

Advances in Research on the Use of ICU Diaries in Post-ICU Syndrome

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Abstract: This article reviews the concept of ICU diary and the related contents of post-ICU syndrome, focuses on the current application status of ICU diary in post-ICU syndrome, problems faced, and suggestions for improvement, aiming to provide a reference basis for improving the physical and mental health of ICU patients and their families.

Keywords: ICU diary; Post-ICU syndrome; Psychological well-being; Family support

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1. Introduction

Intensive Care Unit (ICU) is designed to provide comprehensive and high-quality care to critically ill patients and plays a vital role in improving cure and survival rates ^[1, 2]. Its significant reduction in mortality in critically ill patients has led to a growing population of transferred patients, with millions of patients being transferred from ICU each year in the United States alone ^[3]. However, an increasing number of patients and their families face mental health problems such as fatigue, sleep disturbances, and anxiety ^[4]. As many as 50% of ICU patients may develop post-ICU syndrome, which manifests itself as a multitude of physical, cognitive, psychological, and social problems, and approximately 50% fail to return to their previous work or school status one year after discharge, and many do not return to their initial level of health ^[5, 6]. ICU patients often experience memory gaps or unpleasant memories after discharge from the hospital, which are often closely associated with the onset of symptoms such as anxiety, depression, and post-traumatic stress disorder (PTSD), which in turn negatively impacts health-related quality of life ^[7-9].

Studies have shown the value of ICU diaries in processing emotions, gaining insight, reducing stress, documenting important information, and facilitating communication between medical staff and patients ^[10]. Diary

writing enables ICU medical staff to reflect on their daily work and care for each patient. The use of diaries has spread across Europe and North America and is gradually expanding to other continents ^[11, 12]. In regions where this tool is offered, patients and families usually initiate the use of diaries from the beginning of the hospitalization period ^[13]. Thus, the ICU diary serves as an effective intervention aimed at preventing long-term mental health problems and significantly improving the physical and mental health status of patients and their families.

2. Overview

2.1. Concept of post-ICU syndrome

The concept of post-intensive care syndrome (PICS) was first introduced by the American College of Critical Care at the Global Conference on Acute and Critical Care in 2010, aiming to describe new or worsened physical, cognitive, or mental health problems in critically ill patients after ICU treatment, which can appear within 24 hours after ICU admission and can persist for 5–15 years after discharge ^[14, 15]. At the same time, the process of patients receiving treatment and post-care in the ICU also brings significant stress and burden to their families, leading to psychological and physical disorders, a phenomenon known as Post-Intensive Care Syndrome-Family (PICS-F), which is collectively referred to as Post-ICU Syndrome (PICS) ^[14, 16]. In 2012, at the second global conference, a commitment was made to comprehensively improve the understanding, management, and intervention of PICS to improve the prognosis of critically ill patients and their families ^[17].

2.2. Concept of ICU diary

Bäckman *et al.* defined an ICU diary as a daily record written by ICU healthcare staff and the patient's family ^[18]. This record is a patient-centered account of the patient's experiences, daily life, and behaviors during hospitalization using an empathetic and reflective language style. As a nurse-led therapeutic tool, the ICU diary has gained wide acceptance among patients, families, and medical staff. Its use not only promotes recovery and reduces post-traumatic stress for both family members and patients, but also helps to strengthen communication and emotional connection between nurses, family members, and patients, and facilitates the expression of emotions and feelings ^[19].

3. Forms of ICU diary in post-ICU syndrome

3.1. Original paper ICU diary

ICU diaries were first introduced by Backman and Walther in 1999 as a method of documenting a patient's experience of care in the ICU, with the aim of helping patients to review events that occurred during their hospitalization ^[20]. ICU diaries not only fill in the gaps in patients' memories but also help to reduce the risk of psychiatric disorders for both patients and their relatives after discharge from the hospital. Currently, ICU diaries are widely used in hospitals in several countries, including Norway, Denmark, and the United Kingdom ^[21].

Typically, diaries begin with a short introduction stating their purpose, followed by a summary of the patient's experience to date, including daily care, disease progression, and patient improvement or deterioration. During writing, it is necessary to use plain language to explain specialized medical terms, avoid abbreviations, and sign the text. In the Netherlands, about 87% of ICUs offer this diary service, which is mainly written by the patient's family and may contain content in the form of photographs, drawings, or poems, while protecting patient privacy ^[22]. Most ICU diaries are in paper form, sometimes accompanied by pamphlets and other informational materials ^[23].

