

Special Article

Family caregiving research: Reflecting on the past to inform the future

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Objective: Family caregiving research has evolved since its inception in the late 1970s. The objective of this brief report was to summarize the research areas and findings to date with the goal of highlighting directions for future research.

Design: Narrative review.

Setting: Not applicable

Participants: Published scientific articles in neurological populations including spinal cord injury, traumatic brain injury, and stroke.

Interventions: Not applicable

Outcome Measures: Not applicable

Results: Caregiving research began with a description of the impact of providing care on caregiver health and wellbeing. Intervention research followed to support caregivers in their role and improve caregiving outcomes. Recent reviews conclude a “one size fits all” intervention will not be sufficient to support caregivers. New research suggests caregivers have different patterns of adjustment to the caregiving role highlighting heterogeneity in the caregiving population. Research is also advancing to support patients and families as they transition across care environments by enhancing the timing of intervention delivery. Health care systems do not routinely adopt evidence-based caregiver interventions. As a result, recent research has begun to identify factors that influence the adoption of evidence-based caregiver interventions by health care systems. Ultimately, family centered care that addresses the needs of not only the patient but also the caregiver may be the best way to meet the needs of a heterogeneous group of caregivers across the care continuum.

Conclusions: Family caregivers make an important contribution to the health and wellbeing of individuals with spinal and other neurological conditions. Ultimately, system changes, like family centered care, may be best suited to meet the complex needs of this heterogeneous group of caregivers.

Keywords: Caregiver, Neurological injury, Stroke, Traumatic brain injury, Spinal cord injury, Family centered care

Family caregivers play an important role supporting the recovery, rehabilitation, and community re-integration of adults who experience a neurological injury including stroke, traumatic brain injury, and spinal cord injury. They support a range of everyday activities and self-management strategies.¹⁻³ In the context of spinal cord injury, the physical care provided by family caregivers matches and often exceeds the

receipt of formal care (e.g. from personal support workers).⁴ Caregivers also support transitions across care environments and often report this as challenging.⁵ Approximately one in four adults are caring for a family member or friend with a disability residing in the community.⁶ Their unpaid labor is substantial and, therefore, essential to the sustainability of health and social care systems.^{7,8} In recognition of their important role, family caregiver research has been growing and evolving over the past 40 years. It is important to reflect upon the research conducted to date to inform our next research priorities. This article will review the

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history of caregiver research and provide suggestions for future directions to support family caregivers to individuals with neurological injury.

The earliest caregiving research aimed to understand the impact providing care had on caregiver health and wellbeing including burden (e.g.^{9–11}). Some of the earliest research with caregivers to people with stroke was published in 1981,¹² spinal cord injury in 1989,¹³ and traumatic brain injury in 1994.¹⁴ Research findings highlight the negative impact providing care can have on caregiver wellbeing including depression, anxiety, and social restrictions.^{10, 15–18} Examining positive outcomes associated with caregiving has been less common. Happiness,¹⁹ resiliency,²⁰ and wellbeing¹³ have been identified as some key positive outcomes associated with providing care. Caregivers who report higher levels of social support report fewer negative and more positive outcomes (e.g.²¹). Findings from this research suggests negative and positive consequences of caregiving on caregiver outcomes are common across illness populations.

As the number of studies describing the impact of providing care increased, research shifted towards the development and evaluation of interventions to improve caregiver outcomes (e.g.^{22–24}). Qualitative research often provides the basis for developing complex interventions for family caregivers.^{25,26} These interventions tend to be multicomponent and offer psychosocial education and caregiver training (e.g. skills training,^{1,27} problem solving²⁸). Research evaluating caregiver outcomes of psychosocial interventions have yielded mixed results.²⁹ A meta-review of systematic reviews of interventions to support caregivers concluded there is no “one size fits all intervention to support carers” suggesting caregivers varied in their needs and ability to benefit from different types of interventions.³⁰

