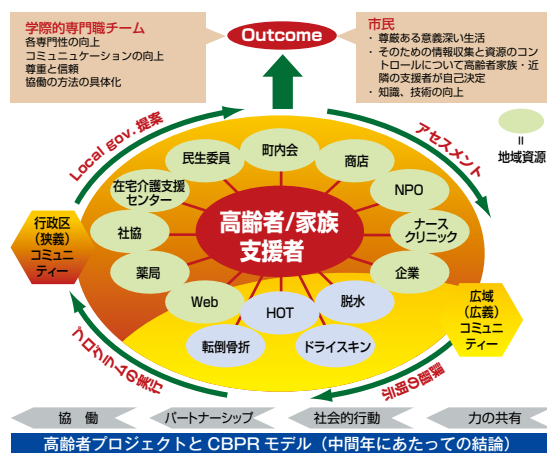


Figure 1. Person-centered care and CBPR Model

regarding future programs. Through analysis of these processes, we developed an person-centered care and CBPR model (Figure 1).

### Development of a Telenursing System for the Elderly with HOT

We are continuing our survey on the trial use of the telenursing support system (Figure 2) for patients with respiratory failure and home oxygen therapy (HOT). Completed essentially during the last fiscal year, the system consists of: (1) Internet terminal at home, (2) nursing monitor/telementoring center, and (3) text and web textbooks. The data accumulated to date and results of interview surveys on users have confirmed that this system is able to enhance the self-management awareness of respiratory failure patients through simple operations, enables patients to understand their bodily changes themselves, and has psychological effects for reducing anxiety. We also analyzed the “tele-nurse” function of the system, and applied it to telementoring by tele-nurses in a telementoring training seminar organized by the Japanese Telemedicine and Telecare Association.

Based on evaluation of the systemization of the regional GP-HOT patients-telenursing system, protocols were established and monitoring is currently carried out.

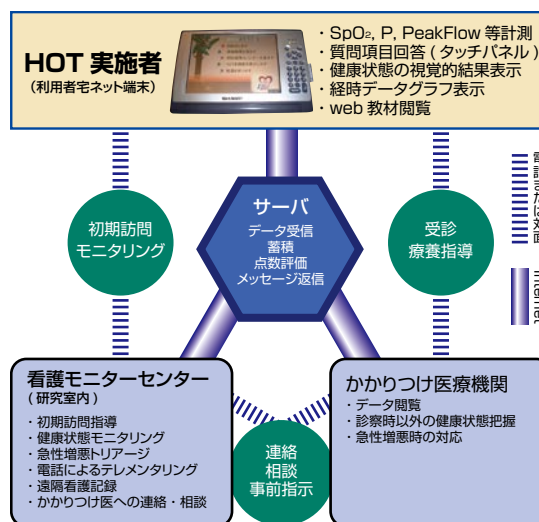


Figure 2. The system of telenursing for HOT

### EVALUATION

We were able to collect and analyze information on the detailed needs of the elderly and their families in the community throughout our research this year, and clarify community leaders in the region, meaning that the infrastructure for promoting a Person-centered Care approach based on the elderly patient CBPR model has been established.



## *Women-Centered Care: Support for Victims of Sexual Abuse*



Project Leader

**Shigeko Horiuchi**

Victims of Sexual Abuse Project Members:

Yaeko Kataoka, Hiromi Eto, Kaori Osumi, Yukari Yaju

Families Experiencing Stillbirth Project Members:

Naoko Arimori, Masako Momoi, Yaeko Kataoka, Madoka Tsuchiya,  
Naoko Ota, Akiko Hiruta, Keiko Ishii, Shoko Horiuchi

## BACKGROUND AND SIGNIFICANCE OF RESEARCH

Domestic violence (DV) means violence inflicted by husbands or intimate male partners against women; it is a social problem worldwide. DV causes multiple health disorders in women, including serious psychological impact such as depression, post-traumatic stress disorder (PTSD), anxiety, etc. DV during pregnancy has also been reported to have adverse effects not only on the mother in the form of miscarriage, premature birth, sexually transmitted disease (STD), complications, etc., but also on the fetus in the form of low birth weight, fetus stress, fetus death, etc. Still, Japan has no specific care plans for DV, and the development and dissemination of care guidelines should contribute vastly to support for DV victims in the medical scene.

## RESEARCH PROGRESS AND OUTCOME

Based on the research evidence accumulated to date, we compiled “A Guideline for Supporting Victims of Perinatal Domestic Violence Based on Evidence-Based Medicine (EBM) Technique 2004 Edition” which details the ideal methods of providing realistic support on the early discovery of perinatal DV in Japan, mediation, and cooperation (published by Kanehara & Co., Ltd.). The guidelines will not fulfill their role if they do not disseminate sufficiently in the clinical scene and be actually used.

In preparing for the 2005 edition, we clarified the problems and obstacles encountered in the provision of care for DV victims at medical centers outlined in the above guidelines, and started active research to review effective strategies for improvement of this situation. At model hospitals, the research carried out ranged from tracking the current situation, preparations to implement the guidelines, implementation of the guidelines to evaluation. The 2005 edition will also be published on the Internet of the Japan Council for Quality Health Care, Minds (Medical Information Network Distribution Service) (<http://minds.jcqhc.or.jp>). This project is funded by the Ministry of Health, Welfare, and Labor, and to date, medical care and treatment guidelines for medical professionals on 16 diseases and guidelines for the general public on seven diseases have been published.

### Academic Papers

Yaeko Kataoka, Yukari Yaju, Hiromi Eto, Naoko Matsumoto, Shigeko Horiuchi. (2004) Screening for Domestic Violence Against Women in the Perinatal Setting: A Systematic Review, Japan Journal of Nursing Science, 1(2), 77-86.

### Conference Presentations

Hiromi Eto, Yaeko Kataoka, Yukari Yaju, Shigeko Horiuchi. (2006) A Model for Developing Evidence-based Guidelines for Domestic Violence Prevention Program for Perinatal Women. Prevention and Management of Chronic Conditions: International Perspectives, Bangkok, Thailand, 106.

## EVALUATION

Since presenting our research results, there have been several hospitals that have expressed their interest in using our guidelines as well as the screening and measurement devices that were developed by Yaeko Kataoka, indicating the need to establish a system for disseminating the guidelines. We plan to wait for the evaluation of ongoing action research and link it to the next revision.

## BACKGROUND AND SIGNIFICANCE OF RESEARCH

Stillbirth is a serious health problem bringing tremendous sadness to mothers and families. Still, this sadness is seldom understood by those around them, and there is a tendency for such deaths to be regarded as taboo in society (there is a social background for such deaths to be regarded as taboo in society). Many of those who have experienced stillbirths have been reported to avoid going out after such separation by death and become isolated. Thus, given the need for those who have experienced stillbirths to gather and talk about children and share their sad experiences, we launched a self-help group consisting of persons who have experienced stillbirths, “Tenshi no Hogosha Luka no Kai” (Guardian Angel St. Luke’s Gathering) in September 2004.

## RESEARCH PROGRESS AND OUTCOME

The aim of this research was to develop a “Tenshi Kit” (Angel Kit) as a resource for supporting the encounters and separations of families experiencing stillbirths and caregivers as a natural, not culpable, phenomenon, and to evaluate the kit and its effectiveness.

The following were the three main activities:

1. Compiled a booklet “The Trauma of Families Losing Their Babies Through Stillbirth and Deaths of



Photo 1. A booklet for families who have experienced stillbirth



Photo 2. Angel kit: A memorial box, baby clothes and ceremony cards

## *Women-Centered Care: Support for Families Experiencing Stillbirth*

Newborns” (see Photo 1). Incorporated evidence from surveyed literature and needs for care by mothers and families experiencing stillbirths, and reviewed care items and details from hospitalization to discharge. We listed regional resource lists that could be introduced reliably.

2. Based on the results of reviewing research and overseas activities related to the care needs of mothers, we created a trial “Angel Kit”. The kit was developed jointly with Quilt Leaders Tokyo of the Japan Handicraft Instructor’s Association and Komoda Industry Co.(see Photo 2)
3. Based on comments by the participants of “Tenshi no Hogosha Luka no Kai” we held every month, held the “Angel Quilt” jointly with Quilt Leaders Tokyo, a gathering to make presents for the tiny angels who have returned to heaven(see Photo 3). The results of these efforts suggest that the act of making gifts for children leads to assurance of the identity of mothers-to-be, and mothering.

### Academic Papers

Nagisa Miyamoto, Naoko Ota, and Shigeko Horiuchi:  
Care for Mothers of Stillborn Babies: Self-Help Meeting to Encourage Their Psychological Growth, Journal of St. Luke’s College of Nursing. 9(1), 45-54, 2005.

### Conference Presentations

- 1) Shigeko Horiuchi, Naoko Ota: Care for Mothers of Stillborn Babies: Self-Help Meeting to Encourage Their Psychological Growth, Prevention and Management of Chronic Conditions: International Perspectives, Bangkok, Thailand,106.
- 2) Shoko Horiuchi, Shinobu Matsunaga, Naoko Ota, Keiko Ishii, and Shigeko Horiuchi: Self-Help Group of Parents Experiencing Stillbirth, 25th Japanese Society of Social Psychiatry Research Conference, 110, 2006.

## EVALUATION

We are planning trial use and evaluation of the booklet and “Angel Kit” at model hospitals.



Photo 3. Angel quilt: Hand-made teddy bears and cremation urn covers

## Nursing Practice Development Research for People-Centered Care

6

### *Development of Women-Centered Care Models for Infertile Women*



Project Leader

**Akiko Mori**

Project Members:

Shigeko Horiuchi, Masako Momoi, Miki Koyoh, Madoka Tsuchiya

Project Participants:

Mayumi Okanaga, Naoko Takiguchi

Today issues such as how we engage in the practice of reproductive medicine and support infertility patients are among the major social issues in Japan. Although public awareness has been increasing, some prejudice or misunderstanding still exists, such as viewing infertility as being undutiful and unhappy. In addition, due to a lack of laws and regulations for reproductive assistance medicine as well as clinical guidelines or systems of informed consent and counseling, patients receiving infertility treatment face two psychological stresses caused by “infertility” itself and its “treatment.” Developing a care program that enables patients to cope with such stress, as well as the sharing of information by specialists and patients, for patients or couples to be able to make their desired choice as patient support should be effective for both parties.

Jointly launch a booklet on  
informed choice for infertility  
treatment with  
self-help groups

This year we could jointly launch a 16-page booklet “Infertility Treatment of Personal Choice” on informed choice for infertility treatment that we co-wrote with the selfhelp group the Friends of Finrrage (Finrrage-no-kai). This year, we printed 4,200 copies. We also collected 87 questionnaire replies regarding the booklet from 53 people from the general public and 34 medical related personnel (December 2005). Amongst the replies, 83 replied they wanted to introduce the booklet to others, three provided no replies, and one person provided other reply. The number of requests for the booklet from the public directly (FAX, e-mail, postcard, etc.) has reached 539 (March 2006).



#### Related conferences:

- \* August 4 and 5, 2005: The 23rd Japan Society of Fertilization and Implantation Research Conference (Osaka)
- \* August 6, 2005: Seminar in collaboration with the Japanese Society of Infertility Nursing (Kobe)
- \* August 27, 2005: 3rd Japanese Society of Infertility Nursing Research Conference (Chiba)
- \* September 3, 2005: Let's Talk About Infertility (Tokyo)
- \* March 4, 2006: Funabashi City Women's Center Seminar “Infertility: Treatment of Personal Choice” (Funabashi)

#### Mass media:

- \* July 18, 2005: (Mon) 22:15 to 22:55 (40 minutes)  
NHK Radio 1  
Holiday Journal "Want Babies: Infertility Treatment 2005"
- \* September 14, 2005: Mainichi Newspaper Morning Edition, Treatment of My Choice, Booklet Launched by Those Who Have Experienced Infertility Treatment and St. Luke's College of Nursing
- \* FINRRAGE Report Volume 89, etc. Introduced also on the website
- \* Other women's magazines (Kobunsha, Orange Page)

#### Individual approach for reducing patient stress

In continuation from last year, we carried out the following research 1) and activities 2).

- 1) For women undergoing infertility treatment to cope with their stress, we carried out intervention studies of two support programs we developed. The results suggest that for women in programs that have them use homework notebooks on stress management, their health related QOL scores dropped less easily, and were maintained at a certain level. The results of the study for setting up the two programs were submitted to a conference (2004, oral presentation).

Akiko Mori, Naoko Arimori, Masako Momoi, Shigeko Horiuchi, Noriko Fukuda: Application of Needs Focus Group Interview for Women in Early Stage of Infertility Treatment to Care Programs for Reducing Stress, Japanese Society of Infertility Nursing, 2(1): 12-19, 2005.

- 2) Provided consultation using e-mail (individual consultations). We received about 15 requests for consultation in 2005.

#### Group approach for providing information to patients and nurses, and for education

In continuation from last year, 1) was carried out for the public and 2) for specialists

- 1) On May 28, 2005, we held a public seminar "Importance of Informed Choice in Infertility Treatment" at the St. Luke's College of Nursing. We invited Atsuko Masano, a journalist who has experienced infertility treatment herself and author of "Receiving Infertility Treatment in Japan" (publisher Iwanami Shoten). About 70 persons participated.
- 2) August 6, 2005, we held a seminar, "Nursing for Couples where the Male Partner is Infertile" with the Japanese Society of Infertility Nursing at the University of Marketing and Distribution Sciences (Kobe). About 50 nursing professionals participated.

#### Cooperation between medical personnel and those who have experienced infertility

This is a network formed between nurses specializing in infertility and journalists (including those who have experienced infertility); project leader Akiko Mori, St. Luke's College of Nursing staff and the college's graduate school students participate.

## EVALUATION

The greatest achievement of this project this year was the launch of the booklet with the self-help group. It has been well received by the public as well as professionals. In the next fiscal year, we plan to expand our joint projects through outreach activities, promote the booklet, and once we run out of copies, distribute it via the Internet. We also plan to develop the next booklet. In the next year, we hope to reinforce our research foundations on joint activities, and present our research results at conferences and to the public.



