

Caring for Patients With Intractable Neurological Diseases

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Abstract

This is a qualitative descriptive study examining nurses' attitudes about caring for patients with intractable neurological diseases, with a focus on dedication and conflicts. Semistructured interviews were conducted on 11 nurses with more than 5 years of clinical experience in addition to more than 3 years of experience in neurology wards. Senior nursing officers from each hospital selected the participants. In general, these nurses expressed distress over the inevitable progression of disease. Nurses talked about the "basis of dedication," "conflicts with dedication," "reorganization for maintaining dedication," and "the reason for the change from conflict to commitment." "Reorganization for maintaining dedication" meant that nurses were able to handle the prospect of rededicating themselves to their patients. Furthermore, "the reason for the change from conflict to commitment" referred to events that changed nurses' outlooks on nursing care, their pride as nurses, or their learning experiences. They felt dedicated and conflicted both simultaneously and separately. While committing to their patients' physical care, nurses were empowered to think positively and treat patients with dignity in spite of the care taking much time and effort, as well as entailing considerable risk.

Keywords

qualitative research, intractable neurological diseases, nursing specialty, conflict, commitment/dedication, nursing attitudes, nursing profession, patient care

Introduction

Intractable neurological diseases are defined as those of unknown etiology that have no established method of treatment. This includes motor neuron diseases such as amyotrophic lateral sclerosis, spinocerebellar degeneration, multiple system atrophy, Parkinson's disease, and multiple sclerosis. Most of these diseases are progressive and ultimately prevent patients from living independently. Individuals often feel that their life is not worth living when they are diagnosed or when their condition progresses (Toombs, 1993).

Policy and Practice for Intractable Neurological Disease in Japan

The Japanese Ministry of Health, Labour, and Welfare (MHLW) has supported policies aimed at intractable diseases since 1973. This effort has the following goals: (a) to promote research, (b) to develop and maintain appropriate health care facilities, (c) to reduce the burden of self-health care costs, (d) to expand and improve available health care by working with affiliated organizations and institutions, and (e) to promote measures to improve the quality of life (QOL) of individuals with 1 of the 27 neurological diseases included (Japanese Intractable Diseases Information Centre, n.d.-a).

The health care facilities of interest are long-term care and acute hospitals, advanced treatment hospitals, and research institutes. People with intractable neurological diseases may be living in one of these facilities or at home. However, patients in advanced treatment hospitals or acute care hospitals may not receive long-term care. Such hospitals treat patients and educate health care professionals, but do not have the facilities or abilities necessary for long-term care. Thus, these hospitals are generally used for diagnoses, treatment of acute symptoms, and outpatient care.

Japanese researchers have recently begun to address patient experience, enhancement of home care systems, and welfare development. "Welfare" refers to a social movement that provides basic physical and material well-being and financial support for these patients (Japanese Intractable Diseases Information Centre, n.d.-b, MHLW). Previous studies reported that nurses caring for patients with intractable neurological diseases may be conflicted, but the reason for this is unclear. One possibility is that these nurses may

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feel a sense of powerlessness due to the gap between the ideal situation and reality.

Professionalization of Nurses

Why do nurses go through conflicts in caring for these patients? Professionalization of nursing might be one reason. According to Sandelowski (2000), nurses claimed to be professionals because they introduced and used devices and new technology; this change altered nurses' position of providing "tender loving care." However, nurses who care for patients with intractable neurological diseases do not use devices or new technology. Therefore, there is no doubt that their work is truly nursing.

While nursing may also involve spiritual care, many nurses in Japan do not understand the concept of spirituality (Nagase et al., 2013). In certain functional or acute care hospitals, nurses who care for patients with intractable neurological diseases may be aware that their patients suffer from spiritual distress. However, they may believe that it is unnecessary or inappropriate to provide "spiritual care." Rather, they are committed to helping patients execute activities of daily living (ADLs).

