

Rights of the Critically Ill Patient: Position Statement of the World Federation of Critical Care Nurses

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Critical care nursing involves the specialised nursing care of critically ill patients who are vulnerable and may be unable to voice their needs or have their human rights recognized or addressed. The World Federation of Critical Care Nurses (WFCCN) accepts and supports the Universal Declaration of Human Rights and the need for critically ill patients to be cared for with humanity, and to advocate for the rights of their families and communities. In the above context, WFCCN determined the need to create a document that was focused more specifically on the rights of critically ill patients. To this end, in August 2007, the WFCCN released its first Position Statement on the Rights of the Critically Ill Patient - The Declaration of Manila (WFCCN, 2007). The fundamental aim of this Declaration was to inform and assist critical care nursing associations, health services, educational facilities, and other interested parties to realize the rights of critically ill patients. Due to changes in critical care worldwide, as well as increased global migration, the WFCCN Board of Directors commissioned a review of the 2007 Declaration. As a result of this review, revisions were undertaken. This document represents the 2019 revised WFCCN Position Statement on the Rights of the Critically Ill Patient.

Keywords: critically ill patient; rights; World Federation of Critical Care Nurses; human rights; position statement

INTRODUCTION

In 1948, the United Nations proclaimed the *Universal Declaration of Human Rights* (United Nations, 1948). This work led to two other important and related documents: the International

Covenant on Civil and Political Rights (United Nations, 1966), and the International Covenant on Economic, Social and Cultural Rights (United Nations, 1966). The specific rights of patients in healthcare have also been stated by many nations

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and healthcare groups, and in approximately 350 languages.

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Definitions

For the purpose of this position statement, the following definitions were used:

Patient: an individual receiving nursing care within a critical care environment.

Proxy or decision-maker: the designated individual making care decisions when the patient is unable to do so, for example, a bloodline relative, significant other, or legal guardian.

Family: the person(s) defined as family by the patient.

METHOD

The 2007 Declaration of Manila was reviewed by the review group chair, and a worldwide call was made to WFCCN members for reviewers. Subsequently, several organizations were identified to participate in the review group. Previous content categories were reviewed, and review group members agreed on the addition of new sections in accordance with newly published literature. A review group member was assigned to each section to focus the literature review and draft the content.

To identify relevant information to inform the review, the following databases were searched: PubMed; National Guideline Clearing House; and CINAHL. The following websites were also searched for relevant information: American Association of Critical Care Nurses; American Nurses Association; Australian College of Critical Care Nurses; Australian Commission on Safety and Quality in Health Care; British Association of Critical Care Nurses; European Federation of Critical Care Nursing Associations; Institute of Medicine; International Council of Nurses; Neurocritical Care Society; Society of Critical Care Medicine; World Federation of Societies of Intensive and Critical Care Medicine; and United Nations General Assembly. In addition, WFCCN members were requested to provide documents related to human rights.

In October 2018, a revised draft of the position statement was presented for review at the WFCCN annual meeting in Belgrade, Serbia. Input was solicited from attendees, which was incorporated into the revised document. The final draft of the position statement was approved by the WFCCN Board of Directors on July 8, 2019.

CONTEXT

The notion of human rights embedded with this position statement refers to “the application of human rights principles to the context of patient care” (Cohen & Ezer, 2013). Patients’ rights, as a concept, has gained momentum in response to

evidence of human rights violations in health-care settings, which include threats to decision-making, privacy, autonomy, and life itself. Adoption of a human rights approach provides an appropriate framework to apply contemporary ideas of human rights within healthcare settings, which are consumer- and community-focused, to guide the care of critically ill patients. A human rights approach to the care of the critically ill patient should include a professional guarantee that an individual and their family have a right to the highest standard of care framed by humanity, respect and dignity.

Globally, ideas that are recognized and encompassed within the human rights approach include the critically ill patient's right to: protection from unnecessary suffering (Wijma, Zbikowski, & Bruggemann, 2016); non-discrimination; culturally appropriate care (WFCCN, 2016); care choice and equality; privacy and confidentiality; effective and compassionate communication of accurate and meaningful information; protection of self and bodily integrity; available remedy, care choice, and safe care; family involvement at the level desired; and to be cared for by appropriately trained healthcare professionals (Cohen & Ezer, 2013).