## Community-Based Palliative Care (Hospice Care at Home)



Project Leader

**Hiromi Kawagoe**

**Project Members:**

Kiyohito Hirose, Hiroko Nagae, Masako Sakai  
Naoko Yoshikawa

**Project Participants:**

Sakiko Fukui, Hiromi Ogane, Chikako Uchida

### Development of a Community- Based Palliative Care (Hospice Care at Home) Program and Systems:

Building a community for spending  
one's last days at home

With the aim of "building a community for spending one's last days at home," the project is proceeding with research and studies to develop palliative care in the community through the active participation of citizens, and in collaboration with experts. Specific research objectives are as follows:

#### Construction of a Community-Based Participatory Palliative Care System

1. To establish the unambiguous concept of a community-based palliative care team
2. To develop standards for a community-based palliative care teams

#### Development of a Program Necessary for a Community-Based Participatory Palliative Care System

1. Visiting nurse station for palliative care (specialty visiting nurse station)

2. Day-care hospice program (conducted by visiting nurse stations in collaboration with citizen volunteers)
3. Training program for citizen volunteers participating in palliative care at home

### ACTIVITIES IN FISCAL 2005

1. After the community network forum

Driven by discussions at the community network forum in 2004 and also at the request of citizens, a study meeting for care managers in the Chuo Ward, Tokyo was held in June 2005. The meeting was co-hosted by Chuo-Ward Liaison Council for Nursing Insurance Service Providers, Guide Volunteer Network for At-Home Care, the Elderly Care Section, Welfare Department of the Chuo-Ward, Tokyo, and St. Luke's College of Nursing 21st Century COE Program, in which 60 people participated to share a lively session.

2. Holding of workshops for citizen volunteers participating in palliative care at home

Based on health promotion in collaboration between citizens, experts, and government administrations, lectures for citizen-focused hospice care at home were held. Citizens were involved from the planning stage and in the management of the three workshops. They were organized by St. Luke's College of Nursing 21st Century COE Program and co-sponsored by the Social Welfare Councils of the Chuo and Sumida Wards, Tokyo, in which 45 citizens participated through the Kango-net and public relations magazines of the social welfare councils. For more details, please refer to the report by COE research fellow (Naoko Yoshikawa).

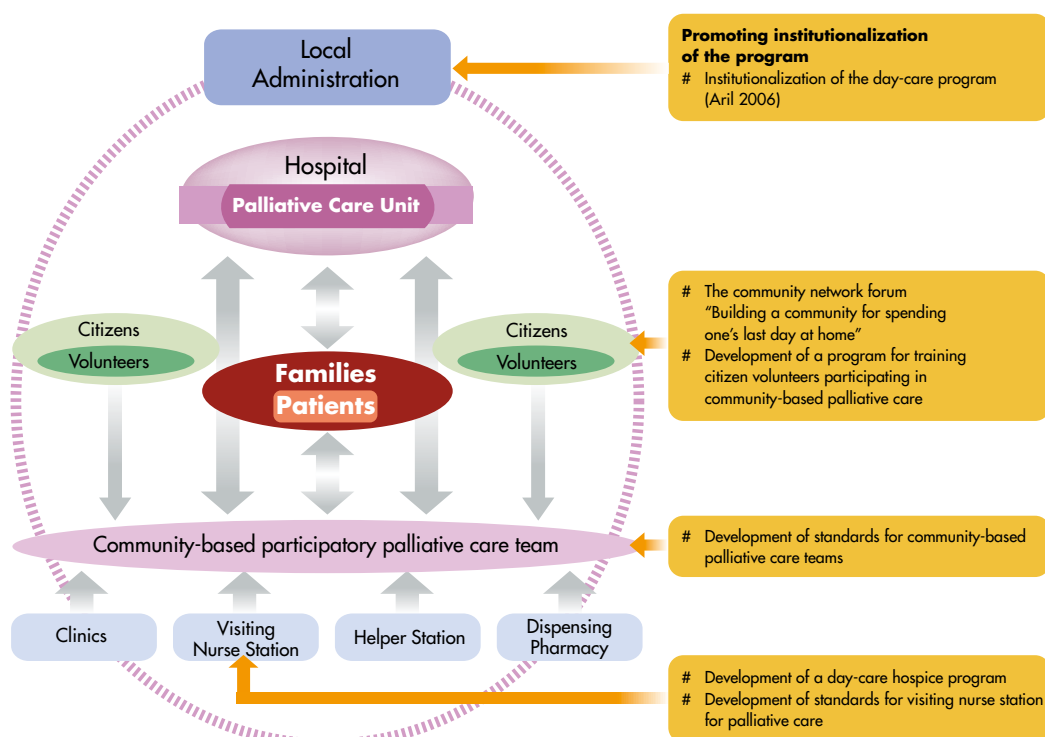
3. Development of standards for community-based palliative care team

We conducted a nationwide survey of the visiting nurse



Home palliative care volunteer program

## Development of a Community-Based Palliative Care (Hospice Care at Home)



stations providing care for the purpose of establishing criteria for a community-based palliative care team and analyzed 1,398 cases from 981 institutions from which we received answers. The results show that in cases where people were able to spend their last days at home, care had been provided by the same organization's doctor and nurses together with a care manager and a caretaker; however, there was hardly any participation by other team members. Cases where a clinical nurse who had had professional training in hospice care got engaged were less than 1%.

In 689 cases of death at home (49.3%) subjective evaluations by team members and the substance of care were significantly higher than the cases of hospital death. These results revealed situations in which professional nurses, in spite of relatively low participation, had aided until the patient's life ended. For the future, I believe that at an early date, it will be necessary to educate nurses with specialized instruction in areas identified through literature review to become the key members of teams.

### 4. Visiting nurse station for palliative care (specialty visiting nurse station)

We created requirements necessary for a community-based visiting nurse station for palliative care (consolidated 45 items) and asked all visiting nurse

stations (approximately 3,700) to collaborate for research. We are going to make an analysis of the research.

### 5 Day-care hospice program (conducted by visiting nurse stations in collaboration with citizen volunteers)

As stated in last year's evaluation column, we made policy proposals to get the day-care hospice program institutionalized. Consequently, expenses for day care by visiting nurse station were newly set up in care insurance, enabling terminal cancer patients to receive care by visiting nurse stations; thus, the support system for spending time at home has been strengthened.

## EVALUATION

Through the project, citizen-led hospice care at home has been gradually developing. Future challenges are: how to assist and develop the activities, and how to link them to our target, building a community for spending one's last days at home with peace of mind. At the same time, by having made policy proposal, a day-care hospice program for visiting nurse stations was approved as a medical treatment fee; it will be necessary to assist it to disseminate across the country.

## Systematic Development of Home Care Program for Children



Project Leader

**Ikuko Oikawa**

Project Members:

Yuko Hirabayashi, Tomomi Ono, Yukiko Manabe,

Project Participants:

Chizuru Kawaguchi, Harumi Asano, Atsuko Tada, Chie Suzuki,

Katsue Tanaka, Yoko Furumizo, Yumi Ishii, Yoshie Ohara,

Kajie Tamura, Yumi Yokoyama

With the progress of highly specialized medical services, there are an increased number of children who stay home and go to school while wearing medical devices to receive continuous medical treatments. In order to allow such children and their families to receive home care without anxiety, coordination among medical practitioners, social workers, and teachers is essential. Nevertheless, various problems have been pointed out, such as inadequate coordination among relevant sectors, unclear contact points for coordinators, and lack of service and support systems for home care. And, there are regional gaps of available pediatric care, social resources and readiness of schools. In addition, weakening family ties and disparity of local customs are making the health care environment surrounding children increasingly complex. Under such circumstances, it is necessary to develop a detailed support system tailored to the needs of the children, their families and their communities.

This project aims to systematically develop a care program which effectively coordinates the children, their families, medical practitioners, social workers and teachers, for ensuring the quality of home care provided for children with disabilities and chronic illness.

## RESEARCH PROGRESS AND OUTCOME

1. For collection of fundamental data on three selected areas of the Kanto region (namely, Tochigi, Fukushima and Chuo-Ward, Tokyo), we made collective analysis of district materials that had ever been made available to the public. Then conducted questionnaire surveys of children with chronic illness and disabilities and their families. Also, in the three communities, focus group interviews were conducted with nursing personnel, including nurses in inpatient/outpatient wards, public health nurses, visiting nurses, school nurses, and communities, to analyze the current status and issues of nursing care for children with chronic illness.
2. Based on our findings, we discussed activity details mainly with the focus groups of each district (in some communities, children's parents joined) and expanded project activities. The substances of activities by community for this fiscal year are as follows:
  - 1) In the Tochigi district, we created a brochure, mainly for nursing personnel at hospital, that describes social resources for the sake of coordination among medical service, welfare and education, and distributed it to medical institutions, etc. (introduced in last year's report).



Photo 1. A Booklet for children with chronic illness and disabilities and their parents

The result of a survey on utilization status over six months shows that a gradual penetration has occurred: it has been used to expand of staff knowledge and doctors' explanations to families. Also in the Tochigi district, a symposium for a regional partnership among public health nurses, visiting nurses, nurses in inpatient/outpatient wards and school nurses was held; 68 participants including families had lively exchange of views.

- 2) In the Fukushima district, since distribution of our brochure had fallen behind schedule, simultaneously with distribution we conducted a survey on the contents and convenience. The brochure was created (see a photo) with the aim of having knowledge on the regional activities of nursing personnel and social resources; it was distributed to hospitals, visiting nurse stations, schools, etc. From the questionnaire survey, we received responses, especially from visiting nurse stations, indicating the high level of interest in home care programs. Also in the district, a lecture meeting with regard to the support by public health nurses for children under long-term treatment was held; 30 people participated. Exchange of views on coordination with schools, difficulties at the time of discharge from hospital, and school attendance was conducted among school nurses and caseworkers.
- 3) In the Chuo-Ward of Tokyo, we again held "Nurse Clinic" six times in total this year (see photo). We had conducted research on health issues, including chronic illness, of the district targeted for early childhood, and based on the results, we implemented Nurse Clinics on the themes of allergies, dieting, developmental disorders, epilepsy, etc. On average, around 20 people participated, including patients' families, children's nurses, school nurses, registered nurses, and public health nurses; there were

exchanges of opinions concerning recent knowledge on the themes, and individual issues and worries. Since the Chuo-Ward is in central Tokyo, living areas and medical districts of children with chronic illness are not necessarily the same; thus family-centered participation became is an issue for the future. Nonetheless, we received high ex post facto evaluations from families.

## EVALUATION

Based on the respective characteristics of the three districts and building on our past research about the needs of children with chronic illness and their families, we have continued our community-based approach. There has hardly been any regional partnership or gathering of nursing personnel that focuses on home care for children in these three districts. The community research and questionnaire survey we conducted the first year has become a good opportunity to know more about the communities. In addition, we have formed focus groups of nursing personnel to have repeated discussions on the creation of a brochure for social resources and held workshops which we believe could contribute to the establishment of a foundation for mutual understanding and cooperation. For the future, in order to strengthen a community network, it is important to facilitate ongoing engagements, including review of case examples, training and study sessions. And it is also necessary to encourage diagnosed children and their families to participate based on the situation in each area.

It was agreed that the foundational investigation in the three areas would be concluded this fiscal year, and that for the next year, an independent activity by area would be continued. At St. Luke's, we have been conducting activities centering on Nurse Clinic in the Chuo-Ward of Tokyo, and are planning to continue it for the next year. Specifically, by increasing participation of families in a community network forum, we would like to carry forward activities in order to gradually evolve planning and management into autonomous activities by participants. Furthermore, we would like to transmit information internationally during and after the next year.



Photo 2. Nurse clinic



## *Research, Development, and Implementation of Effective Programs for Health Education and Practice Appropriate for Japanese Characteristics*



Project Leader

**Fumio Kikuta**

### BACKGROUND NEED FOR RESEARCH

- Increase in actual and potential patients with lifestyle-related diseases
- Dramatic increase in gross national medical expenditure
- “Dead” health education does not link to health actions
- Human beings as animals tend to be controlled by instinct
- The results of a medical examination including a complete medical checkup does not produce improvements in daily lifestyle habits

### APPROACH

Based on the purpose of this research, we continue to develop and practice citizen-focused health education programs in and after FY 2005, supported by experts so that citizens can create their own lifestyle suited to themselves. The programs are likely to produce the following effects:

1. Aiming at prevention and/or control of lifestyle-related diseases, a community sports club can be launched in the Tsukiji and Akashi-cho areas in Tokyo. Advice and assessments are to be provided

by medical professionals. It could contribute to formation of a lifestyle that naturally incorporates sports into people’s livelihoods at least once or twice a week.

2. By utilizing holidays to practice a seasonal program in which one is able to enjoy experience activities and sports in nature while staying at lodging facilities with one’s family in an area richly endowed with nature, we can provide them with a trigger to review day-to-day living habits, and an opportunity to feel the importance and value of life and health.

### RESEARCH PROGRESS AND OUTCOME

During FY 2005, with a focus on 2), as in the previous year we implemented four health education programs that convey the importance and splendor of life and well-being through experiences in nature, dairy farmer experiences, and activities in which one can feel nature with the five senses. In August 2005, based on the past planning and accomplishments of the family camps, we planned and practiced “Long-Term Children Camp 2005: Feel Life, Nature, and Yourself,” an 11-day, 10-night program. In addition, we have been planning a single-day program of experiences in nature entitled “Discover! Explore! Our Towns’ Nature” to be conducted in the areas of Tsukiji, Tsukishima, and Tsukuda in Tokyo, where we are living, on March 18, 2006. The program incorporates activities to learn through experiences that allow us to feel life or nature in the metropolis in which we live daily, in addition to fields richly endowed with nature.



Camp of Exploration into Winter Forest

By combining existing family camps of two days and one night and the metropolitan program we attempted to create an opportunity for citizens to be able to sense the splendor and importance of life, nature, and health during the course of our lives.

### The programs conducted in FY 2005

1. Family Camp: Feel Life Putting Forth Buds: Hunt for Treasure in Vernal Forest

This program was held from May 14 (Sat.)-15 (Sun.), 2005; with 36 participants from 10 families whose purpose was to experience the beginning of life in wild animals and plants in a forest of spring. We created an opportunity for the participating children to think about their body growth through contact with neonatal jersey cows.

2. Family Camp: Feel Joy of Harvesting: Experience of Plucking Japanese Plums & Hunt for Treasure in a Forest of the Rainy Season

This program was held from June 18 (Sat.)-19 (Sun.), 2005; with 22 participants from 7 families. We created an opportunity for the participants to look back on a human life that had been kept alive with a blessing from nature, through a crop experience of Japanese plums, while enjoying the green of a forest during the rainy season that supports the life of wild animals.