By the late 1980s in the United States, despite historically high salaries, multithousand dollar signing bonuses, wide-open career ladders, work that produced immediately tangible results, great opportunities for learning, and visual guarantees of employment for nurses who wanted to work, nearly one third of the registered nurses in the United States were not practicing nursing (Reverby, 1987). Part of the reason may lie in the inherent contradiction of being "ordered to care," which means that emotional work, usually spontaneous, is a required part of the job. Smith (1992) categorized nursing as emotional labor.

Outcomes of Research in Social Science

Many theorists and researchers have addressed the issues of health, illness, well-being, suffering, and caring. Galvin and Todres (2013) attempted to show how a personal philosophy toward life and research can offer valuable ways to approach the relationship of health-related caring and well-being. The lifeworld concept is used in philosophy and in some social sciences, particularly sociology. An important and central theme of work of Galvin and Todres is caring for well-being, which refers to providing specific and delineated directions for care. "Directions for care" means providing resources to ensure the well-being of a patient based on symptoms and disease progression.

The work of nurses has been described as both dirty and good. McMurray (2011) considered what happened when nurses established specific roles and hierarchically organized professional divisions. Charting the struggles of a group of advanced nurse practitioners, the article considered the ways in which claims to license, place, and mandate are employed to negotiate new occupational places. In a departure from situations that place managerialism and entrepreneurialism

above professionalism, the article showed how the executive authority that comes with entrepreneurial ownership could bolster professionalizing claims, thus disrupting and reversing hierarchically organized professional divisions. In addition, Simpson, Slutskaya, Lewis, and Höpfl, (2012) described the complexity, fluidity, and contingency of dirty work—how occupational boundaries, work practices, and the meanings associated with dirt and cleanliness are accordingly more fluid and subject to reinterpretation and change, rather than being fixed, stable, and rooted in a job task—in addition to how individuals manage and construct the "clean/dirty" divide and how dirty workers negotiate taint in the management of identity.

Mission

In the present article, we analyzed the narratives of 11 nurses. Despite what was reported by Nagase et al. (2013) regarding the spiritual distress of patients and the nurse's role in providing spiritual care, the nurses interviewed spoke eloquently of their own nursing care, beliefs, policies, and so on. In the study by Nagase et al., researchers believed that nurses provided spiritual care and could talk about their own spiritual care; however, the nurses said that they did not provide spiritual care that patients evidently needed.

We used these data (Nagase et al., 2013) to clarify nurses' differing levels of dedication and conflict. We clarified that nursing is a professional occupation even without the use of new technology. In this study, we define nurses' dedication as their strong love, care, and support for patients and their families, as well as the expenditure of time or energy. In addition, we define nurses' conflict as a situation in which there are opposing ideas, opinions, feelings, or wishes on nursing care for patients with intractable neurological diseases in acute hospital setting.

Method

Semistructured interviews using our own interview guide were conducted during this qualitative descriptive study. To date, little research has focused on nursing for patients with intractable neurological diseases in acute care hospitals. The questions addressed to participants fell into the following categories: the value of nursing, the patient's distress, and what they did and felt at work. We also asked what, based on their impressions and experiences, were the most important parts of treating patients and whether they experienced any internal conflicts. Individual interviews were conducted in a quiet private room to protect privacy. One interviewer conducted and recorded the interviews, which were then transcribed. The transcripts were then analyzed by four researchers. The interviews lasted approximately 60 to 90 min per person, and took place between August 2011 and March 2012.

Before the interview, we explained the purpose of the study, the methods, and ethical considerations, after which

Table 1. Elements of the Dedication of Nurses Caring for Patients With Intractable Neurological Diseases.

