ICU-RESPECT: An index to assess patient and family experiences of respect in the intensive care unit

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ABSTRACT

Purpose: The purpose of the study is to develop a brief index of patient and family experiences of respect in the intensive care unit (ICU).

Materials and methods: We designed a questionnaire with 44 items representing 12 themes that emerged from prior in-depth interviews with ICU patients and families. After pilot testing, items with minimal variability were eliminated. The resulting 21-item questionnaire was administered to patients and families in 5 adult ICUs. Psychometric analyses were conducted.

Results: Fifty-seven questionnaires were completed. Factor analysis resulted in a unidimensional scale consisting of 10 items with an α of .85 and an Eigen value of 11.3. Factor loadings ranged from 0.54 to 0.84, and item-test correlations ranged from 0.47 to 0.71. The mean total score was 7.25 out of a maximum of 10. Scores were lower for surgical than medical or disease-specific ICUs.

Conclusions: The "ICU-RESPECT" index demonstrates high reliability and concurrent validity in ICU patients and families. Future research should validate this index in other ICU settings, assess its predictive validity, and evaluate different methods for maximizing response rate. As hospitals address patient experience more broadly in response to national metrics, the index could identify particular behaviors or ICUs that would benefit from interventions to enhance respectful treatment.

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1. Introduction

Respect for persons is a fundamental ethical principle. The relevance and application of this principle to patient care have been explored extensively in the conceptual literature on biomedical ethics [1,2]. A few empirical studies [3,4] provide evidence that respectful treatment is a salient aspect of patient care. Despite its central importance, there are limited data on exactly how treatment with respect or the lack thereof manifests itself in clinical practice, particularly in the context of critical care. Intensive care units (ICUs) are unique settings that can pose specific threats to respectful treatment because of the severity of the patients' medical conditions and treatments, anxiety among patients and their family members, and high levels of stress among members of the care team.

In a review of available measures of "respect and dignity" that have been used in the hospital context, we were not able to identify any that were sensitive and specific enough or validated for use in the critical care environment. Existing measures of respect in the inpatient setting are limited to "global assessments" of patients' overall hospital experience (Hospital Consumer Assessment of Healthcare Providers and Systems [HCAHPS]) [5-7] or specific assessments of dignity-related distress at the end of life (Patient Dignity Inventory [PDI]) [8]. The HCAHPS is not specific to respect and has a high ceiling effect. The PDI is narrowly focused on the loss of dignity at the end of life. For different reasons, these instruments are poorly positioned to reveal particular ICUs or specific behaviors that would benefit from intervention or aspects of respectful treatment that may be different from violations of dignity.

To address the gap in our understanding of how patients and families experience respectful treatment in the ICU and our ability to measure it, we previously conducted a multimethod study of respect and

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dignity in 2 ICUs at 1 large, academic medical institution [9-13]. Based on interviews with patients and their families, direct observations, and clinician focus groups, 12 broad themes emerged that characterize what it means to be treated with respect. Examples include clinicians' use of greetings and introductions, their demeanor/bedside manner, how well they listen and share information, attention to body/modesty/appearance, honoring patients' preferences and choices, and responsiveness to patients' needs and requests [9]. Based on our pilot study to assess the feasibility of administering a self-report questionnaire to ICU patients and families [10], it was evident that a briefer and simpler instrument than the HCAHPS or PDI and one that captures particular behaviors reflective of respectful treatment in the ICU would be extremely useful. The study described here was designed to develop such an instrument.

2. Materials and methods

All data are based on questionnaires completed by patients and/or by family or friends who were visiting the patients. This study was reviewed and approved by a Johns Hopkins University School of Medicine Institutional Review Board. The development of the index involved 3 phases.

2.1. Phase 1: Development of a draft instrument

The research team developed an initial set of items for the draft instrument based on the literature as well as qualitative analysis of the transcripts of interviews and focus groups and direct observations, discussed in detail elsewhere [11-13]. Each of the specific types/sources of respect/disrespect identified by a participant or a direct observer was converted into a discrete candidate item for inclusion in a questionnaire. The initial questionnaire included 44 items, representing the 12 thematic domains. The response categories included a 5-point Likert scale ranging from "all of the time" to "never" as well as a "not applicable" category.