Nurses are increasingly faced with complex human rights issues, often arising from changes in the social landscape such as conflict situations within various jurisdictions, political upheaval, and war (United Nations, 1948). These geopolitical events can contribute to marginalization of a group's or population's rights to non-discrimination, culturally safe care, equality, and access to healthcare. Nurses provide care to critically ill patients in many ways and need to be equipped to recognize how patient diversity, personal circumstances, and vulnerability may impact care provision and care inequality (United Nations, 1948, 2015). Vulnerable populations commonly constitute women, children, prisoners, and stigmatized groups such as people with disabilities, or other

influences, that lead to them being regarded as "different" by others. WFCCN advocates that patients cared for within the critical care environment should be protected because of their significant vulnerability. Due to their severity of illness, impairment of communication, and reduced or absent decision-making capacity, patients are inherently susceptible to potential violations of their basic human rights. As a result, nurses should be aware of potential professional and institutional power imbalances that could negatively impact critically ill patients (International Council of Nurses, 2011). To increase awareness, it is imperative that nurses enculture human rights and understand how contemporary issues associated with inequality, poverty, and social marginalization contribute to suffering and health deterioration. Without this foundational awareness, advocacy on the behalf of those whose rights may be at risk, denied, or neglected may not occur (Cohen & Ezer, 2013).

The WFCCN endorses the International Council of Nurses (2011) proposition that healthcare is a right of all patients, irrespective of financial, political, geographical, racial, or religious considerations (United Nations, 1948). The principles of non-discrimination and equality with respect to patient care encompass patients' right to the highest attainable standard of health, as well as their civil and political rights. These range from the patient's right to be protected from inhuman treatment and discrimination, to the right of security (Cohen & Ezer, 2013; International Council of Nurses, 2011; United Nations, 2015). Thus, critical care nurses should practice with respect for the inherent dignity, worth, unique attributes, and human rights of all patients, setting aside any bias or prejudice (International Council of Nurses, 2012; United Nations, 1948). Acknowledging that the worth of a patient is not affected by illness, ability, socioeconomic status, functional status, or proximity to death (International Council of Nurses, 2012), critical care services should provide care that meets the diversity of patients' needs; irrespective of

individual or intercultural circumstances. This, in turn, requires the provision of a clinical environment that supports safe care, wherein the staffing, physical environment, and multidisciplinary teamwork combine collaboratively to support the best interests of the individual. In order to prepare critical care nurses to adequately address human rights and issues, there is a need to integrate these concepts into all levels of nursing education programmes, as well as within professional and ethical codes of nursing practice within their own jurisdictions (United Nations, 1948).

The Right to Privacy and Confidentiality

All critically ill patients have the right to privacy and confidentiality regarding the care they seek and receive. Management of information extends to the safe handling of information exchange about the patient from health professionals providing care, to family, significant others, visitors, and staff not involved in the direct provision of care. This right is inclusive of the requirement to ensure that patients have access to appropriate information in an efficacious manner to provide optimal patient-centered care (Zhang, Schmidt, White, & Lenz, 2018). Further, the critically ill patient or decision-maker has a right to be given the opportunity to object to information sharing to specific staff and others in the evolving context of care delivery (Francis et al., 2017). This right extends to include the exchange of information to other regulatory agencies or interested parties, such as police or health insurers, until the patient is able to make and articulate an informed decision for themselves or via their substitute decision-maker (Peden-McAlpine, Liaschenko, Traudt, & Gilmore-Szott, 2015). These rights are reflected in ethical and legal frameworks (Johnstone, Hutchinson, Redley, & Rawson, 2016). As such, the nurse's code of conduct includes an obligation to protect, defend, and advocate for the rights of the critically ill patient to ensure that, during periods of physical and cognitive incapacitation, reputation, personhood, and confidences are safely protected. This conduct should be balanced with the wishes of

the patient or proxy, legally mandated disclosure, and/or protection of public interest (Johnstone et al., 2016).

Organizations and healthcare providers have an obligation to ensure the security of medical informatics systems, through provision of legal frameworks and policy guidance to ensure the security and efficacious management of all forms of patient information and care communication (Francis et al., 2017). The security and information tracking about the patient across their healthcare experience must ensure that systems are in place to maintain the security of electronic devices (e.g., password protection and strategies to prevent malware invasion) in the context of evolving patient record management technology (Chinthapalli, 2017; Savel & Munro, 2013; Sittig, Ash, & Singh, 2014). Further, critically ill patients have the right to be cared for by staff who are routinely educated on the legal and ethical requirements set forth surrounding data privacy and confidentiality (Savel & Munro, 2013).

The Right to Receive Effective and Compassionate Communication of Accurate and Meaningful Information

Critically ill patients often lack the physical or cognitive ability to speak due to the presence of artificial airways, medication effects, delirium, or neurological disease (Happ et al., 2011). The severity of the patient's illness often influences the timing of communication of health information. However, all patients and decision-makers have the right to timely communication of health information to enable informed decisions regarding health, treatment of illness, and treatment options to be made (International Council of Nurses, 2015).