Category	Subcategory
The basis of dedication	Commitment to patient's hope Pride in their own nursing Promoting the progress of recovery
The conflict with dedication	Difficultly sustaining interest in patients Powerlessness or impatience Hesitation to do the work
Reorganization for maintaining dedication	Considering the division of roles between the staff nurses Information sharing Controlling emotions
The reason for the change from conflict to commitment	Encountering many patients Gaining experiences Pride as a nurse

each participant gave written consent. A withdrawal form was also distributed in advance for participants who might wish to leave the study after the interview. This study was approved by the Ethics Committee for the Faculty of Health Care and Nursing, Juntendo University. The mention of the transcripts was anonymized, and the transcripts will be destroyed after the end of this study.

We interviewed 11 nurses with experience in caring for patients with neurological intractable diseases; each had more than 5 years of clinical experience in addition to more than 3 years of experience in neurology wards. The senior nursing officer at each hospital was asked to select the participants. While the right to withdraw was offered, no participant withdrew from the study. In addition, two acute care hospitals and three wards were involved.

We collected data through interviews and performed a continuous comparative analysis of the data as they were obtained.

Results

The nurses had worked for 6 to 20 years as a nurse and for 6 to 9 years of experience in a neurology ward. Five of all participants had cared for only patients with brain or neurological diseases. The remaining five nurses of all had worked in a mixed ward, including ophthalmology, orthopedics, and neurology facilities.

They talked about “the basis of dedication,” “the conflict with dedication,” “reorganization for maintaining dedication,” and “the reason for the change from conflict to commitment” (see Table 1). They experienced dedication and conflict both simultaneously and separately.

The Basis of Dedication

Commitment to Patient Hope

Nurses are aware that intractable neurological diseases gradually reduce the ability of patients to perform ADLs and ultimately render them unable to live independently. One participant said, “There is limited time left for the patient and his family. That’s why we hope they value every minute of the here and now.” They thought that patients and their families should concentrate on the positive aspects of the situation.

It was often too difficult to provide disabled patients with the level of personal care that allows proper performance of ADLs. Time and physical effort is necessary to fully support and care for these patients. For example, when a patient wants to sit in a chair, the nurses do not simply transfer him or her from the bed to a chair. Nurses must manage this transfer safely while keeping the patient comfortable. By moving to a chair, the patient can better talk with others, draw a picture, read a book, or use a computer. Thus, the nurses help their patients with intractable neurological diseases to live life with dignity. However, they said that there are not enough personnel to provide sufficient support to maintain the QOL of patients.

Pride in Their Own Nursing

All participants mentioned that they thought of the nursing profession as more than just caring. One of the participants expressed the following: “Our nursing care allows patients to improve their conditions. Improvement in the quality of life is the outcome of nurses’ care, because nursing care is based on nursing assessment.”

Nursing care is also about recognizing the patient’s preferred lifestyle and supporting that way of life and their values. Participants mentioned that nurses to help patients meet the needs of daily life. The work is hard but also challenging and rewarding. The reason behind the nurses’ comments is their belief that nurses are health care professionals. The majority stated, “Because we are nurses, we provide care on the basis of evidence and think that we should do our best.”

Promoting the Progress of Recovery

Participants stated that an underlying belief in nursing care is that neurological function will be restored and that nursing care will use wisdom and innovative ideas to assist in the recovery of the function. If nurses do not perform their duties, patients’ physical abilities will rapidly decrease; however, if nurses empower their patients, the patients may be able to live independently for much longer, which would promote patients’ QOL. Nurses are deeply concerned about having a negative impact on patients’ QOL, such as causing

functional deterioration, making the patient bedridden, or causing further disability.

Therefore, many of the participants may feel remorseful after working with patients to accept their disease and condition. The following quote is an example of such remorse:

I thought that there might have been a better way to do it. For example, it might have been better if we had worked in collaboration with the physical therapists more, or if we had asked a doctor for an adjustment of the medication. That way, just maybe, she [the patient] could walk now . . . but we need much more time, I think . . .

