

## **Patient Centered Research on TBI Psychiatric Problems**

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**Background:** Literature on patient centered outcomes research (PCOR) on neuropsychiatric symptoms after traumatic brain injury (TBI) is limited.

**Aims:** The overarching goal of our project funded by the patient centered outcomes research institute (PCORI) was to establish a diverse group of TBI stakeholders and engage them in focus group discussions to (1) determine catalysts and challenges in the management of neuropsychiatric symptoms after TBI, (2) identify various strategies for engaging TBI stakeholders in future research projects and creating a PCOR network (3) list important TBI neuropsychiatry research topics, and (4) determine important policy changes related to neuropsychiatric symptoms after TBI.

**Methods:** A diverse group of thirty TBI stakeholders including persons with TBI, caregivers, coordinators, and clinicians were engaged in five focus group discussions. Each focus group lasted for three hours with intermittent breaks. Discussions focused on the following domains: (a) success and challenges stakeholders have experienced in the care and management of neuropsychiatric symptoms after TBI; (b) strategies to maintain the TBI-PCOR network; (c) topics that stakeholders would like researchers to address relating to neuropsychiatric symptoms following TBI; and (d) health care policy changes they would like administrators to implement to improve quality of life after TBI. To summarize each focus group, the project leader (VR) also conducted an in-depth interview with a volunteer from the group on the same day the focus group was conducted. All discussions were audio recorded. All data collected from the discussions were subsequently de-identified. Qualitative analysis was conducted both manually and using Dedoose software by identifying and coding general themes.

**Results:** Participants identified embarrassment and stigma associated with experiencing neuropsychiatric symptoms and inadequate insurance coverage for management of these

symptoms as barriers for recovery. Catalysts or facilitators included education on neuropsychiatric symptoms following TBI in the acute trauma period, provision of literature and resources on TBI mental health at discharge from emergency rooms and acute care trauma units, and providing a comprehensive Do's and Don'ts caregiver plan to caregivers of persons with TBI. Best strategies for engaging and continuing to maintain a brain injury PCOR network included working on a project with clear goals/mission, having regular meetings and providing continued education on TBI neuropsychiatric symptoms to network members. The three common research topics identified by participants included relationship between TBI and aging, determinants of positive outcomes after TBI, and relationship between addiction and TBI. The three important policy changes included making TBI mental health education accessible to all stakeholders, providing incentives for clinicians involved in care of persons with TBI and improving affordability and accessibility of TBI neuropsychiatric care.

Please see attached infographics for complete description of results.

**Conclusion:** We have used this project as a platform to engage TBI stakeholders in discussions on a variety of topics on TBI neuropsychiatry. We hope to use results from this study to develop other projects meaningful to our participants and the larger TBI community. In future, we also hope to continue to engage our participants as partners in other research projects.

**A Request:**

We would like to continue to get feedback and comments from our participants and the brain injury community on the current research project, thoughts, and ideas on other projects. Kindly take a few moments to click on the below link and complete the survey. We thank everyone in advance for his or her effort and time.

