

# Creation and Dissemination of Genetic Nursing in Japan

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## **【Goals】**

1. Developing and evaluating specific care programs for children and adults to share thoughts as a community in terms of family, school, and society in order for them to live their own lives in the ways that they have inherited from their parents.
2. Identifying concepts required for the realization of People-Centered Care in genetic nursing that have been obtained through the aforementioned activities.

## **【Plan and Implementation Process】**

The COE Program, consisting of eleven projects, aims to realize People-Centered Care (PCC) tailored to the health and subject profiles of each project. Based on the model shown in Figure 1, this diagram forms a flow consisting of the development of care (Step 1), followed by the delivery of care (Step 2) and the evaluation of which leads to the adjustment of care (Step 3).

Part of this model is the genetic nursing project, in which a range of activities have been taken place involving the general public who were stimulated to think deeply about how to live a unique "life", through heredity and genetics learning. The following is an overview of the phased implementation process of this project.

### **Step 1: Development of care**

Specific care programs to support the goal attainment of this project include ones that: (1) utilized existing care programs, and (2) were developed from the initial creation stage. Our initiatives at the this stage of the development of care are reviewed in terms of individual programs including the specific population focus.

#### **A) Education on heredity and life targeting the general public (society)**

- Inspired by the "Learning about Life" initiative in primary school pupils for which there had already been activities in place, and based on the concept of "parents and children sharing the appreciation of the birth of a life", we called on the Internet for essays under the title of "Precious of Life", which eventually led to another set of initiatives as a book publication (Year 3).
- "Learning about Life" has grown into a research initiative in which participants are asked for opinions as to the possibility of shifting from schools in the community to the hospital where a learner was born as the setting for learning activities (Year 4).
- Initiatives using interviews with working women to address how to support their reproductive health (Year 3), and evolved the results into implementing specific support activities.
- In the genetic education forum, to begin with, researchers experienced with programs developed overseas provided us with education and training (Year 3). In the final year, this evolved into a genetic education forum project for parents and children in a community of the Chuo Ward.
- Collection and management of educational materials for genetic and life education has been in place since the first year.

#### **B) Genetic nursing education for nursing professionals**

For genetic nursing education, our project research members developed a perinatal genetic

nursing program including genetic nursing practice guidelines reflecting current standards of practice. This guideline is in the process of becoming available as an online education program. A "Down's Syndrome Calendar" has been distributed to domestic and international nursing education providers over the two years since Year 1, getting feedback as to the possibility of its application to educational use (approximately 100 copies).

C) Introduction of decision-making support for the general public and healthcare professionals

Our project members have already developed the Ottawa Personal Decision Guide, a Japanese version of the Decision Conflict Scale, and "decision-making supporting website" (Year 2), in order to gain higher attention from the general public and healthcare professionals.

**Step 2: Dissemination of care**

At Step 2, dissemination of care was initiated through three vehicles, namely (1) website, (2) in-person activities, and (3) publications and television programs. The following is an overview of the activities for the dissemination of care for each field:

- (1) Web media: All activities are reported on our website, Kango-net.
- (2) In-person activities: Forums for face-to-face meetings that have taken place include initiatives such as "International Relay Symposium" to address shared issues together with the general public, and "Learning about Life" and "Celebrating Women's Health: Bouquet Festival" where healthcare providers joined citizens and communities for activities. Our pioneering initiatives such as "Health Support for Working Women", "Evaluation of Learning about Life Education", "Let's Visit the Hospital Where You Were Born", and "Genetic Nursing Education" have been reported at academic meetings and in academic journals as contents to be shared by among healthcare professionals.
- (3) Publications and television programs: The project "Precious of Life" has become available at bookstores nationwide, with coverage by the national broadcasting network NHK educational channel.