Studies have shown that reading an ICU diary has a positive impact on the patient's ability to cope with the trauma experienced during their stay in the ICU ^[24].

In addition, relatives who participated in diary writing improved their own mental health in terms of emotional support ^[25]. ICU diaries written by nurses help patients and families to understand the ICU environment, which reduces fear ^[26]. ICU diaries also provide caregivers with the opportunity to reflect on and process their experiences, supporting their emotional and psychological well-being ^[27]. This process not only enhances caregivers' self-awareness but also helps to promote professional growth and increase job satisfaction.

3.2. Digital ICU diary

During COVID-19, family members' access to ICU diaries was also limited due to visitation restrictions and infection control concerns ^[25]. With the advancement of "Internet Plus" and information technology, mobile health (mHealth) has emerged and is widely used in medical practice. Researchers can utilize mHealth technology to develop an electronic ICU diary platform that provides families with the opportunity to stay in touch with their patients from a safe distance, through which they are able to easily upload photos, videos, and audio clips and collaborate with other family members to compose content.

In addition, the digital platform helps nurses to provide timely updates about the patient. Haakma *et al.* developed "Post-ICU" a web-based application designed to allow family members to collaborate on writing in a digital diary and interact with the patient remotely ^[28]. The app can be used on any connected device with a display (e.g., smartphone or tablet) and allows families to not only send text messages, but also to elaborate on the patient's personal situation. Hart *et al.* investigated the introduction of video calls to facilitate family-patient contact and communication with healthcare professionals ^[29].

With the accelerated progress in the digitization of patient self-care, the transition to technology and scientific methodology is becoming more urgent. Li *et al.* investigated an ICU e-diary platform built on a co-design approach and validated its applicability ^[30]. The platform was designed to facilitate the seamless transmission of video, audio recordings, and images, thereby saving time, simplifying information storage, and gaining acceptance among healthcare professionals, patients, and their families. This innovation not only contributes to improving patients' mental health and quality of life, but also significantly improves the efficiency of medical staff. Thus, digital diaries play a crucial role in improving the quality of care in ICU ^[31].

4. Effectiveness of ICU diary in post-ICU syndrome

4.1. Reducing anxiety and depression in ICU patients and their families

Psychological factors have a direct impact on the quality of life of ICU patients, especially anxiety, depression, and post-traumatic stress disorder (PTSD), all of which are important factors in the recovery of ICU patients ^[32]. The ICU environment often leads to a variety of complications, such as polyneuropathy, dysphagia, organ damage, and muscle weakness due to chronic pain, all of which have a serious impact on a patient's overall health ^[32]. Villa *et al.* found that ICU diaries can help patients better understand their experiences during their stay in the ICU ^[33]. By filling in memory gaps and rationalizing the sequence of events, ICU diaries give new meaning to difficult experiences for patients ^[34]. In addition, ICU diaries have been shown to improve personal emotional resilience and provide emotional support to patients ^[35].

Recording the patient's feelings and experiences facilitates communication between healthcare professionals

and family members, and helps the patient adapt to daily life more quickly after discharge. This record makes patients feel cared for by healthcare professionals and valued by their families, which in turn increases confidence and hope in treatment ^[36]. Haines *et al.* showed that family members often develop negative emotions such as anxiety, depression, and PTSD due to the severity and uncertainty of the disease during treatment in the ICU, and that family members can read the words and pictures in the ICU diary to better grasp and understand the patient's situation, thus reducing the psychological burden ^[37]. In addition, Jones *et al.* found that ICU diaries helped to improve ICU-related PTSD outcomes ^[38]. Gazzato *et al.* showed that ICU diaries significantly reduced the incidence of PTSD, anxiety, and depression in ICU patients ^[39]. Studies have shown that uncertainty is an important factor contributing to anxiety in family members, and the provision of information is key to reducing uncertainty and anxiety ^[40, 41]. Therefore, ICU diaries significantly reduce negative emotions such as depression and anxiety by providing basic information to ICU patients and their families.