3. Raising Cattle & Experiencing Nature Up to the Hilt – Feel Life and Feel Grateful to Life

This program was held from December 3 (Sat.)-4 (Sun.), 2005; with 11 participants from 3 families. We created an opportunity for participants to nurture the

notion that human beings have been kept alive with a blessing from the “life” of animals, through experience of dairy husbandry and the making of butter and bread, and gratefulness for blessings bestowed by animals through a work-study program or parent-child conversations during those activities.

4. Camp of Exploration into Winter Forest: Family Feel Life of Forest

This program was held from March 4 (Sat.)-5 (Sun.), 2006; with 15 participants from 4 families. We conducted an activity to joyfully experience scent, color, sound, touch and taste in the winter forest using the five senses. In addition, we spent time in which we could imagine wild animals’ living in the forest while looking for traces of wild animals living strongly in the forest in a severe winter.

## EVALUATION

The citizen-focused health education programs we proposed as part of the research project are original consisting of three main pillars: one that can be adopted in daily life, one that can be adopted several times a week, and one that can be adopted once per season.

Life experience simulation family camps, which have been planned and implemented since 2004, are a program we could expect citizens to adopt once per season into their lives. The family camp program will mark the 6th time at the end of FY 2006. We received feedback concerning “how to make use of the experiences in a camp for families’ daily life (lifestyle)” as well as regarding the overall programs, each time from the participating families. We will understand and analyze how the substance of experience in a field richly endowed with nature is and will be utilized in urban city daily life, in terms of life, nature, and health, as well as conduct an interview with the participating families. Thereby, we will examine the effectiveness of life experience simulation family camps.



Raising Cattle & Experiencing Nature Up to the Hilt

## *Development of an International Collaboration Practice Model Contributing to “Health for All”*



Project Leader

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**Project Participants:**

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### **Background and Significance of Research**

St. Luke's College of Nursing was designated a WHO (World Health Organization) Collaborating Center for Nursing Development in Primary Health Care in 1990. Since then, it has been working as a collaborating center with the aim of resolving the regional gap of healthcare among world countries, and at enabling people all over the world to equally live a healthy life in a humane manner, which has been advocated by the WHO. The world efforts against the regional gap of healthcare, furthermore, have been more actively moving ahead in the framework for the setting of the UN (United Nations) Millennium Development Goals (MDGs) in 2000 and activity planning at the WHO global network; the importance of the international collaboration activities has been growing more than ever.

During the period from fiscal 2002 to fiscal 2004, we had developed an educational training program for nursing personnel in Japan that would allow strengthened assistance for higher-quality nursing

and midwifery in developing countries. In fiscal 2005, as a research achievement, we inaugurated education through a master's degree program of “international nursing” at our graduate school. As the first phase of development of an international collaboration practice model, we had finished building bases for education and research for international nursing experts. Starting this year, as the second phase, we have launched development of a collaboration development practice model for fostering and educational programs to strengthen nursing and midwifery human resources, which will enable health improvements in developing countries. Such fostering of personnel to be engaged in nursing and midwifery is the fourth priority of the WHO's “Strategic Directions for Strengthening Nursing and Midwifery Services.” We believe that the development of a cooperation practice model for the training and education of personnel who will be able to reinforce nursing and midwifery in developing countries can make a contribution toward achieving the objective of “Health for All” and/or the UN MDGs.

### **RESEARCH PROGRESS AND OUTCOME**

During the current year (FY 2005), with financial assistance from International Medical Center and research aid of the COE, we have commenced a study on ideal development cooperation for personnel development program that strengthens regional capabilities of community nursing in developing countries, in order to develop an international collaboration practice model, in domestic collaboration with the National Institute of Public Health, IRCME (International Research Center for Medical Education) of Tokyo University, The Japanese Red Cross College of Nursing, and the Japan College of Nursing. We set up three teams for research in our College and started a study on cooperation for human resources development which strengthens regional nursing in each host developing country.

The objective of the first team was to develop cooperation for strengthening women health workers





to engage in maternal and child health in the rural areas of Myanmar. In two of the rural communities, we conducted research twice in engagement in relations with the women workers group, with the aim of improving capabilities as a worker.

The objective of the second team was to cooperate for upgrading the education program of the community nursing science course of master's programs in graduate schools in Kenya, based on the local nursing needs. To begin, we were able to get a researcher at the Department of Advanced Nursing at University of Nairobi in Kenya as our counterpart and commenced activities. This year, we organized a research plan based on the last field investigations; in addition, we conducted interviews with the Nursing Council of Kenya, National Nurses Association of Kenya, and the health ministry to clarify the needs and issues of the current advanced education.

The objective of the third team was, as part of reconstruction assistance for Afghanistan, to develop nursing education to groom new, future leaders of nursing specialist personnel, especially for the community nursing education program, based on needs for community nursing. This fiscal year, we assessed nursing education needs by conducting hearings with Kabul Medical University, and trainees from the Ministry of Public Health and Ministry of Higher Education in Afghanistan, which visited Japan through the Japan International Cooperation Agency (JICA) due to poor security, and by organizing the existing data.

In November 2005, we held a research workshop which integrated the research outcome from studies to strengthen education for in-service public health nurses in Fiji and to reinforce PHC nursing in the South Africa that had been implemented by two institutions in domestic collaboration with our College's three research teams. We invited international collaboration experts as advisors to conduct an international research workshop. The research of the five teams revealed that regional nursing capabilities were related to local residents, health workers, providers of regional nursing service, the present education, the nursing

administrators, administrative officers who manage the services, and quality of a comprehensive human resources development system, and that a total of regional nursing activities conducted by the above-stated human resources would be reflected in health conditions of community residents.

Also in November, we held the International Relay Symposium entitled "Sharing Wisdom, Experiences and Courage: Women Supporting Each Other in Society." Presenters described how women could share experiences, learn each other, and grow with people different from themselves. We recruited a female leader who had lost her little child, a foreign female leader who is living in Japan, a Japanese midwife for women workers in Myanmar, and a nursing expert from the U.K. who had worked for women in the Central Asia, to give lectures and exchange views. (Refer to p48).

## EVALUATION

The development of "an international collaboration practice model" as the second stage started with the challenge of development cooperation for nursing personnel in developing countries, and the beginning of collaborative activities with respective counterparts outside the College. We decided that we could improve first-year research results by collaboration with researchers in the U.S. and Europe who had worked as advisors at the international research workshops, cooperating and making exchanges cumulatively for about twenty years. This year, we established a counterpart in developing country Kenya involved in the activities. Now, we believe that in order to hear the voices of target persons for collaboration and to move in concert, we need mutual understanding for realization. We have determined that for construction of an international collaboration model for a long-term goal toward a reduction of the regional gaps of healthcare "Health for All," it is firstly necessary to further conduct continuous research activities for the next year personnel development with the purpose of strengthening the regional nursing capabilities, and to proceed with theorization.





## *Creation of Health Resource Digital Contents and E-Learning Program*



Project Leader

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The development of web-based e-learning, which is not subject to physical and temporal constraints, has facilitated assistance for learning by nursing personnel further providing potential to improve citizens' health. At the same time, it has become possible for community people to learn about health, make decisions, and take actions accordingly. In the United States, a myriad of Internet-based activities have already been expanded by universities and hospitals as outreach activities for the general public. Given this factor, we attempted to sort out such e-learning in terms of characteristics, the broadening of learning method options, background learning theory, and the possibility of outreach for nursing personnel and citizens.

## RESEARCH PROGRESS AND OUTCOME

### 1) Characteristics of e-learning

E-learning enjoys the following advantages:

- (1) Ubiquitous on-demand learning that enables learners to study at any time and place that he/she chooses.
- (2) Learners can obtain updated evidence and data to have communications based on the latest information.
- (3) Learners can freely search for and utilize necessary courses and learning materials.
- (4) Learners who have common objectives can form a learning community.
- (5) The web itself forms a borderless learning society in the world of e-learning.

In other words, it can be said that we are building a society in which everyone can share learning tasks and the latest learning materials for such tasks, and anyone can help another at any time, anywhere.

### 2) Broadening the options of learning methods

E-learning can be organized into 7 styles in total or 4 main styles (Refer to Table 1). The blended learning method that enables creative use tailored to learning tasks or environments are recommended.

### 3) Background learning theory

For the proper use of learning methods, learning theory serves as a reference. Within the context of learning science and instructional design theory, three principles are pointed out, namely: behaviorism, cognitivism, and constructionism. Regarding behaviorism, learning is defined as a process of behavioral change caused by reactions to stimuli, which are enhanced as the result. It is therefore believed that repeated practice allows for the acquisition of such change. In principle, however, a psychological process between such input (stimulus) and output (behavior enhanced) is a black box. In cognitivism, focusing attention on such a black box, the emphasis is placed on the methodology of how to appropriately convey the substances of learning materials.

In these two philosophies, such conveyed inputs are regarded as objective and unchanging, while they are regarded as subjective and changing in constructionism. How do individuals create meaning for inputs within themselves? It is considered that learners combine knowledge, experiences, and new information to create meaning inside them. Especially,

Face-to-face learning	Formal: learning with lecturer	Lecture, training, workshop, on-the-job training (OJT), coaching mentoring	
	Informal: learning without lecturer	Group learning, team learning, colleague-to-colleague relationship, role-playing	
Collaborative learning, CSCL and learning community	Synchronous: real-time learning	Web-based lecture, web-based meeting, chatting, e-mentoring	
	Asynchronous: non real-time learning	E-mail, discussion board, blog, Wiki software, mailing list, online community	
Self-learning	Interactive learning materials	WBT, CBT (CD, DVD), simulation, scenario learning, game, self-assessment	
Information provision and support	Information provision on the web	Text, diagram, illustration, video, voice, animation, collection of web links, help desk	
	Information provision by methods other than the web	Book, magazine, guide/manual, newspaper, television, radio, telephone, FAX, and mail	

Table 1. Methods of Learning

social constructionism recommends learning on a group basis from the perspective that “knowledge is constructed socially through interaction with others.” Incidentally, it coincides with the viewpoint of education for adults (= andragogy), which is distinguished from one for children (= pedagogy). The characteristics of andragogy include self-determination, objective orientation, emphasis on practicality, and confidence from life experiences.

#### 4) Potential of outreach for citizens by nursing personnel

Assuming that we apply such education for adults to nursing personnel, we believe that a community on the web, which is created by nursing personnel themselves, is effective. Of course, it does not always have to limit those to be empowered to nursing personnel - it is believed that any citizen can participate within those confines. Since health information on the web has begun to overflow and there has been a problem of information reliability, new specialist functions and helping each other in the learning community are indispensable.

As the American Nurses Association suggests in the definition of nursing “the diagnosis and treatment of human responses to health and illness,” it is contemplated that the definition is consistent with the challenge of learning science: how responses to health and illness react to stimuli, and how they transform behavior. Given that the role of nursing personnel is to assist patients and citizens with respect to learning about health issues while being nearest to them, it will be effective to establish an environment for learning with those who are beneficiaries of such assistance.

## EVALUATION

For the construction of people-centered healthcare systems, web-based learning activities, which allow on-demand provision and exchange of information, will be of extreme importance. It is said that eight out of ten American Internet users already look through information on healthcare on the Internet. It is recommended that the research on the relationship between web use (eventually mass media) and health, and also health-communication studies be conducted without delay.



## *Utilization and Evaluation of People-Centered Nursing Services*



Project Leader

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The healthcare system in Japan has been assuming an aspect of increasing sophistication and complexity under the circumstances in which health insurance reform has been ongoing due to the shift toward an aging society and a poor financial condition in Japan. On the other hand, there has been a shift in the public's awareness about healthcare, which resulted in a demand for nursing services and medical care of higher quality. In order to offer high-quality nursing services, we believe that it is important to construct a structure to provide better medical services through mutual understanding between citizens and nursing personnel, and citizen participation as members of the healthcare team. Meaningful research and activities are required.

### Research Activities

#### Appropriate Assignment of Nursing Personnel Necessary for High-Quality Nursing Services

In the United States, there is an organization called the California Nursing Outcomes Coalition

(CalNOC). CalNOC has been pouring their efforts into appropriate assignment of nursing personnel and patients considered necessary for patient safety and provision of better nursing care on the pretext of conducting scientifically sound research and studies, where analysis of collected data regarding an index necessary for assignment of nursing personnel and the construction of a database for the study of personnel distribution have been conducted. In addition, the organization is analyzing the relationship between nurse staffing and adverse events (including overturns and falls, physical restraint, and pressure ulcers). This fiscal year, we participated in the annual conference of CalNOC to gather up-to-date information about the studies on nurse staffing in the U.S. Moreover, we conducted a study on the theme of "Nurse Staffing for Patient Care Safety and Its Outcomes" by making use of the data collection items which CalNOC has been using.

The ratio of nursing personnel to patients per ward is determined by the medical care law and medical fee schedule in Japan. The highest standard of nursing personnel distribution is described as "2:1 or greater (patients per nurse), 70% or above (ratio of registered nurses), and/or 21 days or less (average length of hospital stay)." The patient to nurse ratio (2:1 or greater) means that if the number of patients in a ward is 50, it is necessary to assign 25 or more nurses. There are instances where registered nurses and assistant nurses are assigned in the same ward. The ratio of nurses, 70% or above means the ratio of registered nurses among all nursing personnel; therefore, at least 18 have to be qualified as registered nurses among 25 nurses. The average length of hospital stay is an index that shows how many days on average a patient stays in a hospital.

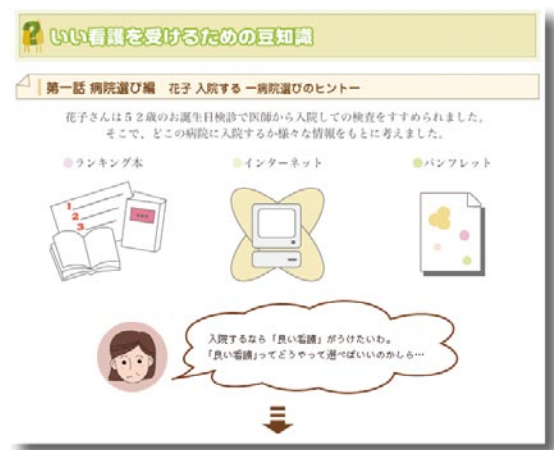
If the number of days of hospital stay is reduced, mildly symptomatic patients will tend to decrease, and the degree of severity of hospitalized patients will tend to be higher in a hospital. Such an increase in severity has required nursing personnel's provision of more devoted nursing services. However, in order to provide careful nursing services, there will be a need for an appreciable mechanism that secures manpower and so on. Nurses working in clinical settings express a sense of crisis that this standard is not satisfactory for dealing with changing circumstances in wards, and for providing sufficient nursing services. To overturn the status quo, we would like to continue to consider appropriate nurse staffing.

