

Child- and Family-Centered Care:

Support System for the Development of Child- and Family-Centered Care in the Community
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【Goals】

With progress in medicine, more children with chronic illness or disabilities now live in the community while receiving medical treatment. In order for these children and their families to be able to live with a sense of safety, it requires comprehensive support involving not only medical but social welfare and education. However, an array of challenges have been identified, including the varying available pediatric medical services and social resources, and the variability of accepting systems at schools among different communities, making it difficult to have smooth coordination among all the services. These challenges have brought about the necessity to develop a more fine-tuned system to tailor the needs of the children, their families and communities.

This project aims to develop support networks in coordination between children, parents, and medical/ welfare/educational sectors, to ensure the quality of home care provided for children with chronic illness and disabilities. In consideration of regional characteristics, this project has been carried out in three locations, namely Tochigi, Fukushima, and the Chuo Ward of Tokyo. In our activities here at the St. Luke's College of Nursing (located in Chuo Ward, Tokyo), since FY2005 and we have extended our worked beyond children with chronic illness and disabilities to reach children and their families who live in Chuo Ward and those who are engaged with children and their families. Thus, the results are presented under the category of Tochigi/Fukushima and the Chuo Ward.

【Plan and Implementation Process】

1. Checking regional profiles (FY2002): for each of the three locations, we reviewed various resources, gathered information to identify needs, and checked regional profiles.
2. Conducting needs surveys (FY2003): regarding children with chronic illness in Tochigi/Fukushima. While in the Chuo Ward, a survey could not be conducted on children with chronic illness, hence a health/lifestyle survey was conducted in FY2005 to cover infants going to nurseries.
3. Holding focus groups of each region consisting of nursing professionals (including hospital nurses, health nurses, school nurses, and visiting nurses (FY2003-2004): with the promotion of networking in the respective regions, we discussed the present status with nursing professionals in each area.
4. Creating a brochure and holding a symposium in Tochigi/Fukushima (FY2005)
5. Organizing "Nurse Clinic" sessions in Chuo Ward (FY2003-present): We continue to provide "Nurse Clinic" sessions for children and their families, and those engaged in daily contact with children living in Chuo Ward.

【Goal Attainment】

1. Research activities

- 1) Activities in Tochigi/Fukushima

In the Tochigi district, we created a brochure in FY2005, mainly for nursing professionals at hospitals, that describes social resources for coordination among medical, welfare, and

education sectors, and distributed it to medical institutions. Its utilization status after six months showed that it was used for staff training at medical institutions and doctor's giving explanations to families. In partnership with parents' associations of the region, a symposium was held by public health, visiting, hospital and school nurses and drew 68 participants.

In the Fukushima district, we created a brochure with the aim of having knowledge on the regional activities of nursing professionals and social resources. The brochure was distributed to schools, visiting nurse stations and other organizations dealing with children with chronic illness. A lecture meeting was also held to discuss support by public health nurses for children under long-term treatment, which addressed issues such as difficulties in working in coordination with schools at the time of child's discharge from the hospital or admission to school. In FY2006, we collected information concerning medical care at schools and had talks about revising the brochure and activities at special-needs schools for children in need of medical care.

In Tochigi/Fukushima, connections across nursing professionals are being formed as a result of the series of research activities; each party has come to know about their own roles and activities, which has made it easier for them to have talks or contact each other than before the project. While it will take more time to have children and parents involved in the activities, members in the area continue their own research activities independent of the research team since FY2006.

2) Activities in Chuo Ward: "Nurse Clinic" activities to address child health issues

Goals

Children and their families living in Chuo Ward work together with nursing professionals to build a support network for child health issues

- ① Using learning and networking meetings as a health resource for children and their families living in Chuo Ward
- ② Finding clues for partnership and cooperation through interacting between children/families and professionals
- ③ Building a support network to address child health issues

Activities in progress

Planning and organizing for "Nurse Clinic" programs:

Project team members: As focus group interviews prompted members to know about each other's activities and to recognize the necessity of working in partnership, interviewees became the Nurse Clinic project members. Other nurses, health nurses and nursery nurses subsequently joined as members.

