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Telling Stories about Illness and Disability: The Limits and Lessons of Narrative

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Abstract

Autobiographical narratives of illness and disability are influential in popular and medical discourses of illness and disability, in part because these narratives represent illness and disability within a sociocultural context, intersecting with other categories of difference. Clinicians can benefit patients through a critical understanding of the formal and social conventions that shape illness and disability narratives and the effect these conventions can have on the lived experience of illness and disability. I analyze the 2003 edition of Lucy Grealy's *Autobiography of a Face* to illustrate these socio-narrative conventions, especially in light of an afterword that significantly revises the ending to Grealy's narrative. I explore the parallels between narrative conventions—such as the "recovery narrative"—and caregivers' expectations that shape the role of the "good patient," as well as the resistance to conventions of closure, represented by the

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ABSTRACT Autobiographical narratives of illness and disability are influential in popular and medical discourses of illness and disability, in part because these narratives represent illness and disability within a sociocultural context, intersecting with other categories of difference. Clinicians can benefit patients through a critical understanding of the formal and social conventions that shape illness and disability narratives and the effect these conventions can have on the lived experience of illness and disability. I analyze the 2003 edition of Lucy Grealy's *Autobiography of a Face* to illustrate these socio-narrative conventions, especially in light of an afterword that significantly revises the ending to Grealy's narrative. I explore the parallels between narrative conventions—such as the “recovery narrative”—and caregivers’ expectations that shape the role of the “good patient,” as well as the resistance to conventions of closure, represented by the “renegotiated ending.”

HEALTH-CARE PROVIDERS may be better able to understand and even treat their patients by reading illness and disability narratives critically and understanding the social forces that shape them. Clinicians who recognize that “narrative provides meaning, context, and perspective for the patient’s predicament” (Greenhalgh and Hurwitz 1999) know that the practice of listening to patients’ stories and responding sensitively to them provides an opportunity for more clinically effective, as well as more empathic, care (Brody 1994; Charon 2006; Wear and Varley 2008). Clinicians can also help patients to formulate the

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