## Continuation of a website: “Bits of Knowledge for Receiving Good Care”

### Explaining Nursing Services to Citizens as Comprehensively as Possible

In order to convey “nursing services” to citizens more comprehensively, we utilize a website, “Bits of Knowledge for Receiving Good Care.” The purpose is to give an explanation about nursing services in an understandable way through the experiences of fictional citizens, the Yamada family.

The first story begins with Hanako-san’s selection of a hospital. After that, we released contents on the website which were related to “the reasons that it seems like a nurse is always busy,” “medical safety” together with “reason why changing hospitals is suggested” and “encounter with a specialized nurse,” which Hanako-san wanted to know about.



A website “Bits of Knowledge for Receiving Good Care”

## Development of Brochure and Video concerning Outpatient Care from a Nursing Viewpoint

### Necessity of Information Provision to Help with Outpatient Care

It can be said that outpatient care is the first opportunity for citizens to choose and experience medical services. We started developing a brochure and video for the purpose of offering useful information when receiving outpatient care from a nursing viewpoint. We are planning to incorporate information, including the importance of having a regular doctor in one’s daily life, the important elements in receiving a medical

examination, and precautions for drug treatment into a brochure as advice from clinical nurses. Furthermore, we are going to create a video in order for citizens to get a better grasp of and utilize the contents of the brochure. In the future, we are considering action to review the effectiveness of utilizing such developed materials with citizens.

## EVALUATION

### Activities for the Next Fiscal Year

For us to provide high-quality nursing services in the future, we believe it necessary to define the indices of “Distribution of Nursing Personnel” and “Related Outcome” to determine the calculation method and conduct data collection and analysis. It will be important to propose an appropriate personnel assignment based on the data, to convince citizens of the model, and then to change the healthcare system together with the public. In this country, the highest standard for nurse staffing had finally been reviewed since April this year; and “2:1 or greater” patient-to-nurse ratio will be changed to “1.4:1 or greater”. We are thinking about proceeding with further consideration to a proper assignment of nursing personnel based on the results of research conducted this fiscal year by paying close attention as to how the substances of nursing services will be changing owing to the modification of the standard.

Input from the questionnaire given to participants of the International Relay Symposia last year, etc. lead to the creation of “Bits of Knowledge for Receiving Good Care” and the development of brochures and videos regarding outpatient care. In the next fiscal year, we would like to go over the current nursing services with citizens based on past activities, and to work toward the “creation of new nursing services” which citizens will be able to utilize more proactively.



## *Nursing Techniques for Supporting Daily Life*



Project Leader

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This project consists of two pillars: one is the “Let’s learn about our body” caravan, and the other is development of techniques for supporting daily life, both of which are activities based on fundamental knowledge of the body. “Let’s learn about our body” caravan started with the idea that knowledge about basic health information concerning the body will be necessary for citizens to become a central figure in their own well-being. We aim at providing children of about five years of age (they will be responsible for the next generation) with a learning program that will enable them to understand the body, and expect that the children will grow up to be citizens capable of controlling their own health.

Supporting daily life is based on the knowledge of one’s own body. Another objective is to develop and offer nursing techniques that accommodate the bodily mechanism for supporting daily life.

## RESEARCH PROGRESS AND OUTCOME

### “Let’s learn about our body” caravan

We reflected on the development process of educational materials for children five years of age which had been done until the last fiscal year, and considered what a study to create people-centered healthcare should be. As a consequence, we found that the study had been started on the initiative of researchers evolved into a project that encompasses children of five years of age, their parents, and those surrounding them: childcare workers, kindergarten teachers, school nurses, public health nurses, and citizens who are interested in the study, and that it met the needs of children five years of age and citizens surrounding them, which has been taking on an aspect of community-based participatory research. Those results were presented at the meeting of St. Lukes Society for Nursing Research (entitled “Development of Educational Materials for Children to Learn About Their Body”) and were published in



A session at a nursery school

the Bulletin of St. Luke's College of Nursing in March 2006 entitled, "Let's learn about our body for children five years of age: Process of Research Aimed at People-Centered Care."

In conjunction with the work, we have been conducting questionnaire surveys with the intent of learning the reality of the knowledge five year-old children possess about their bodies. In addition, we have attempted practical education at two nursery schools and one kindergarten through the use of our developed program about the digestive system (a picture book, a picture-story show based on a picture book and a T-shirt with digestive organs). In each case, a childcare worker presented and project members observed it. Also, we are planning a questionnaire survey targeted at guardians and childcare workers who implemented it regarding the significance of the program and usability of the educational materials. As for details of the survey, we are in the process of drafting it now; it is expected that there is an educational significance in teaching children about their body, and thus developing program materials. From here on, we are planning to make modifications to the picture book and develop a training aid for other systems of the body.

We were interviewed by a news writer with respect to our activities and an article was published (July 25, 2005); we contributed an article to the Juniors' Visual Journal, which was published in Health Care News (March 8, 2006).

### Development of techniques for supporting daily life which accommodate the bodily mechanism

A study to measure the effects of applying a recovery facilitation program for patients with cranial nervous system disorder using posture stimulation during hospitalization has made progress. After we implemented "a nursing care program to 'erect oneself'" for patients with acute-phase cerebrovascular disease, we obtained the results that the number of days until the patient could attain a sitting posture had been shortened, and the percentage of leaving the ICU (intensive-care unit) with a wheelchair had increased.

Another study is on the technique applying hot compresses applied to the lumbar region (nerves from that region regulates the functions of the intestines. Special hot compresses have been developed. Currently, we have just started experimental testing for people who have difficulty due to constipation.

## EVALUATION

This fiscal year we announced a research process for the "Let's learn about our body" caravan of this project at the evaluation committee (in December) and workshop (in January). Although children's learning about the body itself is consistent with the farthest-reaching parts of St. Luke's COE, we would like to give credit to the fact that, at the same time, the way this project exists itself has been transforming into an activity to embody a people-centered concept to which COE has been striving. It has been quite a year for us to be able to witness the fact that even something that began as an initiative of medical personnel could meet the needs of citizens, and that an initiative of citizens would determine the substance. We believe that we were able to show evidence that we could overcome barriers between citizens and medical personnel, which will be a standard to suggest what future people-centered care should be. In the days ahead, we will be further developing educational materials by an initiative of children five years of age and the citizens surrounding them to finish the program to learn about one's body.

As for the development of techniques supporting daily life which accommodate the bodily mechanism, our challenge is to publish the results at related academic conferences and to make the techniques useful for nurses and citizens.



T-shirt with digestive organs

# Release of Health Information and Development of a Mutual Communication System

## *Kango-net: A Community Website Connecting Citizens and Nursing Personnel*

<http://www.kango-net.jp/>

“Kango-net” (<http://www.kango-net.jp/>), a community website connecting citizens and nursing personnel, was established at the end of 2004, to disseminate the research outcomes of each project to citizens and nursing personnel more extensively. Since its establishment, contents have been frequently added. As a result, the website has maintained more than 20,000 visits per month; However, visits show no sign of substantial increase at this time, one year after the site was made available to the public. For this reason, the objective and potential of Kango-net have been reviewed.

### RESEARCH PROGRESS AND OUTCOME

#### Reconsideration of the objective and potential of Kango-net

We have already been proceeding with reviews on three keywords necessary to accomplish the project, namely “health communication,” “e-learning,” and “consumer health informatics” by collecting information on related research and practices. A summary based on the work runs as follows:

- (1) To provide information in order to support the enhancement of citizen health literacy; “health literacy” means “a degree of capability to obtain, organize and understand health information or services that are required for appropriate decision making concerning health” (Healthy People 2010, 2001).
- (2) To provide an opportunity to learn a way of looking at evidence, the methodology of EBM (Evidence-based Medicine) and decision-making, and a forum for people to communicate.
- (3) To drive home nursing personnel’s ability to play a role or attempt to play a role in a positive manner in decision making. For that purpose, introduce nursing personnel’s research outcomes with regard to assistance for decision making

and at the same time, to become an advisor on the internet in order to provide an opportunity for citizens to choose nursing personnel as a mentor for decision making.

- (4) To provide a place and assistance for citizens who have already acquired health literacy or “expert patients” to exchange information and work; it is a place to make use of citizens’ knowledge (problem-solving ability). “Expert patient” means a patient who has a good deal of knowledge through his/her experience with illness and is able to give an initiated patient advice regarding self-management or a way of utilizing information/services, and to give an explanation and advice based on his/her real experience. In addition, to support and interact with such expert patients because they have the potential of becoming citizen researchers or a citizen think-tank.
- (5) In each instance of (2)-(4), to explore implicit knowledge, based on the analysis of the way citizens and nursing personnel understand health and medical services, situations and consequences of information utilization and support, and narratives between citizens and nursing personnel (narration or story: in the substance on which a person speaks, one’s life or history will be made, which represents “a self as a narrative”), to transform it into formal knowledge. Also, to collect information about the opposite process.
- (6) Through collaboration between citizens and nursing personnel, to promote citizens’ initiative in health-insurance medical care, which is different from the conventional participation of citizens, by creating a community that has functions of empowerment and advocacy and forming social capitals (society-related capitals, a trust in human relationships, etc.).

#### Inauguration of Online Health Counseling

In response to the above-stated (3) and (4), we inaugurated a Message Board for counseling in March 2006, in which one can look at the knowledge of nursing personnel and citizens more openly, and the counseling contents are not to be limited. In this section, everyone can write consulting contents to which everyone can respond; we have both the party seeking advice and responding party identify himself/herself as “general citizen,” “person with experience,” “registered nurse/public health nurse/midwife”; we have given extra consideration to make knowledge of “experienced” citizens and nursing personnel clear, from which we are expecting expansion into the above-stated (5) and (6).



## EVALUATION

As for the website traffic of Kango-net, there are many visits to "MedWave News (Medical Information)," "1-click Questionnaire," "What Is Nursing?," "Nurse of the Month," and "Message Board." Accesses to constantly varying new information and the basic substance of nursing, such as news, message board and questionnaire, stand out.

Although the actual number of postings onto the Message Board is not so large, the amount of browsing is more than 100 times as much as writing, and so-called ROMs (read only members) have been on the rise.

As for access time, "Infertility Treatment" and "When Your Child Catches a Cold" have long visits. We believe that although there is a quantitative problem with the contents, the reason for such long "looking and listening" is because those sections "give specific comprehensible explanations" about "methods of practical treatment or care".

Evaluation of the access status shows that a section in which we can point out the importance of understandability or a section like "What Is Nursing?" in terms of substance originally attracts attention. For further reinforcement, we are moving ahead with the planning of "Kango-net for KIDS."

Likewise, it is speculated that the reason why there is a good deal of ROM for the Message Board is that although it draws attention or is prospective, there may be circumstances in which it is difficult to write. Also, several reasons have been put forward, including the reasons that the objectives and themes are not always specified; therefore readers do not always know that they can ask questions, they do not necessarily know that a moderator exists, and there are instances where no response is received from the moderator, etc. In the future, devising an operation policy for persons in charge of each message board is required.

Also, although the traffic to MedWave News suggests a high demand for news, it is believed that website-wide traffic is too low for us to be engaged in nursing news as a business. MedWave News encompasses contents that are not necessarily considered appropriate for citizens. If we can create health-related news for citizens and nursing personnel by citizens and nursing personnel, we will be able to expect more visits. We are presently hoping to recruit and foster human resources capable of taking on the duty of news making. It is hoped that health communication (which can be called a "health version" of the method used to facilitate

citizens' easy understanding of science and scientific communications), for which education research has recently been active in Europe and the United States, will be introduced into education research institutions in Japan.

In reference to the above-mentioned objectives and potential, for (1) and (2), it can be cited that information to assist the enhancement of health literacy and ways of looking at evidence and contents concerning methodology of evidence-based health care (EBHC) are insufficient at present. As for contents regarding assistance for decision-making, another project in Japan has launched a website with respect to decision making which releases the Ottawa Individual Decision Aids to citizens. In conjunction with it, we are going to consider production of general contents for enhancement of health literacy along with ways of looking at evidence.

Lastly, in order to comprehend the needs of citizens and nursing personnel, we are planning to investigate an evaluation which anyone can complete on the website for the purpose of assessing the site and content that cannot be grasped through access logs only. We would like to develop Kango-net to achieve our objectives by incorporating the opinions of people who already visit the website with various expectations.





## Fostering Young Researchers – Results of COE Research Fellow

### *Japanese Cancer Nursing:*

*Development of a Care Provisioning System for  
Multidisciplinary Approach to Cancer Nursing*



COE Research Fellow

**Naoko Hayashi**

### **Cancer Medical System Centered on Patients as a Primary Focus**

Technologies of cancer diagnosis and treatment are advancing at a surprising pace. Over recent years, it has become possible to discover cancer in very early stages and treat it using more effective methods with lesser burden on the body. On the other hand, the percentage of deaths from cancer is growing yearly. Given this situation, the “Japanese Cancer Nursing: Multidisciplinary Approach” project group is currently conducting research on the theme as to how patients can select the treatment best suited to them from the various treatments available, and how the side providing medical care and patients can cooperate so as to maintain patient quality of life while recuperating. The following introduces activities which COE researchers have taken part in this year from among the various ongoing research activities.

### **Awareness of Medical Care Provider and Patient in Multidisciplinary Approach to Cancer Nursing**

The multidisciplinary approach integrates medical services covering different medical fields “which provides patients access to a team of highly qualified healthcare providers specializing in diagnostic radiology, breast surgery, medical oncology, radiation oncology, plastic surgery, pathology, nursing and counseling” (excerpt from the Suburban Breast Center homepage <http://www.suburbanhospital.org/breastcenter/Multi Approach.html>). Based on the situation of the medical scene indicated here, in our research, we take the multidisciplinary approach to cancer nursing as “medical care providers cooperating with each other overcoming differences in diagnostic departments and professions to provide diverse care and treatments to cancer patients on various treatments”. Last year, we carried out an interview survey on the multidisciplinary approach among medical care providers involved in cancer medical care, and patients mainly at outpatient treatment departments, and the results clarified the following four key elements of the multidisciplinary approach: “involvement of multiple professionals for one patient” (multiplicity), “cooperation across the borders of the care scene and medical departments” (continuity), “decision-making and evaluation based on diverse specialty and reduction of burden” (mutual dependency), and “demonstration of specialty of profession” (autonomy). We then conducted a survey on medical care providers and patients on how they look at the current situation from their individual perspectives. We conducted the entire survey ourselves, from preparing the questionnaires, to collection of replies and their analysis.

