

## Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

### People Caring for a Family Member with a Traumatic Brain Injury Can Benefit from Self-Care Supports

A traumatic brain injury (TBI) can result in lasting brain damage from an accident or other head trauma. A TBI may be mild, moderate, or severe. TBI survivors may develop physical or cognitive disabilities and sometimes need help with daily living tasks like shopping, transportation, and keeping track of appointments. Often, the TBI survivor's spouse or a close family member or friend takes on much of this caregiving responsibility. Becoming a caregiver for a TBI survivor can be challenging, especially in the first months after the TBI. In a recent NIDILRR-funded study, researchers looked at the experiences of these caregivers during the first six months after TBI. They wanted to find out who is most likely to become a primary caregiver to a TBI survivor, how caring for someone with a TBI affects the caregiver's involvement in their own life activities, and what resources caregivers use for support. They also wanted to know what kinds of concerns caregivers most likely have during the first months after the TBI.

Researchers at the [University of Washington Traumatic Brain Injury Model System Center](#) collected data from 153 individuals who provided care to a friend or family member with moderate or severe TBI who had been discharged to the community. The caregivers completed two interviews, one just prior to the time of discharge and one at six months after discharge. The researchers asked caregivers about their relationship with the TBI survivor, their participation in community activities, and their use of various resources for support or services. The researchers also looked at additional data from half of the caregivers, who were randomly assigned to a telephone counseling intervention where they learned how to use a problem-solving approach to address their specific concerns during biweekly phone calls.

From the interviews with all of the participating caregivers, the researchers found that:

- Most caregivers had a close relationship with the TBI survivor where many were spouses or parents of the survivor. They had known the TBI survivor for an average of almost 25 years, and most lived with the TBI survivor or spoke to him or her up to several times per week. Most caregivers were female, while most TBI survivors were male.
- Many caregivers reduced their own personal and financial involvement in activities after they began caregiving. Over the six months following discharge home, 77% of caregivers reported cutting back on leisure activities, 58% reported making financial sacrifices, 47% reported reducing school or work hours, and 43% reported taking at least a month off from school or work to devote more time to caregiving.
- By six months after discharge, many caregivers were returning to work, school, and doing things they enjoyed. At that time, 45% of caregivers reported cutting

back on leisure activities, 20% reduced their work or school hours, and 12% reported taking a month or more off of work or school. The financial outlook also slightly improved, with 43% of respondents reporting making financial sacrifices.

- Caregivers were more likely to reach out to family and friends for support rather than tapping into more formal resources. Only a small percentage of caregivers reported using formal resources like caregiver support groups, counseling, or government-funded home healthcare assistance.

Next, the researchers looked at the topics discussed during the telephone counseling sessions to learn more about the types of concerns that caregivers have in the first 6 months of caring for a new TBI survivor. The researchers found that these caregivers had a variety of concerns. Each caregiver who participated in the counseling intervention brought up an average of eleven concerns during the six-month period. Overall, caregivers were most concerned about managing their own emotions, getting things done such as housework, helping the survivor manage emotions, and maintaining their own healthy habits like exercise and good diet.

The authors noted that needs of the TBI caregiving community are wide-ranging, particularly in the first few months after injury. The concerns brought up for problem-solving during a telephone counseling intervention might not represent all of the concerns that caregivers might have. In addition, caregiver concerns and challenges might change over the years after a TBI occurs. Researchers may want to look at the longer-term experiences of caregivers to find out how to best support them.

According to the authors, caregivers may find it challenging to balance their own needs with those of the TBI survivor. Caregivers may be hesitant to reach out beyond their family circle for their own emotional support, or they may not be aware of the available resources in the community. Caregivers may benefit from the opportunity to discuss these kinds of issues with clinicians while the TBI survivor is still in the inpatient setting. Planning respite care and ways for caregivers to engage with community resources before leaving the hospital may help ease the stresses of caregiving. The TBI survivor's follow-up medical appointments may present another good time for clinicians to check in with the caregiver and address concerns.

#### To Learn More

Understanding TBI Issues for Caregivers is a free online training course from the Rehabilitation Research and Training Center on Developing Strategies to Foster Community Integration and Participation for Individuals with TBI. The 5-unit course covers communication issues, emotional and behavioral changes, managing attention problems, managing memory problems, and problem solving issues.

[http://tbicommunity.org/resources/courseAvenue/caregivers\\_course.htm](http://tbicommunity.org/resources/courseAvenue/caregivers_course.htm)

The Center on Brain Injury Research and Training offers many resources for families facing TBI including two interactive learning courses and a curated reading list:

<http://cbirt.org/resources/family/>

BrainLine.org, a service of WETA, offers a diverse collection of articles, guides, and forums for people with TBI, their families, and professionals. <http://www.brainline.org>

To Learn More About this Study

Powell, J.M., Wise, E.K., Brockway, J.A., Fraser, R., Temkin, N., and Bell, K.R. (2017) [Characteristics and concerns of caregivers of adults with traumatic brain injury](#). Journal of Head Trauma Rehabilitation, 32(1) E33-E41. This article is available from the NARIC collection under Accession Number J75310.

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