

Respect and Dignity: A Conceptual Model for Patients in the Intensive Care Unit

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Abstract. Although the concept of dignity is commonly invoked in clinical care, there is not widespread agreement—in either the academic literature or in everyday clinical conversations—about what dignity means. Without a framework for understanding dignity, it is difficult to determine what threatens patients' dignity and, conversely, how to honor commitments to protect and promote it. This article aims to change that by offering the first conceptual model of dignity for patients in the intensive care unit. The conceptual model we present is based on the notion that there are three sources of patients' dignity—their shared humanity, personal narratives, and autonomy—each of which independently warrants respect. The article describes each source of dignity and draws on examples to illustrate how clinician attitudes, actions, and behaviors can either contribute to, or detract from, expressions of respect for patient dignity.

Key Words. Autonomy, Dignity, Intensive Care Unit, Patient, Respect

Dignity is a commonly invoked, but rarely defined, concept in clinical care. Hospital brochures and Patients' Bills of Rights inform patients that they have a right to be treated with dignity (Johns Hopkins Medicine, 2013), professional codes increasingly direct clinicians to provide dignified care (American Medical Association, 2012–2013; International Council of Nurses, 2012), and patients in a variety of clinical settings report that receiving dignity-preserving care is important to them (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002). At the same time, a

growing number of studies have concluded that as many as one-half of all hospitalized patients experience "a loss of dignity" during interactions with the health care system (Gordon and Betty Moore Foundation, 2012), a risk that is heightened for patients in intensive care settings (Baillie, 2009; Turnock & Kelleher, 2001).

Despite dignity's presence in the clinical lexicon, there is not widespread agreement—in either the academic literature or in everyday clinical conversations—about what dignity means (Gallagher, 2011). On some accounts, dignity is primarily, if not

exclusively, about respecting patients' autonomy (Pinker, 2008; Macklin, 2003). On other accounts, respecting patients' dignity involves attention to a constellation of factors, including patients' medical fears and anxieties, bodily privacy, cultural and religious differences, and relationships with others (Chochinov, 2002). Without a common framework for understanding dignity, it is difficult to determine what threatens patients' dignity and, conversely, how to honor commitments to protect and promote it.

As part of a larger project aimed at eliminating preventable harms to patients in intensive care units (ICUs), the Gordon and Betty Moore Foundation included "loss of dignity" as a previously overlooked and "unrecognized harm" to patients (Adamy, 2012; Sugarman, 2015). Unlike traditional clinical harms (such as hospital-based infections or surgical complications), which can be measured and addressed using standardized criteria and treatment regimens, harms to patients' dignity are more difficult to identify and rectify in part because we lack a conceptual lens through which to view and correct them.¹ To fill that void, and ultimately improve the care that patients in ICUs receive, we embarked on a project to conceptualize respect and dignity as they relate to patients in that setting.

The conceptual model that we offer, which is based on our review of the philosophical and clinical literature on respect and dignity, is focused on understanding the sources of, and ensuring respect for, the dignity of patients, regardless of age or level of consciousness. In this article, we focus on the model's application to adult patients in the ICU. There are particular and important nuances of this framework when applied to infants and children, and to adults in other clinical settings, that we do not address herein. It is equally important to consider how to ensure respect for the dignity of clinicians and patients' loved ones in the ICU, but we reserve those questions for a later date.

1. Some qualitative data about dignity-related harms have been gathered. See Chochinov, Hack, Hassard, et al. (2002) and Chochinov (2002).

In this article, we claim that respect is owed to ICU patients because they possess dignity. Respect is an attitude, behavior, or feeling toward an entity that conveys proper regard or consideration for that entity,² in this case, patients in the ICU. Dignity—derived from the Latin word *dignus*, meaning worthy—is a multifaceted concept that both signifies a patient's moral worth and grounds an obligation to respect the patient.