The Conflict With Dedication

Difficulty in Sustaining Interest in Patients

Nurses who care for patients with intractable neurological diseases use a great deal of time and energy. Doing all this work alone leads to burnout. One participant said, “If you work in that ward long-term, or for a long time, you will lose your mind.” This was her concern; however, she also mentioned that nurses are emotionally wounded when the dignity of their patient is not protected.

You think about how drastically the patient’s life is altered when he or she becomes unable to use the bathroom or to eat in everyday life . . . to provide care is such an unglamorous task . . . when you’re changing diapers 30-odd times during a night shift, you just wonder what you’re doing . . . you think to yourself, “What am I doing with my life?” . . . but, as difficult as it may be to merely change diapers or take a patient to the bathroom, I think you have to remember how important such care is. Providing nursing care for patients with intractable neurological diseases is a really unglamorous task, and it’s not at all dramatic . . . it really wears you down. (I know this might be wrong, but) I honestly think I can empathize well with family members who engage in abuse. For family members, care is a 24-hr job. If someone were to tell me, “You must stay in the ward for 24 hours,” I would quit. Without a doubt . . . so, in other words, I’m up to my neck in working in this ward . . . when a patient’s human dignity, for example going to the bathroom or eating, is threatened, it throws his or her psyche out of kilter, and takes a toll on us staff, too . . . if a patient says, “I want to go to the bathroom, but I can’t” or “If I can’t even go to the bathroom, I don’t want to live,” it’s understandable. But, when the patient makes a nurse call saying “I want to go to the bathroom” on an hourly basis, and you have to take the same patient to the bathroom over 10 times each night, you get driven to the point of insanity.

Some nurses were seriously worried about not making a commitment to the patient and had a guilty conscience. These narratives refer to it (being difficult to sustain an interest in patients).

Powerlessness or Impatience

Participants said that it was difficult for patients to understand that intractable neurological diseases are unlike cancer. In the case of cancer patients, nurses can relieve pain and other symptoms, and prepare for the patient’s death. However, in the case of patients with intractable neurological diseases, the patient and their families, and even nurses and physicians do not necessarily have to immediately deal with the prospect of the patient’s death. The patients try to stay alive as long as possible and do not give up on the possibility of further treatment, which can add to the time and energy spent by nurses in caring for these patients.

Some of all participants also mentioned feeling helpless about slowing the progression of the disease or preventing the development of symptoms. Relapses disappoint patients and nurses.

“I can no longer do things (for instance, walk, eat, sit during the day, so on). Even though I want to go to the toilet, my legs don’t move! Then I don’t want to keep living” one patient says. But these demands are a patient’s right and they deserve dignity. So, we say to patients, “Shall we go to the toilet?” But it is very difficult work, and we are driven almost to the brink if a nurse call for needing the bathroom sounds every hour or 10 times a night. It is just what does really the truth. Exactly!

However, one participant said, “Nurses in other wards say that nursing care should be rationed because of a limited workforce and time.” They do not understand the point of care and do not think that such care requires a professional. This may be because they are in acute care hospitals, where medical care requires the use of new technologies. “I often feel bereft,” said one participant.

Hesitation to Perform the Work

Caring for patients with intractable neurological diseases makes nursing students feel good. However, the students obtain a nursing qualification and begin to work with neurological patients, and the pleasure fades drastically. They work desperately for the first few years instead of thinking about better care. They mature as a nurse, and begin to doubt whether the work they are doing is actually nursing. “I couldn’t believe that our work is nursing when I was an inexperienced nurse,” some of the participants said.

In the first few years on the job, new nurses are working frantically instead of thinking about providing better care. After several years, many nurses begin to experience doubts about whether they made the right professional choice. Many complain that their responsibilities seem more similar to a care worker than a nurse. There is a national qualification in Japan for “care workers.” Care workers assist with the daily life of the older people and disabled, but they are not involved in health care. Thus, while some of their work

overlaps that of nurses, care workers are not officially professional nurses.

