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Improving the Patient Experience by Implementing an ICU Diary for Those at Risk of Post-intensive Care Syndrome

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Abstract

The critical care literature in the US has recently brought attention to the impact an ICU experience can have long after the patient survives critical illness, particularly if delirium was present. Current recommendations to mitigate post-intensive care syndrome (PICS) are embedded in patient and family-centered care and aim to promote family presence in the ICU, provide support for decision-making, and enhance communication with the health-care team. Evidence-based interventions are few in number but include use of an ICU diary to minimize the psychological and emotional sequelae affecting patients and family members in the months following the ICU stay. In this paper we describe our efforts to implement an ICU diary and solicit feedback on its role in fostering teamwork and communication between patients, family members, and ICU staff. Next steps will involve a PICS follow-up clinic where trained staff will coordinate specialty referrals and perform long-term monitoring of mental health and other quality of life outcomes.

Keywords

Post-Intensive Care Syndrome, ICU diary, evidence-based practice, family-centered care

Introduction

Patients and their family members are often unaware of the challenges that intensive care unit (ICU) survivors face after discharge from the hospital. These challenges can be compounded by a lack of familiarity with and access to recovery and rehabilitation resources. Although not a new condition, post-intensive care syndrome (PICS) and PICS-Family (PICS-F) are relatively new terms for the physical, neurological, and emotional sequelae affecting patients and family members long after an ICU stay. Keeping an ICU diary reportedly benefits patients and family members at risk of PICS and PICS-F (1). Intensive care diaries have been found to alleviate anxiety and depression, reduce new-onset post-traumatic stress disorder (PTSD), and improve health-related quality of life after critical illness (1). Prevalence rates for PICS and PICS-F are reported in the literature to range from 15% to 50% (2,3) with mental, cognitive, and physical impairments lasting 5 to 15 years (4,5). One-third of family members demonstrate PTSD symptoms for up to 90 days following the critical illness, and symptoms may last for years following patient discharge (3).

According to Garrouste-Orgeas et al, various studies have described strategies helpful to family members looking for support for themselves and the patient including flexible visitation policies, involvement in nursing care, and participation in maintaining a diary during the ICU stay (6). The ICU diaries have been widely used in European countries, Scandinavia in particular, since the 1970s and 1980s as a low-cost technology to improve the quality of life after critical illness (1,7). Qualitative studies reveal that the diary enables patients to evaluate their recovery and improves communication with their families about their experiences, thus sustaining family-centered care (1,6-11). Intensive care unit diaries may also enable patients to make sense of their intensive care encounter, which they previously may have failed to understand (1). For these reasons, the ICU Team, led by registered nurses

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(RNs) with the support of senior physicians, implemented an ICU diary.

Following much planning to ensure the proper tools, teamwork, and resources were available, an ICU Diary Project was implemented at our institution to assist at-risk patients and families with their communication and healing needs. This article will briefly describe the experience.

Selecting an Evidence-Based Practice Model and Forming a Team

The Iowa Model of evidence-based practice (EBP) was used to guide the development of the ICU Diary Project (12). The PICOT (Population, Intervention, Comparison, Outcomes, Time) question was: In patients who score positive for the Confusion Assessment Model (CAM)-ICU or patients who have been intubated longer than 24 hours (P), how does the use of an ICU diary (I) versus not keeping an ICU diary (C), impact patient, family, and staff engagement and satisfaction (O) throughout the admission episode (T)? The PICS and PICS-F were identified as the problem-focused trigger. This clinical problem is an emerging health-care phenomenon which is increasingly confronted, as greater numbers of ICU patients survive life-threatening illness and injury. Our team included a diary project leader who was an RN, an EBP expert who was a clinical nurse specialist, a nurse scientist, 2 critical care nurse champions, and a minimum of 2 acute care ward nurse champions from each medical–surgical and step-down ward. The groundwork for the ICU diary project was made possible by a small monetary award used to purchase supplies such as binders, cameras, DVD players, a color printer, and a television channel that was used as part of the hospital's multimedia patient education platform.

Critique and Synthesize Research for Use in Practice

We performed a limited search of Joanna Briggs Institute EBP Database, PsycInfo 1987 to 2015, EBM Reviews Full text, Ovid MEDLINE 1946 to 2015, and Google Scholar using a combination of the following search terms: ICU, intensive care unit, diary, and post-intensive care syndrome. Additionally, we hand searched the references in each article to find other relevant studies not yet identified. The search returned 94 eligible results from the literature published between 1946 and 2015. Two of the ICU diary project team members (M.M. and S.E.) evaluated the citations for diary implementation strategies; this resulted in 21 articles describing introduction of an ICU diary in sufficient detail and with a population of adult critically ill patients similar to ours in a tertiary care teaching hospital. A table was constructed to grade the articles on strength and quality, and this was shared with all ICU diary project team members.

