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Original Article

Nurses' Experiences of End-of-life Care in Long-term–Care Hospitals in Japan: Balancing Improving the Quality of Life and Sustaining the Lives of Patients Dying at Hospitals

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SUMMARY

Purpose: In Japan, about 80% of deaths occur in hospitals, especially long-term-care beds. The purpose of this study was to clarify the nursing practices used for such older patients at the end-of-life stage in long-term-care wards via the modified grounded theory approach (M-GTA).

Methods: Data were obtained through semi-structured interviews of nineteen nurses working in cooperating long-term-care wards, acute care wards, or hospice services (to allow for constant comparison between these types of wards) in western Japan in 2014. We analyzed the transcribed data using M-GTA.

Results: The core category that emerged from the analysis was "Balancing enhancement of patients' daily life quality and life-sustaining care in the face of uncertainty about the patients' character." 11 categories emerged, such as Seeking older patients' character with their family, Supporting families' decision making, Rebuilding patients' daily life in the ward, and Sustaining patients' life span through medical care.

Conclusions: Nurses experienced uncertainty about the care needs of older patients, the ethical problems of Enhancing the patients' QOL by using risky care, and the evaluation criteria used to judge their own nursing care after the patients' death. All nurses had the goal of ensuring a natural death for all patients. Nurses' acceptance and evaluation of their own care was critically influenced by the patient's family's responses to their care after patients' death. Further research is necessary to develop evaluation criteria and educational programs for end-of-life nursing care of older adults.

Introduction

The rapidly aging population of developed countries such as Japan [1] has made end-of-life care for older adults more relevant than ever before, particularly the place where these older adults wish to die [2,3]. Approximately, 60% of Japanese older adults wish to die out of the hospital, and most older adults hope to die at their own home [4]. Despite this, approximately 80% of all deaths in Japan occur in hospitals [5]. Although the Japanese Ministry of Health, Labour and Welfare has aimed to improve the prevalence of home healthcare at the end of life [6], the dehospitalization of older adults has been unsuccessful.

Nurses working in general wards that do not have palliative or hospice care functions tend to encounter serious problems during their older patients' end of life. For example, many are unable to provide ideal nursing care because they feel exhausted and

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powerless in the face of patients' deaths. This suggests that nurses' skills and mentality can present many barriers to developing quality end-of-life care in general wards [7,8].

Problematic nursing care at the end of life is particularly serious in long-term–care wards. Long-term–care wards were created in 1992 in Japan as an effort to improve the care of older patients requiring long-term medical treatment and nursing. In 2001, long-term-care was defined by the Medical Care Act as "any hospital bed or clinical bed—other than psychiatric hospital beds, infectious diseases beds, or tuberculosis care beds—that is primarily for the hospitalization of patients requiring long-term recuperation" [6]. Most inpatients are aged 65 years or older, and around 40% of them are discharged by death [9]. Although there might be a need for effective end-of-life care in these wards, previous studies [9,10] have reported that palliative care is not commonly provided in long-term–care wards when compared when general wards, home-visit nursing services, and long-term–care facilities. Furthermore, staff at these long-term–care wards have noted that the end-of-life care delivered in these wards is insufficient.

This deficiency is likely related to two other characteristics of long-term–care wards. First, most of the geriatric patients within these wards have multiple diseases or complex conditions. Second, the wards are meant to serve a support function after patients have undergone advanced medical treatments, such as continuous monitoring and management for central venous nutrition, ventilators, chronic obstructive pulmonary disease, dialysis, delirium, and depression. These two characteristics indicate that patients in long-term–care wards have complex clinical features [11]. Another reason is that nurses' workload in these wards seems heavier and they tend to have more responsibilities. For example, the current guidelines for nursing personnel distribution in long-term–care wards, as dictated by the Medical Care Act, indicates that each nurse should care for as many as 20–25 patients, whereas general ward nurses are advised to care for only around 7–15 patients.

