Quality of Life for Children Living with Severe Neurological Impairment and Their Families: How Can We Understand It Better, and Whose Lives Are We Talking About? (FR438)

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Objectives

- Recognize symptom scales and other instruments used in clinical care and empirical research to describe quality of life (QOL) in pediatric patients; appreciate their varied focus on emotional, physical, and interpersonal dimensions of daily life; and identify their optimal applications and limitations.
- Recognize how attention in the medical literature to QOL emerged around care for neonates who were critically ill and has since been focused on a range of different clinical contexts, including the lives of children with severe neurological impairment.
- Discuss and distinguish between (a) informing, framing effects, shared decision making, and the influence of implicit bias; and (b) the subjective experiences of those whose “lives” are being discussed—the child’s and the family caregivers’.

Describing, discussing, and contemplating quality of life (QOL) is central to developing treatment plans in the practice of hospice and palliative care. Family caregivers assess and act on the subjective experiences of their children living with severe neurological impairment (SNI). Health professionals integrating principles and practices of hospice and palliative care into treatment for children with SNI can enhance the services by achieving deeper understanding of the concept of QOL—its assessment, its history in the United States, ways to discuss it explicitly with family caregivers, and strategies for incorporating values into decision-making.

This session will include an innovative exploration into QOL for children with SNI and their families in three parts. Participants will

1. gain familiarity with symptoms scales and other instruments used in contemporary clinical care and empirical research to describe QOL in pediatric patients; appreciate their varied focus on emotional, physical, and interpersonal dimensions of daily life; and identify their optimal applications and limitations
2. review how attention to QOL in the US medical literature emerged in the 1970s around care for neonates who were critically ill and has since been focused on a range of different clinical contexts, including the lives of children with SNI
3. focus on distinctions between (a) informing practices, framing effects, shared decision-making, and the influence of implicit bias; and (b) the subjective experiences of those whose “lives” are being discussed—the child’s and the family caregivers’—in the course of conversations about QOL for children with SNI and their families.

Through a combination of case-based illustration, didactic presentation, and interactive audience discussion, seminar faculty will help participants reach a new and deeper understanding of QOL for children with SNI and their families.