Patients and decision-makers have identified that timely, ongoing, clear, and complete communication by clinicians, are important factors that contribute to high quality critical care (Nelson et al., 2010). Timely communication is essential to reduce the risk of ineffective treatment, enable

early care goal discussion, and reduce critical care length of stay (Aslakson et al., 2010). This results in the benefits of improved care outcomes, and satisfaction of patients and decision-makers (Krimshstein et al., 2011). Despite this evidence, communication with critical care patients does not always occur in a timely and effective way (Gruenewald et al., 2017).

Recent guidelines recommend that organizations implement a multi-faceted, multi-disciplinary approach to improve timely communication of health information; from the highest level of governance to the point of care delivery (Australian Commission on Safety and Quality in Health Care, 2016). Guidelines also suggest that decisions in critical care are made in partnership with the patient, their proxy, and the healthcare staff, including participation in ward rounds (Davidson et al., 2017). If the patient is incapacitated, a substitute decision-maker should be established to manage ongoing communication (Mitchell et al., 2015). As point-of-care providers, all critical care nurses should receive training in effective communication and patient and family meeting facilitation (Davidson et al., 2017).

The Right to Protection of Self and Bodily Integrity

Human rights are based on the principle that all human beings have dignity and value and therefore have the right to bodily integrity in alignment with their economic, social, and cultural situation. Bodily integrity emphasizes the importance of an individual's personal autonomy and self-determination over their own body. For bodily integrity to exist, three elements are required: sufficient risk and benefit information to make an informed decision; capacity to express choice; and voluntary decision-making (Fields & Calvert, 2015; Hall, Prochazka, & Fink, 2012). Informed consent concedes that a patient maintains the right to refuse offered treatment without pressure or sanction. As such, the healthcare team (or critical care nurse) must give close attention to individual differences, and the rights of minority and vulnerable populations (Tschudin, 2003).

To support these elements, nurses should ensure that care is provided within the resources available, with appropriate information and consent given, utilizing understandable language. Nursing knowledge of different cultural beliefs, values, and practices and an attitude of respect, sensitivity, and openness to accommodate cultural differences in a patient's healthcare decision-making is therefore required.

The Right to Available Treatment, Care Choice, and Safe Care

Several international organizations have published guidelines, policies, or scientific statements related to the rights of safe care and access to available and state-of-the-art treatment (International Council of Nurses, 2012; Souter et al., 2015). WFCCN affirms that patients have the right of choice and safety in their care, and that nurses have an obligation to afford patients such choices. Complementary and traditional therapies should be included in these choices. Complementary alternative therapies are emerging as potential adjuncts to traditional treatment strategies (Greenlee et al., 2017; National Center for Complementary and Integrative Health, 2015). In the United States and Australia, surveys have identified that critically ill patients and/or their families may request a range of complementary and alternative therapies (Cooke, Mitchell, Tiralongo, & Murfield, 2012; Tracy et al., 2005). Surveys suggest that complementary alternative therapies use is increasing worldwide, with reports of their use ranging from 30% to 80% in some populations (Shirwaikar, Govindarajan, & Rawat, 2013; Vohra, Feldman, Johnston, Waters, & Boone, 2005). Therefore, it is conceivable that requests for complementary alternative therapy among critically ill patients will increase. Some non-pharmacological integrative therapeutic approaches, including relaxation, guided imagery, and massage, may favourably affect patient outcomes by promoting comfort and relaxation (Hadjibalassi, Lambrinou, Papastavrou, & Papathanassoglou, 2018; Papathanassoglou et al., 2018).

The reasons for critical care patient requests for complementary alternative therapy are various, and may include: management of symptoms not relieved through standard treatment (such as pain, agitation, anxiety, nausea); continuation of therapy used prior to hospitalization; concerns about complications related to pharmacological and invasive treatment; personal involvement in care choices; cultural practices; and end-of-life care (Kramlich, 2016). Hence, the critically ill patient's right to access complementary alternative therapy emanates from their basic rights to: relief of suffering according to the current state of knowledge; respect of one's culture, values, and right of choice; and continuity of care (World Health Organization, 1994). Critical care nurses should promote the patient's right to access to complementary alternative therapy, while ensuring their safety with regard to potential complications and interactions of such approaches, and taking into consideration ethical and legal implications (Tracy & Lindquist, 2003).