We contend that patient dignity is grounded in three characteristics of patients, each of which independently warrants respect. The first source of patient dignity, and the one that all patients possess equally and absolutely regardless of age or level of consciousness, is shared humanity. Shared humanity is an immutable feature of persons that cannot be taken away or diminished. It requires a baseline level of respect for patients as human beings, regardless of any specific characteristics they may or may not possess. Beyond shared humanity are two additional sources of dignity that are unique to each patient and that ICU patients may express and experience to varying degrees. These sources of dignity, which also warrant respect, are patients' personal narratives and their actual or potential autonomy. Patients' personal narratives include, among other things, their familial and societal roles, relationships with others, likes and dislikes, religious views, and lived experiences. Patients' autonomy encompasses making choices that allow them to live a life based on their distinctive values, preferences, and plans. In the case of infants and children, we respect their emerging capacities for autonomous choice and relational potential.

Although the model distinguishes among the three dignity-generating features of patients—shared

2. Respect has been understood in other ways as well, for example, as a principle (Frankena, 1986). Respect is entity generated, meaning that it is not driven by the interests or desires of the person respecting the entity, but rather by some feature of the entity itself. Accordingly, we may not like a particular entity, but we may still have a duty to respect it because the entity possesses moral significance independent of us (Dillon, 2014).

humanity, personal narrative, and autonomy—the model also acknowledges that these sources of dignity, and the respect they demand, at times intersect (Figure 1). Patients’ personal narratives, for example, frequently influence the health care decisions they make as autonomous individuals. To respect both sources of patients’ dignity, clinicians can adopt a nonjudgmental and accepting attitude toward each patient, even when patients’ values and choices conflict with clinicians’ beliefs and recommendations. In the ensuing discussion, we describe each source of dignity and draw on examples to illustrate how clinician attitudes, actions, and behaviors can either contribute to, or detract from, expressions of respect for patient dignity.

Shared Humanity

All patients, and indeed all people, possess dignity simply by virtue of being human. There is a theological basis for this view, in which humans derive their dignity from their creation in God’s image (Barilan, 2009; Shultziner, 2006; Torrance, 1988), and there is a secular version, in which humans derive dignity from their shared humanity (Margalit, 2007). On both interpretations, all human beings possess dignity intrinsically and equally (Meyer, 1989). Whether old or young, wealthy or poor, Nobel laureate or trash collector, individuals are entitled to be treated with equal respect for their dignity befitting their value as human beings.

