AACN Advanced Critical Care
Volume 30, Number 3, pp. 287-293

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Role of the Critical Care Nurse in Disclosing Difficult News

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Susan is a nurse in the medical intensive care unit. For the past 3 days, she has cared for Ms B, a 59-year-old woman admitted with pelvic pain. Ms B was transferred to the medical intensive care unit because of hemodynamic instability after vaginal blood loss. She has undergone diagnostic tests and has a new diagnosis of uterine cancer. Ms B retains decision-making capacity but is critically ill and decisions need to be made about her treatment. Ms B has not yet been told her cancer diagnosis because she speaks Cantonese and the health care team has been working to coordinate a meeting where a certified health care interpreter can help deliver this news.

However, in the meantime, a medical intern has inadvertently disclosed Ms B's cancer diagnosis to Ms B's aunt, Mei, while she was visiting the hospital one afternoon. Mei, although devastated by the new cancer diagnosis, is even more distraught at the thought of her niece living with the knowledge that she has cancer. Mei explains, "Doctors in China don't tell patients they have cancer and my niece would lose hope if she learns of her diagnosis, become depressed, and no longer want to live." Yesterday, while talking with Susan through a telephone interpreter, Ms B asked if something was seriously wrong with her. Susan was unsure what to say, so quickly redirected the conversation when the phlebotomist came into the room to collect samples for laboratory tests. Susan feels Ms B has a right to know her health information but also understands the concerns of Ms B's aunt. Today on rounds, Mei implored the health care team to conceal Ms B's new cancer diagnosis. The team explained that because Ms B has the ability to make her own decisions, they need to inform Ms B that they have new information about her health and ask if she wants to know more. Ms B's attending physician has several other patients to see and plans to fit the meeting into his schedule late in the day, so he wants to use a telephone interpreter instead of an in-person interpreter. The family has reluctantly agreed to attend a meeting with the health care team and patient where, through an interpreter,

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The authors declare no conflicts of interest.

DOI: https://doi.org/10.4037/aacnacc2019436

they will explore Ms B's preferences for learning her new health information. Susan, as part of the health care team, feels she has a role to play in resolving the ethical dilemmas that have arisen around the possibility of disclosing Ms B's new health information; however, she is unsure what her role is. Susan plans to have her nurse manager cover her patients while she attends the scheduled meeting for Ms B.

The case of Ms B involves the disclosure, or release, of important and sensitive health information to a patient and her family. In the midst of the disclosure process, several ethical issues arose, including ensuring true informed consent, respect for patient autonomy, privacy and confidentiality, truth telling, nonmaleficence, and beneficence. Although other providers are typically the ones to tell patients about new diagnoses or other difficult news, nurses in the critical care setting are frequently involved in such cases and may be unclear about their role in addressing ethical issues that arise during these disclosures. Like Susan, intensive care unit (ICU) nurses may be torn among the interests of the health care team, patient, and family and therefore be unsure of what their role should be or how to execute their role within the interdisciplinary team. In this article, we use Ms B's case to demonstrate the specific ways that ICU nurses might respond to the ethical issues surrounding the disclosure of a new diagnosis such as cancer and how they might respect patients' preferences regarding information the patients are told.

Practice of Disclosing Difficult Information

Disclosure often involves the release of difficult information; it is sometimes called breaking "bad news" in the literature. Disclosure of difficult information involves the exchange of any "significant information that can negatively alter people's expectations or perceptions of their future."[1] What a patient or family perceives to be difficult information will depend on various factors, including one's social situation, expectations, life experiences, and values.[2] Many patients will spend some time in the ICU setting, and nurses may be thrust into navigating the boundaries of disclosure, especially when, as in the case of Ms B, full and complete disclosure has not been achieved.

It is common practice to have physicians, physician assistants, or nurse practitioners lead conversations about difficult news such as a new cancer diagnosis.[3] However, ICU nurses practicing at the bedside are integrally involved in the broader process of disclosure[2,4,5] because disclosure of difficult news is not just a one-time event when news about a diagnosis, prognosis, or treatment is given; it is a process.[2] As clinicians with considerable patient interaction, ICU nurses are part of the events leading up to the delivery of new and potentially difficult information. They may also participate during the delivery of such news and are present with patients after the delivery of this news (Figure 1).[2,4,5]

