Conceptualizing People-centered Care Kiyomi ASAHARA

1. People-centered Care and COE Projects

Following a disappointing diagnosis, patients or people who have health concerns as well as their families usually find themselves in a difficult situation; they are distressed from worrying about their situation and at the same time are forced to resolve their health issue by themselves. Essentially, nurses are "supposed" to serve as the partners of those people by being there for them by their sides, helping them become healthy, live long, and helping dying people die peacefully. However, patients and those concerned apparently consider nurses in a different way. Five years ago, we concluded "People-centered Care (PCC)" applicable to such activities of nurses, but we did not know what sort of care this was specifically, what nurses were really supposed to do, and how we were supposed to work together with the people and those concerned. To determine this, we decided to start off by working together with consumers and interested parties, and launched 15 projects. So PCC is not a concept we fully understood from the start. Care is what we gradually learned about during such joint efforts and activities. Through these activities, we learned the importance of NOT forcing people to do what we thought was right, but instead asking people and those concerned what we did not know, and formed such a relationship with them. We realized for the first time, the obvious,- that sharing knowledge and skills to resolving problems together and what we mutually wanted helps create better lives for both the people and those concerned as well as for nurses. What did we do to realize this, and overcome difficulties faced in our activities with the public and those concerned? We finally realized that such acts and activities themselves were PCC.

2. Process to Realizing/Conceptualizing PCC

For this report, we attempted to recollect and summarize the sort of PCC activities that we carried out, and what we learned together with the people and those concerned. We therefore decided to survey the process of the 15 projects including the details and achievements that constituted the joint activities, with participating members of the public and interested parties.

First, we asked the following questions to the participants (public and interested parties), members, and leader of the respective projects: how was the process of activities? What type of activities were they? Did the activities proceed smoothly? What were the difficulties? How were the difficulties resolved? We asked these questions because we saw the process of joint activities with the public and interested parties itself as PCC process, and the changes made to the perception and actions of the nurses to overcome difficulties met as the nursing method (care method) for carrying activities

together with the public and interested parties. We also asked the public and interested parties about the achievements made in the joint activities, because we thought that if we could find achievements common to the projects, it would mean that these achievements were made through the joint efforts with the public and interested parties, exceeding the borders of the research area. The interviews carried out for these investigations were discussed over a long period of time in the conceptualization group, analyzing PCC processes, activities, and achievements common to the projects.

3. PCC Process and Activities

The process common to the respective projects consisted of three steps; "creating a stir", in other words making the first move or taking the first step towards the desired activity, "forming the project team," "acting and expanding" (Figure 1). Here, two characteristics were seen. One is the direction of the PCC activities. We found that PCC processes consisting of these three steps started to expand their target of activities from individuals to organizations, and then to communities. At the same time, the form of activities also expanded from the support of individuals to working on policies. This meant that targets and activities were heading towards "progress and enlargement" (vertical axis). We also found that activities were continuing to become steady with time (horizontal axis). The second characteristic was PCC activities consist of activities that are characteristic to a step and activities commonly used throughout the whole PCC process.

The first "creating a stir" step differed from project to project. It may have started from a certain thought of a researcher or specialists as in "hope that children can learn about their body" of the "Knowing Our Body" project, or it may have started gradually from ongoing research as the Development of a Care Provisioning System for Multidisciplinary Approach to Cancer Nursing. In other words, common to all projects was the step where the project leader, research members or nurses started developing interest in a health issue and starting to take action by finding the path to joint partnership with those concerned. In the second step, all projects formed project teams and activities were carried out mainly by these teams. Team members were not fixed from the start, and more and more people from different areas started to participate according to the project activities. For example, in the "Knowing Our Body" project, participation by various people increased with time and as the activities changed. Participants included school nurse, nursery school staff, illustrators, etc. Project activities expanded through events such as symposia, and through appeals made to the community and society by providing and spreading information to communities, appealing to society and establishing policies. For example, the Development of Women-Centered Care Models for Infertile Women project started out from self-help group activities, and later

seminars and networking events were held in eight areas around the country with the support of local municipals to build an environment supporting women with infertility concerns.

The other activity (technique) used commonly in these three steps was found to be indispensable for nurses to work together with the public and interested parties. It indicated the method for nurses to carry out activities together with them, and required nurses to change their perceptions and actions. For example, people who have undergone cancer treatment or are currently undergoing treatment have extensive knowledge and experience on cancer medical care and the problems faced in daily life. Similarly again, mothers with five-year-olds are fully aware of the nature and life of children of this age and how to handle them accordingly. So, just as nurses have special knowledge and skills related to medical care and nursing, the public and interested parties are also specialists with special knowledge and skills in a particular culture. We experienced something that helped us realize this and change our perception. It was realizing the importance of respecting others and this experience formed the basis for building a trusting relationship with the public and interested parties. Common activities (techniques) thus included building trusting relationships and the need for continuous efforts to gain common understanding, which we learned was not an easy activity.