While the patient's right to treatment and choice are endorsed, critical care nurses may be confronted with a situation in which a request is made for aggressive life-sustaining care. This may present an ethical dilemma, when the request is perceived as being inappropriate. A recent multi-society, multi-national policy statement on responding to requests for potentially inappropriate treatments in the intensive care unit (ICU) informs this ethical concern (Bosslet et al., 2015). The consensus statement provides several recommendations:

- Institutions should implement strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of expert consultants.
- The term "potentially inappropriate" should be used rather than futile, to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians

believe that competing ethical considerations justify not providing them.

- Use of the term "futile" should be restricted to the rare situations in which a surrogate may request interventions that cannot accomplish their intended physiologic goal.
- The medical profession (healthcare providers) should lead public engagement efforts and advocate for policies and legislation about when life-prolonging technologies should not be used.

Critical care nurses should work with patients and other members of the healthcare team to ensure the rights to treatment and choice, while also establishing when care interventions may be potentially inappropriate. Critical care nurses should be included in the strategies to prevent intractable treatment conflicts, including proactive communication between the healthcare team, patients, and their family.

While an organization may affirm the patient or proxy's choice as a basic right, there are several cultural and clinical realities that may conflict with understanding and acting upon the patient's or proxy's wishes (Wolf, Berlinger, & Jennings, 2015). Concern for patient safety may be one consideration. The drive to improve quality and safety of care has existed for some time. However, the movement was accelerated in the United States by two key reports: *To Err is Human* (Institute of Medicine, 1999) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (Institute of Medicine, 2001). These documents estimated the impact of medical errors and outlined a framework to improve the quality and safety of healthcare. In the United States, hospital reimbursement has since been increasingly aligned with quality measures and many professional societies have developed a quality and performance improvement platform.

The Society of Critical Care Medicine published both a guideline outlining the safe medication use

in the ICU (Kane-Gill et al., 2017) and a document outlining the importance of process of care and ICU structure to improve outcomes (Weled et al., 2015). Also, the European Society of Intensive Care Medicine has published a set of performance measures that may be used to improve quality in intensive care (Rhodes et al., 2012). As quality and safety of healthcare continue to evolve in many countries across the world, nursing care should be considered when evaluating quality, and critical care nurses should take an active role in optimisation of personal education and speciality certification, and should be actively involved in the development of educational standards (Goldsworthy, 2016).

The Right to Family or Proxy Involvement

Engaging patients and their proxies as active partners in healthcare is a fundamental right for all patients (Cené et al., 2016). Family engagement presupposes the right to family presence and flexible visitation policies, which may still be limited in many critical care settings worldwide (Athanasidou, Papathanassoglou, Patiraki, McCarthy, & Giannakopoulou, 2014). The family can play a vital role in promoting the overall well-being of the critically ill patient. In the United States, the Institute of Medicine (2001) strongly recommends patient-centered care and family involvement as a key component of healthcare quality. A recent meta-analysis concluded that patient- and family-centered-care-focused interventions resulted in decreased intensive care length of stay and improvements in patient outcomes; including achievement of treatment goals and reduced mental health sequelae (Goldfarb, Bibas, Bartlett, Jones, & Khan, 2017). Research evidence from several countries suggests that families need to be part of the caring process; however, they require clear guidance and specific support (Coyne, 2015; Fateel & O'Neill, 2016). Nonetheless, several barriers, including a trend for shorter stays in the critical care unit and hospital, and nursing shortages, make family involvement challenging (Henneman & Cardin, 2002).

Accumulating evidence highlights the significant impact of critical illness on family members. In addition to the pressures of hospitalization for critical care, such as stressful decision-making, family members bear a significant caregiving burden; over half of intensive care survivors have post-discharge disabilities (Davidson et al., 2017; Desai, Law, & Needham, 2011). Also, families exhibit a high prevalence of anxiety and depression symptoms, which hinder their ability to comprehend information and provide care to critical illness survivors (Azoulay, Chaize, & Kentish-Barnes, 2014). Therefore, improving family outcomes is an important part of improving patient outcomes.

Family engagement in the critical care unit requires active partnership among health professionals, patients, and their family to improve healthcare outcomes (Brown et al., 2015). Family engagement incorporates, but is not limited to, participation in direct care, communication of patient values and goals, and activities to promote and protect individual comfort, well-being, respect, and dignity. Recent guidelines, endorsed by national and international organizations, include open and flexible family presence, support, and communication with families, as well as the need to address operational and organizational issues that may impeded family involvement (Davidson et al., 2017). However, it is important to appreciate that proxies have varying levels of capacity to decision make.