We distributed the questionnaire to doctors and nurses of 457 hospitals authorized by The Japanese Breast Cancer Society across the country, and the breast cancer patients visiting these hospitals. We received replies from nursing administrators of 249 hospitals, 1,655 doctors, and 1,954 breast cancer patients. The results clarified that only 30% of the hospitals hold multidisciplinary conferences where professionals involved in the diagnosis and care of breast cancer patients such as nurses, surgeons, and pharmacists work together. Notwithstanding, 80% of medical care providers are aware that the multidisciplinary approach is important for enhancing the quality of therapy and nursing, have the determination to change the present situation, and are aiming to enhance their knowledge and skills for demonstrating their role as a team member. On the other hand, the results also showed that systems required for these efforts are not

fully available, and they are aware that the top priority task to be undertaken is “cooperation crossing the boundaries of treatment, care scene and department”.

According to the replies of patients, more than 80% feel that they are feel safe in the treatment currently received, they are treated by medical care providers from various departments, and the medical care providers promptly respond to their wishes and problems. Less than 60% answered that their wishes are being conveyed to other medical care providers, and they have been introduced to counselors or medical personnel to whom they can talk to about their illness and life under treatment.

We are planning to conduct more detailed analysis of the above results, and present the results at the conference held during the next fiscal year.

Based on the survey results this time, we proposed models of three mediatory systems; (1) development of tools for sharing information between patients and medical care providers, (2) installation of multidisciplinary conferences (by doctors, nurses, and pharmacists of different diagnostic departments) for integrating and evaluating patient information, and (3) deployment of nurses who can provide decision-making support and advise when outpatients are pressed to make decisions such as selection of treatment. We are currently reviewing the specific details and methods of introducing the systems to the clinical field next year.

#### “Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care” Symposium

Today, breast cancer is the most common form of cancer in Japanese women. Focusing on the fact that 30,000 women are diagnosed with breast cancer every year, we held the International Relay Symposium to discuss team-based care embodying multidisciplinary approach. The entire symposium was self-organized, including program planning, concert program planning, external negotiation activities, and compiling questionnaire results.

The symposium owes its success to the fact that from the initial stages of planning, meetings including doctors involved in breast cancer treatment and patient volunteers were carried out, the opinions of both parties were taken into account, and both parties were able to freely discuss the current situation of breast cancer treatment from their respective positions and needs. Results of questionnaires handed out to participants at the end of the symposium indicated that general participants hoped to become more involved in

medical care, and that the symposium proved beneficial to the participants.

#### Nurse Clinic: Support Program for Women with Breast Cancer

We have been involved in running “Support Program for Women with Breast Cancer” since it was launched in November 2004. In 2006, meetings were held ten times. Gathering more than 200 participants, these meetings provided the opportunity for participants to talk about how to live with cancer, and about the various problems faced in leading daily lives while on treatment and the improvements made to resolve these problems. This year, we are planning special mini lectures by the doctors of St. Luke’s International Hospital on hormonal therapy and alternative treatments, to enable participants to put forth questions which they otherwise would not be able to ask during usual outpatient visits.

We carried out various activities throughout the year, and common to all was the goal of pursuing medical care required by the public and patient-centered medical care.



Scene from the International Relay Symposium Concert  
In the closing ceremony of the symposium, there was a poem reading and harp performance, which helped to calm all the heat and excitement built up during the discussions.

## Fostering Young Researchers – Results of COE Research Fellow

### *Community-Based Palliative Care (Hospice Care at Home)*



COE Research Fellow

**Naoko Yoshikawa**

#### **Development of a Community- Based Palliative Care (Hospice Care at Home) Program and Systems:**

Building a community for spending  
last days at home

The purpose of the project “Community-Based Care (Hospice Care at Home)” is to develop palliative care in communities through active citizen participation and in collaboration with experts; in other words, to “build a community for spending one’s last days at home.”

Led by Hiromi Kawagoe, Project Leader, we are working toward the development of a community-based palliative care system with a focus on several fields of activities. For details, please refer to the report on the community-based palliative care project. We are concerned here with the development of a fostering program for citizen volunteers (holding a workshop for citizen volunteers participating in palliative care at home).

In June, we held a preparatory meeting prior to holding the workshop. We had called for participation through Kango-net (a community website connecting citizens and nursing personnel) and community network forum; 17 citizens joined from the planning stage. In addition, with the entry of visiting nurses for palliative care at

home mainly from the Chuo and Sumida Wards in Tokyo, the staff from the social welfare councils of the Chuo and Sumida Wards, nursing care managers and college-related people, we held the preparatory meeting with a total of 26 people. In cooperation with citizens and experts, we undertook program development for the workshop for people in the community volunteering to be involved in palliative care at home.

For the September workshop, 45 people, randomly chosen from approximately 60 applicants, attended the lecture. As for the substance of program, we invited practitioners of home hospice care as instructors, who gave us lectures on hospice care at home and team-based care from the standpoint of a doctor, visiting nurse, and volunteer coordinator. In addition, we incorporated “communication” and “how to obtain information” into the workshop, driven by the strong needs of citizens who participated in the planning.

Section managers for elderly care at the level of government administration also joined the workshop, enabling interaction among citizens, social welfare councils, and government entities. We carried out a questionnaire survey before and after the workshop, and also conducted an interview with the focus group. The contents of evaluations were as follows;

- I. Questionnaire about the workshop
  - 1) The way of conducting the workshop
  - 2) Program contents
  - 3) Change in participants before and after the lectures, which was evaluated on a subjective basis
- II. Focus group interviews about the workshop
  - 1) Change in the awareness of hospice care at home
  - 2) The role of volunteers in the care team
  - 3) Participants' comments about workshop

Consequently, 94.3% of the participants gave a positive response that the workshop was beneficial; 86% replied that they were able to understand the function of home hospice care, increasing their knowledge about volunteer work. The number of people who think that they could spend their last days at home in case of having cancer increased from 28.2% to 51.4% after the lectures. This may indicate that the recognition of feasibility of making a good end at home in case of having cancer has been significantly greater. Participants who had completed the lectures started enrollment in the existing home palliative care volunteer group (10 people) and involvement in building the foundation for volunteer activities based at St. Luke’s College of Nursing (10 people). Furthermore, increased understanding and recognition of volunteer

activities (86%) and alteration of behaviors (44%) were identified, which suggested the effectiveness of the workshop.

## EVALUATION

The work shop revealed two issues; one is geographical limitation. Although citizens from a good number of communities in various regions joined the Kango-net, I recognized the necessity to focus on specified areas in case we actually began “building of a community for spending one’s last days.” The second is importance of collaboration with citizens in program development. It was collaboration with citizens that enabled us to incorporate citizens' needs into the program.

For the further facilitation of “building a community for spending one’s last days at home” it is important to collaborate with not only citizens, but also government authorities and social welfare councils. This time, we paid numerous visits to the social welfare council to win the understanding for co-holding the workshop with them. In order to develop these activities, there is a need to consider how to proceed with cooperative work that is initiated by academia.

The screenshot shows the 'Kango-net' website with a recruitment page for a workshop. The page title is '家で死ねるまちづくり 準備会メンバー募集' (Building a community where you can die at home Recruitment of Preparatory Committee Members). The main text describes the workshop as a 3-day program held in September, aimed at building a community where one can die at home. It mentions that the workshop is held in collaboration with the local government and social welfare council. The application method is via email or fax, and the application deadline is August 31st. The contact information for the preparatory committee is provided at the bottom of the page.



Home palliative care volunteer program





# Promoting Collaboration Between the Public and Healthcare Experts

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## Health Information Service Center for Citizens: **Luke-Navi**

In May 2004 we established St. Luke's Health Navigation Spot (Luke-Navi) on the 1st floor of Building 2 of St. Luke's College of Nursing for the purpose of offering a health information service for citizens. Since St. Luke's studies nursing related to health and livelihood, we opened a place in our college, for all people to utilize as a resource for living healthy life, free-of-charge. The Nursing College had been seeking a way to help citizens obtain information necessary for addressing their health concerns on their own.

In order to make a decision for oneself with regard to one's health, appropriate and adequate information is necessary. We believe that although medical professionals have abundant health information, it is not within citizens' grasp, or even if it is within their reach, citizens find it difficult to make judgments. A gap in the amount of available information leads to a gap in power; there is a feeling that decisions regarding health and medicine are made far from one's own hands.

Luke-Navi, in collaboration with nurses and librarians, offers the service of information search through books, pamphlets and the Internet and of health counseling and a blood-pressure check by nursing personnel. We position Luke-Navi as a place for citizens to "drop-in" and get the health information necessary for themselves.

### 1) A day at Luke-Navi

The health coordinator, a full-time librarian, opens Luke-Navi at 10:00 in the morning. If the doors are open, anyone is able to take a look at leaflets anytime. Visitors can receive health counseling and a brief physical exam when Luke-Navi is open. Computers are available in order to search for health information on the Internet.

Health volunteers, including nurses, a national registered dietitian and a clinical psychologist, are present at the counseling booth (volunteer staff varies daily). Here, a nursing volunteer member takes blood pressure of a citizen using a double stethoscope (that allows two persons to listen) which enable a user to take blood pressure while hearing the sound of his/her blood vessels. With that as a start, health volunteers aid in consultation of healthcare issues for anxious citizens. Volunteers do not ask names or addresses, as Luke-Navi is a place to anonymously consider one's own healthcare; they simply record what the problem was about and how citizens responded. Another visitor leaves after taking a look at leaflets and books.

Today is the day of a monthly "Lunchtime Open Lectures on Healthcare & Miniature Concert." From 12:30, a university teacher gives a 15-minute lecture on healthcare without using technical terms and on a mission to convey it in an easy to understand way. In the meantime, an aromatherapy volunteer hands



out free herbal tea. In the latter half, we have a flute concert, also performed by a volunteer. The small venue was full of neighborhood people and employees on their company's lunch break.

In the afternoon, health coordinators start to create PR cards to be put in local stores. They are coming up with ideas of either presenting information on events or a very short healthcare story. They stopped making PR cards when a visitor came in wanting us to measure bone density. As part of screening, we explain that one important aspect is not whether bone density is high or low, but whether you can make use of the measurement result for maintaining good health. At 4:00 p.m., we closed Luke-Navi and the health volunteers left work.

We received a consultation inquiry from a junior high school in the district asking us if we could collaborate for their vocational experience program; it is also necessary for us to devise a plan. Health coordinators ended the busy day thinking that they would need to print additional copies of the original leaflet made by students.

## 2) Research activities

The activities of Luke-Navi itself are the subject of research. We believe that how it is recognized by citizens and utilized as a place to seek health information. Luke-Navi and its activities are a case study of an innovative project. We have been conducting an advertising campaign to promote awareness of Luke-Navi since its opening. This year, we participated in the Chuo City Health Welfare Festival (in November) to introduce Luke-Navi and conduct "Let's listen to our heartbeat with a stethoscope," "Food quiz show," "Picture card show of the human body" and so on. Four residents of Chuo City participated in the event in addition to the Luke-Navi staff; the citizens conducted a verbal survey on a questionnaire and picture-card show. We were able to see a new dimension of research in which we practiced activities that could respond to needs of a community with its actual members.

In addition, this year, we analyzed the consulting records of about one year after the opening to demonstrate nursing personnel's responses to citizen health issues and health counseling. The total number of people seeking consultation during service hours between the opening and March 2005 reached 237; the actual number of consultations was 360 cases. These matters were classified into 1) a specific illness, 2) a counseling for blood pressure and a request for measurement, 3) a symptom for which illness cannot be specified, 4) a checkup, 5) how to relate to

medical professionals, 6) selection of a hospital, 7) how to search for medical information, 8) selection of a lifestyle and future, 9) medical costs, 10) how to relate to one's family and acquaintances, and 11) collection of information on St. Luke's activities. The responses to those consultations were classified into 1) advice regarding daily life, 2) explanations, 3) recommendation to see a doctor, 4) a physical check-up, 5) utilization and provision of information and materials, 6) listening to a visitor's concerns, and 7) impossible to respond.<sup>1)</sup>

The fact that citizens have needs for health consultation and that Luke-Navi has become a place to meet those needs has taken shape. We have provided further insights into citizens' needs identified through data analysis. We need to study whether or not the books that belong to Luke-Navi and the contents of pamphlets are suitable to those needs, and what information is lacking.<sup>2)</sup>

## EVALUATION

We have been practicing Luke-Navi activities by trial and error; and we believe that it will be necessary to record efforts carefully to analyze and consider those from a viewpoint of people-centered care. During the next fiscal year, in order to expand activities further, we are going to take part in "a course on volunteers assisting health" that is scheduled to be offered at our research center.

As for part of our research activities this year we have been presenting at academic conferences and are in the process of contributing articles. Through development of the Luke-Navi activities, we aspire to realize the development of people-centered care by clarifying its process.

### Papers:

Michiko Hishinuma, Hiromi Kawagoe, Naoko Matsumoto, Tomoko Arahata and Michiko Ishikawa: Provision of Health Information from the College of Nursing to Citizens: Attempt at St. Luke's Health Navigation Spot Luke-Navi, Bulletin of St. Luke's College of Nursing: 31, 46-50, 2005.3.

### Presentations:

- 1) Miki Tokuma, Michiko Hishinuma, Hiromi Kawagoe, Keiko Takahashi, Naoko Matsumoto, Michiko Ishikawa and Tomoko Arahata: Citizens' Health Issues and Nursing Personnel Responses: Focus on Health Consultation Opened for Citizens by the College of Nursing, St. Luke's Society for Nursing Research, (Abstract) 9(2), 46, 2005.9.
- 2) Naoko Matsumoto, Michiko Ishikawa: Study of Tools Assisting Health Consultation at the College of Nursing, Japan Medical Library Association, 2005.



