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Caring for the Critical Illness Survivor: Current Practices and the Role of the Nurse in ICU Aftercare

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The success of critical care medicine has historically been gauged by short-term mortality outcome. With technological advances, many patients now survive what were previously fatal critical illnesses, generating an expanding population of critical care survivors. Many survivors suffer with new or worsening impairments in physical, cognitive or mental health status arising after a critical illness and persisting beyond acute care hospitalization which has been termed Post Intensive Care Syndrome (PICS) [1]. This term can be applied to a survivor or a family member who often experiences significant social & psychiatric burdens caring for a survivor of critical illness [1 2]. It is estimated that PICS develops in greater than 2.4 million Americans who survive critical illness each year, including approximately two-thirds of Medicare beneficiaries who survive critical illness [3]. As a consequence of

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both an aging population and the dramatic improvement in mortality rates in those suffering from critical illness, PICS is rapidly becoming a major public health concern. For these survivors, new impairments after critical illness can have dramatic impacts on their quality of life or ability to be employed, and may persist for months or years after hospital discharge.

This review of the will examine emerging practices in relation to ICU after care for both patients and caregivers, with specific emphasis on the critical role of the nurse.

Approaches to ICU Aftercare

The role of the ICU aftercare program is to specifically address the physical, mental health, and cognitive impairments associated with PICS in order to improve the survivorship experience for patients and caregivers. The goal of ICU aftercare programs is to provide personalized care that focuses on the unique needs of ICU survivors, however, there is no one standard model of care in place currently. Peer support, post-ICU clinics, and ICU diary aftercare programs are currently being implemented and investigated internationally with modest results.

[4–6]. A description of each program and modes of delivery is provided in the next sections. These ICU aftercare programs can be implemented in isolation or in combination, depending on resources, to provide a more comprehensive recovery program.

Post-ICU Clinics and Recovery Programs

Post-ICU clinics and recovery programs have been established in many hospital systems internationally [4 7–9]. These clinics have taken a variety of forms in terms of professional input, and process. Wide variation exists in the staffing of post-ICU clinic recovery programs more generally, for example [10]. Some clinics are led by a single discipline (i.e., nurse or physician led) while others include members of the entire multidisciplinary team (MDT) [11]. More recently, single center data has described a model which utilizes staff from both health and social services, with the aim of supporting some of the socioeconomic problems, which patients and indeed their caregivers, face during the ICU recovery period [12]. On a small scale, this approach appears to be well received by patients, however, more work is required to understand the contextual differences across healthcare systems and how this type of support can be optimally implemented [12 13].

There has been debate in the literature regarding the type of expertise the team delivering post-ICU care should have [14]. Some commentators have stated that this care is best delivered by specialists in rehabilitation, while others believe that ICU providers should lead this care either in isolation or in partnership with rehabilitation specialists [15 16]. Recent data suggests that by having staff from the ICU involved in post-ICU care, outcomes and care delivery across the entire ICU pathway may be improved by understanding patient and caregiver experience more fully [17]. Single centre evidence also suggests that having the ICU staff involved in care over the entire recovery trajectory of the patient may help reduce staff burnout and increase joy in work [18].

The interventions delivered within clinics internationally also have variation around their format and process. Some clinics have patients attend as a stand-alone appointment, while some provide follow-up at pre-defined intervals (i.e. 3 months and 12 months). Other models have a similar approach to that of pulmonary rehabilitation in that they offered staggered, regular interventions, to promote goal setting and changing patient needs. This overall lack of a standardized approach and professional input is not necessarily reflective of need, but rather what is feasible within the remits of limited funding and evidence of effectiveness [17].

Peer Support Programs

Peer support during recovery from critical illness is designed for individuals who have experienced a stay in the ICU either as a patient or as the loved one of a patient. Through this approach to ICU aftercare, survivors and their families are provided an opportunity to facilitate their own recovery and improve their quality of life by relating to others with shared experiences [19]. Current models of peer support for ICU survivors and their families include group sessions that coincide with post-ICU outpatient clinic visits, information sessions led by a content expert, group sessions that are co-facilitated by ICU staff, peer-to-peer mentoring, and group sessions that are held for the loved ones of patients while the patient remains critically ill [10 20]. Peer support can also occur online through discussion boards that can be joined and referenced by ICU survivors and their families from around the world, and through teleconference options, which allow for real-time participation for those who live a long distance or are too debilitated to travel and attend the in-person peer support session. Common methods of recruitment for ICU survivor and family participants occur through the distribution of advertisements and brochures around the hospital and medical center, during follow-up phone calls or visits, and/or through direct mailings or emails.