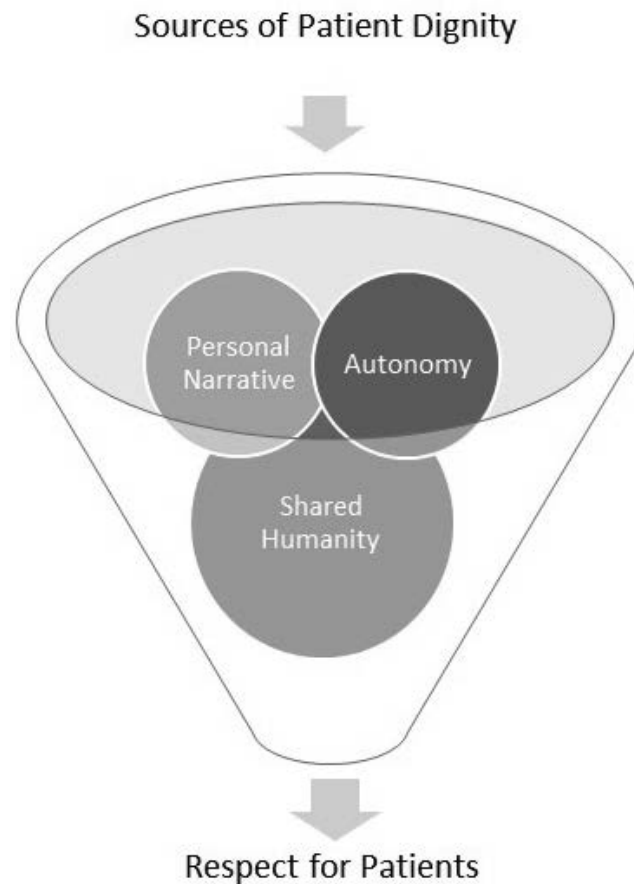


Figure 1. Three Sources of Patient Dignity that Warrant Respect

Shared humanity is the first and central source of dignity in the conceptual model we propose because it applies to all patients, regardless of any specific qualities they may or may not have (Gewirth, 1992; Kolnai, 1995; Nordenfelt, 2004; Spielberg, 1970). A patient in a persistent vegetative state, for example, who may lack the biological, cognitive, and relational capacities that we commonly associate with persons, nevertheless possesses this form of dignity. By contrast, the two other sources of dignity in the model are contingent: Whether someone has a personal narrative upon which they can reflect (or that is otherwise discernable), and whether someone can exercise their autonomy, are capacities that may wax and wane across their disease trajectory. Some patients may have both capacities; other patients may have neither. By focusing first on the source of dignity that patients universally and unconditionally possess, the model imposes a baseline level of respect for all patients.

There are a variety of ways in which care in an ICU can be respectful of this fundamental aspect of patients' dignity. First, clinicians and health care institutions can take steps to acknowledge each patient as having equal moral worth. This requires treating all patients with the same baseline level of respect, regardless of their diagnoses, lifestyle choices, actions, attitudes, socioeconomic status, age, gender, race, religion, or culture (Beach, Roter, Wang, Duggan, & Cooper, 2006). It means, for example, applying resources and treatments equally to patients who are homeless and those who are financially privileged. It means speaking as respectfully to patients who are not adherent to their treatment as those who are. It means showing the same regard for patients who have substance abuse addictions as those who do not. When clinicians or institutions treat some patients as less worthy—not only of their care, but also of their attention and compassion (Blanchard & Lurie, 2004)—they disrespect the universal dignity that all patients share.

Second, clinicians should enter each patient interaction with the presumption that every patient deserves to be respected as a human being. Even when a patient's medical status—for example, deep sedation or unconsciousness—suggests that the patient is likely unaware of how others are

treating him or her, clinicians should err on the side of treating the patient with the same respect owed any other patient. This bright line rule not only removes any ambiguity about which patients are owed respect as human beings (all are), it also reinforces the notion that the dignity derived from patients' shared humanity requires clinicians to treat all patients with the same baseline level of respect.

Respecting the dignity of patients as human beings begins with not objectifying them. When clinicians refer to patients by name, look them in the eye, introduce themselves, and describe the care they are providing, they treat patients as people rather than objects. By contrast, when patients are labeled by their diagnosis, referred to by their room number, or discussed in the third person—even when they are not aware of being objectified in this way—they are not treated with the respect owed to human beings. Patients are similarly objectified when clinicians fail to recognize them at all. This can occur when patients are subjected to an examination without permission or explanation; when procedures are performed on them in an indifferent, rote, or distracted way; or when one clinician speaks to another about the patient as if the patient were not there.

As human beings with shared dignity, patients also are owed respect for their bodily and physical privacy. Unlike objects, people have expectations of privacy, and they experience feelings of vulnerability, shame, and humiliation. Even when patients' medical status precludes them from experiencing these emotions, their shared humanity requires attention to their bodily privacy. During the course of receiving care, ICU patients are stripped of their clothing and belongings, and they are dressed in hospital gowns in which they may feel physically exposed. Their intimate bodily care, including washing and toileting, may necessitate assistance from others, sometimes of the opposite sex. Patients' medical treatment may require them to be uncovered and touched by strangers in ways that interfere with space they consider personal. Their door or curtain may be left open for others to peer in. Collectively, these intrusions can pose challenges to patients' sense of dignity (Matiti & Trorey, 2004).

Clinicians can navigate these privacy boundaries with sensitivity and respect for the patient's moral worth as a human being. As a first step, clinicians might think of the patient's hospital room or bed space as the patient's private space. Clinicians should introduce themselves upon entering the patient's space and explain why they are there. These actions signal respect for the patient's physical privacy, while also creating a setting in which more intimate examinations or procedures can take place. When clinicians must undress or touch a patient's body for an examination or procedure, they should discuss what is about to take place with the patient in a manner consistent with the patient's capacity for understanding and conveying a choice. In cases in which the patient has the capacity to understand and respond, clinicians should ask permission before uncovering or manipulating the patient's body. For example, a clinician might say, "I need to listen to your heart and lungs now. Is that okay? You will feel the stethoscope on your chest as I listen." When the patient lacks capacity or awareness, clinicians should nevertheless respect the patient's bodily privacy by informing the patient of their intent. The clinician might say, for example, "I am going to change the bandage over your IV. You will feel a pull on your skin as I remove the tape, and it will feel cool as I cleanse the area. You may feel pressure as I replace the bandage." Clinicians can further communicate respect for the patient's bodily privacy, and thus her or his dignity, by closing the door or drawing curtains around the bed (where available), and redraping the patient when any procedure is complete.