## Promoting Collaboration Between the Public and Healthcare Experts

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### The Fourth International Relay Symposium

#### I. Introduction

To allow people-centered care to be accepted into the community, serve as a useful benefit in the actual clinical setting, and be finally established as a necessity of the community, activities to increase people's health based on partnership between healthcare providers and people are indispensable. To facilitate such collaboration, five International Relay Symposia have been held to discuss people-centered medical care (Table 1). Under the common theme for fiscal year 2005 "Supporting Each Other and Sharing to Lead Healthy Lives," the fourth and fifth symposia were planned and run in cooperation with people in communities to discuss "Cancer: Team-Based Care" and "Women's Health" respectively.

1st	7/17/2004
Building a Community for Spending One's Last Days at Home	
2nd	10/3/2004
Let's Talk about Healthcare! Patients are Part of the Team	
3rd	11/21/2004
For Living a Life of Your Own Choice	
4th	10/29/2005
Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care	
5th	11/27/2005
Sharing Wisdom, Courage, and Experience: Women Supporting Each Other in Society	

Table 1 Outline of the St. Luke's College of Nursing 21st Century COE Program International Relay Symposia

### *Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care*



With the focus on the 4th symposium "Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care," the authors review the important elements for establishing people-centered care, which have been gradually identified through activities based on partnership with the public, and discusses future challenges and prospects.

## II. Common Elements of People-Centered Care

The common theme of the International Relay Symposia was established by clarifying the common elements of people-centered care aimed at by the COE program, and understanding how they are incorporated in each symposium theme. During discussions under the themes of “Cancer: Team-Based Care” and “Women’s Health,” it was emphasized that patients are required to be positively involved in choices related to treatment and lifestyle, effectively use their own strengths and health resources which can be mobilized, and obtain the drive to enhance their health regarding their treatment and care of women with breast cancer, as they make choices from multiple therapies. Specifically, the importance of “Sharing” was given. In continuing treatment for 10 years, for example, there is a need for patients to share information and knowledge individually acquired instead of being isolated from

each other, as well as share the anxieties and dilemmas resulting from their awareness of cancer and death in daily life. The other essential factor is “Supporting Each Other.” Since patients have to choose from diverse treatment choices available to them and continue self-care over a period of many years, medical systems that allow patients to decide the course of care independently and allow health providers, on the other hand, to support that process in collaboration with patients. For the other “Women’s Health” symposium, it was agreed that “Sharing” and “Supporting each other” were important elements. Accordingly, the common theme was derived to be “Supporting Each Other and Sharing to Lead Healthy Lives.”

## III. Towards the Era of My Choice: Patient-Centered, Team-Based Breast Cancer Care

### Symposium organized together with women who have experienced breast cancer

To provide quality team-based care for patients and families, the formation of a patient-centered collaborative care unit is necessary. The symposium therefore aims to have women with breast cancer experience being the “main player” of team-based medical care, to participate from the planning stage as organizing committee members and to work with them to incorporate patient needs. The process is as follows:

- 1) Meeting and sharing with women who have experienced breast cancer

The objectives and aims of the COE program and International Relay Symposia were explained to all participants of the support program for breast cancer patients held by St. Luke’s College of Nursing to recruit cooperative members for the planning committee. Two women who had experienced breast cancer volunteered to help, and thus joined as members. The agenda, program, and approach of the symposium were discussed with the two women over several meetings. Finally, an interactive symposium, unique amongst symposia designed by healthcare professionals, as well as a concert to share the symposium theme with participants, “Messages of Sound and Words” were planned.

The leaflet is for the 4th symposium, titled "患者中心の乳がんチーム医療" (Patient-Centered Breast Cancer Team Medical Care). It is organized by St. Luke's College of Nursing (聖路加看護大学) as part of the 21st Century COE Program. The event is scheduled for October 29th (Saturday) from 1:00 PM to 4:30 PM at the Atrium-Centennial Memorial Hall (アリス・C・センチュニオンメモリアルホール) of St. Luke's College of Nursing. The theme is "We support each other, share our experiences, and live healthily" (「支えあい、分かちあい、健康に生きる」). The program includes a lecture by Dr. Taniuchi (上野道子) on the importance of patient-centered care, a panel discussion with Dr. Taniguchi (田中清高) and Dr. Tanaka (田中久美), and a Q&A session with Dr. Tanaka. The leaflet also lists the speakers, the organizing committee, and the contact information for the symposium.

Promotion leaflet for the 4<sup>th</sup> symposium



## Promoting Collaboration Between the Public and Healthcare Experts

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Photo 1. Symbol quilt

### 2) Enriching symposium agenda by participation of volunteers

The planned concert “Messages of Sounds and Words” consisted of a poetry reading and harp performance. Four poems were chosen by the women with breast cancer experience from the poetry collection of Shuntaro Tanikawa: “To be Alive,” “Nothing,” “Morning,” and “Tomorrow.” The songs and program of the harp performance were planned with the help of concert volunteers to match the poems. The planning and preparation of the symbol quilt were carried out with the cooperation of the Japan Handicraft Instructor’s Association Quilt Leaders Tokyo and women who experienced breast cancer. Each participant was asked to write a message on a pink ribbon, the symbol of the campaign to wipe out breast cancer, and these ribbons were tied to the heart of the quilt to complete one symbol quilt (Photo 1).

### 3) Knowing the medical needs of participants

The symposium was started by asking participants, “Let’s think about team-based care together.” In response to the question “Do you feel that you are part of the medical care team when receiving treatment in the current medical care system?” about 85% replied, “No.” On the other hand, in response to the question “When deciding on your treatment, would you like to participate in a team conference conducted by the medical providers?” most of the participants demonstrated a strong response of, “Yes.”

### 4) Learning from team-based care of the US

During the symposium, Dr. Naoto Ueno, Associate Professor of the University of Texas M. D. Anderson Cancer Center in the US, gave a lecture on the topic “Status quo of patient-centered team-based medical care and clues to future progress,” discussing the transition of team-based care in the US, how teams are actually formed, and advantages of team-based care while comparing with the case of Japan. He indicated the basics of team-based care: “The attitude of providing medical care aiming at patient satisfaction is very important in doctors, nurses, pharmacists, and other healthcare providers. Particularly, co-medicals such as nurses and pharmacists should have common specialist knowledge to provide quality team-based care,” “patients should make an effort to acquire knowledge on their illness, and adverse effects of medications instead of just knowing the name of their illness,” and “doctors are human and can be wrong sometimes. It is therefore important for them to know their own limits and try not to discourage co-medical staff.”

### 5) Breast cancer team-based care aimed jointly by patients and healthcare providers

During the symposium, Dr. Kumi Suzuki of the Research Center for Development of Nursing Practice, St. Luke’s College of Nursing spoke from the nurses’ standpoint about the current situation of breast cancer and treatment in Japan, the need for team-based medical care, and the role of the nurse in the team. Dr. Seigo Nakamura, director of St. Luke’s International Hospital Breast Center, emphasized the importance of division and integration of medical care based on the daily clinical practice. He discussed that medical accidents can be prevented and better quality care can be provided if independent medical providers fulfill their roles with the focus on patients. Speaking on the behalf of patients, Ms. Yoko Hatano, a participant of the breast cancer support program, indicated the importance of the role of healthcare providers who

support the making of treatment choices and clarified the need for team-based care supporting patient treatment and daily life as a system, during discussions with the symposium chairperson and Dr. Nakamura. There were proposals for appointing administrators (not necessarily a doctor) to serve as the liaison to patients requiring advice, and relay the questions of these patients to the appropriate doctor.

After presentations by the three symposists, Ms. Joyce Newman, an advanced practice nurse at the University of Texas M. D. Anderson Cancer Center in the US specifically discussed the education of advanced practice nurses in the US and roles of nurses in team-based care as a commentator. Given that nurses in particular play the role of speaking up for patients, she said nurses have the important role of providing support to enable patients to ask more questions to doctors. The active discussions successfully provided hints on how to promote team-based care such as (1) the basis of team-based care lies in communication, and patients should also learn how to convey their conditions clearly, (2) efforts should be made to enable patient doubts and concerns to be resolved, and to this aim, co-medicals should try to accumulate technical knowledge and expand their role, and (3) it is important to build resources for patients to promote self-care, including their families.



The 4<sup>th</sup> COE international relay symposium



## Promoting Collaboration Between the Public and Healthcare Experts

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### IV. Evaluation of the Fourth International Relay Symposium

#### 1. What was found in the evaluation by general participants

There were 202 general participants, and the number of participants rose to 250 when planning committee members and organizing volunteers were included. The general participants were asked to evaluate in a questionnaire the conformance of symposium theme with needs, effectiveness of plans, and requests in relation to realizing team-based care. The collection rate of the questionnaire survey was 59.8%. Participants consisted of people including breast cancer patients (53.1%) and healthcare providers (41.6%), indicating more or less the same number of general public and healthcare providers among the participants.

The evaluation by symposium participants was generally positive, with 86.5% replying that the symposium responded to needs, and 94.1% saying that the agenda was significant. In addition, 94.1% replied that the symposium will contribute to both receivers and providers of healthcare, demonstrating that the symposium was meaningful. Moreover, needs for realizing patient-centered, team-based care include the "stance of patient and healthcare providers" in team-based care, "expectations on the growing role of nurses" in team-based care, "ideal team-based care," and "challenges of the medical care system."

Regarding the stance of patient and healthcare providers, there were many comments from receivers of medical care on the need for patients to change their attitude such as "Patients (we) should learn more about their (our) conditions and accumulate knowledge," and "Patients must also change." On the other hand, there were also comments, though few, that doctors must change their attitude as well, such as "We were told that it is bad for patients to dig around for information, and so it was quite difficult to communicate with the doctor," and "Doctors should have been involved actively in patient care." There were also comments on the need for effort on the part of both patients and doctors to change their thinking, such as "There is a need for patients to be involved more actively in their treatment and for doctors to be more passionate in responding to patients," and "There is a need for a majority of both doctors and patients to change their way of thinking with regard to medical treatment." As expectations on the growing role of nurses, requests on the role of nurses were indicated, including "Nurses

should not just be the assistants of doctors but be independent," and "It would be encouraging if nurses could accompany patients into the examining room and listen to the diagnosis with them, then the atmosphere of the examining room would be more open."

Regarding challenges of the medical care system, many comments from receivers of medical care voiced hope for an easy to use medical system such as "(We) need a place or person(s) from which/whom patients can seek advice." Healthcare providers on the other hand gave needs related to the establishing of systems to better enhance team-based care such as "more relaxed shifts or an increase in number of staff" and "a scheme or system that allows hospitals practicing team-based medicine to acquire the required budget based on the evaluation of such care."

The symposium was also joined by external evaluators. They gave favorable comments such as "The needs of participants are accurately grasped," "It was successful that the selected issues of the overall medical system were discussed from a broad viewpoint including comparison of Japan and the US while focusing on specific diseases." In addition, several comments suggested that symposia can provide policy proposals: "Perhaps, the lectures suggested the future course of medical care in Japan" and "The system reforms aiming to broaden therapeutic options for clinical trials and enhance medical standards, an achievement of the symposium, can serve as a proposal on specific measures for promoting participatory medical care."



## V. Future Prospects

### 1. Current Situation of Breast Cancer Treatment and Sharing of Challenges

In our routine use of medical systems, rarely do we think about it from a broad perspective or think about ways of improving it from the viewpoint of ourselves as users. In order for healthcare providers and users to talk about the current situation and challenges as common topics, attempts were made in this symposium to discuss such issues as common topics through quizzes and panel discussions. As a result, frank opinions and common needs were obtained from both the users and providers of medical care. This could have been the first time that particular issues were actually brought up in public, including examples such as “concern over possible loss of the close relationship with her attending doctor because of team-based treatment,” “can’t really feel I am part of the medical care team when receiving treatment in the current medical care system,” and “is it OK to ask such a question to doctors who we know are really busy?” They were the questions which each and every participant has in common. It has been reported that every member of the community does not necessarily see issues from the same perspective as professionals, and that the public must be involved in addressing issues that may affect the health of the community. The comments made by the participants of this symposium thus provided the opportunity to raise common challenges. By clarifying the current situation and challenges from the viewpoint of medical care users, it

Signatures of participants



should be possible to focus on challenges that need to be resolved, and pinpoint methods and resources for all involved to make concessions and cooperate with each other as well as develop more specific and realistic goals.

### 2. Awareness and milestones discovered in relations

Several comments of participants of the symposium indicated the awareness of the role of patients in medical care, such as “Patients should also learn and be able to convey their own views.” At the same time, “the need for healthcare providers to involve themselves more enthusiastically in patients and respond to their requirements” was also pointed out. In this way, the need for efforts and change of thinking by both patients and healthcare providers was raised in the symposium and this fact can be said to germinate new viewpoints on the promotion of participatory medical care.

More than 90% of the symposium participants showed a very active response of wanting to participate in conferences by healthcare providers when selecting their own treatment. Just as Nelson stated that “every one of us has the right to use our potential for growth and individual capabilities to the maximum,” it has been clarified that most people sense the importance of the right to select and decide the treatment which she believes to be better when receiving care that is directly relevant to survival.

In conclusion, new perspectives required for team-based care were seen to be invested in both the planners and participants of the symposium. As external inspectors have commented, the point lies in linking future COE activities to specific movements for enhancing medical care. To this aim, the COE program is required to indicate the specific steps to realize the movements and the requirements and responsibilities of participating patients.



## Promoting Collaboration Between the Public and Healthcare Experts

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### The Fifth International Relay Symposium



*Sharing Wisdom, Experiences and  
Courage: Women Supporting Each  
Other in Society*



### 1. Intent of the Symposium

The Fifth International Relay Symposium was implemented on the initiative of two projects, "Women-Centered Care" and "Development of an International Collaboration Practice Model Contributing to 'Health for All'" (hereinafter referred to as "International Collaboration"). Specifically, our College planned the symposium with the aid of a series of research activities and networks, including the WHO Collaborating Center for Nursing Development in Primary Healthcare.

In the process of exploring collaboration with citizens, we focused on phenomena occurring in a certain community. That was represented by the theme of the symposium "Sharing Wisdom, Experiences and Courage: Women Supporting Each Other in Society." We thought that we would like to search for a shared component through directly hearing their opinions on their respective community experiences: how they face the difficulties in the community, and how they try to get over or have gotten over them.

