

Family and Support Networks Following Critical Illness



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KEYWORDS

• Psychosocial outcomes • Informal caregivers • Social support • Critical care

KEY POINTS

- Caregivers of intensive care patients can experience significant emotional and social problems during and after exposure to the critical care environment.
- Emotional issues such as anxiety, depression, and symptoms of posttraumatic stress disorder are prevalent in this group in the months after a critical care discharge.
- There is minimal interventional research exploring how best to support this vulnerable group.
- Future research should focus on caregivers, with specific emphasis on health and social support.

INTRODUCTION

Within the last few decades, the critical care community has increasingly focused on outcomes after an intensive care stay and morbidity attributable to intensive care unit (ICU) survivorship.^{1,2} This survivorship literature uses a variety of different patient-reported outcome measures,³ which has resulted in the standardization of such outcomes.^{3,4} Comparatively, the focus on family-reported outcomes has been significantly less. With the emergence of terms such as postintensive care syndrome—family^{5,6} and family intensive care syndrome,⁷ and the development of family-centered care guidelines,⁸ greater attention has been drawn to the impact of critical illness on

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family members. Reviews have synthesized the existing family outcomes literature that highlights the adverse outcomes experienced during the ICU admission.^{9,10} These problems persist in the short term; however, the longer term impact (beyond 2 years) is currently unknown.^{9,10}

This gradual shift to focus more broadly on the outcomes of the family and not just the patient will contribute valuable knowledge to our understanding of survivorship. This factor is particularly important given the reliance on family members in Western societies to adopt the role of informal caregiver to support the patient once discharged home. For consistency with our previous research in this field, we have used the following definition of an informal caregiver reported in the critical care literature by Choi and colleagues¹¹: “the individual who provided the majority of emotional, financial, and physical support for the patient or the individual primarily responsible for caring for the patient on an unpaid basis.”

The dependence on informal caregivers to provide care has far-reaching societal and economic implications. As Cameron and colleagues¹² highlighted, in the United States and Canada, this unpaid contribution to patient care would have cost \$642 billion and \$27 billion, respectively, if professionals had undertaken this role.^{13,14} Unfortunately, caregivers may have to provide care to the patient at a time when they might be psychologically vulnerable.^{9,15}

In many countries worldwide, formal follow-up and aftercare is not a routine part of intensive care service delivery. Instead, many patients and their caregivers must learn to adapt to their new lives and impairments with limited support from the health care system. In an attempt to rectify the current services gaps, clinician-researchers are now designing and conducting interventional studies with the aim of reducing the morbidity experienced by caregivers. It must also be recognized that caregivers have distinct and differing needs from patients and, therefore, ought to be treated differently in terms of outcome measurement and design of interventional research.

This article reviews the literature on outcomes of informal caregivers of ICU survivors and describes newer approaches to potentially decrease psychosocial morbidity, highlighting the current knowledge gaps. We discuss innovative approaches and improvement methods to design ICU aftercare programs that can rapidly build social support networks for patients and families and identify key areas for research. We have chosen to focus solely on caregivers of survivors because we believe bereaved caregivers are a different cohort with different outcomes and needs that are beyond the scope of this article.

PSYCHOSOCIAL OUTCOMES OF INFORMAL CAREGIVERS ACROSS THE CARE ARC

A previous systematic review by the author (KH) documented the psychosocial outcomes of informal caregivers from the ICU to long-term follow-up (out to 2 years after ICU discharge). This review of 14 studies identified depression as the most commonly reported outcome with a prevalence of 76% during the ICU admission, decreasing to 23% to 29% at the 1-year follow-up. This rate is comparable with those observed in caregivers of people with dementia.⁹ For the purposes of this article, we reran the search using the original terms and synthesized the state of the science of caregiver psychosocial outcomes since this earlier systematic review.⁹

We were able to identify 8 new studies and provide a summary of quantitative and qualitative studies in **Tables 1** and **2**, respectively. The most common measures of psychological distress included depression, anxiety, and posttraumatic stress

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