Personal Narrative

Unlike shared humanity, which patients possess universally and absolutely, the extent to which patients have and can reflect upon a personal narrative is contingent and may wax or wane during the course of a patient's illness. Most patients have a unique biographical story, even if they do not currently have the capacity to share or reflect upon it. Having a personal narrative is a characteristic frequently associated with possessing human dignity. Some philosophers refer to this feature of humans

as generating a "dignity of identity" (Nordenfelt, 2004, p. 74), whereas others describe it as a dignity of biographical "uniqueness" (Rolston, 2008). This source of dignity demands respect for people who have created, invested in, and internalized a personal narrative—one in which their family role, societal role, likes and dislikes, religious preferences, worldview, and lived experiences, among other things—make them uniquely who they are. At its core, respecting this source of dignity is about respecting individuals' perceptions of themselves and what matters to them.

When people are hospitalized, they frequently experience a shift in their personal narrative. Often that shift involves a transition from being a healthy, able-bodied person to a critically ill, dependent patient (Coventry, 2006; van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2013). A growing number of empirical studies have demonstrated that, in these situations, patients measure their dignity by the degree to which their personal identity remains intact during medical treatment and the extent to which they are able to adapt their personal narrative to alterations imposed by their disease or treatment (Coventry, 2006; Matiti & Trorey, 2004; van Gennip et al., 2013). Relevant factors in patients' assessments often include whether they can continue to function in their previous roles, whether they can control their behavior, and whether their bodies remain recognizable to them. The inability to do any one of these things is commonly accompanied by feelings that one's dignity has been diminished.

In the ICU, respecting a patient's personal narrative begins with clinicians' openness to discovering the uniqueness of each patient. How does the patient perceive herself and her identity? What roles and relationships (familial, professional, or community based) are meaningful to her? Does she define herself by a commitment to any cultural, religious, or other values? Are there any aspects of the patient's self-image that may be particularly challenged by a hospital environment? For example, what are the patient's norms around modesty? Is appearance especially important to her? Is she typically formal in her interactions with strangers? What are her fears and concerns about her

hospitalization and illness? If the patient is sedated or unconscious, who was she before she became ill?

Understanding how a patient perceives these dimensions of her identity is the first step in providing care that is respectful of this aspect of her dignity. Establishing who a patient is and what it is about her life, as she has lived it so far, that matters to her is a critical next step—not only because that knowledge may inform a medical decision, but also because it can help clinicians to provide care that is respectful of the unique person they are treating. Personal narratives can help clinicians to view their patient not only as the person they now see, but also as an accumulation of the person that the patient was before her hospital admission. For example, including questions about the patient's personal narrative in routine assessment tools and constructing a space where pictures of people central to the patient's life can be displayed are ways to "re-personalize" ICU care. Just as the personal narrative of a woman who loses her only child is always inclusive of her being a mother, a patient's personal narrative before her hospitalization may be central to her, even if she cannot return to it after her illness.

Once clinicians have developed an understanding of a patient as a particular person, they can provide care that acknowledges and supports that patient's identity. In this context, respecting the patient's dignity requires treating the patient as a particular person. When health care providers treat patients with the same diagnosis with equal regard, but fail to address each patient's discrete needs, they may respect the dignity related to patients' shared humanity, but disrespect the dignity connected to each patient's personal narrative. This can result in treating a patient's narrow health problem, while ignoring his general well-being.

Respectful care, therefore, requires making efforts to "meet patients where they are." When clinicians address patients by name—referring to patients who express a preference for formality by their title and last name (e.g., "Mr. Smith"), and to patients who prefer a more casual approach by their first name—they signal respect for the individual patient before them. Discussions about treatment options should be similarly sensitive to each patient's desires, fears, and values, including

any religious and cultural beliefs that may impact individual health care decisions. For example, patients may have religious beliefs about the sanctity of human life that inform their decision making about certain medical options near the end of life. Clinicians may not always agree with or understand a patient's values, but openness to them is a crucial part of respecting the patient's personal narrative, and as we discuss, it is also a necessary step in respecting their autonomy.