聖路加看護大学  
21世紀COE国際研習シンポジウム 第5回

2005年度COE国際研習シンポジウム全体テーマ  
「支えあい、分かちあい、健やかに生きる」  
**知恵と経験と勇気を分かちあう  
社会の中で支えあう女性たち**

**日時** 2005年11月27日(日)  
PM1:00~PM4:00

**場所** 聖路加看護大学内  
アリス・センター・メモリアルホール

**入場** 皆さまご参加を  
**無料** お待ちしております

**プログラム**

12:30	開場
13:00	COE国際研習シンポジウム 小黒道子氏
13:10	シンポジウムに先立ち 堀内成子氏
13:20	歩調を合わせてつづくと 〜ミッドラン・セントジョージスグループの経験から〜 小黒道子氏
13:40	いざなふとくしたあしあふれあふれ 石井美津子氏
14:00	◆聖路加看護大学の国際化の取り組み 「ワールド・メッセンジャーズ」の活動 長岡ジュディ氏
14:20	(休憩 (20分))
14:40	◆ワグネル・ヘルツォーグ・ヘルツォーグ・ヘルツォーグ グローバルな視点での女性の健康 大坪信子氏・バーフィット氏
15:20	ディスカッション
16:00	終了

**お申し込み方法**  
お名前、お電話番号、人数、所属を明記の上、FAXまたはイン  
ターネットでお申し込み下さい(定員300名)  
FAX: 03-6226-6379  
http://www.sango-net.jp/  
お問い合わせ先: COE事務局 (TEL: 03-6226-6379)

**講演者**

**小黒道子氏**  
聖路加看護大学准教授  
国際化推進として、ミッドラン・セントジョージスグループの経験から、看護活動の向上をめざすための女性グループの  
育成活動を行っています。この活動の現状や課題についてお話を  
いただきます。

**石井美津子氏**  
お茶の水女子大学助教授 看護学専攻  
児童・児童看護を専攻された方々のセルフ  
ヘルプグループの運営者として、子供を失うと  
いう大きな悲しみを経験し、支えあうための  
交流活動についてお話しいただきます。

**長岡ジュディ氏**  
NPO法人ワールド・メッセンジャーズ 理事長  
異文化である日本での結婚・出産・子育ての経  
験を生かし、同じように悩む女性に日本国内  
女性に支えあえるために、NPOを立ち上げた  
経験をふまえてお話しいただきます。

**バーバラ・バーフィット氏**  
クラスヌー・カレドニア大学看護  
WHO 看護・助産師教育センター  
グループ・ヘルプ・ネットワーク事務局  
国際看護、家族看護を専門とし、市民のキャ  
パシティ・ビルディングにおける看護の役割に  
ついて、オーストラリア等の看護教育・システ  
ム・看護の発展から講演をいただきます。  
※同時通訳あり

聖路加看護大学  
21世紀COEプログラム

This report is an excerpt from the Journal of St. Luke's Society of  
Nursing Research, Vol.10, No.1 (Permission obtained from  
St. Luke's Society of Nursing Research)

Promotion leaflet for the 5<sup>th</sup> symposium



## 2. Outline of the Symposium

The four speakers were: Ms. Michiko Oguro, who assists a women's group in the Union of Myanmar as a midwife; Ms. Keiko Ishii, who runs the self-help group for people who experienced miscarriage, stillbirth or newborn death; Ms. Judy Chonan, representative of the NPO World Nook Shonai that supports foreign women living in Japan; and Dr. Barbara Parfitt, who has practiced nursing education and training citizens in Tajikistan and other countries. We had them talk about their respective activities. A brief summary follows.

### 1) Activity to support training a group of women in Myanmar

Ms. Michiko Oguro, who had been dispatched as a midwife of an NGO since 2003, told about activities in Myanmar, entitled "Activity at a slow but steady pace: Experience of involvement in fostering a women's group in the rural villages of Myanmar." The main activity was to develop a women's group to promote empowerment with the aim of improving healthcare for mothers and children. Ms. Oguro's efforts started with organizing a group of "women who are literate and interested in healthcare for the village." In the movement involving foreigners, to whom the women



A meeting with a women's group in Myanmar

were unaccustomed, at the beginning there was a great deal of tension. However, we could see a gradual change in them through participation in training to learn practical techniques or wisdom for a real life: e.g. creation of a map and a seasonal calendar of the village (in which times when there are a lot of people who catch a cold, the busy farming season, festivals of the village, etc. are written), thermometry, first aid for injury, and creation of a stretcher with fabrics



Signatures of participants



## Promoting Collaboration Between the Public and Healthcare Experts

3

at home. They had been given the opportunity to personally make remarks and express their opinion to the village mayor, and voluntarily make suggestions on a theatrical performance of healthcare education for the people in the village. At the conclusion, Ms. Oguro showed photos of women whose expressions had become lively, saying that “recognizing themselves as a useful person and being trusted by everybody may have led to motivation in the womens’ activities”.

### 2) Support for sharing grief of losing an innocent life

Ms. Keiko Ishii, representative from Kanto affiliate of With the Angels In the Sky (WAIS), has been engaging in a supportive activity as the director of a self-help group for people who experienced miscarriage, stillbirth and newborn death to share their great sorrow of losing a child and mutually support each other. WAIS was inaugurated in 1999; its main activities are to publish a newsletter and hold a parent’s association meeting. Since mothers’ sorrow for unborn babies is difficult for other people to understand, they lose a place to express such grief. Under these circumstances, participants of the parent’s association meeting of the Angels do not hesitate to cry, talk about sorrow, anger, or suffering there; by expressing their sadness, they are enheartened by relief of “not being alone,” and the existence of persons who have the common worries and are facing similar feelings and lives. In the association, they refer to their lost children as

“angels,” and speak without reserve, and as the “mother of the angel,” they make a handmade doll or a toy, thinking of their children. Talking about sorrow is a kind of task for confirmation of a life that really existed; expressing sorrow leads to reflect on oneself; and creating something is a kind of task for mourning, said Ms. Ishii. Additionally, she mentioned that the self-help group is not a gathering for weak, sad people to solace each other; it is for them to share such great grief with other people and overcome, to become a thoughtful person and hope to place importance on one’s livelihood. Also, she said that through participation of medical professionals, such as nurses and midwives, in the Association we will be able to understand each other; one single association’s activity will allow many people to be connected and deepen understanding.

### 3) Supportive activities for foreigners living in Japan

Ms. Judy Chonan, originally from the Philippines, was married in Yamagata prefecture 22 years ago. She has been conducting various sorts of activities for supporting foreigners living in Sakata, Japan, including the inauguration of “Sakata International Exchanges Salon” as a place of interactions among foreigners living in Japan, the launch of a group that is engaged in translation, interpretation and home tutoring, and the creation of a “Medical Guidebook (Shonai dialect into foreign languages).” After having conducted those activities, Ms. Chonan established an NPO, World Nook Shonai, in 2003 in order to assist foreign women living in Japan who have worries about a land they are unaccustomed to. She told us enthusiastically that she placed her hope in “a nook,” which also has a meaning of “a corner”; through the activities of the Nook, making the globe nuk-nuk (comfortably warm) to build a society in which bright, various cultures can be shared, and to make the globe become a big family. Currently, she is energetically exerting herself to resolve troubles of women living in a different culture, while conducting a variety of activities (such as introducing different cultures and holding a cooking class for various countries’ cuisine).



Venue of the Association for Parents of Angels



Association for Parents of Angels: Hand-made toys for angels



Seminars on traditional Japanese culture: Wearing a “yukata” & Japanese manners





A newspaper article about World Nook Shonai

#### 4) Activity of family healthcare nurses

Based on her experiences in countries of Central Asia for ten years, Dr. Barbara Parfitt, a specialist in international nursing and family nursing, emphasized that women are key persons. For healthy livelihood of community residents, it is important that female independence is acknowledged, and that women be empowered, in order for women's groups be promoted to build capacities. Also, through the research targeted for women living in Tajikistan, the outcomes and challenges with regard to the role and effects of family healthcare nurses for services with a focus on family were presented.



A research for women in Tajikistan

#### 5) Discussion: Collaboration regardless of different positions

In the discussions after the Symposium, in response to the question of "What is an important thing when working with someone in a different position?" each speaker made a comment: "To believe that they are the ones who are able to do for themselves," said Ms. Oguro; "To understand each other's feelings and what can be done," said Ms. Ishii; "To convey what you would like to do, and to give an explanation until you make yourself understood- to understand each other," said Ms. Chonan; and, "An important thing is to respect each other even when having a different stance," said Dr. Parfitt. The comments by speakers who have been pursuing activities for women to protect their well-being as well as their own personal experiences have implications and considerable persuasive power. We obtained suggestions for future activities from their proposals and indications which could not be noticed from the viewpoint of medical professionals.

At the end, there was a question from the floor; "If we collaborate with citizens, is there any particular advice or for society having continued for so long?" and Ms. Ishii answered, "my advice would not be so aware of continuation." At that moment, many participants nodded in agreement.



The four speakers



# COE Evaluation

## 1. The Evaluation Committee

### Purpose

The COE Evaluation Committee, consisting mainly of external evaluators, is organized for the purposes of evaluating the administrative performance and progress of the COE program, providing advice so that functions as an international center of excellence for nursing science can be exercised effectively, and indicating directions for further development.

### Committee Members

#### National members:

Sumie Asatori	NPO “Onna-no benri cho” (Women’s Yellow Book)
Masahiro Ishida	Member of the executive board, Japan Nursing Federation
Yasuhiko Ohta	Editorialist, Nihon Keizai Shimbun
Machie Kanegae	Deputy mayor, Chuo Ward, Tokyo
Norihiko Tanikawa	Managing director, NSK Ltd.
Haruko Saeki	Tokyo Simulated Patient Institute

#### International members:

Dr. William Holzemer	University of California, San Francisco
Dr. Caroline White	Oregon Health & Science University
Dr. Chung Yul Lee	Yonsei University
Ms. Kathleen Fritsch	WHO Regional Office for the Western Pacific (WPRO)

The Evaluation Committee consists of 10 members altogether.

### Evaluation Criteria

In order to promote the COE Program, “Nursing for People-Centered Initiatives in Healthcare and Health Promotion,” the following evaluation criteria were adopted:

- (1) Congruity of the program with the needs of citizens
- (2) Degree of collaboration with citizens
- (3) Sense of unity with citizens and communities
- (4) Practical application of research results by citizens, professionals and the administration
- (5) International significance

Criteria in addition to the above include the support of young researchers and the status of organizational and financial operations of the program.

## 2. Overview of the Evaluation Strategies

### Evaluation of the International Relay Symposia by the national committee members

We invited them to participate in two Relay Symposia we implemented during the current fiscal year, and used the same evaluation sheet as the last year. Through discussions with planners and administrators, we obtained evaluations for the specific programs and overall approach of the COE.

### External evaluations by national and international members

The Evaluation Committee meet on December 2 and 3, 2005. On the first day, the international evaluators and the COE project leaders meet to review the progresses, the results of interim assessment and current concerns, etc., and we confirmed the plan for the next day's activities. On the second day, we explained the concept of people-centered care that has been clarified so far and presented descriptions of four program projects. The international evaluators offered comments and suggestions.

The results of evaluations are reported according to their sources: (1) the International Relay Symposia and (2) the Evaluation Committee.



# COE Evaluation

## (1) Evaluation from the International Relay Symposia

### About the International Relay Symposia

This fiscal year two symposia were presented. In addition to the audience evaluation, each was also evaluated by the external evaluators and the organizer in charge.

### Themes of the International Relay Symposia

These themes are the “relay baton” that connect each symposium to the ones that precede it and the ones that follows:

1. Providing a time and space for dialogue between community people and nursing personnel,
2. Providing information for everyone to take an active part in healthcare,
3. Making a contribution in consideration of health and lifestyle most suitable to us from an international perspective,
4. Building a partnership with citizens.



### Results of Evaluations by Theme

#### Theme 1:

Based on last year's evaluation, we had citizens join us from the planning stage of the symposium and made the best use of their inventiveness to set up and run them, e.g. by incorporating in cooperation between citizens and nursing personnel into the substance of a symposium. We received comments that the

symposium had become more able to fit the needs of participants. Also, the evaluations suggested that, in order to guide those making policy proposals and thus improve all aspects of health services, it is important to gain better insights into the diverse needs of citizens concerning medical service or health and increase mutual dialogue and learning between citizens and nursing personnel.

#### Theme 2:

We received feedback that through the symposium, people who had health issues (e.g. women with breast cancer) or difficulties (e.g. women who experienced stillbirth) could learn how to gain zest for living in good health. We could confirm that the importance of proactively or actively participate in healthcare could be passed on to the participants, as above all things, we received a comment saying “I think we (patients) have to learn and obtain knowledge about receiving medical care.”

#### Theme 3:

From new information from the overseas lecturers and invited speakers, citizens and healthcare professionals could obtain suggestions for what future healthcare should be and also orientations for thinking about support and assistance for citizens with health issues or difficulty living in good health.

#### Theme 4:

We made efforts to cooperatively conduct planning and operation of the symposium with citizens' participation. Because of this, it was acknowledged that we were building a partnership with citizens. In addition, at each symposium, we created a symbol quilt with citizens, which forged close ties between us.

From these responses we conclude that we had by degrees become able to plan and operate a symposium that was at the citizens' eye level and tailored to citizen needs. However, at the same time, it has become apparent that a simple device is needed to help us share the results of the symposium publicly for the common good.

## (2) Evaluation from the Evaluation Committee

The Evaluation Committee, with the attendance of four international and three national evaluators, gave us an assessment with respect to the progress of the COE Program and suggestions regarding directions for possible future development. Additionally, one national evaluator who had been absent on that day gave us a written evaluation of our progress.

Each evaluator gave us high marks in regard to diversity of the activities that had been implemented so far, and promotional undertakings making use of feedback from citizens or evaluators, and to efforts for conceptualization of people-centered care.

Firstly, there was the opinion that it is important to convey the activities and results of the COE Program to citizens. “Kango-net” was launched, and the transmission of information has been attempted in diverse ways. For the future, there will be a need for a device or means that will enable interactive communication.

Additionally, it was pointed out that it is necessary to plan for utilization of outcomes, such as dissemination of accomplishments of each project and developing policy proposals based on the research findings. We received feedback that it would be necessary to

approach the aforementioned actions with a view as to how we should continue each project after the termination of the COE Program funding, as we have already passed its halfway point.

Next, we received a comment that there would be a need to clarify a goal for the entire COE project based on the past processes of each research project, and current conceptualizations of people-centered care, and to consider how to incorporate that concept into communities in the future. Some evaluators said that to that end, additional collaboration among the projects and aspects common to them might be helpful.

Thus, due to the fact that we have passed the halfway point of the COE Program, it became apparent that our challenge would be to link each project and proceed with our shared conceptualization of people-centered care as the overall COE goal. Furthermore, we received a suggestion that it would be necessary to consider how to disclose and utilize individual project activities and outcomes and link them to the overall COE and its future.

