Peer Support as a Novel Strategy to Mitigate Post–Intensive Care Syndrome

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ABSTRACT

Post–intensive care syndrome, a condition defined by new or worsening impairment in cognition, mental health, and physical function after critical illness, has emerged in the past decade as a common and life-altering consequence of critical illness. New strategies are urgently needed to mitigate the risk of neuropsychological and functional impairment common after critical illness and to prepare and support survivors on their road toward recovery. The present state of critical care survivorship is described, and postdischarge care delivery in the United States and the potential impact of the present-day fragmented model of care delivery are detailed. A novel strategy that uses peer support groups could more effectively meet the needs of survivors of critical illness and mitigate post–intensive care syndrome.

Keywords: critical illness; survivorship; quality of life; resilience; peer support

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Post–intensive care syndrome (PICS), a condition defined by new or worsening impairment in cognition, mental health, and physical function after critical illness, has emerged as a common and life-altering consequence of critical illness. Unfortunately, PICS is also resistant to change, with several randomized controlled trials showing no benefit of various promising strategies. New strategies are urgently needed to mitigate the risk of neuropsychological and functional decline after critical illness and to prepare and support survivors on their road toward recovery.

In this article, we outline the present state of critical care survivorship. We focus on the impairments and vulnerabilities of this population of patients. We then detail postdischarge care delivery in the United States and the potential impact of the present-day fragmented model of care delivery. To bridge the gap between what survivors currently experience and what is needed, we offer a novel strategy that uses peer support groups and may more effectively meet the needs of survivors of critical illness.

Critical Care Survivorship

In the United States alone, approximately 5.7 million adult patients are cared for annually in an intensive care unit (ICU), and nearly 1 million of these patients will require mechanical ventilation. Advances in care have improved survival, resulting in millions of critical care survivors being discharged back into the community each year. Many survivors experience new or worsening functional impairments, leading some experts to herald these developments as a “hidden public health disaster” even as they praise the remarkable success of critical care medicine in reducing short-term mortality.

PICS Sequelae

At the time of hospital discharge, 46% to 80% of survivors experience cognitive impairment. At 3 and 12 months after discharge, 40% and 34%, respectively, of previously healthy survivors remain impaired to a degree that would be consistent with moderate traumatic brain injury. At 12 months, clinically significant symptoms of anxiety, depression, and posttraumatic stress disorder are present in 20% to 30% of survivors. Functional impairment, defined as impairment in activities of daily living (i.e., activities that allow a person to live independently such as finances and medication management), afflicts 27% of survivors at 12 months. The result is that the majority of survivors of critical illness appear to suffer from PICS.

In addition to cognitive, mental health, and physical impairments, critical care survivorship frequently encompasses chronic pain, sexual dysfunction, disability, financial loss, and inability to return to work, all of which culminate in reduced health-related quality of life in survivors.

Qualitative studies of patients with severe sepsis and acute respiratory distress syndrome and their caregivers have illuminated the present-day experience of critical care survivorship. Survivors and their caregivers crave information at each step of recovery, yet frequently lack the knowledge required to understand what they have experienced and what to expect. Survivors struggle with the enduring impact of critical illness on their own health and the impact on caregivers. They lament the lack of support after discharge to tend to or learn to cope with their ongoing health needs and lack of independence. Although additional studies are necessary to fully grasp the challenges experienced by survivors, and to identify strategies that facilitated recovery, the available evidence provides a blueprint for what survivors need.

Post-ICU Follow-up

Contemporary follow-up of ICU survivors in the United States is fragmented and uncoordinated. The fragmentation is characterized by poor communication between care providers, a reality exacerbated by the multitude of discharge destinations for survivors and high rehospitalization rates. A small number of ICU follow-up clinics have been established in the United States to combat this fragmentation. These clinics draw on 2 decades of experience from the United Kingdom and incorporate into clinical practice the identification of neuropsychological and physical problems and timely referral to other
health care providers. Although conceptually appealing, the effectiveness of nurse-led ICU follow-up clinics in the United Kingdom was not demonstrated when tested. More proximally, in a separate trial, increasing physical and nutritional rehabilitation during the post-ICU acute hospital stay did not result in improved physical recovery or quality of life as measured by the Short Form 36 Health Survey. However, germane to the constructs of preparation and support, the intervention that was paired with informational content delivery led to improved patient satisfaction with physical and nutritional support, coordination of care, and preparation at discharge. Additional studies drawing on the lessons learned from these seminal trials are needed.