**Step 3: Evaluation of care**

We have asked a wide range of communities where our care programs have been introduced, including schools, workplaces, and the settings for genetic medicine, for evaluations to help develop future activities. For "Learning about Life", some adjustments are being made for the next program with feedback from the participating primary school pupils and their parents. Other programs are still at Step 2, "dissemination stage," and yet to be at the stage for obtaining evaluation and making adjustments.

**【Goal Attainment】**

1. Research activities

1) Goal 1:

The "Learning about Life", "Genetic Nursing Education", and "Decision-Making Support" programs that researchers had already worked on before the beginning of the COE Program were able to be taken into Step 2, the "dissemination of care" stage.

It took until the final year for the "Learning about Life" program to finally receive recognition and requests for the program from parents and businesses.

Regarding the "Decision-Making Support" program, the development of a "Decision-Making

Support Website" that presented specific support tools and accompanying decision conflict scale for the evaluation of care on the web (Kango-net) has led to increases in inquiries from researchers since Year 4.

Several other programs, are still in the beginning phases however, including "Let's Visit the Hospital Where You were Born" and "Health Support for Working Women" which were launched in the first year of the COE Program, have only recently entered into Step 1, the "development of care" stage as a care program, that reflects the voice of the public.

As described above, the level of goal attainment has been partly determined by whether the specific care program existed before the COE Program. Those that had been at the stage of care delivery since the first year would reach a stage where they finally received recognition from the subject community members in Year 5, the final year of the Program.

Whether or not such characteristics seen in the process of implementation stem from the very nature of the themes as "heredity/life" will need to be discussed together with the concepts required for the realization of PCC in the "genetic nursing" described in the following.

## 2) Goal 2

In conceptualizing PCC in genetic nursing, discussions have been made in terms of (1) PCC perceived through the nature of heredity/life" events, (2) PCC from the standpoint of Shared Decision Making (SDM) and (3) PCC from the standpoint of citizen and professional power (knowledge and information), based on the results of the focus-group interviews by project members and other research studies.

(1) Figure 2 shows the "level of interest in life and health issues" on the vertical axis with the horizontal axis representing the timeline. Excitement about birth or interest in life does not normally increase in everyday life without the occurrence of a certain special event. An encounter with a emotionally evoking care model resource such as the "Learning about Life" and "Thank You for Coming into the World", however, may help children recognize anew how they were born, and how celebrated they were by people around them when they were born, encouraging a firmer confidence in their existence.

In today's prenatal diagnosis, women may often come to know that there is a technology that enables to know the condition of a child before birth and that they have choice only when they become pregnant. This causes them to face tremendous stress that they have never even thought about before that point.

These health issues are such that a person comes to recognize their necessity only when they have first-hand experience of the care, thus it is hard for such issues, by nature, to raise needs among those in need of the care. It is therefore critical for healthcare professionals to communicate their necessity to society.

(2) Healthcare issues often involve various therapeutic methods and accompanying choices. While it goes without saying that persons in need of care are the central decision maker, such a decision-making process is also shared by professionals specialized in the relevant area. Figure 3 illustrates the roles that the general public and healthcare professionals are required to play in the effort to establish decision-making aids or supporting communication, such as the Ottawa Personal Decision Guide, as a factor to enable such shared decision-making processes.

(3) In the "Genetic and Life Education" and other fields where new lines of care are currently needed, healthcare professionals themselves were seeking such care. It was this fact, that

healthcare professionals personally experienced such care, that "excited" them and made them "want to share" it with others, that acted as a trigger for the "Learning about Life" and "genetic education" programs. It has taken eight long years for the word-of-mouth by parents who took the "Learning about Life" program to create parent-led requests to the medical profession for the "Learning about Life" program. Because these particular health issues were "new health issues" and "issues influenced by individual values of heredity and life" it was more difficult to offer uniform programs. As the information and knowledge was newly emerging into the healthcare field, health care professionals were empowered to translate the knowledge into a format compatible with the public's level of comprehension and acceptance. In this case the diffusion of knowledge began with the professionals in professionally led groups.