In the literature, patients have cited the role of nurses in helping them meet multiple needs during the disclosure process.[6] For example, the patient or family in the ICU may require follow-up conversations after a disclosure meeting to further clarify technical terms and jargon used during discussions, understand the meaning of the difficult information itself, or discern the implications of the diagnosis or potential treatments.[7] In addition, some patients and families prefer to converse with bedside nurses rather than other providers about new information pertaining to their health.[8] This may be because nurses' proximity to patients, especially in the ICU, fosters the development of the nurse-patient relationship and enables the nurse, when discussing potentially difficult news, to exhibit a level of concern that patients feel is preferable to professional detachment that may be perceived from providers who may be less familiar with the patient.[1] In Ms B's case, we witness Ms B eliciting information about her health from her nurse, Susan, during the course of routine patient care. This inquiry directed at the ICU nurse is a common way patients express their preferences for new or difficult information.[9] Although Susan is positioned to address Ms B's questions, she also faces many challenges to being involved in disclosing the new and potentially hard-to-receive information.

Challenges to Nurses' Involvement in the Disclosure of Difficult News

There are multiple ways that ICU nurses can be involved in the process of disclosing difficult news. These range from participating in interdisciplinary team meetings to offering ongoing support and education. However, ICU nurses may feel challenged when trying to participate in the disclosure of difficult news,

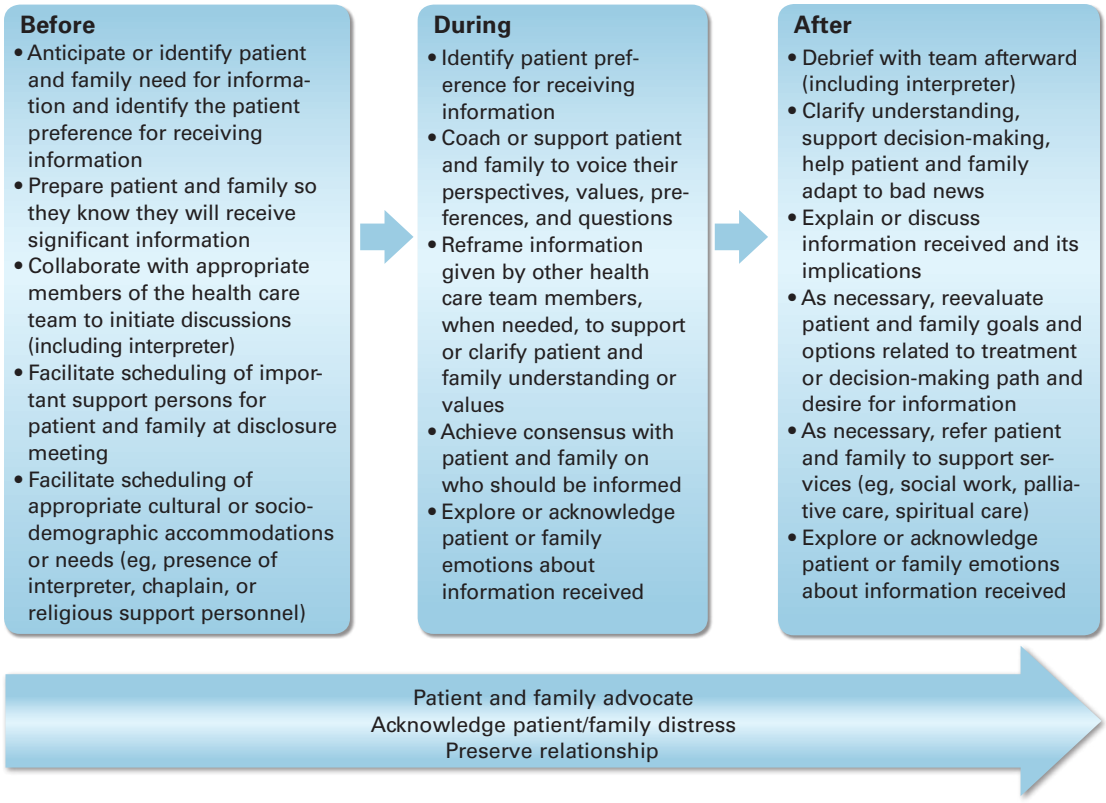

Figure 1: Involvement of intensive care unit nurses throughout the disclosure of difficult news.

