

## Editorial

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# Setting a research agenda for caregiving after neurotrauma and neurological disability

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**Abstract.** Research on caregiving after neurotrauma and neurological disability critically extends the focus beyond individuals with neurological conditions to family, friends, and significant others who also are greatly impacted. This article introduces a thematic issue of *NeuroRehabilitation* on the topic with 10 articles that coalesce around the three approaches of (a) literature reviews, (b) empirical studies, and (c) caregiver intervention studies. This introductory article introduces each of these articles and synthesizes them to chart important future directions for research on caregiving after neurotrauma and neurological disability including: (a) a focus on evidence-based common factors caregiver interventions, (b) dissemination and implementation science approaches to imbedding caregiver interventions into health care systems, and (c) cultural considerations in the context of caregiving. This thematic issue helps rehabilitation clinicians incorporate more of a systems perspective to improve the functioning not only of individuals with neurological conditions but also their caregivers.

Keywords: Caregiving, neurotrauma, neurological condition, disability, neurorehabilitation

## 1. Introduction

The responsibility of care for individuals with neurotrauma and neurological disability (NND) defaults to informal caregivers (e.g., family members, friends, significant others), who often lack the knowledge, skills, and supports to optimally facilitate the health and well-being of their loved ones and themselves. For example, depending on injury severity, half of informal traumatic brain injury (TBI) caregivers devote over 60 hours a week to the care recipient (Perrin et al., 2013). Caregivers are at risk for

poor psychological and physical health; persistent and common NND caregiver issues include burden, depression, and anxiety (Kreutzer et al., 1994; Marsh et al., 1998a, 1998b, 2002; Nabors et al., 2002; Ponsford et al., 2003). These problems can become so severe that one study found that over 20% of TBI caregivers were suicidal within 4 months of assuming their caregiving role (McKee et al., 2021). Caregivers' health care service use increases as burden increases (Martindale-Adams et al., 2016), and a chronic burden of caregiving leads to higher rates of health care utilization, hospitalizations, and mortality (Hall et al., 1994; Marsh et al., 1998a, 1998b; McPherson et al., 2000; Schulz & Sherwood, 2008).

This thematic issue of *NeuroRehabilitation* builds upon this platform of existing caregiver research to debut a series of 10 articles illuminating the needs of NND caregivers. Each article conceptualizes care-

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giving as a critical research focus of the field of neurorehabilitation and incorporates new insights into how the field may be better set up to support NND caregivers in their important role. The articles coalesce around the three approaches of (a) literature reviews, (b) empirical studies, and (c) caregiver intervention studies. This introductory article will thematically introduce each of these 10 articles and then draw upon the work contained in this thematic issue to highlight three important future directions for research on caregiving after NND.

## 2. Thematic issue articles

### 2.1. *Literature reviews*

In the first article, Kjeldgaard, Soendergaard, Wolffbrandt, and Norup (this issue) reviewed 24 published studies that holistically found that brain injury caregivers had higher burden if they cared for an individual with more severe injuries, decreased physical and neuropsychological functioning, and lower mental health. Caregivers also had higher burden if they spent more time caregiving, had greater unmet needs, and had lower mental health themselves. The authors suggested that future intervention research target brain injury caregivers with these specific characteristics given the risk for increased burden. They also suggested that future research focus on caregiver coping style, problem-solving ability, and personality which are relatively understudied areas in the caregiving literature.

Hines et al. (this issue) reviewed 18 published studies on resilience interventions for individuals with acquired brain injury and their caregivers. The authors found that dyadic and caregiver resilience interventions can improve heterogeneous mental health outcomes, but unfortunately lack of a standardized conceptualization or index of resilience limited the generalizability of these interventions. The authors argued that acquired brain injury caregiver- or dyadic-specific conceptualization and measurement of resilience in intervention studies would help the field better assess the effects of these interventions.

### 2.2. *Empirical studies*

Rasmussen, Howe, Andelic, and Soberg (this issue) used a structural equation model in a sample of 60 individuals with TBI and 62 family members

to examine the associations among resilience, self-efficacy, mental health-related quality of life, and family dynamics. The authors found that these protective factors were highly associated with positive family dynamics, suggesting that the improvement of family dynamics after TBI may be a key to increasing protective factors in both individuals with TBI and their family members.