ICU Diary Programs

As seen in the ever-expanding body of evidence related to the patient's ICU experience, it has become clear that as a result of gaps in memory, such as during periods of sedation that occur with mechanical ventilation or during periods of delirium, many patients suffer from lingering stress after their time in the ICU, manifesting as long-lasting anxiety, depression, and posttraumatic stress disorder (PTSD) symptoms [21–23]. In a few small clinical trials, ICU diary programs have been associated with reductions in the incidence of post-traumatic stress response in ICU survivors and their families [24–26], and are recommended in guidelines for family-centered care in the ICU [27]. Written by the patient's loved ones and hospital care team members, the ICU diary may help the ICU survivor begin make sense of time they have forgotten, and provide a unique approach for reflection on their critical illness experience. Along with providing the patient information about what is happening, which equipment is making noise, and who is spending time with time, the entries provide messages of support, encouragement, and hope for recovery. ICU diary programs are unique to each healthcare system and may include photographs of the patient throughout their critical illness, so that progress can be visualized. The loved ones of a patient may feel empowered with a sense of purpose as they write daily entries in the ICU diary [27]. Loved ones help the staff understand who the patient is by filling out the pages that highlight the

patient's preferences. Patients are encouraged to write in their own ICU diary if and when they feel able.

ICU diaries are not always immediately read by the patient once they leave the ICU. Rather, after several weeks or months, the patient may feel ready to debrief their ICU stay.

Debriefing occurs by reviewing the diary with a hospital care team member during a post-ICU clinic visit, discussing entries of importance during a peer support session, or by going through the diary with their loved ones independently from the hospital care team. Patients who do not remember any of their stay in the ICU use their diary to put names to faces during peer support sessions or during a planned visit to the unit when they feel ready for it.

The Role of the Nurse Leader in ICU Aftercare

Nurses are uniquely trained and positioned within the health care system to become leaders within ICU aftercare programs.

Clinician

As ICU survivor research continues to evolve, more evidence will be available to guide the development of ICU aftercare programs. Nurses will undoubtedly continue to play a significant role in translating these discoveries into action for our patients and family members who have experienced critical illness. Nurses, with the foundational training in patient-centered care, are uniquely qualified to lead initiatives in both the development and implementation of these programs. Currently, advanced practice registered nurses (APRNs) as well as RNs have roles in the creation, facilitation and education, leadership, and staffing of post-ICU clinics, peer support groups, and ICU diary programs. Existing peer support programs for ICU survivors are often utilizing nurses as the key facilitators [20]. In many instances in the US, the APRN leads the interprofessional team that designs and establishes a peer support program which works within the confines of the individual institution. Identification and recruitment of survivors for ICU aftercare programs can be performed by the APRN through follow-up phone calls and rounding on ICU survivors after their transition from the critical care unit. Many post-ICU clinics also utilize the APRN as one of the outpatient providers. Throughout the world, ICU diary programs are often initiated by nurses. Along with educations and supporting family members to write entries, nurses are also the most likely care team member outside of the patient's loved ones to utilize the ICU diary. Debriefing the ICU stay with the patient and their ICU diary is also often performed by a nurse at the post-ICU clinic or at a peer support session. Evaluation and education of ICU aftercare programs is commonly managed by nurses, who solicits feedback from participants and works with the team to make adjusts to the programs as needed. The nurse also shares pertinent information with the staff nurses to improve care delivery at the bedside.

Advocate

To ensure that patients and families recovering from critical illness receive needed support during recovery, raising awareness of PICS is essential. Nurses can advocate for the ICU survivor and their family through educational initiatives that target colleagues as well as

patients and family members. Additionally, assisting patients and their families in identifying ICU aftercare resources will support their recovery trajectory and overall well-being. Nurses can also advocate for the ICU survivor through the fostering of the multidisciplinary collaboration seen in ICU aftercare. A team approach to ICU survivor care provides an avenue to an interdisciplinary plan of care. Finally, empowering ICU survivors to play an active role in the creation of patient-centered goals allows patients to take control of their health care decision and actions affecting their recovery trajectory.

Researcher

Nurse scientists play a valuable role within healthcare delivery systems [28]. Research focused on ICU aftercare is necessary to evaluate effectiveness and outcomes and to establish evidenced-based recommendations which organizations can use to create new programs. Nurse scientists can effectively lead this research and contribute significantly to the science of recovery from critical illness. Examples of research, where nurses have delivered central roles include: *Psychological Outcomes following a nurse-led Preventative Psychological Intervention for critically ill patients trial (POPPI)* [29] and *Intensive Care Syndrome: Promoting Independence and Return to Employment program (InS:PIRE)* [19].

Future Directions for ICU Aftercare

As the numbers of available ICU aftercare and recovery programs continue to expand, the demand for such programs is also likely to increase. Currently, many of the available programs are in large urban centers and are associated with large academic medical centers. Innovative aftercare delivery models are being explored to address these barriers such as the use of mobile ICU recovery programs [30] or the use of telemedicine services for ICU survivors.

An underdeveloped area in our understanding of post-ICU care delivery is the support needed by caregivers. Caregivers and close family members are known to experience similar social and emotional problems to patients in the year following critical illness [31]. However, it is not clear whether caregivers and family members have the same recovery trajectories. Spikes in emotional and mental health problems, for example, may appear at different stages. Future research and innovation must attempt to address the recovery arc of caregivers and how to best intervene to improve outcomes for this vulnerable group.

Conclusion

PICS morbidities contribute to ongoing challenges for survivors of critical illness and their family members. Post-ICU clinics, peer support, and ICU diary aftercare programs offer approaches to reinforce family-centered care in the ICU as well as enhance patient and family member experiences with recovery from critical illness. As demand for ICU aftercare programs increase, nurses will play an important role in the development, implementation, and sustainability as key members of the multidisciplinary ICU recovery team.

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