International Journal of Nursing & Clinical Practices

Case Study | Open Access

Special Issue: Case Studies of Family Nursing Practice

Support in Making Choices for a Family Facing Challenges in Selecting a Treatment Location for a Terminally Ill Patient-A Case Where the Relatives' Wishes were Significantly Prioritized in the Decision-making Process

Minori Takeshita*, Izumi Zenba and Mayumi Konno

Kanagawa Prefecture Ashigarakami Hospital, 866-1 Matsudasoryo, Matsuda, Ashigarakami District, Kanagawa 258-0003, Japan

Abstract

Objective: The study aimed to clarify the collaborative intervention of advanced practice nurses (APNs) for a family whose relatives intervened the decision-making process on the location of the facility for patient's terminal care and created challenges in the process.

Methods: We organize the nursing records chronologically, focusing on the content of the APNs' practice and the family's subsystem and decision-making patterns. We obtained approval from the ethics review committee of the affiliated institution regarding the publication of the results. The participants in the study were informed of the research objectives, assured that their identities would remain confidential, and told that choosing not to take part would not result in any negative consequences, after which we obtained their consent.

Results: Even though the location for his end-of-life care had already been determined, Mr. A's wishes were not being respected due to the significant influence of his biological father's cousin (hereafter referred to as "the cousin"). The APNs confirmed the relationships between the family members involved with Mr. A and assessed that the cousin objected to the decision because he wanted to support Mr. A, whom he loved like a younger brother. As a consequence of the APNs' efforts to support Mr. A's choices, including symptom control and other measures to promote mental and physical well-being, Mr. A was able to leave the hospital with his wishes respected.

Discussion: At the same time, as APNs worked together to understand the relationships between Mr. A and his family members, the information shared by the nursing team led to consistent nursing care. The nursing staff allocated responsibilities, assessed how the family made decisions, and encouraged them to persist in this process. Consequently, the family could choose a proxy decision-maker and determine the setting for end-of-life care in a manner that suited them.

Conclusion: The fact that the nursing staff integrated their respective perspectives to support the family led the family to make decisions that were appropriate for them, with Mr. A taking the lead.

Publication History:

Received: January 23, 2025
Accepted: February 08, 2025
Published: February 10, 2025

Keywords:

Cancer in the terminal stages, Family nursing practice, Decision-making support

Introduction

When it comes to making decisions about a patient's treatment and care, it is often presumed in Japan that family members are positioned to speak for the patient. As a result, medical professionals also tend to encourage family members to take charge of decision-making [1] and honor the choices made by their kin. We hold the view that this arises from our deep awareness as healthcare professionals that the family serves as the patient's advocate. In clinical settings, we frequently encounter instances where relatives who are not typically engaged suddenly become part of the decision-making process, impacting the ultimate choice regarding the patient's treatment strategy and altering the initial plan.

In this case, a relative who had not been directly involved in the decision about where the patient should be cared for at the end of life suddenly visited the hospital on the day before the patient was to be transferred and expressed a wish to cancel the transfer during a meeting in which the patient was not present. This made it difficult to decide where the patient should be discharged afterward.

The average length of stay for cancer patients in Japan is 19.6 days [2], and it is common for patients to decide on a place to recuperate while discussing it with their family, who are the key persons in the patient's life and then to be discharged from hospital. In this case, however, the registered nurse (RN) was confused because several relatives appeared and expressed their opinions regarding where the patient should be discharged. In such cases, collaborative practice interventions by advanced practice nurses (APNs) are often effective in supporting decision-making in Japan. However, previous research on this topic has not clarified how collaborative support can facilitate decision-making within families.

In this paper, we report on a case in which collaborative intervention was provided by the APNs, including the oncology certified nurse specialist (OCNS), local cooperation nurse (LCN), and certified nurse specialist in family health nursing (CNSF).