Klyce et al. (this issue) examined the associations between emotional awareness, emotional functioning, and empathy in 90 individuals with TBI and their caregiver's burden. In regression models controlling for demographics and other variables, the authors found that high levels of hostility and low emotional self-awareness in individuals with TBI were uniquely associated with higher caregiver burden. The authors argued that screening for these predictors of increased caregiver burden and behavioral management treatment for these neurobehavioral issues combined with patient and family education could be helpful to minimize the negative impacts on caregiver burden.

Pugh et al. (this issue) conducted a confirmatory factor analysis of the Affiliate Stigma Scale in a sample of 148 Parkinson's disease caregivers from Mexico. The authors found extremely poor model fit in both the one-factor and three-factor models and implemented an item trimming approach to arrive at a final five-item Affiliate Stigma Scale Spanish Short Form that had adequate internal reliability, good convergent validity, and an adequately fitting one-factor structure. The authors argued that the new short form of the scale will facilitate future research on measuring caregiver affiliate stigma in Spanish-speaking populations and also in the development of caregiver interventions to reduce affiliate stigma and its harmful effects.

Kuzu, Perrin, and Pugh (this issue) similarly translated the Affiliate Stigma Scale into another language (Turkish) and examined the psychometric properties of the scale in 82 Turkish spinal cord injury/disorder (SCI/D) caregivers. The authors, like Pugh et al. (this issue), found extremely poor model fit in both the one-factor and three-factor models. An exploratory factor analysis helped identify six items to retain in the Turkish short form, which showed adequate or good fit in a follow-up one-factor confirmatory factor analysis. The short form showed good internal consistency and convergent validity with measures of caregiver anxiety and burden. The authors noted the potential of the Turkish Affiliate Stigma Scale Short Form to facilitate research on affiliate stigma in SCI/D caregivers and in Turkey in particular where

very little research to date has been conducted on this population or topic.

### 2.3. *Caregiver intervention studies*

Martindale-Adams, Zuber, Burns, and Nichols (this issue) conducted a two-arm randomized clinical trial comparing interventions to help 163 parent caregivers of adult children veterans with polytrauma, TBI, and/or posttraumatic stress disorder (PTSD). The authors compared the effects of Resources for Enhancing All Caregivers' Health (REACH) to pre-recorded online educational webinars in improving caregiver depression, anxiety, burden, and management of troubling and concerning behaviors. While caregivers in both arms improved in all outcomes, REACH caregivers showed additional improvement in the management of concerning behaviors. The authors argued that while REACH may be particularly helpful for caregivers, prerecorded online educational webinars may also be beneficial for caregivers in resource-limited settings.

Juengst et al. (this issue) conducted a multi-site randomized feasibility trial across three sites of Problem-Solving Training (PST) for 94 caregivers of individuals with TBI during inpatient rehabilitation. The authors found that caregivers completing greater than three sessions were less likely to be employed and more often spouses. Though their study was underpowered to examine intervention effects, small-to-medium sized improvements in caregiver depression and burden occurred. The intervention may be particularly useful for caregivers of individuals with TBI who spend more time in inpatient rehabilitation, as those caregivers completed a greater number of sessions.

Rhudy, Hines, Farr, Esterov, and Chesak (this issue) conducted an observational pilot study examining the feasibility and acceptability of the Resilient Living Program in a sample of 16 individuals with stroke or brain tumor undergoing comprehensive acute inpatient rehabilitation and/or their family caregivers. The authors generally found the intervention was feasible and that it yielded statistically significant improvements in fatigue, anxiety, and physical function. This article serves as a platform for larger trials examining resilience interventions in this population, particularly through a caregiver/care recipient dyadic lens.

In the last article of the thematic issue, Perrin et al. (this issue) conducted the first systematic, large-scale randomized clinical trial of a TBI caregiver interven-

tion in Latin America. Their five-session Transition Assistance Program uniquely targeted 89 TBI caregivers during and after the transition from hospital to home after an acute TBI, and the authors collected data both from TBI caregivers and individuals with TBI at baseline, 2 months after hospital discharge, and 4 months after discharge. Intervention group caregivers had lower burden than those in the control at the two follow-ups, and individuals with TBI whose caregivers had been in the intervention group had lower depression. The findings underscore the importance of evidence-based caregiver interventions immediately after neurotrauma when family members are first learning to provide care, especially in medically underserved global regions.

