

Original Article

Measuring the Quality of Dying and Death in the Pediatric Intensive Care Setting: The Clinician PICU-QODD

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Abstract

Context. In the pediatric intensive care setting, an accurate measure of the dying and death experience holds promise for illuminating how critical care nurses, physicians, and allied psychosocial staff can better manage end-of-life care for the benefit of children and their families, as well as the caregivers.

Objectives. The aim was to assess the reliability and validity of a clinician measure of the quality of dying and death (Pediatric Intensive Care Unit—Quality of Dying and Death 20 [PICU-QODD-20]) in the pediatric intensive care setting.

Methods. In a retrospective cohort study, five types of clinicians (primary nurse, bedside nurse, attending physician, and the psychosocial clinician and critical care fellow most involved in the case) were asked to complete a survey for each of the 94 children who died over a 12 month period in the pediatric intensive care units of two children's hospitals in the northeast U.S. Analyses were conducted within type of clinician.

Results. In total, 300 surveys were completed by 159 clinicians. Standard item analyses and substantive review led to the selection of 20 items for inclusion in the PICU-QODD-20. Cronbach alpha for the PICU-QODD-20 ranged from 0.891 for bedside nurses to 0.959 for attending physicians. For each type of clinician, the PICU-QODD-20 was significantly correlated with the quality of end-of-life care and with meeting the family's needs. In addition, when patient/family or team barriers were encountered, the PICU-QODD-20 score tended to be significantly lower than for cases in which the barrier was not encountered.

Conclusion. The PICU-QODD-20 shows promise as a valid and reliable measure of the quality of dying and death in pediatric intensive care. *J Pain Symptom*

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Key Words

Pediatric intensive care units, palliative care, outcome measures, end-of-life care, quality of dying and death

Introduction

Over the last several decades, both researchers and practitioners have made a concerted effort to improve care at the end of life for adults^{1–7} and, in the last decade, children.^{8–12} These efforts have begun to distinguish three separate but interconnected constructs: quality of end-of-life care, quality of life at the end of life, and quality of the dying and death experience.^{13,14} Quality of end-of-life care typically refers to an assessment of the actions taken by clinicians. In contrast, both quality of life at the end of life and quality of dying and death encompass the experience of the patient. Quality of life at the end of life refers to the functional status and fulfillment of needs essential to living in the face of terminal illness. Special tools to measure this construct among terminally ill adult patients have been developed.^{15–17} Quality of dying and death is a construct that focuses more specifically on the final stage of illness, just before death, and is an attempt to measure the degree to which a “good death” has been achieved. This article focuses on the latter construct.

The quality of dying and death has received considerable attention in the adult intensive care setting. A tool developed and validated by Curtis et al.¹⁸ to measure the quality of dying and death among adults has been adapted for the intensive care setting.^{19–23} Regardless of the setting in which death occurred, Curtis et al. defined the quality of dying and death for adults in terms of the degree to which “the preferences of the adult patient as reported by others after his or her death” were met.¹⁸ Central to this definition is the assumption that an adult has considered his or her death and has preferences and ideas about his or her last few days and hours. One feature of this model is that it strongly privileges the experience of the patient and relies on the

family and clinicians primarily as surrogate reporters on this outcome. Whether the preferences and/or needs of the family are met is relevant primarily to the extent that they are important to the patient, which is of course often the case.

The death of a child is qualitatively different than the death of an adult. The death of an adult may sometimes be understood as the natural conclusion of a long and completed life, whereas this is, by definition, never the case for children. In addition, the death of a child, regardless of the cause or the location, often profoundly impacts the family for the rest of their lives.²⁴ In the pediatric intensive care unit (PICU), the experience of dying and death varies according to the age of the child. On one end of the continuum, for example, are small children or babies who have never experienced or expressed preferences and at the other end are adolescents or young adults who may have had detailed conversations with their family and caregivers about their hopes and expectations during the dying process. Because typically those who experience the death of a child most acutely in the pediatric setting are the parents and/or family of the child who is dying—whose memories of their family’s and child’s experience will last forever—we defined the quality of dying and death in the pediatric setting as “the degree to which the hopes and priorities of the patient and/or the family for the process of dying and the moment of death are respected and met.”

The pediatric Quality of Dying and Death questionnaire (QODD), therefore, takes a somewhat more inclusive and holistic approach than the adult QODD because it ascribes intrinsic value to the experience of the family members, rather than merely the derivative value of this experience as reflected in the adult QODD. In addition to their role as reporters for the experiences of the patient, in the pediatric

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