

## **AcademyHealth, Annual Research Meeting 2007, Orlando, FL, June 3-5, 2007**

**Title:** Making Visible the Invisible: Using Action Research to Understand Living with Brain Injury

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**Research Objective:** To gain an understanding of the issues, concerns, and strengths of traumatic brain injury survivors living in the community

**Study Design:** For this action research study, eight members of 'Mild' Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project. Photovoice is a type of action research in which people represent their lives, point of view, and experience using photographs and narratives. Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice. The author facilitated this project with two brain injury survivors: the support group founder and a group member with photovoice experience. The participants took photographs of living with their brain injury, discussed them in a group, wrote narratives to accompany their selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Each survivor took at least two roles of film using a disposable camera with 27 exposures. Participants chose which photographs they wanted to discuss during the meetings and include in the exhibit, and wrote personal narratives for their selected images. The participants, facilitators, and author worked together to develop the exhibit categories and decide where each photograph should go.

**Population Studied:** The participants were all members of the 'Mild' Brain Injury Survivor Support Group, Framingham, MA and volunteered to participate in this additional support group activity. Four received their injuries in car accidents, one when a sign fell on her head, and one through domestic violence. Two participants had an injury resulting from a brain tumor (one with a co-occurring stroke). All were long-term survivors, having received their injuries between three and 31 years prior to the start of the project. Several respondents have been working or volunteering part-time in the community; all receive support from state and/or federal programs.

**Principal Findings:** The participants entitled their exhibit: 'Making Visible the Invisible: Living with Brain Injury.' They grouped their photographs and narratives under eight categories: The Journey, Lost Dreams, Chaos, Challenges, My Advocacy Story, Comfort and Support, Acceptance, and Hope for the Future. Taking photographs triggered participant reflection on their situations and what they wanted to convey to others about living with brain injury. Talking about their photographs with the group prompted deep discussions of emotional and other issues that had not surfaced during regular support group meetings. Study data indicate that from the perspective of these survivors, healing from brain injury is a gradual process that continues over time, even years.

**Conclusions:** This research project provided the participating brain injury survivors an opportunity to play a participant-expert role in the research process. The participants' images and narratives convey their challenges and sense of mutual support as they work to accept their different abilities and move on with their lives.

**Implications for Policy, Delivery or Practice:** Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and the facilitators and barriers to rehabilitation. Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations.

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