Reorganization for Maintaining Dedication

Considering the Division of Roles Between Staff Nurses

The participants in this study were all expert nurses. Their difficult work was made easier by younger nurses providing some of the necessary care for ADLs. “Younger nurses have such patients (seriously ill patients), and older nurses can take care of other seriously ill patients,” some participants said, in addition to, “it wasn’t as difficult and tough because of the younger nurses.”

Information Sharing

Nurses share information regarding patient’s care and current conditions. Some of the participants said, “We want to take care of any important needs for the patient.”

When each of the nurses understands the patient’s needs, a lot of time isn’t required for nursing care, and we have less stress. The chief nurse is informed about the patient’s needs and demands from staff nurses and shares how to care for the patient. We have conferences for such things.

Controlling Emotions

Nurses are dedicated to patients but not overly committed. Participants said that they were able to shift certain emotional gears to keep from feeling depressed or bereft.

Reasons for the Change From Conflict to Commitment

Encounters With Many Patients

Participants met many patients with intractable neurological diseases and some of these patients became aware of the amount of work required.

At first, I wasn’t particularly concerned about patients with ALS (Amyotrophic Lateral Sclerosis). The reason is, I was a less experienced nurse, I think. After I gained experience and became in charge of some ALS patients, the experience let me notice their suffering or hope. It’s something that I understood only after I’ve been experiencing it.

Furthermore, participants commented that patients with intractable neurological diseases have survived and are often determined to defeat the illness. The reason for this is not clear, but the participants feel full of vitality or passion within the patients’ own.

For example . . . if a patient catches pneumonia, physicians try to give him treatment for as long as necessary. I thought it’s just that. But the people who expect treatment are really the patient and his/her family. That’s to say, the patient and his/her family prefer to get treatment rather than give up . . . I have been thinking that a person really survives until his end . . . that the patient lets me feel his will to live such as he has the will to eat something by mouth, or to walk or stand or sit.

Gaining Experience

Most of the participants said that it was difficult to maintain dedication and concern. The majority of new nurses felt “conflict with dedication” and most of them changed to feeling a sense of commitment because they gained experience and were at ease with themselves.

. . . When I became a nurse, a lot of doubts arose because of that feeling of still being a student . . . Then I had resigned myself to what cannot be helped . . . when I became competent in handling my duties, and when I could understand our ward completely, other doubts arose in my mind again, like the right to self-determination or ethics.

Pride as a Nurse

The participants regained pride as nurses when they were able to persuade themselves that their work was truly nursing. In other words, nurses need to understand the meaning and effectiveness of nursing care, as well as persuade themselves that they fulfill patients’ needs and demands.

“How are we nurses different from other caregivers without a nurse’s license?” I’ve thought that. But there is a difference, clearly. Other caregivers help patients, but nurses attend to the patient as a whole . . . the basic human needs are satisfied for patients with intractable neurological diseases, and the fundamental human rights are demanded for them . . . that’s just the nursing care at this ward, I think. We shouldn’t forget it.

Discussion

Benner (1984) proposed a phenomenological nursing theory comprising five stages in which nurses become experts. First is the novice stage, which refers to focusing only on patient data, such as vital signs, regardless of the situation. Next, in the advanced beginner stage, nurses begin to recognize and focus on meaningful situations that occur repeatedly. In the competent stage, that is, the third stage, they can provide care based on the nursing care plan. In this stage, nurses typically have 2 to 3 years of experience in the same area or in similar day-to-day situations. In the proficient stage, that is, the fourth stage, nurses are able to understand the overall situation. Finally, in the expert stage, they can intuitively grasp the situation, and their performance is now fluid, flexible, and highly proficient.

In the present study, all participants were expert nurses. At university hospitals in Japan, nurses generally accumulate experience through 2- to 4-year ward rotations. Rarely does a nurse work in one ward for more than 6 years. There are hardly any nurses limited to specific fields except advanced practice nurses (APNs), certified nurse specialists, and certified nurses. Therefore, the present participants' experiences are very valuable.

