Living with Brain Injury: The Survivor's View

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Some of the authors of this publication are also working on these related projects:

- Community Integration of Older Adults with Acquired Brain Injury View project
- Supports and barriers to exercise for adults living with brain injury in a supportive community setting: An exploratory study View project

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Lorenz, Laura S. "Living with Brain Injury: The Survivor’s View." Unpublished manuscript, Brandeis University, Waltham, MA, USA.

Abstract: Introduction: To gain an understanding of lived experience with brain injury, this qualitative study used photovoice methodology to explore the lived experience of 11 adult survivors of acquired brain injury living in the community. Methods: A purposive sample of 11 recently injured persons accessing outpatient rehabilitation services, and 8 members of a brain injury survivor support group who were injured between 1 and 35 years ago was included. The study took place between 2007 and 2009. Data were collected in two phases: (1) photovoice interviews with the participants and (2) photo elicitation interviews with the participants. Results: Based on the participants' visual illness narratives, two overarching themes emerged: (1) Brain Injured Self Dominates and (2) Encompassing Darkness and Light. Conclusions: This study provides a typology of ABI stories. First, the new (brain injured) self dominates and feelings of confusion, loss, and frustration consume living with ABI (Williams, 1984). This presentation provides 1 excerpt from each case study’s visual illness narrative, each themes that emerged from their photographs and interviews appear to represent something important about the experience of the participants. Participants talked about their photographs in photo elicitation interviews with me, and b) when photovoice participants discussed their photos during project meetings. Results: The analysis of the data indicated that the participants’ visual illness narratives are telling stories of their own lived experience with ABI. Although the participants were injured at different times, the themes of new self and old self are present in each participant’s visual illness narrative. The themes of new self and old self are in dialogue with each other. Feelings of loss and grief are present, but the new self and old self are in dialogue and are embracing each other. The participants’ visual illness narratives are telling stories of their own lived experience with ABI. Conclusions: The analysis of the data indicated that the participants’ visual illness narratives are telling stories of their own lived experience with ABI. Although the participants were injured at different times, the themes of new self and old self are present in each participant’s visual illness narrative. The themes of new self and old self are in dialogue with each other. Feelings of loss and grief are present, but the new self and old self are in dialogue and are embracing each other. The participants’ visual illness narratives are telling stories of their own lived experience with ABI.