***Corresponding Author:** Minori Takeshita, Kanagawa Prefecture Ashigarakami Hospital, 866-1 Matsudasoryo, Matsuda, Ashigarakami District, Kanagawa 258-0003, Japan; Tel: +81 80 1086 6660.

Citation: Takeshita M, Zenba I, Konno M (2025) Support in Making Choices for a Family Facing Challenges in Selecting a Treatment Location for a Terminally Ill Patient-A Case Where the relatives'Wishes were Significantly Prioritized in the Decision-making Process. Int J Nurs Clin Pract 12: 407. doi: https://doi.org/10.15344/2394-4978/2025/407

Objective

This study clarifies collaborative interventions with family members by the advanced practice nurses (APNs) in a case where the relatives participated in decisions about where to receive treatment, making it difficult to make a decision.

Methods

Data collection

The nursing records and nursing practices carried out by the APNs were reviewed, and the intentions involved in determining the place of recuperation, care for the patient and his family members, the family situation and assessment, and nursing practices were summarized in chronological order. The nursing practices were recorded by the APNs (OCNS, LCN, and CNSF) based on the information they gathered from their respective responsibilities and the assessments they made, while sharing information. The table 1 shows the analysis results of how these nursing interventions influenced the relationships between the patient and his family (subsystem), viewed from multiple angles.

Data analysis

The APNs and others had the opportunity to discuss the information they had gathered, the assessment, and the practice, as well as to consider and share how the intentional practice had affected the decision-making of Mr. A and his family. The results were also reported to the RNs on the ward, and it was confirmed that there were no differences in the meaning of the content to ensure reliability.

Ethical consideration

Approval was obtained from the ethics review committee of the facility to which the researchers belong. The study's objectives, the maintenance of anonymity, and the fact that there would be no disadvantage to the research participants for not participating were explained verbally and in writing to the research participants, and their consent was obtained.

Case Introduction

Overview of the facility

The facility in question is a core general hospital located in the western part of the Kanto region, with 296 beds and 20 departments. It functions as a secondary emergency medical facility, a disaster medical base, a designated medical institution for infectious diseases of Type 2, and a regional medical support hospital. The hospital's guiding principle is to deliver dependable, top-notch healthcare that caters to the community's unique needs while fostering a continuous medical support network from when a patient arrives until they are supported at home after discharge.

Summary of the case

Mr. A is a male in his 50s who underwent an artificial anus operation in 20XX after being diagnosed with rectal cancer. Around 1 year after 20XX, he began to feel general fatigue and shortness of breath and was admitted to the hospital with the aim of controlling his symptoms at the end of his life. After being accepted, he was given non-steroidal anti-inflammatory drugs and narcotics as palliative care, and at the same time as controlling his symptoms, arrangements were made for him to be discharged to a place where he could face his final days.

Family structure and relationships

The family living together consists of Mr. A, his wife, and his biological mother. His wife is in her 50s, has been suffering from a mental illness for about 5 years, and needs supervision in her daily life. His mother, in her 80s, has difficulty hearing yet remains self-sufficient in her everyday activities. The couple's daughter, who is in her early 20s, has just started living in a dormitory after finding a job.

Mr. A has a previous teacher, Mr. B, with whom he has been acquainted since elementary school. This teacher had served as a key person, playing a crucial role in Mr. A's treatment since the onset of