Issues of survivorship are rarely addressed during the period of critical illness. As knowledge translation is notoriously slow, outpatient providers are most likely unaware of PICS and thus are even less likely to address issues of survivorship. The result is that millions of survivors of critical illness are being discharged into the community, unprepared and uneducated about what to expect and how best to cope, adjust, and recover. Impairments will therefore frequently go unrecognized and/or undermanaged. A substantial burden will fall on their informal caregivers, many of whom may be struggling with their own emotional sequelae from their ICU experience. Family members and caregivers are not immune to the psychological trauma of the ICU; in fact, they are also vulnerable to developing a form of PICS known as post-intensive care syndrome–family (PICS-F), which includes mental health consequences and may include physical symptoms and social isolation.

Novel strategies to augment survivors’ social support structure may be important to promoting a culture of resilience. These strategies would complement initiatives that aim to improve survivors’ physical and neuropsychological well-being. Additionally, these strategies could also facilitate coordination between inpatient and outpatient settings. Peer support has the potential to fulfill these imperatives.

Peer Support

We propose that peer support for ICU survivors may serve a crucial role in both improving the recovery of current survivors and in accelerating the progress of knowledge about recovery. We define ICU survivors in this context—in contrast to our technical use above—as patients and their loved ones who have emerged from critical illness. We believe that the continuum of survivorship begins at ICU admission and may continue for years or decades afterward. We define peer support as the process of providing empathy, offering advice, and sharing stories between ICU survivors. Peer support is founded on the principles that both taking and giving support can be healing if done with mutual respect. Peer support is centered on the notion that survivors can help each other through problems and have the willingness to do so. Peer support is not a clinician-centered model; the role of clinicians is to help provide the safe space in which survivors can work together to discover what they share to help each other.

The potential benefits of peer support emanate from the establishment of a community that promotes health and well-being through the shared experience of illness and recovery. The potential benefits, applied to survivors of critical illness, are many: mental reframing (hope, optimism), effective role modeling, information sharing, and practical advice that is not readily available to health care professionals at present. Peer support has proven effective in people with mental health disorders and substance abuse issues, in the self-management of diabetes, and among cancer survivors. It can lead to empowerment, self-advocacy, and improved outcomes. However, although “authentic empathy,” “validation,” and “acceptance” are important contributions offered by the peer support model, programs that formally integrate education into the program appear to be the most valuable. In the near future, sharing effective coping and compensation strategies by health care providers and peers may accelerate recovery further.

As survivors and their caregivers have first-hand experience of the challenges that survivors face, these individuals are well suited to educate and prepare peer survivors for certain aspects of the recovery process. In addition, because spirituality and religion appear to be important in survivors’ support networks, and given the reluctance of health care providers to engage in the spiritual aspects of illness and recovery, peer support groups may be a vehicle through which these aspects of recovery can be explored and acknowledged.
Although the challenges experienced may differ between the adult, pediatric, and neonatal populations, the principles of peer support and the inherent potential of this strategy apply to each group, including hundreds of thousands of pediatric and neonatal survivors of critical illness.

**Structure and Process of Survivor Support Groups**

The ideal structure, process, and timing of support groups for survivors of critical illness is unknown—a fact that bears emphasis. We remain at a fluid, innovative stage of discovery as to how peer support is best used after critical illness. An urgent need and opportunity for creative practitioner/survivor combinations exists to invent a new layer of post-ICU support and then evaluate it rigorously. Some general structural principles we recommend, drawn from the general peer support literature45-40 and applied specifically to survivors of critical illness, are included in Table 1.