Activities:

- Planning "Nurse Clinic" project: Project members are responsible for planning "Nurse Clinic" sessions and distributing posters and leaflets to nurseries, kindergartens, primary and secondary schools, children's centers, and medical institutions. As for children and their families, members work to recruit persons to engage in project planning and organizing from among volunteers participating to "Nurse Clinic" sessions.
- Ways of operating "Nurse Clinic" sessions: Topics were determined for each session in line with the respective fiscal year's project theme, and meetings are arranged to provide the latest knowledge and discuss it, as well as networking. Sessions are arranged for the convenience of more children and families to encourage their participation, including providing snacks and

child-care service. The sessions occurred from 18:00 to 20:00 on weekdays.

- Status of "Nurse Clinic" session organization (Photograph 2: Clips from "Nurse Clinic" Sessions)

FY2004: Theme: "Gathering of children with chronic illness and their families, and public health and nursing professionals" 3 sessions with a total of 20 participants

FY2005: Theme: "A child's body of a child, illness, issues regarding hearts and minds, and what we can utilize" 6 sessions with a total of 106 participants

FY2006: Theme: "Let's learn and think about child health" 5 sessions with a total of 132 participants in FY2006; 6 sessions are due in FY2007

Participant evaluation:

At each "Nurse Clinic" session, we ask participants to fill in a questionnaire for the purpose of project evaluation.

For theme-based lectures, feedback found in the responses included "Useful", "Helpful", and "Highly concentrated lecture and very informative"; as for the opinion exchange and networking part, comments included " Exchanging opinion was meaningful", "I'm satisfied to be able to share opinions from various standpoints", "Atmosphere was conducive to sharing opinions", "Good to have a small-group session", "Satisfied to have had a variety of information", and "It is hard to have an opportunity like this". On the other hand, some pointed out concerns over the small number of participants and poor public relation activities. Overall, "Nurse Clinic" appeared to have gained recognition as one health resource.

Goal Attainment

①What has been found out through "Nurse Clinic" activities

- In many instances, learning meetings provided opportunity for participants to ask experts for advice on an individual case, which gave clues for solving challenges otherwise hard to solve in daily life.
- In initial sessions, participants consisted mainly of those who are engaged in supporting children and families such as nursery staff and teachers in charge of health education at schools for the handicapped, who had chances to nurse network and make acquaintance through the sessions. Beyond "Nurse Clinic" sessions, they would also share information individually.
- Improved understanding of the ways of each profession's engaging in contact with children and their families led to better recognition of each other's roles within the community setting.
- Challenges each profession faced at nurseries and schools were better understood, leading to a fresh recognition of the importance of sharing information and hence the necessity of having such a setting.
- In some cases, activities and solutions used in one profession were found to be useful for problem solving in other settings, or offer an opportunity to help others see directions in their future activities.
- Challenges were identified as to how the issues of medical practice (such as managing medicines) within communal life should be dealt with by medical institutions and families.
- In addressing child health as a common need, it appeared that the selection of themes taking into consideration the ways to deal with children with difficulties as well as seasonality, lifestyles and environment would lead to working in partnership and collaboration.
- Some participants eventually became repeat participants.
- Information owned by other professions, such as that about various human resources in the

community or of meetings among professionals, has proved to be important for planning the project.

A summary of findings through participants' questionnaire responses and actual status of session participation and activities are shown in Figure 1. Participants to "Nurse Clinic" sessions, ranging from children and their families to nursery staff, school teachers, teachers in charge of health education at schools for the handicapped, and those engaged in social welfare service, are all citizens who are in daily contact with children and fellows to address problems together. While each of them is normally working on health issues in their own work field, a "Nurse Clinic" session serves as a forum for them to gather around, think, and talk with one another. There is 'cross-border' interaction, one that is beyond the differentiation between professionals and non-professionals and free from sectionalism among institutions such as public health centers, schools, and so on. Based on each theme, participants acquire knowledge, solve individual problems, listen to each other's stories and understand them, share sympathy to similar problems that others may have, and identify new issues and challenges that need to be solved. Such a process gives them, be they parent or professional, the ability to make their own judgments or thoughts and helps them empower themselves to have willingness or confidence and to cope with that which faces them. Mutual understanding of and sympathy toward each other also builds trust in each other, creating a sense of cooperation in that they may consider seeking advice or making contact on another occasion. This would eventually lead to sharing their struggles and wisdoms, forming a new partnership for health development in children.