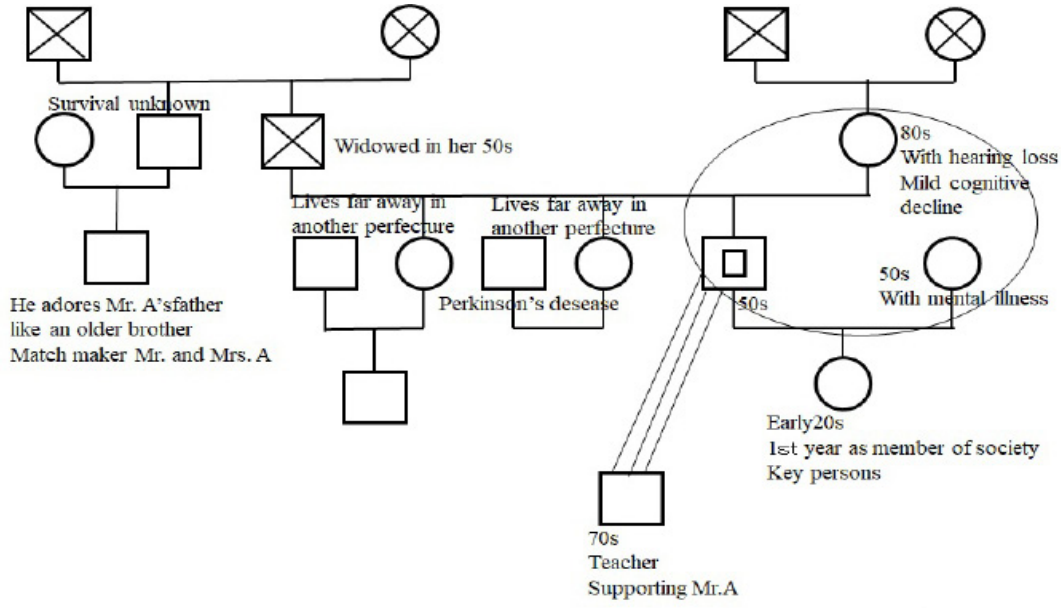

Figure 1: Genogram of Mr.A's family

Hospitalization Days	Patient's Symptoms	Patient Care	Family Situation	Family nursing practice		
				Ward Nursing Staff	Local Cooperation Nurse (LCN)	Certified Nurse Specialist in Family Health Nursing (CNSF)
Day 1	The patient developed general malaise and breathing difficulties and was hospitalized in a wheelchair.	He was taking Loxoprofen and 40 mg of Oxycontin per day before being hospitalized.	He was accompanied by his former teacher (Mr. B) when admitted to the hospital.			
Day 2 to	Suspected cholangitis. The attending physician explained DNAR to Mr. A. Mr. A requested that everything be conveyed to Mr. B.	Missed meals. Fluid replacement started. An interview with Mr. B was arranged in accordance with Mr. A's wishes. Morphine 60 mg/day subcutaneous injection started.	Visit from Mr. B			
Day 4 to	Insomnia Difficulty hearing due to being in a daze The artificial anus is self-managed. Difficulty moving by himself Epidermal peeling appeared on the sacrum. DESIN-R: d1s3e0i0g0n0p04 points.	Talking to Mr. A about where he will receive treatment in the future. Transferring the management of his artificial anus to a nurse Changing to an air mattress		Adjusting the position Staying by his side and touching him. Talking about work or hobbies to change his mood.	Interview with Mr. B Information is obtained that the wife has a mental illness and the mother has mild cognitive impairment. Information is obtained that the patient has a child. The interview at the hospice is usually conducted with family members, but Mr. B was asked to attend.	
Day 14 to	Fever Restlessness Disoriented Falling asleep with eyes rolled back Feeling dazed Sitting square at night and unable to sleep Falling over in the toilet Edema worsening Hb 6.0 g/dL	Regular administration of Acelio started. Use of Serenace at night Moved to a private room. IV fluids were reduced, and a blood transfusion was administered.	The father's younger cousin visited the hospital. He distrusted the private room fees and Mr. B's involvement. When his eldest sister and nephew from another faraway prefecture visited, they expressed dissatisfaction with the private room fees and Mr. B's involvement. The second sister also made inquiries about the documents for the transfer to another facility. His child and father's younger cousin went to the hospice for an interview.	Explained to the father's younger cousin that Mr. B's intervention was Mr. A's wish, and that Mr. A had agreed to the cost of the private room. Dealt with each relative and asked that they deal with the matter through the child, who is the key person.	Re-adjusting the key person, changing from Mr. B to the child and the mother.	
Day 24 to	Following the decision on the transfer date, he expressed anxiety, saying things like, "I really want to stay here. I wanted to check it out for myself." He also said, "I'm worried about my wife. I want to be able to walk." When in pain, he would ask for help himself.		When the father's elder cousin came to the hospital, he requested that the transfer to the hospice be canceled because he had not been told about it. Mr. A did not participate in the meeting to cancel the transfer at the request of the father's elder cousin.	Listening to Mr. A's appeal An interview was arranged in accordance with the wishes of the father's younger cousin. The head of the nursing department explained to Mr. A that the transfer to another facility would be canceled.	Admission to the hospice has been decided. The transfer date is being arranged with Mr. A and his child.	Asked Mr. A about his family history and family relationships. Confirmed the relationship between Mr. A and Mr. B. Interviewed the child, the key person, and empowered her so that she could play her role.