We are beginning to understand this variability in caregivers’ needs for intervention as we begin to understand that caregivers are not a homogeneous group. Specifically, research has begun to identify groups of caregivers who have different patterns of adjustment to the caregiving role. For example, there is research with family caregivers to individuals with a traumatic spinal cord injury revealing different patterns of depression symptoms over the first-year post injury.²⁰ Caregivers were classified as being chronic (high depression increasing over time), recovering (intermediate levels of baseline depression that initially increased and then decreased over time), or resilient (low depression decreasing over time). Caregivers in the chronic group reported poorer mental health outcomes

and may be in greater need for support.²⁰ Using a similar analytic approach with caregivers to survivors of critical illness, we were able to characterize caregivers with persistent and elevated levels of depression symptoms over the first-year post illness.³¹ These caregivers reported a greater impact of patient care on their valued activities, were younger, had less social support, had less sense of control over life, and experienced less personal growth due to caregiving.³¹ Further, needs in the spinal cord population may also vary by gender, language, immigration status, household income, and injury type.³² This emerging research suggests that caregivers are far from a homogeneous group with common experiences and needs but individuals who have very unique needs for support that may be difficult to meet with ‘one size fits all’ interventions.

Historically, caregiver interventions have been developed for specific care environments including acute, rehabilitation, or community care settings without any strategies to enhance the continuity of care across these environments. At the same time, caregivers commonly highlight the challenges associated with supporting transitions across care environments.⁵ As a result, research has begun to explore caregivers’ experiences and needs over time to inform transitional models of care. For example, the “Timing it Right” framework developed with the stroke population aims to understand how caregivers’ support (*i.e.* informational, emotional, tangible and appraisal) needs change across illness trajectories and care environments.³³ It describes five phases that families experience from the time of the health event, through a period of stabilization, as the patient and family are preparing to return home, the first few months at home, and over a longer period of adjustment at home. Qualitative research has demonstrated changes in caregivers’ support needs over these phases.²⁵ This framework and qualitative research informed the development of an intervention to provide caregivers with the right support at the right time as family’s transition across care environments.^{25,34,35} We have extended this research to understand caregiving phases, changing needs for support, decision-making, and service use in caregivers to individuals with Alzheimer’s disease^{36–38} and critical illness.^{39,40} This research suggests caregivers needs change across care environments and models of care can meet these changing needs for support as patients and family’s transitions across care environments.⁴¹

Recognizing the challenges associated with health care systems adopting new scientific evidence,⁴² more recent research has examined factors associated with

implementing caregiver programs and interventions into clinical practice (e.g.^{43,44}). For example, we identified factors at the individual, organizational, and system levels that may enhance the adoption of caregiver programs into stroke systems of care.^{43,45,46} This research highlights the challenges that need to be overcome to make caregiver support programs part of standard clinical practice.

Due to the complexity associated with meeting caregivers' needs, there has been a consistent call to incorporate family caregivers into patient care (e.g.^{47,48}). A review of models of family-centered care for adult populations has suggested that there are aspects of family-centered care that are universal and applicable across populations and aspects that are illness specific (e.g. patient, family, and health care professional education).⁴⁹ Across illness populations and care contexts, family-centered care models aim to develop and implement patient care plans within the context of families. To accomplish this, enhanced collaboration between family members and health care providers, consideration of family contexts, family-centered policies and procedures, and patient, family, and health care professional education is needed.⁴⁹ Adopting family-centered care may be a timely solution to meet the complex and varying needs of family caregivers.

In conclusion, family caregivers play an important role supporting recovery, rehabilitation, and community reintegration of individuals who have experienced a neurological injury. Caregivers experience positive and negative consequences due to their caregiving. Intervention research struggles to meet the needs of heterogeneous groups of caregivers across the care continuum. Implementation science research has begun to shed light on factors that need to be addressed as we strive to change care models to better support family caregivers. Future research should continue to understand the impact of diversity on caregivers' needs for support. It should also continue to develop and evaluate alternative models of care to meet the needs of caregivers across the care continuum. Family-centered care may be the way forward to optimize care systems' abilities to meet the heterogeneous needs of family caregivers. Ultimately, caregivers must be supported as they are essential to the wellbeing of those they care for and to the sustainability of our health care systems.


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