Confounding the above situation is the lack of research relating to end-of-life care in long-term–care wards in Japan, even though these wards play an important role in providing end-of-life care and a place to die for older patients. Although providing end-of-life care for older patients in long-term–care wards has several problems, the specific reasons have not been clarified. To improve patients' end-of-life care in long-term–care wards, nursing situational practices and why nurses feel that their care is insufficient requires analysis. Consequently, this study clarified the nursing practices for terminally patients in long-term–care wards and the relationship between the nursing practices and their evaluation after patients' death. We adopted the modified grounded theory approach (M-GTA), because qualitative methods are usually used when little is known about a phenomenon [12]. Furthermore, the M-GTA is a suitable method for cases with process characteristics [13].

Method

Design

This qualitative study used the M-GTA [12]. The M-GTA was developed by Kinoshita, and generally adheres to the tenets of the original grounded theory approach (GTA), such as a constant comparative method and grounded data [14]. It is considered "modified" because it clarifies the method of segmenting the data during the analysis. Specifically, it posits that data segmenting is based on two concepts: the analysis theme and the individuals who are the focus of the analysis.

In addition, we decided that the definition of "terminal stage" referred to when nurses determined that patients were going to die. According to a previous study, understanding the death of a patient is crucial for everyone involved, including the patient, their family members, and the medical staff [12]. By adopting this perspective, we can study older adults at their end of life in long-term–care wards. It should be noted that we did not discriminate between type of disease or treatment. Similar to other studies, we also did not differ between beds covered by medical insurance and long-term–care insurance [15].

Setting and participants

There are sampling strategy discrepancies between the GTA and the M-GTA. For example, the strategy of the GTA is to collect and analyze data in parallel and its process proceeds by comparing participants. On the other hand, the strategy of the M-GTA is to collect data for a specific group; then, the researchers analyze this "base data." After this process, researchers collect additional specific data as needed [12].

This study recruited participants from three hospitals located in Western Japan who had agreed to cooperate. First, we recruited from hospital A, which is in an urban city of more than 800,000 people. It is a large hospital with more than 900 beds. Almost all its beds are long-term–care beds and it has a hospice and a general ward. We started at this large hospital because it enabled us to investigate nursing practices with diverse diseases and treatments. In addition, we could compare terminal care between the long-term–care beds and the hospital's other wards.

Next, we recruited participants from hospital B, which was in a rural area and had about 50 beds. The reason for choosing this hospital was to examine the influence of the community and a smaller sized nurse organization. Hospital B also comprised a long-term–care health facility, which was for older adults who were in a similar condition as the patients in long-term–care wards.

Finally, we selected hospital C, which was in a satellite city and had about 200 beds. It was an acute hospital. Most of the patients had cancer and received surgical treatments. This aim was to examine terminal care in a general hospital without a palliative care unit or hospice and compare it against our devised theory.

We asked the nursing directors from each hospital to help recruit research participants. We made sure to recruit one nurse in a managerial position (e.g., head or chief nurse) and one general nurse. We included nurses from various positions to capture unique care experiences. For example, nurse managers must consider the occupancy rate for their wards, which could affect their vision for individual care. There are also differences in ability and authority regarding decision making. We anticipated, for example, that nursing managers could represent other nurses at important meetings, such as when addressing patients' families.

Data collection

We collected data via semi-structured interviews conducted from February to September 2014. Each participant was interviewed once for about 60 minutes by two or three interviewers in a private room and ensured that their comment would remain anonymous. The main interviewer proceeded through the interview using an interview guide. The sub interviewer(s) took notes about participants' voices and reactions and asked participants additional questions (e.g., "why?" and "how?") to obtain more detailed information. Although we used the interview guide to enhance efficiency and equity, we also asked participants to talk freely. The interview guide was created through discussions between clinicians who had experience with terminal care for older adults and researchers including nurses, doctors, and a clinical

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