Continue...

Day 27	Despite being prepared to transfer to a new facility, he was depressed when the transfer was canceled.			Listening to Mr. A's feelings	Confirmed that the relatives were worried about the financial aspects of the transfer to the new facility. Explained the financial aspects to Mr. A.	What was confirmed during the interview with Mr. A The relationship with his father's younger cousin Whether Mr. A has the intention to convey his wishes to his father's younger cousin (Mr. A wants to decide on his own family matters with his family) The decision-making pattern of Mr. A's family The intentions of the proxy decision-maker and the intentions of the proxy decision-maker's supporters
Day 29	Mr. A contacted the hospice himself to arrange the transfer date. He told his father's elder cousin that his family would decide on their own.				Explained the costs and transportation methods for the transfer to Mr. A, the child, the mother, and Mr. B.	Mr. A, the child, and the mother will be given a place to share their thoughts about the intentions of the surrogate decision-maker and their supporters. The mother will be interviewed, and a place will be provided where she can express her thoughts.
Day 32	Transferred to the hospice.					

Table 1: Chronological progress from admission to discharge.

his health issues. Mr. A relied on Mr. B to the extent that he asked Mr. B to acquire the techniques for stoma care after having an artificial anus installed.

Family nursing care plans and interventions

Nursing practice by the oncology certified nurse specialist, cancer expert nurse, and registered nurse

Mr. A had to spend all of his time in bed since he was in so much agony from a general malaise and breathing difficulties. To support him and prevent his physical pain from getting worse, the registered nurse (RN) frequently monitored his symptoms and, after consulting with the doctor, changed his medication. They proposed alternatives for rerouting the way non-steroidal anti-inflammatory drugs and narcotics were administered. At such a time, the younger male cousin of the patient's father (hereafter referred to as "the cousin") suddenly showed up at the hospital for a meeting between Mr. A, Mr. B, and the medical staff, which had been arranged to make the final decision on Mr. A's place of end-of-life care. The cousin demanded that Mr. B be taken out of his role as the key person in the patient's treatment. The medical staff were confused, and the patient's choice regarding his final care location needed to be reset entirely. The RN consulted with the oncology certified nurse specialist (OCNS) and reached an agreement to seek out the best possible course of action for Mr. A. When the OCNS confirmed his true intentions, Mr. A expressed his wish to leave the decision-making process in the hands of his daughter, who would be the key person. Mr. A then said, "I've tried hard enough. I still want to keep going, but the truth is that I don't want to suffer anymore. I've reached my limit. I want to feel better." The RN paid attention to his emotional pain. Considering Mr. A's peace of mind, the RN moved him from the large room to a private room, tried to change his mood by talking about work and hobbies, and adjusted the environment to spend his time comfortably. In addition, the RN listened attentively to Mr. A's complaint that he was unable to be optimistic about being transferred to a hospice, and provided nursing care centered on physical and mental palliative care for Mr. A, including observing the process of accepting his medical condition and place of recuperation.