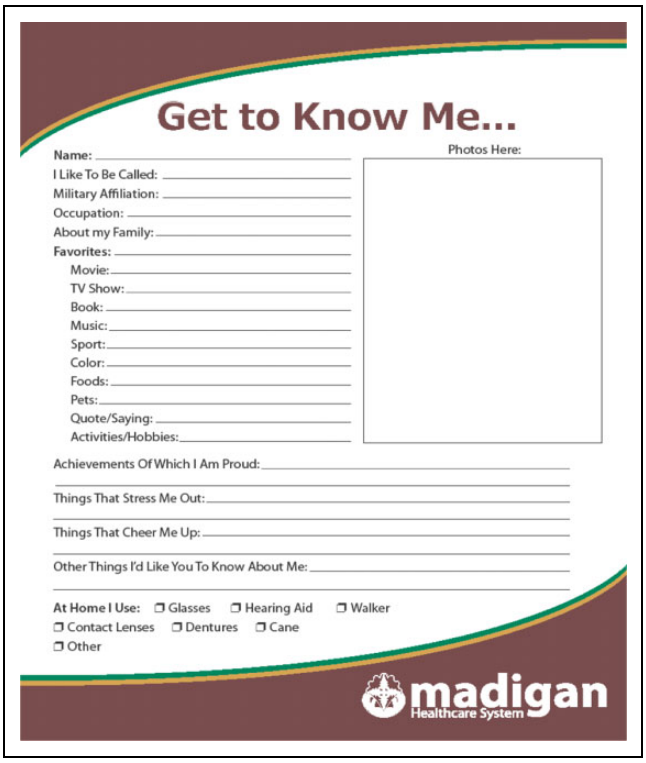

Figure 1. Intensive care unit (ICU) Diary Get to Know Me page.

Project Implementation

After assembling and grading the relevant research, the ICU diary project team agreed that the evidence was sufficiently strong to warrant piloting an ICU diary. Potential stakeholders were identified to include physicians, nurses, chaplains, physical therapists, and respiratory therapists, and all were educated on the purpose and implementation strategy for the ICU diary binder. The binder consisted of a laminated folder containing a welcome page, *Get To Know Me* page (Figure 1) that asks about a nickname, occupation, family members, and pets and solicits favorite sports, hobbies, television shows, music, and activities that cause stress or bring cheer, information on PICS, a list of available resources, blank diary pages, photos of our ICU, and a description of common medical terms. A pamphlet accompanied the binder to guide family and patients how to use the diary, and unit bulletin boards had a prominent display of reference material.

Pilot the Change in Practice

An ICU diary was initiated on the ICU patient population commonly included in other published studies, namely, all patients who were mechanically ventilated for greater than 24 hours or who screened positive for delirium on the CAM-ICU tool (13). This is a valid and reliable diagnostic algorithm that uses 4 features to determine the presence or absence of delirium; acute change or fluctuation in mental

ICU Diary Project Tracker

Patient #	Room #	Billing #	Patient initials	Admit date	Admit to Ward___	Admit to ICU	Meets criteria for diary: Y or N	Diary start date	Date left ICU	LOS ICU	Transfer To Unit:	LOS MAMC	Where D/C	Pt education date	Family education date	OK to contact later Y or N	ICU diagnosis	RN Initiating diary (Initials)	Additional Notes

Figure 2. Intensive care unit (ICU) Diary Project Tracker.

status, inattention, disorganized thinking, and altered level of consciousness (14). The bedside ICU nurse performs this assessment each shift and with any change in the patient's condition. The patient's ICU nurse or a diary champion started the diary with an opening entry to include a welcome and layman's explanation for the ICU admission. After the initial entry, all members of the health-care team were encouraged to write an entry every shift. Intensive care unit RNs educated family members on the ICU diary, its purpose, its benefits, and the symptoms of PICS/PICS-F as soon as it was reasonable, with consideration given to the status of the patient and the availability of the family. Family members watched an educational PICS video produced on-site with assistance from the institution's public affairs office and visual information office after admission procedures were completed. The video was available around-the-clock on a portable DVD player or on the dedicated ICU patient education TV channel. The ICU diary project RN leader made daily rounds in the ICU to identify new patients who were candidates for an ICU diary and to follow up on patients who already had an ICU diary. A Diary Tracker tool was designed for these rounds (Figure 2).