4. Variation According to PCC Health Issues

The speed of progress and activities of each step were seen to differ according to the health issues of each project. From the perspective of nurses, joint activities with the public and interested parties can be grouped into three patterns (Figure 2).

One pattern is the “Collaborating working” type. This applies when there are self-help groups already established by the public/interested parties. An example is the Development of Women-Centered Care Models for Infertile Women project, where organization of the project team and development of activities into social activities proceeded in a comparatively early period. The second pattern is the “Escorting and supporting” type where the health concern is clear but the public and interested parties have yet to make any concerted efforts. The Development of a Care Provisioning System for Multidisciplinary Approach to Cancer Nursing project first formed a small group while nurses provided care to the individual health issues of members, and built the bridge for expanding activities to medical care providers and organizations. The third is the “Identifying needs” type where the public and interested parties do not yet have clear problem awareness. Some examples are the “Knowing Our Body” and “Utilization and Evaluation of People-Centered Nursing Services” projects. Like the Creation and Dissemination of Genetic Nursing in Japan project, the problem is known, but is very private and people are reluctant to make it public. With this type,

nurses had to catch latent needs, provide suggestions by anticipating the care programs needed by the public/interested parties, and expand members, range, venue, and contents of activities.

These three types correspond more or less to four groups based on the characteristics of the health issues of the PCC project. Brought to light here was the fact that the role of nurses working together with the public and interested parties differed according to their health issues. This was a new insight that emerged and was related to having both direct experience and in-depth systematic reflection on the processes.

5. Outcome of PCC

What was achieved when nurses worked together with the public and interested parties? The achievements that were seen from the projects included those aimed for by each project, those gained in the process and changing as projects proceeded (process outcome), and achievements related to systems required for them (Figure 3). Process outcomes seen included resources, relationships, and abilities, and their characteristics differed between consumers and interested parties, nurses and other professionals, project team, and community. Achievements aimed by PCC included carrying out projects, building sense of security in the public/interested parties, and enhancing health awareness. At the community level, they included improving the health index values of death rate, disease rate, reducing medical costs, and improving the quality of care. However, these achievements cannot be gained in a short period of time, and at this stage, activities are carried out aiming at these achievements in each project.

One example of process outcome is “resources.” Gradually, through the project activities, the public and interested parties started to see our university and nurses as resources in the sense that they had more people to talk to for advice, and they learned how to better use the university. On the other hand, through the activities, nurses started to form links with communities and public organizations with which they had no ties with until then, and were able to see them as resources that could be partnered with and used. Project teams also made gains—they acquired methods of carrying out activities through project activities and people with whom activities could be carried out. At the community level, resources such as tools beneficial to the people of the community (for instance, booklets, picture books, T-shirts), venues for exchanging information such as website, systems and human development programs, were gained. These resources did not just include “things,” but consisted of various aspects bringing profits to projects gained through activities. The second process outcome was “relationships.” This is considered unique to PCC. The public and interested parties sited “found that nurses are useful” as an achievement of relations, while nurses achieved

relationships including closing the distance with the public by "finding out what people are thinking about and their capacities" and "being touched by being able to work with the public." In the project team, mutual roles were clarified and a relationship of mutual respect was built. The third outcome was abilities. The public and interested parties said they gained more knowledge, realized their own problems, and were now able to make their own decisions and act. The specialists (nurses) on the other hand said they learned how to determine what care was needed and provide it, the techniques and approach required for working together with the public, and the true meaning of working together. Project teams also demonstrated enhanced teamwork, saying ideas broadened and they were able to deal with problems better. At the community level, process outcomes were manifested integrating relationships and abilities, in that the community was gradually becoming one in which interactions of the people improved, the people were more considerate to each other, and strived to creating something together.

Characteristic achievements of PCC that were seen were: system achievements essential for ensuring final objectives and creating process outcomes. For the public, interested parties, nurses, and related parties to work together and continue the activities enabling, systems were required. Systems during the process of PCC activities were considered themselves to be an achievement themselves.

6. Characteristics of PCC

To clarify what PCC is, in other words, how nurses work together with people and interested parties towards public health, and how these activities should be implemented, 15 projects were enacted starting with joint activities with the public and interested parties. Through this analysis, differences with existing activities and conventional research methods, for example differences with the public health nursing activities and Community-Based Participatory Research, were studied to determine the characteristics of PCC pursued within the COE projects.