## 2. Education of novice researchers

1) Expansion into graduate school students' research themes: at St. Luke's College of Nursing, one postdoctoral and one master's student are preparing a thesis on the theme of genetic nursing and life education. Outside, inquiries about requests for permission for the use of the Decision Conflict Scale have been received from five researchers (interested in pediatric, motherhood, and breast cancer research).

Notably, as a result of a growing recognition of our pioneering initiatives in the field of nursing in genetic medicine, the Project Leader is teaching students as a part-time instructor at two other graduate schools upon their request.

2) Undergraduate education: at St. Luke's College of Nursing, a Family Developmental Nursing II course (an elective; 5-9 students enrolled) has dealt with the topic of "prenatal diagnosis" for a period of two years. In the field of human sexuality, lectures were given regarding "life education for children" to 100 junior students, which eventually led to volunteer work participation for this activity. Also, a Nursing Aids class taught freshmen regarding decision-making support. The Project Leader is teaching students under the topic of perinatal genetic nursing as a part-time instructor at other institute upon their request.

3) Education of the present members: as a result of involvement in the COE Program, some members have considered going on to graduate school (1), given a presentation at an academic meeting and received recognition (3), and written an original article (1). There are requests for a lecturer to speak about genetic-related topics at a continuing education seminar (for certified nurses) from the nursing association once or twice a year.

## 3. International collaborative research

- Cross-national genetic nursing comparison: with Dr. Heather Skirton, former chairwoman of the International Society of Nursing Genetics (ISONG), which has been engaged in genetic nursing education in the United Kingdom, we have co-authored a publication on historic comparisons in genetic nursing between Japan and the UK.

- Collaboration in decision-making support: in relation to the Ottawa Personal Decision Guide and the Decision Conflict Scale 1 (DCS), as well as decision-making research, St. Luke's College of Nursing has been mentioned as Japan's base in the global decision-making network by Dr. Annette O'Conner, a prominent figure of the Cochrane Library.

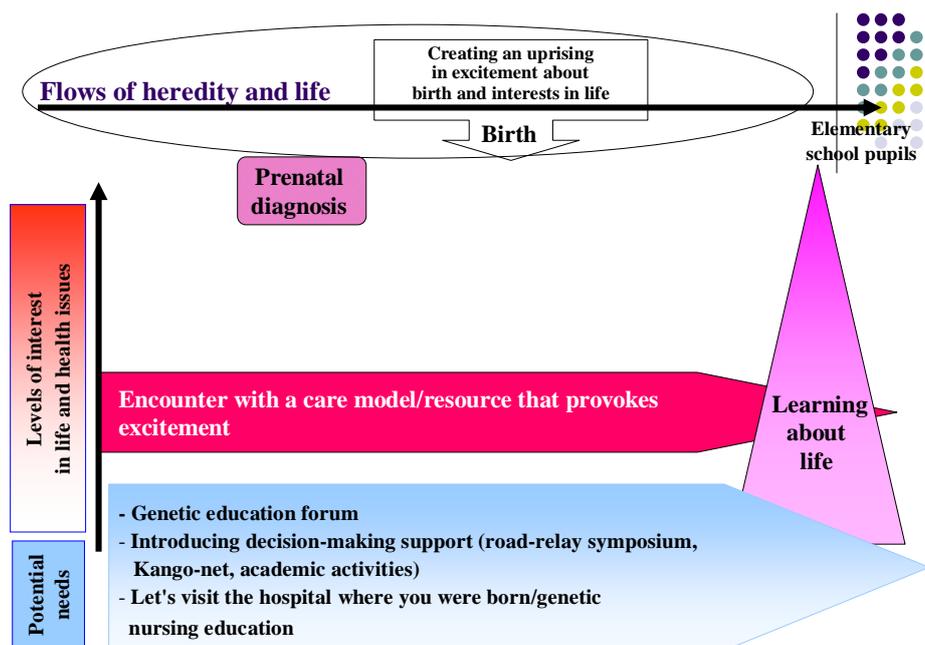
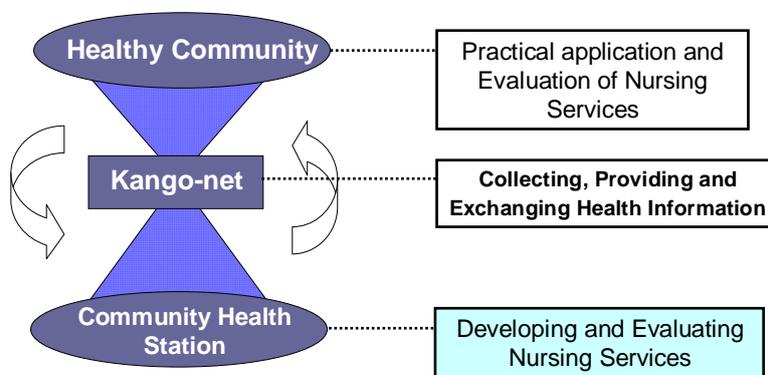
The DCS has been translated into English, Spanish, and German. Based on the results of surveys on Japanese subjects, covariance structure analysis has been conducted with its

