

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

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【Purpose】

The aim is to develop a community-based palliative care system for realizing “Building a Community for Spending One’s Last Days at Home in Collaboration with the Public” as well as to develop community-based palliative care programs and systems for palliative care initiated by the public, and palliative care based on collaboration between the public and professionals in the community.

【Plan and Implementation Process】

- Step 1: In addition to the importance of forming partnerships between the public and professional groups, the future direction and tasks for care systems which can be jointly developed by patients, their families, and professionals for patients to live in familiar communities peacefully are proposed. (A. Symposium, citizen networking event, and workshop for care manager)
- Step 2: To develop programs required for citizen participation in community-based palliative care systems, B. education for hospice volunteer (development of volunteer education program), and C. policies for the institutionalization of day hospices provided by visiting nurse station together with citizen volunteers (day hospice for cancer patients and patients with intractable illnesses at home by care facilities) are proposed.
- Step 3: Development of community-based palliative care team standards for constructing citizen-participation, community-based palliative care systems. (D. Standards development)
- Step 4: To practice citizen participation, community-based palliative care system models, community-based palliative care systems networking for basic plans of administrations are proposed. (E. Establishment of a joint liaison council consisted of members of the community, administrations, universities, medical facilities, and nursing facilities).

【Goal Attainment】

1. Research activities

A. Formation of partnerships between citizens and professionals

We talked with the public (N=300) about “developing a community which allows people to spend their last days at home” under the theme “where would you like to spend your last days?”, and acknowledged the importance of mutually building systems with the public so as to respond to the public’s needs. As a result, some participants of the symposium were led to participating in the hospice volunteer seminars, public networking events, and preparatory meetings. We considered that participants could deepen their understanding of and clarified the aims of the project, drawing further attention to it through the symposium. Following this, we held public networking events with the residents of the Chuo ward (N=20), and as a result of the discussions here, we jointly conducted a study group (N=60) for care managers with the administration to undertake public needs.

B. Cooperation with community: Development of citizen-participated hospice volunteer education course

The public participated from the planning stage of the seminar based on health promotion; preparatory meetings (N=26) were held jointly with core members such as professionals (college faculty and managers of visiting nurse station) and social welfare council members. Sixty people

wanted to participate in this course, and 45 people were picked by draw. The participants showed a significantly higher tendency towards “if I get cancer, I think I can spend the end of my life at home” after attending the course than before ($p < 0.01$), indicating increased awareness of the feasibility of dying at home with cancer. The results also indicated an increased understanding and awareness of knowledge about volunteers (86%) as well as changes in behavior (44%), suggesting the effectiveness of the program. After completing the course, 10 participants registered hospice volunteer groups (10 people). Another 10 participants started to make a group for volunteer activities based on this college as the center and launched a self-help group aiming at developing communities for people being able to die at home. The group meetings were held every month, and tours of facilities and study groups were held to learn about local resources. In addition, opportunities to experience wheelchairs and exhibitions on environment development in the ward were created. Through these 15 activities, groups supporting health are gradually being formed. Of the members, two have left, and though the number of members has changed, the number of members has doubled from 10 to 21. As of this year, we have registered our volunteer group with the social welfare council in the Chuo-ward to start hospice volunteer activities such as visitations to elderly persons living alone in order to realize communities which allow people to live in familiar areas safely until their final moments.

C. Efforts in institutionalization (Setting of new fees for day hospice service by care facilities)

We developed a hospice care program and provided care through a visiting nurse station. As a result of making proposals toward the systemization of day hospice, it has been installed as a nursing care service since April 2006. Day hospice is available for moderate to severe patients with medical and nursing needs including terminal cancer patients and the care service fee is payable from long term care insurance. This further enhancement of a support system for terminal cancer patients at home has been considered an extremely positive evaluation.

D. Towards development of community-based palliative care team standards

National survey questionnaires were sent by postal mail to 2,588 visiting nurse stations nationwide. 1,398 cases of the 969 stations that replied were analyzed. The results indicated that only about 30% of the terminal cancer patients using the visiting nurse stations could spend their last days at home. Such cases were receiving care from the doctors and nurses of the same organization, as well as from care managers and care workers. Other team members were hardly seen. The involvement of nurses with special training in hospice care (cancer care nurses and certified hospice care nurses) was less than 1% of the total. We analyzed the data of 1,398 cancer patients of the responding stations and considered the structure and evaluation of community-based palliative care teams that provided care for terminal cancer patients who were able to spend their last days at home.

