

HPNA Position Statement Definition of Terms

Background

The following defined terms promote consistency across HPNA Position Statements and other official HPNA documents.

Ethics Related Terms

Autonomy: A multidimensional ethical concept. It is the right of a capable person to decide his/her own course of action based on personal values and goals of life. Self-determination is a legal right.^{1,2}

Beneficence: An ethical duty to act to benefit the recipient of care. It is based on the patient's perception of benefit and relates to promoting well-being.^{1,2}

Dignity or Respect for Person: A fundamental ethical principle. Dignity is the quality, state, of being honored or valued. Respecting the body, values, beliefs, goals, privacy, actions and priorities of an autonomous adult preserves their dignity. This is a broader concept than autonomy.¹⁻³

Principle of Double Effect: A bioethical concept that provides moral justification for an action that has two foreseen effects: one good and one bad. The key factor is the intent of the person performing the act. If the intent is good (e.g., relief of pain and suffering) then the act is morally justifiable even if it causes a foreseeable but unintended result (e.g., hastening of death).¹

Fidelity: The ethical imperative to keep promises. For healthcare providers, fidelity includes the promise not to abandon the patient.¹

Informed Consent: A tenet of autonomy. To make an autonomous decision, the person must have sufficient and relevant information as well as capacity to make the decision. Capacity requires that the person understands the consequences of the decision; has sufficient information and understanding about the treatment, likely outcomes, and foreseeable consequences; and be able to make the decision without coercion.^{1,2}

Imminent Death: Refers to death that is expected to occur within hours to days based on the person's current condition, progression of disease and symptom constellation.⁴

Intent: The purpose or state of mind at the time of an action. Intent of the patient/proxy and healthcare providers is a critical issue in ethical decision making around palliative sedation. Relief of suffering, not hastening or causing death, is the intent of palliative sedation.^{1,5}

Proxy Decision Making: Allowed if the person lacks capacity to make an informed choice. Proxy or surrogate decisions should be based on one or more of the following: written advance directives; substituted judgment, which is based on subjective knowledge of the person's values, views on quality of life, goals; or the "best interest" of the person whose wishes and values are unknown and based on weighing benefits/burden of recommended actions.^{1,2,6}

Nonmaleficence: The ethical duty to do no harm. When beneficence conflicts with nonmaleficence, there is a greater duty to avoid inflicting harm.¹

Palliative Sedation: "When terminally ill, conscious patients experience intolerable symptoms that cannot be relieved by expert palliative care, palliative sedation involves administering sedatives and non-opioid medications to relieve suffering in doses that may induce unconsciousness, but not death." ^{7 p. 583}

Refractory Symptom: One that cannot be adequately controlled in a tolerable time frame or at a tolerable level despite aggressive use of usual therapies and seems unlikely to be adequately controlled by further invasive or noninvasive therapies without excessive or intolerable acute or chronic side effects/complications.⁸

Respite Sedation: The use of sedation for a brief, planned period to provide symptom relief and rest with the goal of returning to consciousness and pursuing future therapeutic and/or palliative therapies.^{9,10}

Suffering: An individual and private experience characterized by a state of severe distress induced by loss of intactness of person or threat that the person believes will result in loss of his/her intactness related to physical pain, unrelieved symptoms, spiritual distress, depression, or multiple losses.^{11,12}

Evidence Based Practice

Clinical/Critical Pathways: An intervention in clinical care that includes (1) a structured multidisciplinary plan of care; (2) is used to channel the translation of guidelines or evidence into local structures; (3) details the steps in a course of treatment or care in a plan, pathway, algorithm, guideline, protocol or other 'inventory of actions'; (4) has a timeframes or criteria-based progression; and (5)

aims to standardize care for a specific clinical problem, procedure or episode of healthcare in a specific population.¹³

Clinical Practice Guideline: “Systematically developed statement designed to assist practitioner and patient make decisions about appropriate healthcare for specific clinical circumstances.”¹⁴

Comparative Effectiveness: A type of healthcare research designed “to inform health care decisions by providing evidence on the effectiveness, benefits, and harms of different treatments options.” Specifically, it compares new and emerging clinical interventions to established interventions. This may include procedures, diagnostics and medications for the same disease. Results are summarized in a systematic review.¹⁵

Evidence-Based Practice: “The integration of best research evidence with clinical expertise and patient values.”¹⁶ p. ii Specifically in nursing, evidence-based practice is a integration of patient-centered care, interdisciplinary collaboration, with the integration of the best research with clinical expertise and patient value for optimum care.^{17,18}

Patient-Centered Outcomes Research: Research designed to help people make informed health care decisions and improve health care delivery and outcomes by “producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.”¹⁹

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