configuration factors also examined, which served a basis for the exchange of opinions with researchers of this scale at an academic session at the International Shared Decision Making Conference (ISDM) 2007 held in Germany.

4. Future directions

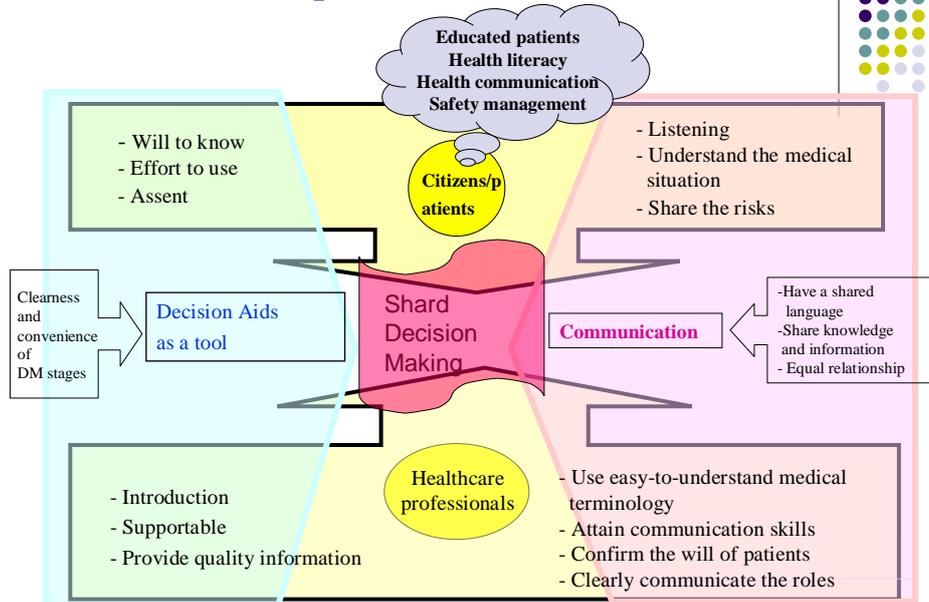
- 1) Goal 1: Research continued to the next step for care programs.
- 2) Goal 2: Narrowing down the themes and reporting as academic papers to communicate domestically and internationally, thereby pursuing general application of the PCC concepts established through the COE Program.

**Figure 1. Model of Nursing for People-Centered Initiatives in Health Care and Health Promotion**



**Figure 2. PCC Perceived through Heredity/Life Events**

## <What is to be required for the realization of SDM>



**Figure 3. PCC from the Standpoint of SDM**