4.2. Giving emotional support to ICU families

ICU diaries have played an active role in giving emotional support to families, helping them to keep track of time and better understand the progress of critical illnesses ^[42]. The diary not only broadened the perspective of ICU care, but also became an important source of information for families ^[43]. Many families expressed appreciation for the diary as a reflection of the support and care of the medical staff. Through the diary, families felt the joint efforts of the medical team and were convinced that the patient was well cared for and valued ^[44]. The diary can improve the family's experience and give hope to ICU patients and their families. Mickelson *et al.* found that ICU diaries became an important tool to support emotional coping, information management, and communication, thus reducing distress among family members ^[44]. In addition, Liu *et al.* found that recording ICU diaries not only conveyed nurses' and family members' concern for the patient, but also increased communication between healthcare professionals and family members, alleviated the patient's delusional memories, and enhanced emotional interactions among family members ^[45]. In summary, ICU diary has significant effects in supporting families' emotions, promoting information sharing, and enhancing healthcare communication. It not only improves the family's understanding of the patient's condition, but also helps to reduce the psychological distress of family members. Through the diary, medical staff can better demonstrate their concern for patients and provide emotional support for patients and families, thus effectively enhancing the quality of ICU care.

4.3. Enhance healthcare team communication

ICU diaries are seen as an important tool to promote patient recovery and family-centered care. While ICU diaries have been proposed as a means of preventing psychiatric symptoms in critically ill patients, families and healthcare professionals can benefit from them as well. Studies have shown that families report unquantifiable benefits from ICU diaries, including improved communication about critical illness, provision of emotional support, and demonstration of ICU staff's humanity. Together, these factors helped families better tolerate the discomforts of an ICU stay ^[46]. In the pediatric setting, diary writing has been identified as potentially beneficial in increasing parent satisfaction, coping skills, and improving communication between parents and healthcare professionals ^[47]. As a communication tool, ICU diaries are effective in improving the exchange of information between the healthcare team and patients and their families.

By recording key information and treatment progress, diaries help to minimize misunderstandings and enhance patients' and families' understanding of and cooperation with treatment plans ^[48]. In addition, diary writing

helps healthcare providers better perceive the human element of their work and serves as a verbal communication aid to improve communication with families ^[49]. In summary, ICU diaries excel in enhancing healthcare team communication and provide effective support for patients and families. By improving information exchange and emotional connection, ICU diaries not only contribute to patient recovery but also enhance family satisfaction and coping skills. For healthcare providers, diary writing improves their professional satisfaction, reduces work stress, and further contributes to the quality of care.

5. Shortcomings and prospects

Up to now, ICU diaries have not been standardized in terms of structure and content, and there is a lack of clear definitions of diary format, record content, storage methods, and ethical standards ^[50]. In addition, domestic policy support for ICU diaries is still insufficient, so it is recommended that hospitals in China accelerate the development of relevant policies to alleviate healthcare workers' concerns about medical disputes. Healthcare professionals generally believe that the heavy workload of intensive care and the shortage of human resources are important factors restricting the promotion of ICU diaries ^[45]. A German study showed that nurses spent less than 6 minutes per day recording ICU diaries for patients, suggesting that there may be a discrepancy between healthcare professionals' perceptions of diaries and their actual time-consumption, partly due to their lack of adequate knowledge about ICU diaries ^[51]. Therefore, recommendations to promote the implementation of ICU diaries need to be approached at multiple levels.

Hospitals should conduct relevant training to reduce the actual workload and issue supportive policies to encourage pilot studies of ICU diaries; departments should increase nurse manpower allocation, flexible scheduling, and set up dedicated positions to realize returning nurse time to patients; and medical staff need to enhance training to change their perceptions. In addition, we should learn from the advanced experience of foreign countries, such as the United States has developed the application of ICU diary, using technology to reduce the workload of handwritten diary ^[52]. Through the above measures, the implementation of ICU diary can be promoted, thus better supporting patients and families and improving the effectiveness of diary application.

6. Summary

In summary, the ICU diary is gaining increasing attention as an important nursing tool, and its use in post-ICU syndrome has demonstrated significant positive effects. However, in order to better fulfill its role, there is an urgent need to address the current deficiencies and promote its standardization and policy support, so as to provide more comprehensive support and care for patients and their families.

Disclosure statement

The authors declare no conflict of interest.

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