because of factors related to disclosure competency. For example, ICU nurses may lack knowledge of professional or ethical guidelines pertaining to disclosure, such as the Code of Ethics for Nurses, that inform nurses' practice. In addition, depending on the institution, ICU nurses will experience variable levels of autonomy in practicing to the full extent of their professional knowledge base.[10] The level of the nurse's professional autonomy will influence his or her comfort with participating in the disclosure process.[7] For example, some nurses report not participating in the disclosure process because they fear being reprimanded for doing so (especially by physicians). Other nurses report hesitancy to be involved because of lack of administrative or unit support.[11,12] These examples highlight the challenge that some ICU nurses face in obtaining organizational support to exercise their professional autonomy and participate in disclosure cases.[13] In the case of Ms B, Susan received coverage support for her patient care assignment from her nurse manager so that she could participate in Ms B's family and team meeting. It is important for nurses to attend such meetings so they can accurately convey or reinforce information that is disclosed. However, to participate, nurses need unit support. Receiving such support may not be easy and may even be impossible in some clinical settings.

Still other ICU nurses may fear consequences that can come with delivering difficult news to patients or families, such as the diminishing of hope or unpredictable responses such as anger, sadness, denial, or even silence.[2,11,12] Susan may have been worried that Ms B would lose hope if she were to learn about her diagnosis, just as family members feared. These examples highlight the challenge ICU nurses face when trying to participate in disclosure cases, especially when they lack training in communication skills. Susan was unsure how to explore Ms B's new diagnostic information, despite sensing that withholding such information may be problematic. This sense of being unclear about how to act, in addition to the lack of training in how to communicate in the context of difficult news, can lead ICU nurses to experience moral distress, defined in this case as a feeling of disequilibrium arising from the uncertainty characterizing Ms B's case.[14] Moral

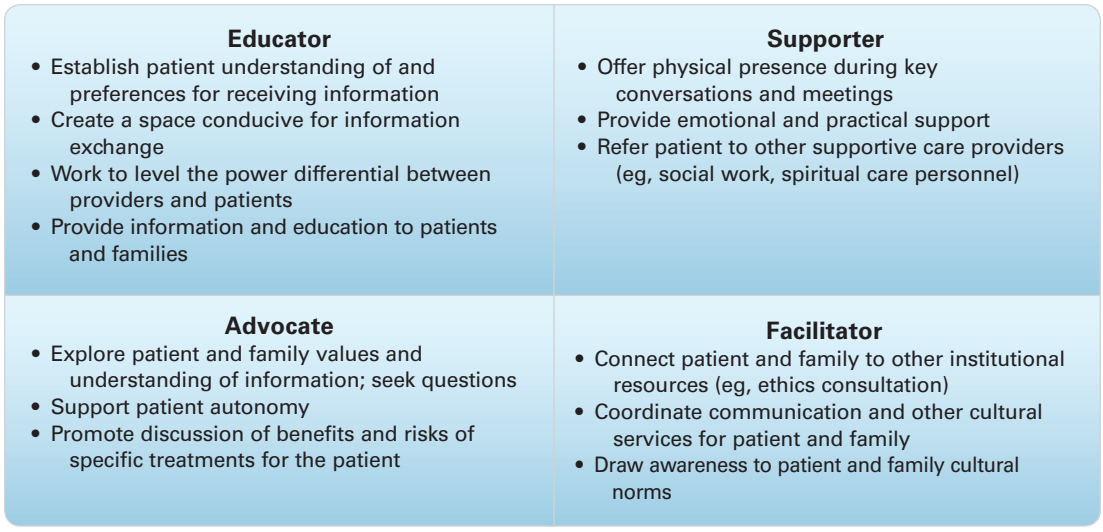

Figure 2: Nurse's role in the disclosure process.

distress can contribute to burnout, a phenomenon that up to one-third of ICU nurses reportedly experience.[15]

Susan's uncertainty about how to communicate with Ms B is likely to be compounded by the critical care environment, where treatment decision-making is time sensitive and can have substantial ramifications.[16] Furthermore, multiple clinicians, including nurses, may be involved with a patient, resulting in lack of continuity and fragmented care. In such a context, achieving effective communication with the patient, especially in the context of disclosure of difficult news, is challenging.[16,17]

Finally, many ICU nurses may wish to engage in the difficult disclosure process but feel they lack the time because of their workload.[2] When faced with a case of disclosure, nurses are not only required to provide care to the patient in the midst of disclosure but also must address their other patients' health and psychosocial needs.[9] Competing professional obligations create a challenge for all ICU nurses, in terms of their participation in disclosure cases. But novice ICU nurses face even greater challenges, given that they lack prior clinical experience and may be unsure how to simultaneously fulfill multiple professional responsibilities.[9] A nurse's perception that she or he lacks the time or resources to provide the care a patient needs is another source of moral distress, because the lack of time or resources constrains the nurse from providing the care she or he feels is necessary.[18]

