

## **Ensuring respect and dignity in the ICU**

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Identifying loss of dignity and lack of respectful treatment as preventable harms in health care, researchers at Johns Hopkins have taken on the ambitious task of defining and ensuring respectful care in the high-stakes environment of the intensive care unit (ICU). Their novel, multi-method approach is presented in a dedicated <u>supplement</u> to the journal *Narrative Inquiry in Bioethics*.

"In health care the importance of respect and dignity is often invoked, but has not been clearly defined in regard to treatment in the ICU," says Jeremy Sugarman, the Harvey M. Meyerhoff Professor of Bioethics and Medicine at the Johns Hopkins Berman Institute of Bioethics. "To prevent harms related to respect and dignity in the ICU there is a prerequisite need for clarity regarding what exactly constitutes optimal treatment in this regard, and then to develop methods to measure it," Sugarman says.

To lay that groundwork, bioethics scholars on the research team developed a <u>conceptual model</u> defining three sources of patient dignity: shared humanity, personal narrative, and autonomy. Each of these sources of dignity demands respect, says Leslie Meltzer Henry, a professor at the Berman Institute and first author of the article outlining the conceptual model.

"In the modern health care system, there is risk of technology-focused communication and decision-making taking precedence over dignity-respecting care," Henry says.



The conceptual model describes the types of respect that each source of dignity requires in the ICU, and offers a framework for identifying and rectifying threats to patients' dignity in that setting. For example, the article states, "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."

Defining and creating a means of measuring dynamic concepts like respect and dignity required input from multiple sources, Sugarman explains. The research team collected data through interviews with patients and families in the ICU, focus groups with <a href="health care">health care</a> <a href="health-care">professionals</a> who work in the ICU, and direct observations.

The data from these three research approaches were then synthesized, and the researchers identified four consensus areas relevant to what constitutes treatment with respect and dignity in the ICU: 1) treatment as a human being, 2) treatment as a unique individual, 3) treatment as a patient who is entitled to receive professional care, and 4) treatment with sensitivity to the patient's critical condition and vulnerability in the ICU. An article entitled "Toward Treatment with Respect and Dignity in the Intensive Care Unit" includes extensive quotes representative of the overarching themes, from all three data sources.

The research team also conducted a pilot study surveying ICU patients to assess their care experiences and perspectives on treatment with respect and dignity; previously, quantitative assessments of ICU care have been largely limited to family members, explains Hanan Aboumatar, Assistant Professor of Medicine and Public Health and Core Faculty member at the Armstrong Institute for Patient Safety and Quality. The surveys were adapted from existing validated surveys and administered to patients after they had been in the ICU for 48 hours. However, Aboumatar acknowledges that the patients' critical condition presented a challenge,



with only 20% of ICU patients able to participate in the survey.

"Having quantitative measures of treatment with respect and dignity in the ICU that could be easily administered would be a valuable complement to the qualitative data resulting from the other research methods, where the respondents answer in their own words," says Sugarman. "Future work will be directed at the feasibility of using a smaller set of survey items that will be easier for both patients and researchers to manage," he says.

This study of respect and dignity in the ICU is the bioethics component of the larger "Emerge" project at Johns Hopkins, led by the Armstrong Institute for Patient Safety and Quality and funded by the Gordon and Betty Moore Foundation. The project aims to decrease preventable harms in the ICU through systems engineering approaches.

"Patients' loss of dignity and lack of respectful <u>treatment</u> are harms that are just as important to prevent as hospital acquired infections and medical errors. The work by the Johns Hopkins team is a critical foundation from which we can build to ensure that all people receive care that is respectful and preserves their dignity, whether in the ICU or any other <u>health care</u> setting," said Dominick Frosch, PhD, a fellow at the Gordon and Betty Moore Foundation.

"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," the researchers state in the article presenting their conceptual model. "Now we have the lens, and we can move forward toward careful measurement and developing means to help prevent loss of dignity in the ICU," Sugarman says.

**More information:** Narrative Inquiry In Bioethics supplement: Towards Treatment With Respect and Dignity In the Intensive Care



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