## 3. **Implications and future research areas**

These 10 thematic issue articles span a strong array of methodological approaches and NND caregiving populations. The three approaches of literature reviews, empirical studies, and caregiver intervention studies build on and complement each other. The literature reviews help the field of neurorehabilitation understand what caregiving research has been conducted to date and where important gaps in caregiving research remain. The empirical studies present novel findings uncovering NND needs across TBI, Parkinson's disease, and SCI/D, with data collected in the U.S., Mexico, and Turkey. Finally, the four caregiver intervention articles concretely demonstrate how these needs can be targeted in clinical interventions to improve outcomes both for NND caregivers and individuals with NND themselves. Despite the comprehensiveness of this thematic issue, much more research on NND caregivers needs to be conducted, particularly in the following domains.

### 3.1. *Evidence-based common factors caregiver interventions*

I respectfully argue that the field of neurorehabilitation should taper down the development of new caregiver interventions in favor of condensing the caregiver interventions that already exist into their essential elements, or common factors. For example, in dementia alone, literally hundreds of caregiver interventions already exist (Walter & Pinquart, 2020). While there are some NND caregiver interventions that target very specific or sometimes novel caregiver outcomes (e.g., sleep, exercise, family

dynamics, spirituality, etc.), the vast majority involve the same—or nearly the same—elements and target similar or very related outcomes (e.g., burden, strain, depression, life satisfaction, NND symptom management, etc.). These approaches often include: (a) PST; (b) stress management; (c) cognitive-behavioral techniques to modify unhelpful thinking patterns; (d) goal setting; (e) social skills or communication training; and (f) connections with secondary caregiving resources. Many also include psychoeducational material tailored to the specific NND, although unfortunately research has suggested that psychoeducation by itself tends not to be very effective in improving caregiver outcomes (Carnevale, Anselmi, Busichio, & Millis, 2002).

Researchers, clinicians, academic departments, clinics, and even funding agencies tend to be extremely disease- or disability-specific in their focus. As a result, resources and efforts to support caregivers tend to operate in disciplinary silos with limited cross-pollination of effective caregiver interventions or approaches by professionals focused on specific NNDs. This unfortunately creates scenarios in which caregiver researchers “recreate the wheel” time and again with new caregiver interventions for their specific NND of interest. This is not in any way to say that all caregiving processes—and as a result needed interventions—are the same. Caregivers who provide support for individuals with sudden-onset NNDs (e.g., TBI, SCI, stroke) tend to go through an extremely quick role transition and therefore have unique experiences in comparison to caregivers supporting individuals with more gradual neurodegenerative diseases (e.g., dementia, Parkinson’s disease, multiple sclerosis, amyotrophic lateral sclerosis, etc.). Further, caregivers who provide support for children, younger or middle-aged adults, and older adults similarly have unique experiences, especially depending on their relationship to the individual with the NND.

As a result, it is important that caregiver interventions be appropriately modified for and tested in different NNDs and caregiving populations. For example, the Transition Assistance Program was specifically created to target quick-onset neurological conditions and support new caregivers as they learn to be caregivers for the first time while the individual with the NND transitions from hospital to home. It was originally developed for stroke caregivers (Perrin et al., 2010), modified for SCI (Perrin et al., 2021), and now in this thematic issue modified for TBI (Perrin et al., this issue). Similarly, the

REACH intervention was created to support caregivers approximately 6 months after assuming their caregiving role or later and therefore by contrast targets caregiving issues encountered in more of the chronic phases of caregiving. It was originally developed for dementia caregivers (Belle et al., 2006) and has since been adapted for SCI/D (Schulz et al., 2009), multiple sclerosis (J. Martindale-Adams et al., 2020), posttraumatic stress disorder (PTSD; Martindale-Adams et al., 2021), and now in this thematic issue parental caregivers of veterans with polytrauma, TBI, and/or PTSD (Martindale-Adams et al., this issue).