Every patient with an ICU diary was identified by a removable sticker below the patient door number. Once the patient transferred out of the ICU, he/she was identified using the white communication boards in the acute care ward patient rooms. A symbolic "diary" magnet was also placed on the patient census board at the nurse's station. The ward diary project champion ensured that the patient was properly identified during hourly rounding or change-of-shift handoffs. Once the patient was awake and alert, the assigned nurse introduced the ICU diary, discussed its intent, and encouraged its continued use.

The ICU diary remained with the patient throughout his/her hospital stay and went home with him/her at the time of discharge. The ICU diary is not considered part of the patient's health record. Occasionally, the patient or family member used our "instant" camera to take a picture of the hospital room or themselves upon discharge. The photos became part of the ICU diary as reminders of the illness trajectory (15).

Evaluate Quality of Care and New Knowledge

In general, feedback was received via surveys and one-on-one dialogue with staff, patients, and families during ICU and ward rounds made by the ICU diary project RN leader. This interaction occurred when the ICU diary project team leader visited with patients and staff providing "on the spot" education about the importance of the ICU diary, encouraged family to use the diary, answered questions, made ICU diary entries, and helped the floor nurses designate a standard location in the patient room to keep it accessible. Family members stated the diary "helps keep track of events because the days run together" and "is a way to communicate to my son who can't hear me." This mother was thankful because she perceived that writing in the diary was actively participating in his care and a way to express feelings she was unable to vocalize even if he could hear her. One patient returned 1 month postdischarge after a major motor vehicle accident. The patient stated that the ICU diary "helped reconstruct a chronological timeline from a fragmented memory, is a constant reminder of the support she received from friends, family, and staff, and is a tool to gauge her progress along the recovery journey."

Many family members used the ICU diary to relay feelings of hope and anticipation as evidenced by this entry, "Sissy ~ you opened your eyes and looked at Kimee and me. Hooray! We are talking to you all the time and telling you to open your eyes or squeeze our hands. Sometimes you do and we get real excited." Other entries described the family love and support whether they were present or sending prayers from long distance. "My phone is blowing up with love and well wishes. Of course Grandma posted on Facebook. You are so loved. So many people are praying for you." Spiritual messages such as this one were also common, "I have been praying around the clock for you . . . I have anybody that I know that can get a prayer through to God praying." One patient's son printed all Facebook posts from friends and family to include in his mother's ICU diary.

Entries by family and loved ones focused on the emotional support for the patient while staff focused on the clinical support, in lay terms. For example, "I am your nurse tonight. You were able to write some words using a clipboard, you asked for a drink of water, and told me that you were having bad dreams. We still have your hands restrained because you wake up startled and we are concerned that you might pull out one of your tubes." The patient takes home with them a chronological "autograph book" of comments and events from caring professionals who recognize them as individuals.

Indirectly, the ICU diary project integrated well into the critical care recommendations for patient safety referred to

as the ABCDEFGH bundle which is an evidence-based bundle of ICU measures that includes: (A) Assess for and manage pain, (B) Both Spontaneous Awakening Trials and Spontaneous Breathing Trials, attention to the (C) Choice of sedation and analgesia, (D) Delirium monitoring and management, (E) Early mobility, (F) Family engagement, (G) Good handoff communication, and (H) Hand the patient and family written information about possible components of PICS and PICS-F (3,16). An ICU diary project can support these efforts by tracking delirium scores, following up on patients and families after the ICU stay, encouraging good handoff communication between nurses caring for the patient and between the ICU Team and family members, and educating all team members involved (3).

The sincerity expressed in ICU diary entries provided a means to discern family frustrations, improve patient and family satisfaction by recognizing areas for improvement, and identify where additional education and resources were needed. One family member stated that the staff used everyday terms in the diary and it increased his understanding of his mother's care as well as served as a measure of hope. It was also a way for family and friends to recognize the hard work done by the patients' caretakers and support staff. Most importantly, the diary humanized the patient experience.