Clinicians can also respect patients' personal narratives by facilitating "role preservation." (Chochinov, 2002; McClement, Chochinov, Hack, Kristjanson, & Harlos, 2004). This involves encouraging patients to engage in their personal, professional, and societal roles and relationships to the extent possible within the constraints imposed by their illness and the hospital setting. Even when a patient's identity has been temporarily or permanently altered by their disease, accident, or treatments, clinicians can demonstrate respect for a patient's current and previous narrative by inviting the patient's loved ones to connect to the patient through the roles they have played in the patient's life. For unconscious or sedated patients, clinicians can express respect for the patient's personal, professional, and societal roles by asking the patient's loved ones to bring in pictures or other artifacts that they believe the patient would find meaningful and familiar in the midst of unfamiliar surroundings. The benefits of these actions are twofold: clinicians can demonstrate that they appreciate who patients are, apart from their illnesses, and an opportunity is given to express ways in which patients' "selves" remain intact despite their time in the ICU.

Finally, respecting patients' personal narratives means helping them maintain their pride, or their perception of their own worth (Chochinov, 2002; Matiti & Trorey, 2004; McClement et al., 2004). Patients in the ICU frequently experience challenges to their self-image. A patient who associates his identity with being well-groomed and conservatively dressed, for example, may not take pride in (or even recognize) himself when his hair is not brushed and his hospital gown does not completely cover his body. Similarly, a patient who defines her identity in large part by her ability to remain composed in stressful situations

may not feel “like herself” when her illness makes her outwardly emotional or her medication affects her impulse control. Although these circumstances can also affect how others view the patient, what matters here is that they confound the patient’s personal narrative as constructed and evaluated by her. When clinicians inquire about how patients perceive themselves, and take steps to help patients to maintain that self-image, they safeguard a critical aspect of patients’ dignity.

Autonomy

As our discussion of shared humanity and personal narratives demonstrates, there are significant steps that can and should be undertaken to respect patients’ dignity in the ICU, even before reaching the more frequently considered issue of autonomy. Nevertheless, the aspect of dignity that has received the most attention in the bioethical literature—both positive and negative—relates to individuals’ capacity for autonomy. Kant (2005) was the first philosopher to provide a thorough account of this view of dignity, which he associated with the distinctly human ability to discern the moral law and live by it. For Kant, dignity included not only an obligation to respect people’s freely rendered decisions, but also the concomitant obligation not to interfere with them by treating people as objects of another’s free will. In the context of clinical ethics, the principle of respect for autonomy and the related requirement of informed consent aim to address this aspect of human dignity.

Importantly, not all patients in the ICU have the same degree of cognitive capacity or even the same interest in making decisions about their care. Many ICU patients intermittently or permanently lack decision-making capacity because they are sedated, chemically paralyzed, or have suffered injuries, diseases, or complications that render them incapable of discussing, understanding, or participating in treatment decisions. Other patients may have the ability to make decisions about their care, but would prefer to defer decision making to their health care team or loved one instead. Still other patients may have the limited capacity to make simple decisions, but insufficient ability to make

more complex choices. For example, an ICU patient may not have the capacity to make decisions with irreversible consequences, such as the discontinuation of life-sustaining therapies, but she may have the capacity to indicate preferences about where intravenous lines are placed or when she wants to receive personal care and by whom. Respecting patients’ autonomy—much like respecting their personal narratives—therefore requires attention to the uniqueness of each patient.

In this context, an inquiry is necessary to learn the extent to which a particular patient has the capacity and desire to exercise autonomy. A variety of tools are available to clinicians to assess a patient’s decision-making capacity (Appelbaum, 2007; Chow, Czarny, Hughes, & Carrese, 2010). These evaluations, which should be a routine part of ICU care, offer clinicians not only an opportunity to examine a patient’s ability to understand, reason, and communicate a choice, but can also provide insight into the values underlying a patient’s preferences.