Nursing practice by the local cooperation nurse

On the very first day of Mr. A's hospitalization, the cousin paid a visit to him. The local cooperation nurse (LCN) learned from the cousin that he was providing financial support for Mr. A's biological mother, who had dementia, and his wife. The LCN appreciated his hard work and shared Mr. A's family relationships with the RN and the certified nurse specialist in family health nursing (CNSF). On the fourth day

of hospitalization, the LCN received instructions from the attending physician to arrange for Mr. A to be transferred to another hospital. The LCN interviewed Mr. A to help him choose a place to recuperate and gathered information about his wishes and family background. The LCN learned from Mr. A that his wife had a mental illness and that his mother was elderly and showing signs of mild cognitive impairment. Considering the current situation, the LCN determined that Mr. A would find it hard to select a place to share his final days with his family, prompting him to arrange for his transfer to a hospice. However, due to the deterioration of his condition and the side effects of the drugs, Mr. A sometimes became dazed during conversations, making it difficult to understand his wishes clearly. Therefore, at Mr. A's request, Mr. B and the LCN met, and the LCN asked Mr. B to help with the transfer procedures to the hospice. While making the necessary arrangements for the transfer to the hospice, Mr. B told the LCN that Mr. A had a daughter and that it would be essential to inform her of her father's condition. In response to this, the LCN interviewed the daughter. The daughter, unaware of her father's health issues, was engaged in her initial year in the workforce and entirely occupied. Yet, once she learned of her father's disease condition, she was moved to tears. The LCN provided emotional support for the daughter and also encouraged her to participate in discussions about deciding where her father would spend his final days.

Nursing practice by the certified nurse specialist in family health nursing

The OCNS and LCN expressed concerns about allowing the daughter to assume the key person role, as she is still young and would also have the added duty of looking after her parents and grandmother. The CNSF then arranged a meeting with the daughter. The daughter was upset by the realization that she had been preoccupied with her initial years of employment, causing her to overlook her family, and she was taken aback to find out about her father's sickness and the details of his prognosis, which she had not been aware of. She also voiced her worries regarding the responsibility of looking after her mother, who was suffering from a mental health condition, a task that her father had taken on before. She conveyed her emotions to the CNSF and slowly reached the conclusion that she would back her father's healing process. The CNSF assured her that those nearby would assist her and pledged to provide support, enabling her to gain strength.

Just as the decision was made to transfer Mr. A to a hospice, however, the cousin vehemently disagreed with the idea, leading to the cancellation of the transfer the day before. Consequently, the CNSF opted to reassess the dynamics among those surrounding Mr. A. The cousin treats Mr. A affectionately, like a younger brother, and even acted as a matchmaker for his marriage. Given that, the CNSF was able to assess that the cousin's actions were born out of his love for Mr. A, who was in the final stages of his illness, and that the cousin was struggling to support Mr. A's daughter in his own way. Furthermore, the CNSF perceived that both the RN and OCNS harbored unfavorable sentiments regarding the cousin and communicated to them that the cousin ought to be taken into account for assistance as well. The CNSF also met with Mr. A's mother, who has dementia. The mother shared her feelings of remorse towards Mr. A and his wife for having made them take over the family business, while also revealing her grief over the chance of her son passing away before she does. By providing the OCNS and LCN with the information, the CNSF attempted to dispel the preconceived notions held by the medical staff about Mr. A's family.

Mr. A has taken on a leadership role in his family and has also been proactive in determining the course of his treatment for his illness. The CNSF shared information with the OCNS and worked to ensure Mr. A's physical and mental well-being while controlling his symptoms so he could continue his usual role following his hospital admission. Their endeavors yielded positive results, prompting Mr. A to actively seek pain control, which he had previously been passive about. Mr. A also expressed his desire for his daughter to act as his proxy in making decisions, and he wished to place his daughter's future in the care of his mother. He conveyed to the cousin that the family would take charge of making decisions for him moving ahead. Following that, the CNSF confirmed once more that Mr. A and his daughter shared the same intentions, resulting in the resolution to transition to hospice care being reaffirmed.