Using proxy decision-makers, three models of decision-making can occur: paternalistic, informed, and shared. The paternalistic approach occurs when the medical team decides for the patient what care will be given. Informed decision-making involves discussions between the proxy and the medical team with final responsibility resting with the proxy. Shared decision-making balances both medical caregiver and proxy opinions to drive care (Carlet et al., 2004; Johnson & Busemeyer, 2010). The model chosen to drive decisions depends on several factors including the decision-maker's wishes, location,

culture, and religious beliefs (Azoulay et al., 2014). Appreciation of the patient and proxy decision-making style is therefore an important first step when assisting families with care involvement and decision-making (Clarke et al., 2003). The right to family involvement in the care of critically ill patients can lead to long-term collaboration, respect, and dignity; participation; information sharing and decision-making; and ultimately to reduced health disparity and improved healthcare outcomes.

The Right to Be Cared for by Appropriately Trained Critical Care Nurses

Critically ill patients have the right to be cared for by appropriately trained critical care nurses with relevant qualifications and experience, working in organizations that are regulated to ensure they meet the required standards of safety and quality (Department of Health and Social Care, 2015). Critical care nurse education, training, and professional development programmes should provide content above and beyond that of basic nurse training programmes (Bray et al., 2010; WFCCN, 2005). Such programmes should include topics such as anatomy and physiology, pathophysiology, pharmacology, clinical assessment (including interpretation of diagnostic and laboratory results), plans of care and nursing interventions, patient and family education, and legal and ethical issues (WFCCN, 2005). Critical care nurses require advanced problem-solving abilities using specialist knowledge regarding the human response to critical illness (Canadian Association of Critical Care Nurses, 2018a). Retaining the wisdom and expertise of experienced critical care nurses ensures the maintenance of a safe and productive work environment (Canadian Association of Critical Care Nurses, 2018b). Critical care nursing organizations encourage nurses to be proactive in the development of multi-professional team working to broaden skill sets to optimize quality patient and family care and ensure a cohesive, quality service (Australian College of Critical Care Nurses, 2017; Bray et al., 2009).

CENTRAL PRINCIPLES

1. Human rights should be considered at all levels of the healthcare system, including the point of individual patient care; at the organizational level through policies, procedures, and protocols; at the local and national healthcare, and legislative level when appropriate, and incorporated in the education of healthcare providers.
2. Critical care nurses should be accountable for their actions and inactions in safeguarding human rights.
3. Critical care nurses should be included in the development of standards guiding the patient's right to choice in healthcare and safe healthcare.
4. Critical care nurses should participate in and/or facilitate communication between the patient or their surrogate and the healthcare team regarding the patient's condition and the patient's preferred wishes for healthcare.
5. Critical care nurse leaders should actively address systems and structures that give rise to discrimination and inequality, and role model professional commitment to social justice across all spectrums of healthcare and health education.

WFCCN POSITION

All critically ill patients and their decision-makers, have the right to:

- Humane care that is accountably delivered by critical care nurses who are skilled in recognizing physical, psychological and existential suffering, and who limit unnecessary suffering by providing non-discriminatory, culturally safe care, irrespective of financial, political, geographical, racial, or religious considerations
- Privacy and confidentiality regarding the care they seek and receive

- Bodily integrity in alignment with each patient's economic, social and cultural situations
- Obtain appropriate information utilizing understandable language so informed consent can be given
- Be cared for by critical care nurses and staff who:
 - Are appropriately trained
 - Set aside bias or prejudice to provide care that meets a diversity of needs with respect for the inherent dignity, worth, unique attributes and human rights for all patients
 - Are educated in communication, ethical decision-making, advocacy, and in support of human/patient rights
 - Are equipped to understand human rights issues in culturally, socioeconomically, geographically and racially diverse populations
 - Encourage family engagement in the care of critically ill patients
 - Are routinely educated on the legal, cultural, and ethical requirements regarding the protection of privacy and confidentiality for all information
- Established policies and procedures to ensure the safe management of all forms of communication and data.
- Early, timely communication and health information with subsequent review, updates/meetings given according to the patient's clinical status or expressed need
- A substitute decision-maker to manage ongoing communication
- Decision-making made in partnership with themselves, proxies, and staff
- Be active partners in the critical care setting via family presence, open and flexible visitation, adequate information-sharing and respect of critically ill patients' wishes
- Healthcare structures that support family involvement in a patient's care at the level desired and in alignment with cultural, religious, and expressed family needs
- Refuse offered treatments without pressure or sanction
- Access and choices for traditional and integrative care strategies, including complementary and alternative therapies
- Hospital systems that encourage communication, early expert consultation, and discussion regarding potentially inappropriate critical care interventions
- A safe environment that minimizes the patient's risk of harm from healthcare delivery errors
- Be cared for in healthcare organizations that are regulated to ensure they meet the required levels of critical care nursing safety and quality

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