Conversations that build trust between clinicians, patients, and (where appropriate) moral surrogates who serve as designated decision makers for patients, are a related and vital step to providing care that respects patients’ autonomy. In these discussions, clinicians should ask about patients’ personal narratives (e.g., their values and their life before their ICU admission) and their expectations for life after they leave the ICU. Clinicians should also inquire and document whether patients have advance directives and a designated health care agent to speak and make treatment decisions for them when they are unable to do so. Collectively, these conversations create a space to discuss treatment options with honesty and candor,³ but also in a manner sensitive to patients’ preferences.

3. *Respecting self-determination requires presenting patients and their moral surrogates with all medically viable choices. However, creating the illusion of choice when there is no real choice—for example, by offering cardiopulmonary resuscitation in the ICU when the clinician knows it is extremely unlikely to restore heartbeat or respiration—undermines authentic patient choice.*

It is, of course, too simple to suggest that clinicians merely need to engage patients and their moral surrogates in conversations about their care to respect their autonomy. Respecting this aspect of patients' dignity also involves accepting patients' or their moral surrogates' informed choices, even when those choices run counter to the clinicians' judgment. In cases where the choices of patients or their surrogates counter the clinician's judgment, respecting the dignity and autonomy of that patient might mean having more discussion to ensure that these choices are truly informed and autonomous or, in the case of a moral surrogate, appropriately reflective of the patient's values and preferences. Although we acknowledge that there are instances where clinicians are justified in overriding the choices of moral surrogates and even sometimes of patients, the moral default setting must be otherwise.

"Authentic respect" for patient autonomy means approaching the patient encounter with a commitment not to a particular outcome, but instead to the "process of understanding and meaning" (Rushton, 2007). It involves accepting patients for the unique selves that they are, not speaking condescendingly to them, and ultimately respecting their dignity by honoring their preferences. In so doing, clinicians' respect for a patient's autonomy frequently overlaps with the respect owed to the patient's shared humanity and their personal narrative.

Conclusion

Despite its generally positive connotation in the context of clinical care, appeals to dignity in contemporary health policy and bioethical debates have received mixed reviews. For some commentators, dignity is a value of such "paramount importance" (Kass, 2008, p. 298) that it should be "a central moral and social aim . . . of everyday medical care" (Dresser, 2008, p. 505) and the *lingua franca* of a just and caring health system (Annas, 2005). For others, dignity is a concept in such disarray that it is at best a placeholder for more precise notions like autonomy (Macklin, 2003), and at worst, "nothing more than a short-hand expression for people's moral intuitions and feelings" (Kuhse, 2000, p. 72).

The dispute over dignity's usefulness and purpose is, in large part, a consequence of not having a conceptual framework or a discrete context in which discussions about dignity's multivalent nature can take place (Henry, 2011). The model we offer aims to change that in the ICU setting by offering an understanding of dignity that is meaningful for participants in that context. By highlighting the three sources of patient dignity—shared humanity, personal narrative, and autonomy—and the types of respect that each requires in the ICU, the model offers a framework for identifying and rectifying threats to patients' dignity in that setting. Although the conceptual model's most immediate contribution is to advance scholarship about patient dignity in the ICU, we believe the model can be effectively operationalized in clinical practice to improve patient care.

Focusing on respect and dignity, however, is only part of the story. Most clinicians are predisposed to respect patients' dignity, but for a variety of reasons may find it difficult to do so. In the ICU, clinicians, patients, and their loved ones meet under conditions of uncertainty, stress, and high-stakes outcomes. Literally, life and death often hang in the balance. In this environment, clinicians may be depleted, burned out, or experiencing moral distress, any one of which can diminish their capacity to treat others with respect (Rushton, Kaszniak, & Halifax, 2013a, 2013b). That reality, coupled with the broader culture and economics of health care delivery, impact the way that clinicians interact with patients. Incentives for professional advancement and financial remuneration, for example, may thwart dignity-respecting care in favor of episodic, technology-focused communication and decision-making. The model we propose can help to identify these types of threats to patient dignity in the ICU, but a careful analysis of how clinician characteristics, environmental factors, and other variables impede respect for patient dignity is well warranted.

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