



Einladung zum Vortrag

Dienstag, 7. Juli 2009 17.30 s.t.

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Experience and Practice with Visual Illness Narratives: Examples of Brain Injury Survivors

Quality of care for acquired brain injury (ABI) patients is a global issue, and their lack of access to person-centered care is a major concern. Rehabilitation from ABI is fraught with unpredictability about the potential for recovery of function, increasing the urgency for person-centered care. As illustrated in the Star Quality model, therapeutic relationships that provide information and emotional support are a key dimension of person-centered quality. However, providers may focus on the empirical knowledge they bring to the clinical encounter. A greater understanding of lived experience with ABI could improve an important dimension of quality from the ABI patient's perspective. The purposes of this study were to 1) gain an understanding of ABI survivors' experiences living with ABI; 2) use visual research methods to promote dialogue about lived experience with ABI; 3) uncover new knowledge about health policy issues related to ABI; and 4) explore how the methodology used and information generated could be applied in therapeutic settings.

Two basic approaches were used to generate qualitative data for this study: photoelicitation and photovoice. Photo-elicitation inserts a photograph into the research interview. Photovoice is a similar process carried out in a group. Eleven ABI survivors took photographs of their lives with ABI and participated in photoelicitation interviews. Eight also participated in a photovoice project. Narrative analysis methods were used to analyze participant photographs and interviews transcripts. Lived experience with ABI is illuminated through three patient case studies, each centered on a visual illness narrative with several participant photographs and their interview excerpts.

Laura S. Lorenz, MEd, Faculty of the Heller School of Social Policy and Management, Brandeis University, Waltham, MA USA is a researcher and educator with international experience identifying and communicating research, management improvement, and program results for global audiences. Her research using visual and narrative analysis methods with brain injury survivors has received attention at more than a dozen conferences in North America and Europe since 2006. Dr. Lorenz is Program Manager for Executive Education at the Heller School, Brandeis University. She works with healthcare organizations to develop tailored education programs to meet their management and leadership needs, and provides training in health policy, the patient-provider relationship, empathy, fair process, and qualitative research methods. Dr. Lorenz has pioneered participatory visual research in the US and South Africa to engage patients and communities and picture local problems and strengths. Her book "Seeing Brain Injury: Through the Eyes of Survivors" is under review for the new series "Disability in Society" from Lynne Rienner Publishers.

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