Whether and how the needs of former patients and caregivers would be expected to differ is unknown. It is conceivable that stress experienced by one group (ie, caregivers) may be the result of impairments incurred by the other (ie, survivors) or vice versa. If so, distinct support groups may be ideal. Yet it is plausible that combined meetings, in the presence of those further along the path of recovery, could be therapeutic and beneficial and mitigate both PICS and PICS-F. Alternative options include a combined model in which both patients and their family members meet together for part of the meeting and then separately for part of the meeting to address the unique needs of the patients and caregivers or individual peer-to-peer mentorship. This area is one of the many in need of empirical evidence.

Meetings should be held at a mutually convenient time for survivors, peer support leads, and clinical staff who may serve as coordinators and/or moderators. The anticipated duration of the meetings is 60 to 90 minutes. Engaging facilitators who have experience with peer support in other venues (eg, oncology patients) early in the process may be useful to align expectations and guide design strategy. Given the frequency of psychological distress among survivors of critical illness, holding meetings away from the ICU—possibly even away from the hospital—may be preferable.

The format of meetings most likely begins with general introductions and explanation of ground rules (eg, confidentiality), followed by shared experiences and encouraging survivors to share what would be most helpful to them. To draw survivors in, a dedicated longitudinal curriculum that addresses various aspects of the survivor experience should serve as the foundation for meetings. However, to facilitate shared group discussion, moderators should aim to encourage open dialogue and be open to go where the experience of those present leads the group. The frequency of meetings will depend on the target audience, logistics, and the availability of volunteers and staff. For example, peer-to-peer support groups embedded within ICU follow-up clinics, or juxtaposed to clinical settings (eg, long-term acute care hospitals), may stimulate the demand to schedule one or more meetings per month.

**Unique Challenges in Survivors of Critical Illness**

The precise problems that create the need for in-person peer support can make attending
in-person support group meetings challenging. A brief list is provided in Table 2, along with potential mitigation strategies to discuss at meetings. Moreover, after critical illness, many survivors are in and out of various forms of health care venues, including long-term acute care hospitals or skilled care facilities. Frequent readmissions to the hospital or ICU32-35 and high short-term mortality55-57 further this challenge.

For survivors with functional impairments, which may include problems with mobility and driving, caregiver involvement and participation will frequently be required to permit the survivor to attend in person. Further, as noted previously, survivors with anxiety and posttraumatic stress disorder may be reluctant to attend meetings if scheduled at or near the ICU or hospital where the patient was admitted. Unlike other populations (eg, cancer survivors), who may have had time to process their illness and their recovery and to perform advanced planning, the nature of critical illness is that it is frequently acute and unexpected. In its wake, therefore, critical illness often leaves survivors with new impairments that they are not equipped or prepared to handle. This unique challenge must be acknowledged within critical care survivors broadly and peer support models specifically.

Sustainability of peer support groups requires engaged and active peer support leadership. Given the frequency and severity of impairments, some if not many survivors will be physically, mentally, or emotionally unable to serve in this role. For those survivors who are physically and mentally able to serve as leads, they may not be able to relate completely or to coach survivors with more severe injuries and disabilities as effectively as those with lesser impairments. Given the economic consequences of critical illness and the toll that it takes on survivors and their caregivers,23 the ability to attend meetings in a voluntary fashion may be cost prohibitive. For these reasons, virtual support is a plausible
alternative that warrants investigation; however, its utility in other populations has not been established.58 If centers of recovery emerge as an effective and financially solvent model, incorporating ICU staff and survivors into peer support staff as full-time employees or volunteers, as done successfully in mental health clinic models,45 may be prudent.

**Design and Development of a Peer Support Collaborative**

In 2015, the Society of Critical Care Medicine (SCCM) initiated the Thrive Supporting Survivors of Critical Illness initiative. Thrive has 3 pillars: a peer-support collaborative, expanding research into recovery, and education within and outside the ICU around PICS.59 The peer-support collaborative began with an international call for applications, the first action of the Thrive group. In the fall of 2015, 6 inaugural sites were awarded on the basis of their innovative and team-oriented design to implement, collaborate, and assess the effectiveness of peer-to-peer support groups applied to survivors of critical illness and their caregivers. The 6 sites include 5 adult hospitals and 1 pediatric hospital. We expect to expand the collaborative by 5 new sites each year for at least 2016 and 2017, balancing the needs of group cohesion with tremendous interest in participation.

