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## Review: 'Living with Brain Injuries: Narrative, Community, and Women's Renegotiation of Identity' by J. E. Stewart

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Book Review for *Women's Studies: An Interdisciplinary Journal*

Reviewer: Susan Davies, Ed.D.

Stewart, J. E. (2014). *Living with brain injuries: Narrative, community, and women's renegotiation of identity*. New York, NY: New York University Press.

J. E. Stewart's 2014 book *Living with Brain Injury: Narrative, Community, and Women's Renegotiation of Identity* provides an in-depth look at the experiences of ten women who sustained brain injuries at different points in their lives. Stewart's qualitative research study highlights the unique and shared experiences of these women. Much of the current brain injury literature focuses on men, particularly combat veterans and athletes. Thus, a book focusing on personal struggles confronted by women with brain injury is both timely and needed.

*Living with Brain Injury* opens with an introduction, which provides an overview of existing research and a description of the qualitative methodology Stewart utilized in his project. The author highlights some of the core identity-related issues that are important in brain injury recovery, including disconnect with pre-injury self, social disconnect and building new relationships, the need to engage in meaningful activities, and the loss of self in the eyes of others. The narratives that follow cycle back to how these threats to self, and the way that "culture disables people" (p. 8), can result in long-term maladjustment. Thus, rather than only focusing on the negative aspects of participants' experiences, the book shines a spotlight on the women's strategies for reauthorizing their life stories and creating new answers to the question "who am I?" Throughout the book, dominant narratives relate to ability, gender, race, age, and the economy.

All ten of Stewart's participants experienced injuries that were classified as severe, but the effects varied considerably. The women shared a common train of past brain injury, but were

diverse in their identification with different communities and values: they represented a variety of religious and ethnic backgrounds, different age groups and relationship statuses, and varied educational and professional backgrounds. Their identification with the “disability community” varied as well, with some participants having no relationship with such a community and others describing how their connections with other people with disabilities were some of their most important relationships and sources of support. Some participants’ injuries were recent, others occurred long ago; duration since injury ranged from 6 months to 28 years. The causes of injury varied (e.g., car accident, stroke, surgical complication, gunshot wound, assault), as did the resulting type and range of deficits. In addition to interviewing the women who had sustained brain injuries, the author interviewed and shared insights from two medical professionals, a clinical neuropsychologist and a psychiatrist, to contextualize the participants’ experiences.

Many qualitative studies have at least one key informant. J. Eric Stewart’s was Cindy, whom he met through her role as an advocate for women with disabilities. The author’s involvement with Cindy, and the fact that they developed a trusting working relationship, led to identification of more than half of the other women who ultimately participated in his study. The author immersed himself in the women’s narratives, highlighting individual experiences and finding common themes within their stories through inductive analysis. As a qualitative researcher, Stewart entered into each woman’s world, got to know her, gained her trust, and kept detailed records of what he heard and observed. The result was thick, rich descriptions of the ten women and their conversations.

The first chapter of *Living with Brain Injury* introduces the stories and backgrounds of the ten women with brain injury and two professionals who were interviewed for Stewart’s study. This chapter also describes the qualitative methodology he employed, including the

establishment of trust with the women he interviewed. Seven of the ten women with brain injuries participated in a single interview that lasted one-and-a-half to four hours; in three cases, follow-up interviews were conducted to allow the women to elaborate upon information. Two participants were interviewed three times over a period of nearly five years; they also participated in a number of informal phone and email conversations. One participant was interviewed three times over a period of two years.

The second chapter, “Meeting Post-Injury,” describes the participants’ early recovery and rehabilitation experiences. The women discuss a range of issues, including managed care and insurance coverage, feeling objectified by rehabilitation professionals, and conflicting expectations about progress among one’s caregivers.

Chapter three, “Oneself as Another,” focuses on the disconnection between participants’ pre-injury and post-injury self-perception (although one participant astutely encourages people to identify “turning points” rather than discrete “before and after” selves). The author’s line of questioning with participants revealed information about their social activity, self-identity, and post-injury adjustment relative to recovery. Instead of focusing on deficits, Stewart focused on recovery and life changes—how these women negotiated and navigated their disabilities, new abilities, relationships with friends and families, and work.

The fourth chapter, “Fighting,” focuses on the decision of when to fight challenges and when to let go. A variety of potential cultural barriers are addressed, including exclusion and oppression at school, work, and in transit. Interestingly, one participant experienced a “fight” because her employer feared she was too disabled to continue working. Conversely, another experienced a “fight” because she did not appear disabled enough and therefore experienced challenges articulating her needs to the college disability services office. A key theme that

emerged in “Fighting” was the fact that marginalization by our culture was, in a sense, more disabling than the women’s impairments.

Chapter five, “Sense (and Sensibility) of Community,” is a key part of the book, exploring one’s sense of place within the community, including finding or creating new communities of support. In this chapter, the author’s own identity as a clinical-community psychologist is evident, as he demonstrated clear understanding of the importance of effective reintegration into community as an essential component to brain injury recovery. Stewart’s key informant, Cindy, is the star of this chapter, with her deep involvement with the disability issues and community. In such a community, participants could be the “knowers” of information and the “givers” of help rather than projects or mascots. The women in the study discussed a variety of communities, including religious communities, the disability community, the women’s community, and the Black community.

The sixth and final chapter, “Wrestling with an Angel,” requires the reader to contemplate metaphysical questions related to brain injury and disability. Many of the women emphasized the role of religion in making sense of their injuries and resulting difficulties. Their beliefs helped them manage feelings of anger, grief, and blame, and helped them reconstruct their lives post-injury. Such a chapter provides an interesting conclusion, reminding the reader of the variety of spiritual narratives and religious affiliations discussed by the women throughout the book.

Stewart’s work acknowledges the lost art of listening that is evident in current research and practice. The result is a beautifully written, inspired piece of writing that prompts readers to think not only about women with brain injury, but about ourselves—the people who live with them, work with them, and are in community with them. While much of the writing, particularly

at the beginning, is complex and academic, the book will be particularly beneficial for scholars and practitioners who require a better understanding of the human experience of their patients and clients. The author is to be commended for his thorough qualitative data analysis and emotional dedication to this project, which shines through on each page. J. Eric Stewart explored these ten women's personal experiences with depth and sensitivity.

Despite these strengths, physicians and therapists seeking a book to pass on to their patients may find this book too complex for many survivors of brain injury. The beginning chapters, in particular, read a bit like a dissertation, with careful coverage of qualitative research methodology and history of the topic. *Living with Brain Injury* would be an excellent supplemental text in graduate-level courses or for practitioners in clinical or community psychology, rehabilitation, disability fields, and medical/health fields. The text would also be a valuable addition to the reading lists of researchers interested in culture, disabilities, or women's studies.

A book like this is important for a number of reasons, one of which is the heterogeneity of brain injuries. The themes that emerged from this research project support arguments against uniform solutions and conceptualizations for care and treatment. The book did not just involve the study of a particular disability; it underscored our ethical responsibility to listen to the individual narrative rather than solely attempt to treat presenting problems. Despite the diversity of the narratives, their compilation created a community among these ten unique women, adeptly describing their adaptations to a range of functional limitations and to the reality that their lives would be different.

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