We collected staff perspectives of this ICU diary project using a short 10-item survey that was placed in staff mailboxes or handed directly to them during shift report over a 2-week period. The survey used a Likert-type scale for 7 statements and 3 open-ended questions to address the ICU diary project's biggest barriers, greatest benefits, and aspects needing improvement. A locked opaque ballot box was used for the return of surveys. Survey response was less than 20%, so the ICU diary project leader conducted informal interviews using the same tool. A total of 30 nurses and 6 physicians provided feedback. Nurses expressed lingering discomfort with what to write in the ICU diary, and physicians expressed a lack of time to write ICU diary entries. However, both nurses and physicians reported a positive impact overall, which was unexpected due to the early opposition to the ICU diary project. One staff member stated, "It is a great way to communicate with the patient on a more personal level." The ICU diary entries bring meaning to the work of caring for patients who may never even remember their ICU stay. Family member entries revealed details of their engagement and connection with the nurses; the staff nurse was recognized by name and was no longer just a shift worker. Communication not only increased between the patient and the staff but also among the staff members as a result of the ICU diary project. Teamwork improved throughout the hospital with ICU diary project participation. Furthermore, the ICU diary project RN leader rounds appeared to increase both staff and patient satisfaction by providing compassionate care in a highly technological and fast-paced environment. Work remains to be done to solicit patient and family member experiences during the ICU admission when no diary was implemented.

Discussion

As with the introduction of any new initiative, the greatest difficulty is with staff buy-in (8). Demonstrating to coworkers and other staff that the ICU diary project was evidence based and patient and family centered helped build the teamwork necessary for success. Initially, an ICU diary project leader was essential to unite all parts of the process and served as the advocate who encouraged staff, patients, and families to participate by starting new ICU diaries and sustaining existing ones. Discussion regarding the usefulness of the ICU diary was solicited from 35 family members; some families had more than 1 individual writing in the diary. The pattern for families was one of early engagement or complete withdrawal from the project. The potential for a powerful impact on family members was apparent to our ICU diary project team during a recent encounter at a conference with a poster presentation titled *Developing an ICU Diary to Minimize PICS and PICS-F*. One individual, nearly in tears, was browsing through our ICU diary binder on display. When questioned about her sad mood, she stated, "I wish they had this when my husband was dying in the ICU. I am a nurse and all I saw was a shell covered in tubing, drains, and wires. I forgot everything I knew, I lost track of time, and I am forgetting special moments as time goes on." This provided yet another reason for us to engage ICU staff and patient families in creating a written account of events and explanations that may provide comfort at a later time.

In the last 10 months, 50 ICU diaries were initiated with only a small percentage of patients offering thoughts and feelings about the diary to date. Patients may only fully appreciate the value of this ICU diary after they have transferred from the ICU to the ward or to a discharge destination. Comprehension and appreciation of ICU diary content vary by individual depending on cognitive status of the patient upon discharge and readiness to revisit potentially negative experiences (17). For the interprofessional staff, education appears to be the key to the ICU diary project's success. Future plans include creation of a PICS Clinic where ICU survivors with unique short-term and long-term needs can be followed by health-care professionals educated about the biopsychosocial consequences that follow critical illness. The goal is to join forces with colleagues in the Internal Medicine Clinic, where the Patient-Centered Medical Home Model guides care and consolidates specialty services such as neuropsychology, behavioral health, and physical and rehabilitation medicine which will greatly enhance care coordination efforts. Evidence-based reports in the literature focusing on quality of life, physical and cognitive function, psychological symptoms, and use of health-care resources following ICU discharge reveal that more research is needed to mitigate patient and caregiver distress (18). Individualized care and the use of tools to monitor outcomes may help establish the contribution of the ICU diary in minimizing symptoms of cognitive and mental health disorders (18). Other important outcomes to assess include health-care

utilization, readmissions, time to return to baseline functional status for activities of daily living, and sleep quality (19).

Conclusion

We have found that implementing an ICU diary is a first step in attempting to mitigate the effects of PICS and PICS-F as well as increase staff satisfaction. Effective, ongoing dialogue between caregivers and ICU patients and family members is an element of many best practice bundles, particularly the one to reduce the risk of PICS and PICS-F. The steps of care coordination, good handoff communication, and patient and family support emphasize how critical it is for professional staff to engage with each other and the patient/family unit for optimal care and outcomes (3, p33). As one ICU health-care professional so eloquently stated, "I've never met a patient more resilient than you. Thank you for teaching me and thank you for letting me take care of you. Every day I look forward to seeing the progress you've made. I look forward to the day we can finally speak." Communication, humanization, and clarification of the care plan benefits both care recipients and caregivers.

Authors' Note

The views expressed in the article are those of the authors and do not reflect the official policy of the Department of the Army, the Department of Defense, or the US Government.

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