

## Research Article

# Narrative Diaries in the Cardiac Intensive Care Unit for the Reduction of Post Intensive Care Syndrome: A Thematic Analysis

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**Abstract**

**Introduction:** The Coronary Intensive Care Unit (UTIC) diary is a shared bedside tool written by healthcare professionals and patients' family members. There is little evidence on its feasibility and how it supports the families of ICU patients. Patients who have been seriously ill experience significant physical and psychological disorders after discharge. Currently, there is no evidence on how the diary of intensive care is used and what we can learn from it.

**Materials and methods:** Qualitative study of CCU diaries conducted with a narrative research approach. Patients admitted for acute heart failure were enrolled in an eight-bed Italian intensive care unit in a secondary hospital. During the ICU hospitalization of patients, relatives and health professionals were invited to report events, thoughts, messages for patients in the patient's diary. A thematic analysis of the contents of the ICU diaries was carried out.

**Results:** Between September and December 2022, 15 ICU diaries were completed, mainly from patients and family members (n=65) and healthcare professionals (n=28). Three main themes emerged: "Social, psychological and spiritual support", "Emotions, feelings and anguish of relatives" and "Life in UTIC". The diaries offer information about relatives' emotions, social support, clinical activities and interactions with healthcare professionals, and progression to recovery.

**Conclusions:** Intensive care diaries are invaluable in facilitating patient-centered care by providing a space for written reporting of patient admission by relatives and caregivers.

**INTRODUCTION**

Numerous studies have shown that patients discharged from intensive care units (ICU) can experience psychological problems, such as post-traumatic stress disorder, anxiety, depression with repercussions in the patient's social life [1,2]. The Society of Critical Care Medicine has coined a new term to describe them: Intensive Care Syndrome: Post Intensive Care Syndrome (PICS) [3,4]. The traumatic events that trigger this syndrome are hospitalization in Terapia Intensiva, sedation, the state of unconsciousness, pain and the severity of the pathology that led to hospitalization.

Among the interventions proposed to elaborate the moment of hospitalization after discharge from intensive care and prevent psychological disorders there is the compilation of a diary (ICU diary): it is a tool shared by health personnel and family members in which they are reported in narrative form in the form of messages, phrases the most important events that have characterized the patient's life during admission to intensive care and sometimes also includes photographs with a simple and

informal language [1,5,6]. It is therefore a record of the patient's stay in intensive care, the patient's daily life, procedures, treatments and visits received. In this way the patient, who has suffered traumatic experiences following invasive treatments, painful states, diagnostic-therapeutic procedures and the stay in places with noises, lights and closed spaces typical of critical area departments, can be helped to reconstruct a part of his experience that would otherwise be lost or remembered in a confused or distorted way. The compilation of the diary does not require much time on the part of the nursing staff and family members: some studies have shown that about 5 minutes per shift are sufficient [7] and that this practice allows the patient to reshape the lived experience and maintain a bond with loved ones during the lost time [8].

Since the 90s the use has spread to the United Kingdom, Switzerland, Portugal, Germany and Italy [9]. Given the importance of the tool and the advantages it can offer, it is therefore necessary to explore the contents of the narrative diaries in ICU written by health professionals, relatives or other visitors of patients admitted to ICU to describe the experience of

patients in ICU, to support the relationship and communication between family members and the health team, provide an informal account of the needs and emotions of patients and family members, to enhance mutual understanding and cope with hospitalization.

## MATERIALS AND METHODS

### Study design

This is a qualitative study that uses an interpretative narrative research approach to analyse ICU diaries [10]. The creation of a narrative is a process that organizes human experiences into meaningful episodes that become accessible to direct observation and interpretation of the researcher [11]. Stories derived from complex situations are fixed in narratives, so events are interpreted and infused with meaning [10]. The narratives, detached from the moment they occurred, become open works relevant to other contexts. The EQUATOR (Enhancing the Quality and Transparency of Health Research) guidelines were used for reporting qualitative research studies.

### Sample

The study involved patients admitted to the ICU of a hospital in southern Italy, from September to December 2022 for diagnosis of acute heart failure. Patients and their family caregivers provided consent to the study. Patients and caregivers who were unable to speak or write Italian correctly due to other nationalities were excluded. The recruitment of study subjects ended with the achievement of "data saturation" [12]. The ICU is an eight-bed cardiology intensive care unit that admits acutely ill patients to the emergency room. The team consisted of 7 doctors, a head physician, 15 nurses, 4 social and health workers and a nursing coordinator. Caregiver visits were allowed 3 times a week for one hour after carrying out a molecular swab for Sars-Cov-2.

