Medical Xpress

Taking care of people with TBI: New tool could speed caregiver research

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A traumatic brain injury happens in an instant: a battlefield blast, a car crash, a bad fall. But the effects can last a lifetime—and can leave the survivor dependent on daily care from their loved ones for decades.

Now, a new tool seeks to give a voice to those caregivers, who spend countless hours tending to the daily needs of family members whose moods, thinking and abilities seemed to change overnight.

Developed by researchers from across the country who worked with hundreds of caregivers of people with TBI, it provides a new standard way to measure the physical, mental and emotional effects of caring for survivors of TBI.

The researchers hope it can form the basis for a new wave of research that could inform clinical care for patients and their caregivers, as well as, caregiver training and support programs, and even caregiver reimbursement policies.

They've published the results of a rigorous evaluation of the tool in a special supplement to the journal *Archives of Physical Medicine and Rehabilitation*, and are sharing the tool on several platforms for researchers.

They also hope the tool, called TBI-CareQOL Measurement System, could be useful to researchers who want to study caregivers of other patients whose "new normal" is very different from the one they had before, and isn't likely to change.

Many TBI survivors suffered their injury in the prime of life, and many during service to the nation. TBI is the most common injury among service members who returned from the wars in Iraq and Afghanistan, with nearly 384,000 service members and veterans affected. One-third of them, and another 90,000 civilians who sustain TBIs each year, are left with moderate to severe disability from their injury.

"Caregivers of persons with TBI are underserved and overlooked," says Noelle Carlozzi, Ph.D., the University of Michigan Medical School psychologist who led the effort. "The medical system treats the patient and sends them home, but behind many of our severely injured patients are family caregivers who we don't do enough to train, support or study in a scientific way."

Carlozzi heads the Center for Clinical Outcomes Development and Application, based in the Department of Physical Medicine and Rehabilitation of Michigan Medicine, U-M's academic medical center.

A team effort

In the new papers, she and her colleagues from Northwestern University, Wayne State University/the Rehabilitation Institute of Michigan, the Walter Reed National Military Medical Center/Defense and Veterans Brain Injury Center, Baylor College of Medicine/TIRR Memorial Hermann, and the University of Delaware lay out how they developed and tested the TBI-CareQOL tool.

The team worked with 560 caregivers who took care of 344 civilians and 216 military service members or veterans who had suffered a TBI more than a year earlier. They found the caregivers through their own institutions and through outreach efforts from the Hearts of Valor caregiver support network run by the Operation Homefront nonprofit organization, and by the Brain Injury Association of Michigan.

By taking time out of their already busy schedules to fill out banks of computerized questionnaires that the research team developed, the caregivers made it possible to create the new tool.

The researchers also got permission to look at the medical records of the patients the caregivers were taking care of, so they could know the severity of the injury and other information.

Thanks to this help, Carlozzi says, the TBI-CareQOL tool should enable a much stronger form of research on caregivers' health and quality of life. This could help bring new resources to this field of study.

Capturing many measures

The tool includes measures of how much of a sense of loss the caregiver feels for themselves or the loved one they're caring for, how much anxiety they feel about their ability to tend to their loved one's needs, how trapped they feel in their role as caregiver, and how much strain the daily demands of their loved one's care places on them. This latter measure includes feelings of being stressed, overwhelmed or even downtrodden by caregiver responsibilities.

Carlozzi notes that in addition to these new measures, the new tool includes standard measures of health-related quality of life used to study patients with many conditions. Called PROMIS measures, they have been previously validated in other studies; the new papers validate them among caregivers of people with TBI.

The team envisions that most caregivers who take part in future studies that use the TBI-CareQOL tool will do so on tablets, smartphones or computers. They've designed it so that caregivers answer questions most pertinent to them based on their answers to previous questions—which means it takes up the shortest time possible but still gets complete information. A paper form will also be available.

The computerized version will be available through Assessmentcenter.net, as well as other online data capture systems. They will also make it available through a website that the team is developing. In the meantime, paper forms are available by contacting Carlozzi.

Potential uses

Measuring caregivers' current state, and how it changes over time, could become part of the routine clinical care for patients with TBI, she says. How well a caregiver is faring can affect how well the patient does, for instance with therapy, medications and behavioral health issues.

"We hope that in addition to the TBI-CareQOL being used for research, clinicians will adopt these measures to screen caregivers during office visits by patients with TBI, and figure out who needs additional services," she says, noting that caregivers usually attend their loved ones' appointments because patients with TBI can have trouble remembering or accurately reporting what their clinicians said or recommended.

Assessing caregivers could also help fine-tune the financial, social and service support they receive from various sources. Currently, some family caregivers who have lead responsibility for caring for current and former military service members with TBI can receive compensation for their time. So can some caregivers of people injured in automobile accidents in states with no-fault auto insurance.

But often these payments are not enough to provide a level of income similar to what they could receive in the workplace, even though many caregivers have to leave their jobs or cut back on their hours in order to care for a loved one with serious lasting issues from their TBI. That financial stress can often compound the emotional stress caregivers feel.

In upcoming papers, Carlozzi and her colleagues will report their findings from measures related to disruption of family life—a topic that has special importance to military and veteran caregivers, who often have small children to care for at the same time they're caring for a TBI-survivor spouse. They also hope to do more to measure sleep and activity levels in caregivers.

"Thanks to the efforts of all our partners, and our funding from the National Institutes of Health and the Defense and Veterans Brain Injury Center, we're glad to share this validated, rigorous tool for assessing the quality of life of caregivers of persons with TBI, which we hope will provide a much-needed understanding of their lives and opportunities to help improve their care," says Carlozzi.

More information: Noelle E. Carlozzi et al, The TBI-CareQOL Measurement System: Development and Preliminary Validation of Health-Related Quality of Life Measures for Caregivers of Civilians and Service Members/Veterans With Traumatic Brain Injury, *Archives of Physical Medicine and Rehabilitation* (2018). DOI: 10.1016/j.apmr.2018.08.175

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