Teams with the highest percentage of terminal cancer patients who died at home (71.2%) were teams composing of two or more visiting nurses, a doctor from the same organization as these nurses, and other professionals from other organizations. This was followed by teams composing of two or more visiting nurses from the same organization, doctors specially participated for the patient, and professionals from other organizations, which successfully cared for 64.7% of the terminal cancer patients at home until they passed away. Professionals from other organizations were mainly care workers and care managers, while some teams were also joined by pharmacists and, medical social workers from the medical care liaison section in the hospital, physical therapists, staff providing bathing services, and public health nurses. There were also teams

which were joined by volunteers, psychiatrists, nutritionists, professional or lay clergy, aroma-therapists, etc., but these accounted for only 1%. These findings indicate that for terminal cancer patients to maintain their QOL to the end with their families at home and to live in peace during this time, there is a need for professionals such as pharmacists, psychiatrists, clergy, etc. as well as volunteers to cooperate together to support the overall livelihood of patients.

In the subjective evaluation of visiting nurses of palliative care teams which had provided care for terminal cancer patients until the end of their life at home, the percentage of replies “we were able to assess users and families in the team and set goals,” “we were able to understand our mutual roles and provide care according to the role,” “members were able to help each other,” “there was a leader figure who led the team” was significantly higher than the visiting nurses of other teams. This suggests the importance of understanding mutual roles, carrying out the roles assigned, and for the whole team to think together about how to support patients and their families.

E. Towards implementing citizen-participated, community-based palliative care system models: Proposals to basic plans of administration (holding joint liaison meetings)

We held meetings between various professions (ward citizens, nurses, doctors, guardians, care managers, volunteers, and government personnel) as well as various facilities (elderly nursing homes, group homes, homes of patients (including family, paid elderly homes, residences with nursing care) for all diseases targeting elderly persons and persons with terminal cancer. We also proposed building a group home (small multi-functional facility) specializing in cancer to improve the quality of the networking between such small multi-functional facilities as an idea on the ideal mechanism by which the ward can run such facilities.

2. Education of novice researchers

- In the four years between 2003 and 2007, one Ph. D. candidate participated as a research assistant.
- In FY2004, one person from the public who participated in this research advanced to graduate school to do research on community development and volunteering as a result of participating in activities.
- In the respective years of 2005 and 2007, COE research fellows started this research, and are currently supporting the research by making presentations about it at COE evaluation meetings, conference symposiums, and international conferences, as well as by writing papers (ongoing). (See Research Achievements)
- In 2005, a COE research fellow conducting this research joined our college as a teacher from 2006 to participate in activities related to this research as well as educational activities for students and graduate students.
- In 2006, a master’s degree student (community health nursing) participated in activities (setting up a booth in the Chuo Ward Town Development Exhibition and on-site training) to spread home hospice care in the community.

3. International collaborative research

As part of the international comparative research between Korea (Yonsei University), Taiwan (National Yang-Ming University), US (Emory University), and Japan (St. Luke’s College of Nursing), attempts were made to clarify the current situation and tasks of hospice palliative care in Japan and review whether current systems can be used as an infrastructure for developing community-based palliative care. (Analysis of hospice law in foreign countries, cost systems,

management systems)

4. Future directions

1) Continuation of current activities

As a result of educating hospice volunteers, a volunteer group was launched to start community-based activities. In addition, as a result of successful systemization by the proposal of policies, we believe that we have successfully made the first step forward to developing communities for people to spend their last days at home. In the future, there is a focus of efforts on continuing these activities by reviewing continuous education for enhancing the skills of volunteers and methods of running organizations. As for the development of standards, it is necessary to continue reviews for developing standards which can be actually used as a reference to those involved in team care, based on national survey results and literature from within and outside the country.

2) Continuation of evaluative research of activities

Based on current research, there is a need to carry out further evaluation and research of activities.

3) Partnership with municipalities

Currently, we are already co-organizing social welfare meetings with the Chuo Ward, and despite some manpower problems, we hope to review cooperation with municipalities where possible for currently activities.