Participants talked about their experiences, including what they thought, felt, and believed. They initially undertook their jobs expecting to promote patients' needs and to provide care to patients and their families; however, after a few years, they were caught in a vicious cycle known as "the conflict with dedication." They needed to find a reason to become recommitted ("reasons for the change from conflict to commitment"), and to develop their own strategies such as "reorganization for maintaining dedication." Through this process, they experienced "the basis of dedication."

The hospital nurse is fundamentally an organization member; therefore, nurses are subordinate to hospital authorities and numerous physicians. In modern medicine, highly technological practices, such as those used in intensive care units, mechanical heart and lung units, dialysis units, and medical research, are considered most important. In other words, nurses' commitments to their patients and the profession's goals are not regarded as meaningful to medicine.

The MHLW, the Japanese Council of Nursing Universities, and the Japanese Council of Nursing are considered creating a new APN designation in Japan. The APN system may offer professionalization and specialization for nurses within specific medical fields. This internal stratification of professions is often rife with specialization. Professional tasks can be so complex that they require considerable specializations, and individual professionals develop enduring identification with specialty work. Our feeling is that if APN is adopted, other nurses may hold normal nursing in low regard because it is "dirty work." The job of a nurse is both considered "dirty work," as defined by Hughes (1951, 1969), and requires "tender loving care," as pointed out by Sandelowski (2000). If anyone is able to perform the majority of "unspecialized" nursing tasks, nursing may no longer be considered professional work. This is just one of the changes that institutionalization and specialization will bring with the introduction of an internal hierarchy (Hughes, 1951). This has been discussed by numerous sociologists as the theory of professions. It is difficult for nurses to accept this, and many nurses have devised a stratagem to deal with professionalization.

However, patients still need nursing care—the "dirty work"—especially patients with intractable neurological diseases. They require a high level of nursing care to lead satisfying lives. Caring for these patients is really dirty work and new technologies are not necessary. "Dirty work" refers to work that nobody wishes to do. If the proposition that nurses wish to become specialists is true, they would not think that their work consists solely of taking care of patients. Some

believe that "advanced nursing practice" involves nursing practice that utilizes the latest medical technology or is associated with the latest treatment methods. As mentioned by a number of participants, neurology wards are not a popular choice in terms of wards that novice nurses who have just graduated from university wish to be assigned to. This is because the work performed in neurology wards appears at first glance to be "simply providing care for patients," in other words, to resemble the work performed by care workers. However, as pointed out by Nagase et al. (2013), the ability to make clinical judgments and assessment ability among nurses are necessary for realizing a high patient QOL.

The nurses accepting these responsibilities should be recognized for performing "true nursing" and highly specialized work. It is necessary to visualize and label nursing actions/interventions, such as "true nursing." Labeled actions and interventions are recognized as a form of technology by both the public and health care professionals (including diagnostic and spiritual care by nurses at the end of life); therefore, spiritual healing that nurses usually provide through attending to patients' daily needs should be labeled "spiritual care" and recognized as care by a nursing professional, as well as highly specialized care. Presently, it is too easy to call spiritual healing just "spiritual care," because the contents of spiritual care are poorly understood and nonsystematic.

Conclusion

Nurses were empowered to think positively and treat patients with dignity while remaining committed to the physical care of their patients. Such care requires time and effort, as well as considerable risk. Participants in the present study talked not only about their current thoughts and experiences but also about past experiences. They expected nursing to be a good job and were dedicated to their patients; however, after a few years, they got caught up in a vicious cycle known as "the conflict with dedication." They had to rebuild pride as nurses and recommit to the profession to find "reasons for the change from conflict to commitment" and to develop their own strategies, such as "reorganization for maintaining dedication." Through this process, they acquired "the basis of dedication."

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