Preparing ICU Nurses for Participation in the Disclosure of Difficult News

During the course of the disclosure process, ICU nurses typically spend more time at the bedside than any other provider and often develop an intimate sense of patient and/or family needs. Therefore, during the disclosure process, nurses serve many roles, including that of educator, facilitator, supporter, and/or advocate (Figure 2).[6,12] Here, we offer several skill- and relationship-based guidelines related to fulfilling these roles; the guidelines are important for preparing ICU nurses to participate in disclosure cases. By implementing these guidelines, ICU nurses can contribute to the fulfillment of particular ethical obligations that arise during the disclosure process.

Nurses as Educators

The role of ICU nurses in educating patients during the disclosure process is significantly associated with patients' satisfaction with care.[19] When providing education during the disclosure process, it is important for ICU nurses to consider the informational or educational content given to the patient and/or family and the milieu for giving such information. Because patients are frequently transferred to the critical care unit, ICU nurses may be communicating with a patient or family they do not know well.[9] In addition, previous conversations may have taken place between the patient and family and other members of

the health care team, and the ICU nurse may lack knowledge about information discussed. Therefore, it is important for ICU nurses to obtain a fuller picture of what has been discussed from the patient and/or family before offering additional education.[16] An ICU nurse can inquire about what information patients and families have received and the patient's or family's preference for obtaining information, including the types and amount of information desired, their preferred decision-making style, and important persons to include in the decision-making process. Nurses can also support patients by helping them understand their prognosis.[16] These steps help the ICU nurse balance respect for a patient's wishes with informed care, and they correspond to the nurse's ethical obligations to respect patient autonomy and ensure informed consent.[7] Applying these principles to the case of Ms B, when Susan was asked direct questions about potential new diagnostic information, she might first respond by exploring Ms B's knowledge of her health status and then determine how best to proceed with offering additional information.

In terms of the milieu for giving information, ICU nurses can help ensure that patient encounters take place in a private space with appropriate support persons present.[6] In a quick-paced ICU setting, nurses can offer an unhurried conversational tone, which can build rapport and trust.[6] Speaking with the patient on the same physical level, such as while sitting rather than standing over the patient, can help level the power differential often felt between patients and health providers and shows respect to the patient and family.[20] In the case of Ms B, although the attending physician was rushed, Susan could model using a calm voice and attend to the physical setting of the meeting. In doing so, Susan helps ensure patient privacy and promotes an environment focused on patient beneficence.

Nurses as Facilitators

Dilemmas may arise for ICU nurses during the course of the disclosure process, which includes information exchange and a robust process of informed consent with patients that incorporates attention to understanding and meaning. For example, patients may disclose previously unknown information that affects the direction of their care, or ICU nurses may learn of information that has implications for other family members and be unsure of how to proceed.[9] ICU nurses may also encounter situations in which patients are not receiving full and frank information about their health from other providers, which can constrain the nurse-patient relationship and further contribute to nurses' moral distress.[21]

Importantly, nurses in the ICU environment do not have to face these uncertainties alone; rather, they can help facilitate the incorporation of other resources within the health care setting that can provide additional consultation. Examples of resources that ICU nurses can access include ethics committees, ethics consultation services, unit-based nursing educators, clinical nurse specialists, and other nurse leaders with expertise in communication skills and disclosure. By using these resources, the ICU nurse can facilitate a process whereby issues of communication, culture, and information sharing are addressed. In the case of Ms B, Susan asked her nurse manager to help cover her patients so she could attend the scheduled meeting with Ms B. The nurse manager may also serve as an expert communication resource for Susan or refer Susan to someone with these skills. If Susan feels discomfort with what is disclosed or withheld during the meeting with Ms B, she can consider facilitating a request for an ethics consultation, which can further assist in ensuring that the disclosure process proceeds ethically.