The aim of the collaborative is to catalyze the development of a network of pioneer in-person support groups, testing the feasibility of peer support and amassing a body of proven experience and skills to grow and support survivors of critical illness. The underlying model of the peer-support collaborative is itself a form of collaborative peer support—that the leaders of the 6 sites convene monthly to share successes and challenges and to brainstorm solutions. The site leaders are joined on the monthly calls by SCCM staff and an international group of experts to be available as a resource for the sites. As the collaborative matures, the aim is for formal monthly communications to parallel frequent and informal idea exchanges and mentoring between sites. These efforts at group cohesion are facilitated by annual site visits by SCCM staff and an international group of experts to be available as a resource for the sites. As the collaborative matures, the aim is for formal monthly communications to parallel frequent and informal idea exchanges and mentoring between sites. These efforts at group cohesion are facilitated by annual site visits by SCCM staff and a member of the Thrive initiative, and in-person meetings at SCCM’s annual congress.

A basic principle of the peer-support collaborative is that no evidence base for providing peer support to ICU survivors exists. We need to invent this future together. It is, by design, improvisational. In some ways, the collaborative is a support group for usually evidence-based clinicians busy working in an area without any evidence yet. The collaborative’s start-up culture is balanced by reporting to the broader SCCM Thrive initiative and to SCCM’s executive committee. Each year, the collaborative will share its current state of the art at SCCM’s annual congress and work to codify best practice in ways that can be scaled up and shared broadly.

We expect that in several years the evidence base will be sufficient to propose definitive clinical trials to evaluate alternative models of peer support. However, premature conduct of such evaluative trials—before the techniques of peer support have developed sufficiently to warrant testing—is not part of the collaborative’s mandate.

**What to Expect**

Based on the experience in the support group context and otherwise at the Vanderbilt Recovery Clinic, Intermountain Medical Center,60 and Toronto General Hospital,29,30,61,62 several recurrent themes should be anticipated when implementing a peer-support group. Chief among these relates to identity—that is, survivors grapple with questions related to who they are after intensive care. Acutely aware of new cognitive deficits, personality changes, and physical limitations, survivors frequently struggle in a quest to cope with loss and to define and eventually embrace a “new normal.” Even as they look ahead and brace for an unfamiliar future, they are regularly buffeted by feelings of frustration, guilt, and regret—sometimes for poor health decisions that led to critical illness and sometimes for contributing to the distress of family members. Regardless of prior health status, they tend to be preoccupied with health concerns, leading to vigilance, social disengagement, and withdrawal. In many cases, they feel powerless and victimized by circumstances, a dynamic that can result in decreased self-efficacy and a burgeoning sense of helplessness.

Facilitating support groups made up of individuals struggling with the aforementioned issues is both satisfying and challenging. Although successful group facilitators share certain characteristics regardless of the patient population in question—traits such as the ability to forge close connections and to relate to
others in a nonjudgmental fashion—effective leaders of post-ICU support groups should possess specialized knowledge. In particular, facilitators need to anticipate the natural history of PICS, as well as the impact of this condition on diverse domains of functioning so that they can expectantly manage and engage the issues that will most likely emerge and facilitate discussion. In addition, facilitators need to understand the resistance that patients often have to addressing important parts of their history, as discussions of their illnesses and in-hospital experiences are often highly traumatic. The group must possess a vision of what constitutes a “good” outcome. This hard-to-define metric will involve acceptance of limitations for some, subtle improvements or more for others, and ideally a richer sense of community and a revitalized sense of hope and purpose for all that attend. Coming together to jointly build this shared vision can be a rewarding part of the group process. Finally, the group must be prepared for how to handle and guide survivors who have medical and psychosocial needs that require attention and extend beyond the scope of the support group.

Conclusions
As the population of survivors of critical illness has grown, so has our understanding of the many challenges faced by survivors. To meet the needs of survivors, innovative strategies are urgently needed. Because so little is presently known regarding how to rehabilitate the functional disabilities that develop after critical illness, a potentially high-yield endeavor to complement hospital-based initiatives is to turn to survivors through the design and implementation of peer-support groups.

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