2.2. Phase 2: Data collection

Initial data collection efforts were aimed at significantly reducing the number of items. To minimize the burden on individual patient/family respondents, the 44 items were divided among 3 versions of the instrument (A, B, and C). Each version had a comparable representation of items from each of the 12 thematic domains. To determine eligibility, research assistants asked the unit charge nurse to indicate those patients/families who would not be appropriate. Patients were excluded if they were actively dying out of respect for their family members, were combative with staff, or were physically unable to respond (intubated/sedated) with no family members present. Next, research assistants checked with the bedside nurses to gain permission to administer a questionnaire to their patient or patient's family. If the nurse agreed, a research assistant would approach the patient or family member to obtain verbal consent. Those who agreed were orally administered one of the versions of the index. After the questionnaire was completed, the research assistant conducted a brief cognitive interview to verify whether respondents understood the items and to seek their input on suggested wording changes.

After collecting 30 pilot questionnaires (10 responses to each version), it became apparent that variability in responses was limited in all versions. Those items with the least variability were eliminated, resulting in a 21-item instrument. We were also concerned that respondents may have been uncomfortable answering the items honestly in person. To address this concern, we decided to leave the questionnaire in patients' rooms in a folder marked "confidential" for patients and families to complete at their convenience.

Eligibility criteria remained unchanged for the administration of the shortened questionnaire. Research assistants checked back at each ICU

every 24 hours to collect any completed instruments. Overall, this method resulted in better response variability; however, response rates were low. To increase the number of completed questionnaires, we administered the 21-item instrument at all of the ICUs for approximately 6 weeks. In addition, fields were added for patient age, race/ethnicity, sex, and the specific ICU where the patient was located. The instruments continued to be left in patient rooms in the confidential folder. A total of 195 questionnaires were left with patients or family members for completion.

2.3. Phase 3: Statistical analysis and psychometric testing of the instrument

Data were entered into a REDCap database [14,15] and exported to Stata 13.1 [16] for analysis. Examination of frequency distributions revealed that the responses to each of the 21 respect items were skewed, with a majority of respondents selecting "all of the time" for positively worded items or "never" for negatively worded items. Because of the skewed distribution, we dichotomized all positively worded items into "all of the time" vs "most of the time," "occasionally," "rarely," or "never," and the 2 negatively worded items into "never" vs "all of the time," "most of the time," "occasionally," or "rarely." Responses of "not applicable" were treated as missing values. The initial set of dichotomized items was subjected to factor analysis using the underlying variable approach where observed dichotomous variables are considered to be realizations of whether underlying continuous variables pass a hypothetical threshold [17].

Following standard methods [18,19], a matrix of the correlations among the dichotomous items was produced, and factor analysis was conducted on the correlation matrix. Eigenvalues were calculated to inform the choice of the number of factors, and oblique (promax) rotation was used to evaluate the loading of the items on the factors. Study investigators discussed the results of preliminary analyses and selected a subset of items based on the frequency of less positive responses (ie, responses other than "all of the time" for positively worded items and responses other than "never" for negatively worded items), item-to-total correlation, and representation of hypothesized conceptual domains of respect. For the final index, an overall Cronbach α was calculated as well as item-to-total correlations, item-to-rest correlations, and α values if an item is removed.

3. Results

Data were collected from April to July 2015 at 5 ICUs in the Johns Hopkins Health System, including 1 that cares only for medical patients, 2 that care only for surgical patients, and 2 that are disease specific and care for both medical and surgical patients. As shown in Table 1, 57 questionnaires were completed, including one-third by patients (n = 19) and two-thirds by a family member (n = 37) or friend (n = 1) visiting the patient at the ICU. Among respondents who provided demographic information, there was reasonable distribution by age, sex, and race.

Table 2 presents the distributions of the most positive responses vs less positive responses for each of the 21 respect and dignity items. "Area outside of room kept quiet at night" was the only item with a minority of respondents endorsing the most positive response (47%). For all other items, the most positive response was endorsed by 60% to 88% of respondents.

In factor analysis using all 21 items, the eigenvalues decreased markedly after the first factor, from 11.31 with the first factor to 1.73 with the second factor, and the proportion of variance explained was 0.54 for the first factor and 0.08 for the second factor. The scree plot also provided strong evidence for a single-factor index with a clear "elbow" at the second factor (see Figure). These findings support the unidimensionality of the index.

The internal consistency of the 21-item index as measured by Cronbach α is estimated at 0.915. For the individual items, the item-