### Data collection

The UTIC team was informed of the features and implementation of the diaries through two 2-hour virtual meetings. The purpose of the diary, the criteria for enrolling patients, and the team's role in journaling were discussed. Questions and doubts about how best to contribute to the narrative during hospitalization were clarified through discussion with the research group. All caregivers were asked to write in their family member's diary. The diary was a 100-page line notebook with a 5 cm x 8 cm hardcover with no specific headings. A sticker with "The diary of" was placed on the cover of the diary. The written guidelines for caregivers were described in an information sheet placed in the diary. The information included the objectives of the study and visiting rules. Caregivers were asked to provide data and sign notes. The research team was available to answer any questions about how to use the diary, which was placed during the stay next to the patient's bedside. During the hospitalization the team could write down events, thoughts, messages for the patient. Upon discharge from the ICU, the original copy was

given to family members, while the photocopy of the diary was collected for research purposes. In accordance with current legislation regarding the processing of sensitive data and respect for anonymity, each participant has given his written consent.

### Data analysis

Each diary has been assigned an identification code consisting of the letter "D" and a progressive number from 01 to 15. Each type of diarist has been assigned an initial: M mother, P Father, F child, Mo Wife, Ma husband, To another family member, I Nurse, O Socio-health worker, Me Doctor. A thematic analysis of the ICU diaries was carried out to describe the data, select the codes and construct the themes according to the six steps described by Braun and Clarke: a) the degree of kinship with the data was recognized by repeatedly reading the ICU diaries and identifying recurring topics by two independent researchers i, with experience in the critical area. Triangulation of data analysis was performed to ensure reliability and credibility; b) The initial codes were generated by assigning an initial alphanumeric code to each identified topic. c) From this codification potential conceptual themes and emerging sub-themes have been identified. d) The identified topics have been examined and validated by all members of the research group. A thematic map has been generated. e) All diaries have been re-read to ensure the completeness of the coding and categorization of all narratives. To ensure the reliability of the entire research path, the analysis and encoding of transcripts were conducted independently by the researchers and consensual validation was subsequently carried out. The initial encoding of the transcripts was carried out by researchers who met regularly to discuss emerging issues. No data analysis software was used. A triangulation of the times was carried out to increase the rigor of the study. At the end, to confirm the reliability of the themes, they were re-presented to the study subjects who said that the themes accurately reflected their experiences. The interpretative analysis was performed to meet the criteria of trustworthiness, including credibility, transferability, reliability and confirmability.

### Ethical considerations

Participation in the study was voluntary. All participants were asked for written consent. To ensure the anonymity of the person, each diary has been either coded or numerically in ascending order. The research was carried out according to the Helsinki guidelines.

## RESULTS

In September and December 2022, 15 ICU diaries were completed, mainly from patients and family members (n=65) and healthcare professionals (n=28). 65 patients with a mean age of 67.05, predominantly male (75%), were involved, with an average length of 10 days of hospitalization. The main socio-demographic data are shown in Table 1. Spouses, parents and children were the main diarists. In seven diaries most of the entries were messages sent by relatives or friends and entered by caregivers and in four diaries the main contributions were

**Table 1:** Participating socio-demographic characteristics.

Average age of patients	67.05
Gender patients, male	75%
Length of stay, days	10
Days with mechanical ventilation	6
Average family age	52,5

made by nurses. A total of 125 daily notes were analysed: half of the entries were entered by a caregiver. The average number of daily diary entries was 5 during the ICU stay. All daily entries were analyzed to identify recurring themes. 35 messages written by health workers were identified, most of them concerning life in the ICU, while the rest were messages of encouragement. Three main themes emerged from the thematic analysis; each has been divided into two sub-themes describing the recurring elements reported in the UTIC diaries. Caregivers, caregivers and patients confirmed the interpretation of the data provided by the researchers through an interview. The citations for each theme and sub-theme identified in Table 2 are shown.