(Summary prepared by Internal Evaluation Committee: Ikuko Oikawa, Kumi Suzuki, Nozomi Setoya, Madoka Tsuchiya)





# Core Elements and Activities and Challenges of People-Centered Care



St. Luke's College of Nursing  
21st Century COE Program Leader

**Hiroko Komatsu**

## 1. Aiming at conceptualization of people-centered care

In order to develop a COE project with consistent orientations that encompasses a wide range of communities, it is a major challenge to clarify common purposes and attain effective methodologies to realize them. To this end, a working group has been set up to discuss core concepts of people-centered care, identify elements common to our ongoing projects. In addition, the group examines issues such as the extent and ways people-centered care activities have been implemented, what problems remain to be solved. The group identifies possible responses to challenges and how the overall picture of people-centered care may be realized.

## 2. Community to create people-centered care

One feature of our COE program may be seen where healthcare providers and people stand in the same arena, beyond a relationship as providers and receivers of care in the conventional health care framework, seeking strong partnership for solutions to health problems faced by the community and proposing practice models based on a scientific approach. Collaboration partners in communities may be categorized into three general groups: those who are faced with an overwhelming variety of choices due to the advancement of medical technologies; those who have to adhere to lifelong lifestyle control in order to cope with chronic illness; and those who feel threatened to exercise their potential or fear they cannot keep their dignity due to stigma. Actually, people affected by such issues tend to easily be isolated or left behind in the complicated social context of present-day society.

## 3. Drive of conceptualization: working group

In order to collaborate with people and identify true health needs, and eventually solve urgent needs, new community-based partnerships between health care professionals and people have been formed; also new

collaboration systems for problem solving are being formed and organized. By patiently building up the results of such projects, the working group makes continued efforts to describe the core elements of people-centered care. The group has used the Process Evaluation Model (participation, relationships, capacity building, empowerment, products/concrete achievements, policy/procedure change, and community work), for people-participating research presented by Chrisman et al. (2002) as a framework, to classify and organize data and also reveal important core elements.

## 4. Core elements of people-centered care seen on the horizon

The following core elements of people-centered care have been deducted from the project activities:

### 1) Participation

where people meet, share certain purposes,  
and start getting involved

Each project includes activities to seek and meet a community to collaborate with, work together to identify the needs of the community, and attempt appropriate collaboration.

Seeking and meeting a community  
to collaborate with

This may include actions such as raising an issue to draw attention or interest. Such activities take a close look at health problems that are hard for people to realize in a real sense, and then communicate about them with people as topics that can draw social attention. Specifically, such activities include raising issues to draw attention or interest, and creating forums or opportunities in the community or on the Internet for people to address specific goals, get together, and work together whenever necessary. In the Japanese Cancer Nursing project, for instance, women with breast cancer living in a city are considered to form a community. Support programs and symposia are held on a regular basis to communicate messages such as “Have you been really able to receive satisfying

treatment for breast cancer when you are faced with such a large number of choices?” and “Would you like to bring your voice into team-based breast cancer care as a person having experience with breast cancer, in order to help develop healthcare in which persons fighting cancer can think about their own life and take charge of it?” The aim is to develop a community that can reshape the care of breast cancer into a one that empowers persons with breast cancer and is more suitable to women's ways of living and their lives.

In addition, activities to streamline and understand problems in collaboration with persons with health problems are carried out on a regular basis to build links for the community to collaborate with. In many of the projects, people with health problems have gathered as support groups, and carried out activities to identify community needs together with people active in the community, including volunteers from educational, political, and welfare organizations. In one project, a working group has also been carrying out activities to identify community needs.

Over the past two years, significant efforts have been made to promote participation in all projects. It is more precise to say that our efforts have been essentially limited to them. This shows that healthcare providers in healthcare provider- or policymaker-led healthcare systems had not been very familiar with developing people's participation as an aspect of their work.

### 2) Relationships

commitment or involvement - social unity  
to mutually share rights and obligations

Commitment is gradually being made by project teams to identify the strengths and resources of the community, choose issues to work on, and achieve results in collaboration with the community.

By gathering people beyond borders of existing medical institutions or organizations, opportunities or forums to clarify opinions, methods, and purposes are established. All projects are making efforts to ensure that groups will continue to function. Joint events, including information meeting or seminars, are organized so that each party may become aware of, and recognize differences in their own claims, positions,

## Core Elements and Specific Purposes of People-Centered Care

and roles. When a woman with breast cancer who presented at the "Patient-Centered, Team-Based Breast Cancer Care" symposium talked about her real feeling of "concern over possible loss of the close relationship with her attending doctor because of team-based treatment," it shocked healthcare providers, giving them an opportunity to become aware of what they otherwise would not know.

### *Commitment and involvement takes place.*

Sharing health problems in the community produces the relationship of mutual aid, in which information is openly exchanged, advice is given to and shared with experts regarding information or resources that are missing in conventional healthcare scenarios, and those who used to receive support shift to being those who provide it.

In order to find clues in solving health problems in the community, joint events are being organized by healthcare providers and people. This has encouraged fresh perspectives required in healthcare, facilitated the formation of networks and creation of new roles that can only be fulfilled by experienced persons (volunteer coordinators, health consultant, etc.). In the team-based breast cancer care, a socially established physician gave an antithesis statement that "physicians are not almighty and do make mistakes; therefore, patients, too, are required to give full attention to what they say and any available information to learn." Thus, the positions of patients as a partner in team-based treatment were made clear and the concentration of strengths started for the purpose of team-based treatment. This in turn creates the attainment of capacity to stimulate participants' genuine efforts and trust/involvement.

### 3) Capacity building

process that enhances potential capacity,  
resources, possibility, and skills  
in individuals and communities

Collaborative partnerships are used to establish mutual

communication of wisdom, skills, and potentials in several projects. For instance, the need for mutual learning among community members led to the implementation of a new (learning-oriented) breast cancer support program; and an interview survey to investigate citizen needs produced a people-participating class to prevent the elderly from falling. In the breast cancer support group, members can work together to shape shared values and targets; there are signs of positive change in each woman: they can mutually learn and grow through activities. Eventually, we may be able to propose and disseminate ways that care receivers may become voluntarily involved to make changes in the care system for their own benefit or advocate for issues that should be handled by society as a whole, such as the prevention of breast cancer.

### 4) Empowerment

ability (or performance) of the community  
to understand and control  
the power of society for improvement

Several attempts and activities have already been initiated.

### *Decision making to maintain collaboration and coalitions and utilization and activation of potential resources*

In the Genetic Nursing project the joint production of materials for informed choice is underway with self-help groups. Elderly care regional foundation networks with a focus on people's needs are being formed by the elderly and their families and policymakers, and others who are participating in fall-prevention classes or care consulting. In joint production of the learning program for children and its on-site evaluation in the community, there have been shifts in information and values as interested parties, acting as core players, disseminate the importance for children to learn bodily functions among other community members. As individual community members start spreading it in a larger community, the open exchange of information,



trust, and wisdom between healthcare professionals and interested people, such as volunteers, become even more important.

*Open exchange of information and integration of equal powers, interests, purposes, and potentials*

In order for those who are in different positions but interested in community health problems to move toward allied problem solving, it is desirable that they participate in specific activities, such as joint research, to together proceed with the process of planning, implementation/management, and evaluation. Through such activities, it is considered that mutual transfers or circulations of individual powers and resources may occur.

In the group to develop regional care systems to support children with chronic illness and their families, teachers, guardians and professionals are working together to identify resources in the region, which can be a grand step toward empowerment. In order for them to move toward the next stage, collaborative activities are being planned so that guardians and teachers are taking part in a research working group to exchange opinions from different points of view, while jointly developing plans to achieve specific purposes and implement them. Meanwhile, in projects for education on life and the human body, too, guardians are encouraged to become involved at an early stage. As a part of such activities, high priority is also given to school-wide collaborations. By having school-wide involvement, it is possible to carry out more organized activities. For instance, fresh information (knowledge on the body) appropriate for each grade may be provided at every grade level, helping secure opportunities for education on the body, and results may be more widely used with other subjects. Such school initiatives may lead to the presentation of suggestions on school education and regional health activities, it is hoped that it will grow beyond region into nation-level health education for children.

## 5) Products

### results - specific accomplishment/achievement

Organizations, resources, philosophy/purposes, and specific activities are to be integrated into life in the community in a sustainable manner. Products may include, for example, presentation of model project plan (including finance and organization), evidence, and, most importantly, visions to accomplish these, in order to realize a new patient-run, team-based breast cancer care system or a new breast cancer prevention system in which women with breast cancer participate as a health resource. Other products may help finance program continuation while also publicizing program element, for example, contracting a company to produce T-shirts with body organs printed on them to sell in the community; collaboration with businesses for advertising on Kango-net.

Kango-net (<http://www.kango-net.jp/>), a meta-database system in which people can have ready access to health-contributing wisdom and skills that have been created through the projects in collaboration with community people and which can interact them to provide useful individualized health information where necessary, is one example of a product created through the projects as a whole. In addition, there are a large number of health information sets that are readily accessible and easily understandable for healthcare users, including healthcare decision-making tools, guides to support women with infertility, and self-care guides for people to live with cancer. While such health information includes various perspectives, it has been accumulated for the shared goals of projects, including decision-making support and self-care promotion, together allowing for important health literacy in the promotion of health in the community as a whole.

# Core Elements and Specific Purposes of People-Centered Care

## 6) Policy/procedure change

influences on other organizations  
in creating changes in policy making

Several projects have already begun to work on requesting cooperation from the Tokyo Metropolitan Area and metropolitan governments in collaboration with people involved in the activities. In Chuo Ward, for example, those who are closer to policymakers than general people such as licensed case workers or school PTA members are asked to play roles of stakeholders linking citizens and policymakers, thereby aiming to lead to suggestions for city planning that will nurture safety and sound living of the young and elderly.

Various other policy suggestions may also be possible, including presenting proposals on the handling of rape victims to relevant organizations, on children's education to the Ministry of Education, Culture, Sports, Science and Technology, or on the comparison of costs and quality of care between the new team-based cancer care against conventional treatment to the Ministry of Health, Labour and Welfare.

## 7) Community work

certain visions are identified, then resources  
and powers are mobilized to realize them,  
resulting in organized activities to support  
the health of people

It is the ultimate goal in the COE program that health problems that reflect urgent needs of community members are brought to the surface, leading to continued and organized resource development and other specific activities to solve such problems. In these organized activities, involvement of volunteers belonging to the community is critical. To begin with, it may be necessary that the persons with actual health problems and those parties concerned should widely communicate with society at large the significance of health problems to be solved and the importance of voluntary involvement in the solutions. Continued community work such as this has already been started in some of the projects. In the projects of team-based breast cancer care and city planning in which people may spend their final days at home, for instance,

workshops and working groups have been launched with the volunteers to be core players. Such activities to increase voluntary involvement and long-term activities are being promoted in annual project plans.

## 5. Challenges to be solved

Key concepts in people-centered care have been discussed above. Based on this, it is concluded that people-centered care is built on the underlying concept of "consumer initiatives." Consumers are to be seen as beneficiaries of medical and health care as commercial products, in which experts incorporate new attitudes to healthcare, different from conventional ones. Examples of such stances include "the sense of deadlock in medical and health care in Japan may not be overcome without the increased involvement of lay expert" and "healthcare providers and people should openly communicate their own knowledge and skills as well as trust and respect." This should in turn give efficient feedback of implicit knowledge gained from people's innate experience encompassing birth, aging, illness, and death, that is based on collaborative research with people. Thus, products collective health of the community as a whole. In other words, it is to produce a paradigm shift in healthcare from the concept of "product-out" to "market-in".

In order for such people-centered care to be realized, some challenges to be solved become clear:

- (1) Extracting core elements of people-centered care, and clarifying specific purposes to be achieved in the COE program as a whole based on such core elements that are turned into perspectives of overall concepts in line with the people-participating research process, including:
  - Suggestion of new socio-efficient healthcare system that incorporates concerns and needs of the citizen society.
  - Formation of a base for the practice of collaboration with citizens for the promotion of a healthy community in which there is an agreement that a community will work together with us.
  - Organization of unions, community advisory groups, and networks for the solution of health problems with the base for practice of collaboration with citizens at the research center of St. Luke's College of Nursing, thereby creating specific activities, systems, and care programs.

- Development of model communities that practice people-centered care; creation of a healthy community rich in voluntary commitment to choices regarding health problems, wise users of health information, and human wisdom, which in turn should foster the formation of a civil society rooted in the sense of safety and soundness.

## (2) Socialization of people-centered care

“Lay-experts,” who are not found in conventional healthcare, such as civic healthcare coordinators and health consultants, are created and gain social recognition.

It is necessary that, in the community, collaborative partnerships aiming at the nurturing of health that can set an example are established as model cases, and given a position in the health and medical systems (for instance, breast cancer prevention in collaboration with those who have experienced breast cancer, and regional promotional project for building a community for spending one’s last days at home).

## (3) Obtaining specific visions in the sustainability of people-centered care

In order for people-centered care to be incorporated into people’s lives as something sustainable in the community, it is necessary to have specific strategies or assessment to enhance economic and social significance and utility.

## (4) Development of research methods and theories for people-centered care

In order to ensure that the COE program may not end up being a once-and-done research and practice activity and that it will be a drive for a paradigm shift in the current deadlocked healthcare state of affairs, it is necessary to present theorization and methodology of people-centered care as something easy to understand and useful. In theorizing about it, we must identify people-centered care that is based on Japan’s national identities and cultural contexts. Thus, the theorizing should address urgent challenges, such as sectorism and authoritarianism among healthcare providers, people with little interest in or expectation of nursing, those who “criticize from the other side of the river but never dare to come across the bridge,” and conflicts among or within groups.

As for methodology, while efforts have been made to maintain scientific consistency in accordance with CBPR, it is necessary to discuss methodologies that may allow all the projects to maintain organic liaisons and thus proceed as organized initiatives with such liaisons as an advantage. At the same time, it is also required that we establish standards and methods for evaluations of process and results for individual projects as well as the overall program.

The COE program is a project full of challenges in its attempt to demonstrate people-centered care. It is our belief that higher educational institutions are expected to be a magnetic field for the birth of new healthy community, with research centers as a base for experimentally attempting to develop necessary know-how, and also providing consultation to society.

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