### *3.2. Dissemination and implementation (D&I) science*

Instead of such a heavy focus on the development of new, heterogenous caregiver interventions, I would argue that the field of neurorehabilitation move much more strongly in the direction of D&I science approaches to determining how best to imbed into health care systems the common factors components of caregiver interventions that already exist and have been shown to be effective. Unfortunately, the vast majority of NND caregiver interventions die as soon as the grant dollars run out and the study is over, or they tend to have extremely limited health system uptake. I say this humbly given that this is also true of the half dozen or so caregiver intervention studies I have been a part of to date. Only once the field acknowledges this reality can we begin to reengineer the caregiving research paradigm so that our interventions more broadly improve the lives of caregivers. If the field of neurorehabilitation truly wants to help the greatest number of NND caregivers, D&I research is a critical next frontier, not the development of caregiver interventions that are substantively similar to existing caregiver interventions but have a slight rebranding.

Caregiver intervention studies would benefit from adopting at the very least a D&I science Type 1 Hybrid Effectiveness-Implementation approach (Curran et al., 2012). This type of study examines the effects of a caregiver intervention on key caregiver outcomes, while gathering implementation data and input from important stakeholders throughout various study phases. A Type 1 Hybrid design rigorously tests a clinical intervention and secondarily gathers data to inform subsequent implementation research trials. Type 1s would measure caregiver functioning or symptoms in response to a caregiver intervention, while simultaneously evaluating acceptability

and feasibility of implementation through qualitative, process-oriented, and mixed methods (Bernet et al., 2013). A Type 2 Hybrid approach simultaneously tests a caregiver intervention and its implementation strategy and finds a reasonable balance between the two. A Type 3 Hybrid design primarily tests an implementation strategy, typically with indices of fidelity to the caregiver intervention and its adoption. Secondary outcomes tap caregiver-level effects of the intervention, such as symptoms or functioning (Bernet et al., 2013).

The U.S. Department of Veterans Affairs (VA) National Caregiver Center at the Memphis VA Medical Center is a great model for caregiver researchers in D&I. Their flagship caregiver intervention is REACH, one of the most widely used and validated NND caregiver interventions in the world. Their research team has specifically taken D&I approaches to determining how to implement REACH across the full VA Health Care System (Nichols et al., 2016). They also have modified and tested REACH for most NNDs, and they have a formal training infrastructure to certify clinicians in the intervention so that they can use it with their own patients and caregivers. The Caregiver Center trains, certifies, and provides REACH materials to clinicians at VAs across the U.S. and also directly delivers the intervention to any caregiver of a veteran nationwide upon clinician referral. To quantify REACH's implementation and spread, in 2020, 341 clinical staff at 173 VA sites received REACH training and enrolled 643 caregivers. In 2020, each VA facility had at least one staff member available to deliver REACH through their site. In 2020, 257 additional staff members were trained, and a total of 1,685 caregivers were served through REACH. In 2020, REACH became a performance standard for each Network Director and Caregiver Support Program team at all local facilities. Each facility was mandated to provide REACH to at least four caregivers.

### 3.3. *Cultural considerations*

Just as with different NNDs, caregiving needs and resulting interventions can vary dramatically across different cultures. Even the construct of caregiving itself can have tremendously different meaning and implications based on one's gender (Perrin et al., 2015) or cultural background. For example, despite having much fewer health system resources than TBI caregivers in the U.S., those in Mexico report lower levels of depression than their U.S. counter-

parts (Juengst et al., 2022). The authors interpreted this finding to reflect the idea that Latino communities sometimes view caring for elders as an honor and a role that family members willingly assume. Similarly, Nguyen, Nguyen, Tran, and Hinton (2021) found that dementia caregivers in Vietnam interpreted dementia symptoms as a normal part of the aging process instead of a disease and saw caregiving as a family and moral obligation, despite voicing notable challenges associated with caregiving. Given these potential differences in the construct of caregiving itself, it is critical that even evidence-based caregiver interventions be tailored for and tested in different cultural contexts, whether within the U.S. or internationally. REACH has been modified for and tested in dementia caregivers in Vietnam (Hinton et al., 2020).

## 4. Conclusion

This thematic issue of *NeuroRehabilitation* on caregiving after NND research reflects a critical area of inquiry, expanding the focus not just to individuals with NND but to their caregivers and family members as well. The 10 articles in this issue together summarize previous NND caregiver literature, identify important needs of NND caregivers, and develop and test interventions for NND caregivers. This thematic issue helps clinicians consider how they can best support NND caregivers in not just looking after their loved ones with an NND, but themselves as well.

## Conflict of interest

The author reports no declarations of interest.

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