Critical care nurses are also key facilitators of cultural aspects that are important to patient communication. Nurses are particularly central in bridging communication between non–English-speaking patients and families and health providers.[11] Patients and families are entitled to receive information in a format they can understand. Therefore, ICU nurses can help orchestrate the relaying of information to patients in their preferred language, using an appropriate mode of communication. Research shows that health care quality is improved with the use of in-person health care interpreters, and these interpreters can provide cultural insight that clinicians lack[22]; however, the cost and limited availability of in-person interpreters can make using them unrealistic.[23] Use of telephones or video-conferencing devices can be viable alternative modes of communication with non–English-speaking patients, but these have their own limitations, including a learning curve for use, limited availability, and increased difficulty in building

patient rapport, especially in critical care settings.[24] For instance, using the telephone as a means of communication prevents interpreters from reading patient and family facial reactions and body language.[24] However, when trained, in-person health care interpreters are unavailable, telephone or video-conferencing communication bridges are preferable to using family and friends as interpreters, because family or friends can compromise patient confidentiality and may filter communication according to their own understanding or values.[24]

Finally, critical care nurses can highlight the cultural norms that shape a patient's understanding about disclosure. For example, Western societies' prioritization of autonomy created a shift in culture during the 1970s around cancer diagnosis from one of nondisclosure to one of disclosure.[25] In contrast, clinicians in Eastern societies have traditionally advocated for nondisclosure of cancer diagnoses.[11] This nondisclosure approach is generally viewed by Western clinicians as paternalistic; however, in some studies, authors report that nondisclosure promotes less anxiety, preserves a higher quality of life, and supports a hopeful outlook on life for some patients[5] who view cancer with a significant amount of fear and uncertainty or for patients who equate cancer with death.[11] In the case of Ms B, Susan might advocate for the use of an in-person interpreter who has expertise in both Cantonese and Chinese culture. If an in-person interpreter is unavailable, Susan could facilitate the use of a certified interpreter through technological means. Susan may also be instrumental in helping the health care team, practicing in a Western context, to be aware of cultural norms in Eastern societies, like China, that shape Mei's request to withhold information from Ms B. In facilitating these cultural components, Susan creates an environment for truthful communication between the health care team and Ms B; the facilitation also respects the privacy and confidentiality of Ms B, because health care interpreters, like other providers, are trained to abide by the Health Insurance Portability and Accountability Privacy Rule.

Nurses as Supporters

Another role in which ICU nurses serve in the disclosure process is one of supporter. When faced with disclosure of difficult news, patients and families may respond in multiple ways. Nurses who practice at the bedside have a close view of the impact of such news and can support positive coping.[6] ICU nurses are key supports to families at the end of a patient's life,[26,27] providing emotional[11,16] and practical support.[6] In addition, the presence of ICU nurses during disclosure conversations increases families' trust of information.[16] Patients who face the disclosure of a new diagnosis such as cancer may newly require pain and symptom relief. ICU nurses can support these needs by helping patients connect with palliative care or pain service providers. Many patients and families who receive difficult news turn to their religious or spiritual beliefs for support. ICU nurses can provide referrals to spiritual care staff, such as chaplains, to support these needs. Patients with psychosocial needs may benefit from consulting with social workers, and nurses are often the first to identify the need for this support. In some cases, families are the strongest support for patients, and ICU nurses can help facilitate family presence in the inpatient setting.[6] In the case of Ms B, Susan can provide many of these types of support to Ms B and her family as the disclosure process unfolds and support needs become clearer.

Nurses as Advocates

In larger meetings where other health care team members are giving patients or families information, ICU nurses can serve as an advocate by answering patient and family questions, establishing patient and family understanding of information, or clarifying the patient's values. When patients are unable to communicate their own values, ICU nurses can communicate their understanding of the patient's values, as understood by family, close friends, other health care providers, or through advance directives. Furthermore, patients may prefer to defer disclosure of health information to their surrogate. This is a valid request, and ICU nurses are key in advocating for extension of the patient's autonomy. Nurses in the ICU setting also can advocate for the discussion of information the nurse understands will affect the patient's future health but may not have been emphasized to the patient. An example would be treatment effects on future fertility; one study showed that only 53% of women who had cancer and for whom future fertility might be a concern had been given this information.[3] This example demonstrates that nurses who work closely with patients in specific settings and who understand potential

risks of treatment options can help facilitate transparent conversations in which true benefits and burdens can be weighed. In the case of Ms B, Susan may serve as an advocate for Ms B's values and her wish for information related to her new diagnosis and potential treatment options.

Conclusion

Disclosing difficult news to patients and families can create situations in which nurses, particularly in the ICU setting, feel uncertain about their role. Disclosure is viewed as a process, not just a one-time event, and nurses are integral to the way the disclosure process unfolds. Specifically, during the disclosure process in critical care environments, nurses serve as educators, facilitators, supporters, and advocates to their patients and their families. Although nurses face real challenges to participating in the disclosure process, by identifying the various roles nurses have, we can better ensure patient care is delivered in a manner that minimizes ethical gaps and is congruent with patients' preferences and values.

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