Discussion

Perspectives on information gathering according to the expertise and role of each healthcare professional

In this scenario, the OCNS, LCN, and CNSF worked in unison, each fulfilling their designated roles and exhibiting their expertise. They offered support to Mr. A and his family members, including his relative, by sharing insights from their distinct perspectives. Through their joint efforts, the family was empowered to choose the location for Mr. A's final care.

OCNSs contribute to providing high-quality nursing care with the aim of enhancing the quality of life (QOL) for both patients and their families. The OCNS played a pivotal role in comprehending Mr. A's background and communicated relevant details to the RN to manage his symptoms, enabling him to live according to his preferences. They assisted him, allowing him to maintain his approach of "choosing his own treatment strategy up until now." As a result, Mr. A was able to participate in decisions about controlling his pain on his own and deciding where he would receive treatment in the future. This was because the advanced practice nurses (APNs) made an effort to carefully grasp Mr. A's intentions accordingly, which enabled them to identify the most appropriate options for him collaboratively.

The role of the LCNs is to support patients and their families so they can live peacefully after being discharged from the hospital. Discharge coordination serves as a management process that integrates the environment, people, and things with social security systems and social resources, based on the wishes of the patient and their family, to realize the patient's self-determination. In this context, it is essential to grasp how much support the family can provide to the patient [3]. For these reasons, LCNs intentionally verify the family's desires alongside the patient's intentions. This approach allows for a clearer understanding of the family background and the individual wishes of each member. At first, the LCN considered Mr. B, his former teacher, as a member of Mr. A's family and worked with him to decide where Mr. A should receive end-of-care. However, various family members appeared in the process of gradually understanding the family background. Therefore, the LCN organized the family information and decided with Mr. A which family members could be key persons. Afterward, Mr. B, who had previously been helping Mr. A and his family, shifted to a behind-the-scenes role in their support. Nevertheless, the LCN took a stance of continuing to watch over Mr. A so that Mr. B, whom Mr. A trusted, could continue to play a role in connecting the members of Mr. A's family. The reason for this was that, rather than blood relations or marriage being an essential

condition, the emotional ties of the family and the awareness of being a family were emphasized [1]. We believe the fact that Mr. B could stay with Mr. A's family contributed to Mr. A's peace of mind. Furthermore, since the LCN recognized that Mr. B was a vital member of Mr. A's family, Mr. A's condition was communicated to the hospice staff, where he requested to be transferred, and outside assistance was arranged to provide ongoing support.

CNSFs aim to facilitate patient recovery by providing support in physical, mental, and social aspects, enabling patients and their families to improve their self-care functions and address challenges on their own. A key trait of CNSFs is their proficiency in resolving problems with the help of systems theory. In this case, the CNSF identified the relationships between the individual Mr. A, his wife, daughter, mother, the cousin, and Mr. B, and ascertained the impact of these relationships on the family as a whole. This helped to clarify the relationship between the cousin and Mr. A. By clarifying the relationship between Mr. A and the cousin, the OCNS and RN were able to change their perspective and reframe the situation. The cousin was also recognized as a target for care as a close relative who was grieving over the loss of Mr. A. In addition, it was recognized that Mr. A had assumed the leading role in family decisions well before his partner faced mental health challenges. Based on this understanding, the ward nurses were encouraged to continue their roles, and Mr. A could continue playing his role within his family until the end of his life. This led Mr. A to choose to relocate to a hospice, where he could spend his last days, and it also provided an opportunity for his daughter, who had previously been distant from the family, to connect with him.

As seen above, the collaborative intervention by the APNs — OCNS, LCN, and CNSF — each fulfilling their respective responsibilities enabled the delivery of personalized assistance to meet the individual needs of Mr. A and his family.