② Byproducts of "Nurse Clinic" project

- In response to requests for a brochure on resuscitation that had been covered at a "Nurse Clinic" session, we created a first-aid guide brochure and distributed it to nurseries, kindergartens, primary schools, and children's centers.
- In response to requests from a nursery PTA for a workshop on first-aid, we engaged in outreach activities.
- We receive inquiries from nurses at nurseries or public health centers for information provided at a "Nurse Clinic" session.
- Creation of a video on emergency treatment for children is planned.

2. Education of novice researchers

Link with MS/PhD students	Educational intention and commitment	Outcome
Participation to and support of organizing "Nurse Clinic" project	Learning about ways to organize "Nurse Clinic" sessions that raise awareness of child health issues and allow discussion about nursing support strategies in the community	Use in CNS Role-playing training (educational encouragement and coordination)

3. Future directions

- 1) Continuing "Nurse Clinic" project: it is now the fourth year since the launch of the "Nurse Clinic" project, and activities there have come to gain recognition among people in the community. While it is an occasion where people come to the university, it has nevertheless

received certain appraisal from participants for the opportunity the project has provided community children and families to gather to participate in workshops and voice their opinions. Although it has not yet to matured into a citizen-led project, participation of families is increasing, and we are continuing to develop a system for planning and implementing the project together.

- 2) Challenges in policy recommendations: cooperation with public administration has not been fully in place, yet allergies, developmental disabilities, and emergency treatment have been found through our activities to be issues with strong needs for guidance. There is also a strong demand for the development of certain standards for medical practice in communal living and of aid personnel to support emergency treatment for children, which we will address in the future in cooperation with public administration.
- 3) Continuing outreach activities: continuing our outreach activities, inquiries concerning child health education and participation in project planning and organization as byproducts of the "Nurse Clinic" initiative, we will further expand the scope of activities while providing information about child health.

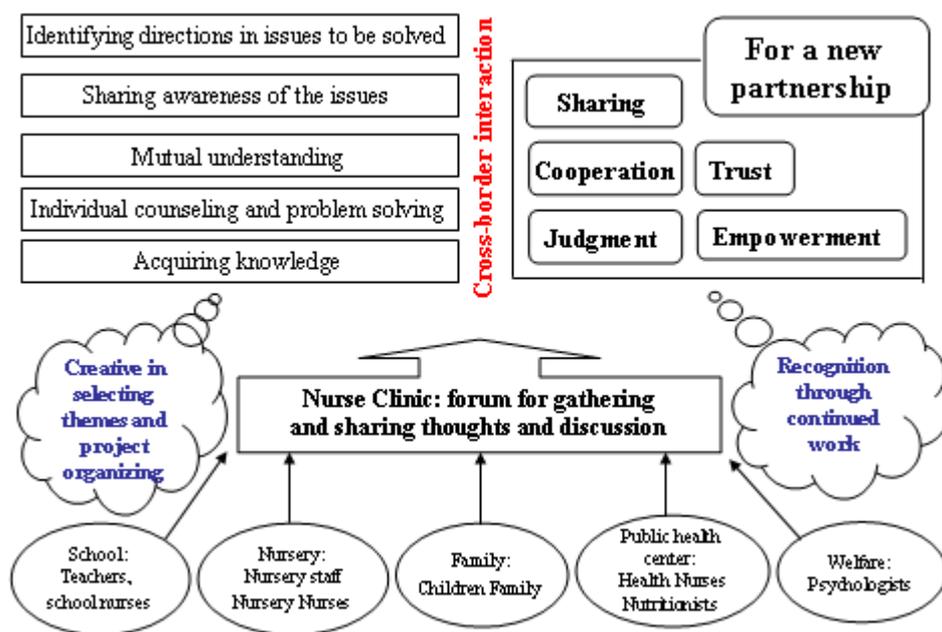


Figure 1. Nurse Clinic for citizens