First, we found these differences to lie in how people saw PCC. We discovered that the public and interested parties can serve as partners with expertise and to be respected, joint efforts between the public/interested parties and nurses can bring about diverse achievements in line with the culture of the people involved rather than individual efforts. These can be skills of people, relationships, systems, achievements for dealing with new problems in the future. When starting out on the PCC projects, we targeted people from the beginning, and saw them as a community with common health issues. The reason is because the public/interested parties and nurses are reluctant to join hands due to various walls or barriers existing between them. For instance, professionals (nurses) see the public/interested parties as subjects to whom they should provide special knowledge to, while the

public/interested parties take it for granted that nurses don’t want to work together with them. Therefore both parties have conflicting perceptions. Naturally, this causes relationships to be one-sided. Such ideas are also influenced by specialist groups, people, organizations to which the people/interested parties belong region from which they come, Japanese culture, etc. Another major influence is policies determining ideal health and medical care. In other words, in order for the public and interested parties and nurses to join forces, such activities need to be considered at the community or social level. In addition, by targeting people as subjects, achievements by partnerships between the public and interested parties and nurses can be accomplished effectively and efficiently. Furthermore, this community does not just refer to people living in a specific area. It is a community taking into account people of the whole Japanese society with common health issues. In the PCC projects, booklets and picture books for all Japanese are made as a social appeal to change the Japanese environment. This may also be related to the nature of COE projects having started from research efforts. This way of perceiving the community differs from CBRP and public health nursing activities which target a specific region, and it enables activities to start from any community, enables activities to cross the borders of time and space, and return the achievements of activities back to the respective regions.

Next, PCC characteristics are discussed in terms of the process and details of activities. PCC is a collaboration model based on mutual respect between nurses and the public/interested parties. Our COE projects were able to successfully demonstrate specific activities jointly carried out between nurses and the public/interested parties, and to detail the process and steps of specific activities. Until now, the importance of partnership between professionals and the public has been pointed out, however rarely have specific activities common to multiple projects been demonstrated in the past. Essential to professions is the principle of cooperation and specific methods for realizing this. The specific activities that we demonstrated include changes made in the actions and perception of nurses to overcome dilemmas and difficulties in the process of carrying out the projects. These indicate the response and care of nurses attempting to carry out effective activities for people in the face of dilemmas and difficulties, by building closer partnerships with the people. This is indeed PCC.

Another aspect of PCC involved “system construction”. It was necessary to build organizations and create opportunities to link the public and related parties and to have an “organized approach” such as activities by project teams and expansion of activities through events. Projects appealing to society and governmental policies are characteristics of PCC activities aiming at cooperation with groups (people), and are considered essential activities based on the Japanese society for the steady continuation of PCC activities, their growth and expansion, and the spread of these activities to communities.

Looking at the health issues of communities, differences were seen in the process and details of activities, and the three patterns in the roles of nurses. Consequently, differences in activities depending on the health issues of communities are considered a feature of PCC. This was made clear because the COE project is composed of various projects, and is a new finding with quite important ramifications.

Finally, the following were found to be important expertise of nurses for partnerships: (1) strong sensitivity and assessment towards health issues as experts, who "create a stir" after identifying communities with health concerns; (2) commitment and driving force to establish project bases and expand business; and (3) expertise and skills to link consumers with government and medical institutions that will provide a sense of security to people, create resources that benefit the community, produce results and yield useful evaluation data. These are elements indispensable to PCC. In particular, the Japanese tend to be reluctant about enthusiastically expressing their own problems. The fact that medical professionals serve as the bridge between medical care and supporters of people may indicate the ideals and values of PCC that are unique to Japan.

Next, another characteristics of PCC that we learned through analyzing the PCC results was that the partnerships formed by professionals and the public/interested parties to join hands in activities under the PCC project generates resources, relationships, and skills at the levels of the public/interested parties, professionals, project teams, and community. This indicated the need to build mechanisms for activities to circulate.

There are additional characteristics of PCC as a project. For example, some of the PCC projects under COE showed a form of multi-cooperative project research promoting 15 diverse research projects comprehensively towards the same goal. On the other hand, given that the COE project has a steering committee composed of leaders managing 15 projects, and is carried out based on cooperation among projects, the COE project itself is considered to be a practical application of PCC including the communities of different projects. It is also research focusing on the process by which PCC is created. There are two courses: creation of new knowledge and returning knowledge to the community. Not to be forgotten is that this project involves graduate school students and serves as an opportunity for them to learn and research. Thus, this COE project demonstrates a type of research system based on an alliance among research, education, and practice.

7. Future Tasks of PCC Conceptualization

The main concepts of PCC were successfully determined from the above analysis (Table 1). In future

our efforts, we hope to select important ideas from these concepts, define and structure them, and create PCC models. Evidently, the concepts we abstracted had much in common with existing research and CBPR activities however the strengths of our PCC research lie in clarifying how nurses should work together with the public and interested parties, how joint activities should be carried out, and specific methods. By showing these methods in a way that nurses can use them easily, it can contribute to the peace of mind of many people and interested parties. We see the dissemination of PCC as our critical mission in the future.