**A) Theme 1: Social, psychological and spiritual support**

**Subtheme 1: Friends and families**

For caregivers, the support of family and friends appears essential in times of discouragement and uncertainty about the outcome. Social support seems to be a source of resilience and emotional strength:

*F: Today there are your children out here... We are surrounded by so much love and this is the important thing. I brought you a gift, your son Carlo (D08).*

Healthcare professionals welcomed the ability to report messages from family and family friends:

*A: How many messages are you receiving. All united in the hope that it can recover and improve (D01)*

Caregivers reported messages of encouragement and hope. Some preferred to print the messages sent on their mobile phones, others instead reported the words of the messages verbatim, others wrote about phone calls or visits received from relatives and friends and showed closeness and support:

*F: Your grandson sends you lots of kisses... Wait for his beautiful and strong grandfather (D05)*

**Table 2:** Themes, sub-themes.

Themes	Sub-themes
Social, psychological and spiritual support	Friends and family Faith and prayer
Emotions, feelings and anguish	Desire for the relationship with the patient Pain, fear and hope
Life in UTIC	Stories of daily activities in UTIC Relationship with healthcare professionals

**Subtheme 2: Faith and prayer**

Caregivers entrust their thoughts to God, praying during hospitalization. Some health care workers have drawn great strength from their faith:

*F: Even if the news is not always positive, my faith helps me to believe that we will return home together... (D04)*

Believing that there is God’s protection instills confidence in both caregivers and caregivers, and God’s help is often compared to that of medicine:

*Mo: We will be able to get out of it with the help of doctors and with the help of heaven (D11)*

Interestingly, health workers are also described as angels.

*M: We Entrust ourselves to the hands of angels and doctors (Q13)*

**B) Theme 2: Emotions, feelings and anguish**

**Subtheme 1: Desire for the relationship with the patient**

One of the biggest difficulties of caregivers is the lack of relationship and physical contact. Caregivers write to their family member to be close to them to emphasize their presence during the state of unconsciousness.

*Mo: These days I have done nothing but talk to you. Talking to you, thinking about you and crying thinking I can’t do it without you... (D13)*

Family members report that they are afraid of hurting their loved ones if they touch them and see that their appearance has been changed by the devices:

*Ma: I miss shaking your hand while we sleep nearby. Now I can only stroke you and I’m afraid of hurting you in some way (D08).*

Family members reported that they perceived a strong sense of loneliness in everyday life and at home they perceived a feeling of emptiness due to the absence of the family member.

*Mo: Without you in our daily life I feel empty, useless, devoid of an important part, as if there were no air... (D08).*

**Subtheme 2: Pain, Fear and Hope**

Health workers faced a strong duality between pain and hope during the family member’s stay in the ICU. The pain described by the caregivers is strong, the fear for the death of their family member is present in the stories.

*Mo: It’s a very bad thing because you don’t know if your husband will come home (D12).*

The waiting time is very painful; The time spent separated from the caregiver is experienced as interminable, despite having fully understood the rules of the visiting hours to guarantee the care activities:

*A: The hours are endless and the pain I feel hurts more than a punch in the stomach (D11).*

Caregivers expressed mixed emotions related to their family member's admission to ICU and their separation from the patient when they are not present in the ICU, at home, or in the waiting room. In the ICU diaries, parents reported on their sleepless nights, the need to cry and the need to cope with the "nightmare" they are experiencing.

*A: When I leave my tears start crying like a fountain. See you tomorrow... (D06)*

Some family members have described defense mechanisms to avoid experiencing all their pain for the admission of the family member in UTIC:

*A: I feel like I'm in a soap bubble, sometimes I don't feel like I feel so much. I think it's a way to defend myself to survive all this... (D08)*

Grief was the dominant feeling especially at the beginning of the narratives in the first days of hospitalization. Subsequently, pain is increasingly mixed with hope. Messages of trust and encouragement followed:

*O: Soon you will be returning home next to your husband (D07).*

Messages of encouragement often describe the disease as a battle or a war to be won. Patients become the fighters who with the support of family and health personnel can emerge as winners.

*I: Hold on and keep fighting the toughest challenge you've ever faced (D12).*

### C) Theme 3: Life in the ICU

#### Subtheme 1: History of daily activities in ICU

Another recurring theme is the narration of the daily activities of the ICU by doctors, nurses and health workers. In the diaries, caregivers reported the events most significant to them such as intervention, planning discharges from the ICU or discontinuation of intravenous medications as well as routine activities concerning nursing procedures and clinical monitoring:

*A: A nurse came to tell me that you will be discharged in the afternoon! What happiness! (D02)*

Family members report examples of nursing routines, such as medication

*F: I told a nurse that he can take the pills even without water (D08)*

Nurses and social and health workers have reported improvements in health conditions or episodes that occurred in the absence of family members:

*I: Today we got together for the first time and you were very good (D01)*

In particular, there are episodes of improvement in clinical conditions:

*O: I washed you and sat down. You took off your mask and drank water yourself. Keep up the good work (D07).*

#### Sub-theme 2: Relationship with health professionals

The relationship with nurses, doctors and operators was a very frequent theme in the ICU diaries. The common element was that caregivers perceived the need to leave the patient in good hands when they had to leave the ward due to the restrictive policy of visits in the ICU. The nurses and doctors in the ward were described in positive terms:

*A: By your side there are amazing nurses and very good doctors who take care of you (D06).*

Healthcare professionals placed great importance on communication with the healthcare team. Episodes of dialogue between the team and the family include:

*Mo: Your father asks a lot of questions and the doctor teased him! (D08).*

The nurses reported the conversations they had with patients:

*I: We can still talk about your favorite dishes and your unconditional love for football (D10).*

## DISCUSSION

The aim of this study was to conceptualize the main themes drawn from the ICU narrative diaries used by caregivers and patients during hospitalization. The syndrome that occurs in patients discharged from a highly complex care environment such as ICU is framed as a dysfunction of physical and/or cognitive health that causes psychological suffering and repercussions in the patient's social life persisting for many years [13,14,4,3,2,4]. Threemain themes emerged from the study: "Social, psychological and spiritual support", "Emotions, feelings and needs", and "Life in UTIC". For caregivers and patients, journaling was a means of expressing their emotions and experiences of their stay in ICU, while healthcare professionals primarily reported events related to nursing care and patient well-being in ICU.

The first theme reports the need for social, psychological and spiritual support. This was often provided through messages and visits from family and friends: this in line with previous research that has emphasized that the use of the diary helps the patient understand his experience in intensive care with a positive impact on depression, anxiety and Post Intensive Care Syndrome. In the study by [15] the use of the diary reduced its incidence at 3 months after discharge (5% vs 13%,  $p = 0.02$ ) with a significant reduction in the symptomatology of post-discharge stress. The study by [2], when comparing subjects with memory impairment, reports a significant reduction in anxiety ( $7.1 \pm 3.8$  vs  $5.7 \pm 2.7$ ,  $p = 0.011$ ), depression ( $8.6 \pm 5.0$  vs  $7.2 \pm 4.3$ ,  $p = 0.003$ ) and acute stress disorders ( $46.9 \pm 13.8$  vs  $43.8 \pm 11.4$ ,  $p = 0.012$ ).

In the study by Knowles et al. (2009), the experimental group presented a statistically significant reduction in anxiety ( $t(1.17) = 2.65, p < 0.05$ ) and depression ( $t(1.17) = 3.33, p < 0.005$ ), measured one month after discharge from intensive care and after 3 weeks. Facilitating the social support of families and individuals is an important strategy to reduce psychological distress. Wishes for a speedy recovery written in the ICU diaries by health workers were also found. Meditation and prayer are considered valuable approaches to reduce stress in caregivers of ICU patients [16].

The second theme that emerged from the analysis of the diaries describes the emotions, feelings and needs of caregivers during hospitalization. Family members expressed feelings of loneliness, emptiness and suffering caused by the inability to communicate with the hospitalized patient. In addition, the hospital environment, communication difficulties and uncertainty regarding the future prognosis have been reported as potential causes of stress. Positive emotional reactions such as hope, pride, joy, empathy and love were also described in the diaries.

The last theme, life in the ICU, includes the narration of the clinic and the activities that take place during the hospitalization. The use of the diary seems to allow the patient to recompose that piece of his life that would otherwise be lost [8] or remembered in a distorted way. This intervention would be able to prevent anxiety, depression, sleep disorders, mental processing problems and limited mobility and, in addition, would result in a low health cost [17-19,15,7,2]. The ICU diary highlights the involvement of staff caring for patients and families, highlighting their contribution in providing information about hospitalization and health conditions. Effective communication between caregivers and the family helps build trust. In fact, nurses reported that journaling played an important role in building a good relationship with family members.

The limitations of the present study are mainly related to the number of samples. Since the diaries could be consulted and read by the whole group, a bias of social desirability could have limited the credibility of the narratives by family members and health professionals. A simple thematic analysis was used which, compared to other methods, did not allow statements to be made about the language used. Because the study was conducted in a hospital located in a context where the Catholic faith is prevalent, participants' attitudes toward spirituality, faith, and social support provided by religious communities may not be entirely transferable to other cultures or contexts.

## CONCLUSIONS

The knowledge generated through this study enhances the understanding of the narrative diary in ICU and their potential benefits, including better communication between family members and caregivers, and family-centered care. Through the diaries, family members expressed their emotions and noted their need for support from relatives and friends, as well as psychological and spiritual support. Health workers also interacted with families through diaries and reported moments of hospitalization experienced. Future work would be needed on how diaries might affect the recovery trajectories of discharged

patients and family members in terms of psychological, social and behavioural outcomes.

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