Decision-making support for families in their late middle age

For late-middle-aged couples, their children have grown up and become independent, and they are now facing the challenges of planning for their own retirement, caring for their parents, and dealing with their own health issues [4]. Mr. A's family had just seen the first year of their daughter's working life, and she had just become independent. In this situation, Mr. A's condition deteriorated, leading to forecasts that he might fall into a state of clouded consciousness due to the progression of his illness in the future, making it necessary to decide on a substitute decision-maker. Generally, when a late-middle-aged patient is in a condition where they cannot express their wishes, the substitute decision-maker is often the spouse, sibling, or parent [5]. However, Mr. A's wife, who is his spouse, has a mental illness and was having difficulty fulfilling her role, while in addition, his biological mother had a mild cognitive impairment. For this reason, his former teacher, Mr. B, was initially the key person. After it was decided that Mr. A's daughter would act as the substitute decision-maker, the OCNS, LCN, and CNSF began to share information, as they were concerned that the daughter, who was in her early 20s, could bear the responsibility. The CNSF, in particular, while speaking with his daughter, asked whether she was willing to take on a new family role that had never been filled by anyone else. At the same time, the CNSF provided support to ensure that the daughter did not feel anxious about making decisions in Mr. A's absence. Consequently, the daughter developed the courage and self-assurance to assume responsibility within the family, while the CNSF's intervention provided essential psychological assistance. Supporting families dealing with terminal illnesses involves the idea that prioritizing the desires and wishes of the patient can enhance their overall peace of mind [6]. We assume that Mr. A's daughter accepted the role of proxy without resistance because she loved her father and thought that taking on his will would lead to his peace of mind.

In cases where young adolescents take on the role of decision-makers for their parents, involving the patients in the decision-making process to the greatest extent can facilitate a seamless shift in responsibilities and the acquisition of new roles.

Evaluation of Nursing Practice and Future Issues

The ability of the nurses working with Mr. A and his family to integrate their perspectives and offer assistance allowed Mr. A to make choices that aligned with his and his family's initial wishes. In the case of terminal cancer patients, if the patient's wishes are unclear due to the progression of the disease, the surrogate decision-maker is often the patient's spouse. As it is rare for a surrogate to be the child in their adolescent years, further investigation of our approach's effectiveness is needed in the future.

Conflict of Interest

Neither the presenter nor the co-presenters have any conflicts of interest with companies involved in medical research that should be disclosed.

Acknowledgements

Our sincere appreciation extends to the patient and his family, who were involved in this study, as well as to the patient's former teacher. Furthermore, we pray for the repose of the souls of the patient who passed away after the publication of this study.

References

1. Kiyoko K, Reiko I, et al (2022) Systematic Nursing Science Course Separate Volume, Family Health Nursing, Igaku-Shoin, pp. 29, 156,.
2. Ministry of Health, Labour and Welfare: Guidelines for Supporting the Balance between Treatment and Work in the Workplace, p. 28.
3. Hiroko U, Kyoko M (Eds.) (2011) Support for discharge and discharge coordination in the future: Outpatient, inpatient, and community care linked by generalist nurses. Japan Nursing Association Publishing Company, pp. 10-17.
4. Kazuko S, Hiroko W (Eds.) (2017) Family Health Nursing: Theory and Practice (4th ed.). Japan Nursing Association Publishing Company, p. 48.
5. Ayumi S, Kiyoko A (2021) Family Experience with Surrogate Decision Making of Acute Stroke Patients. Journal of Health Care and Nursing 17: 24-33.
6. Junko S, Mayumi S, et al (2011) The experiences of family members living with cancer patients in end of life in Japan, Journal of Chiba Academy of Nursing Science 16: 2.

This article was originally published in a special issue:

Case Studies of Family Nursing Practice

Handled by Editor(s):

Prof. Reiko Inoue
Department of Nursing
Tokai University
Japan