Care and Caring: Times and Tools of Connection in the Critical Care Area. The Diary.



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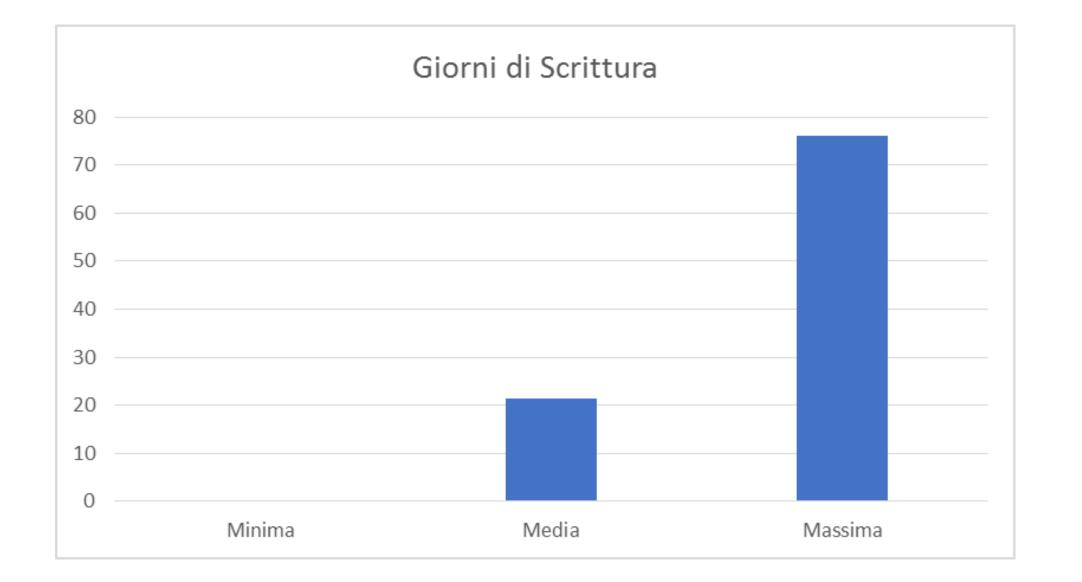


Introduction

It has been known for many years and reported in the literature that the hospitalization in the intensive care unit can represent an abrupt interruption of a person's life course. (Combe 2005; Greco et al. 2009; Ullman et al. 2015; Beg et al. 2016).

Based on the duration, modalities and 'tangible' consequences on the body, this experience can be perceived as a real fracture and generate dynamics of identity shattering and loss of meaning that may lead to the develop of the Post-Traumatic Stress Disorder.

The ICU patient diary is a useful tool for patients to regain possession of their memory and



fill in any gaps in their personal experience. The diary is also intended to be a "meeting place" for all caregivers and an opportunity to shorten the distance between disease and illness, keeping track of all the manifestations of well-being or discomfort observed and/or perceived. Finally, the patient's diary is a tool for dialogue between the perceptions and experiences of the patient and/or caregivers and the expert knowledge of healthcare personnel, and represents a valid opportunity to consolidate that therapeutic alliance which is fundamental for all the actors involved in order to share, face and manage together the stages and times of hospitalisation and the long term recovery.

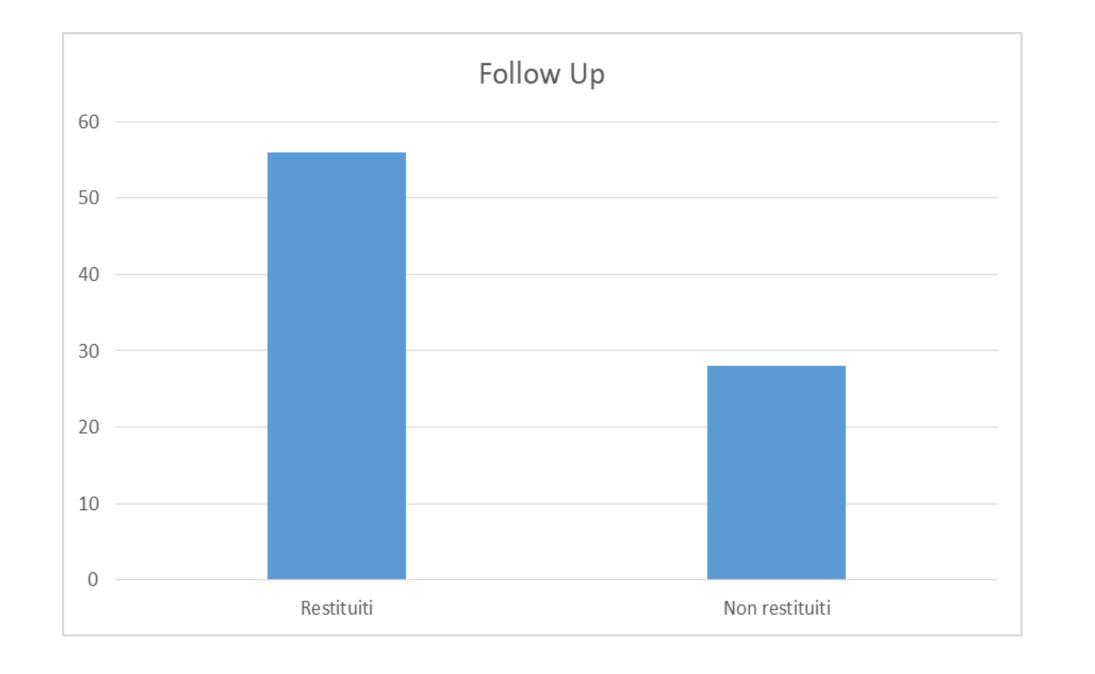
Methods

The diary, designed and applied by the Simple Departmental Organizational Structure (SODs) of Neuroanesthesia and Intensive Care pertaining to the Careggi University Hospital, is a paper document written during the days of hospitalisation. It is a simple notebook with blank pages that is kept by the patient's bedside until the discharge and it is freely filled in by ICU teamwork, relatives and friends during their visits to the patient.

The opportunity to use this tool is offered to all patients with a few inclusion rules: ICU stay of at least 24 hours, overcoming of the most critical phase, caregiver's explicit expression of consent to use the diary by signing a specific information form. Exclusion criteria are adverse prognosis in the short term, language barriers preventing the use of the tool, severe psychiatric pathology.

At the end of the hospital stay the diary is kept in the ward. At least 3 months after discharge, the Follow-Up team contacts the patient or caregiver and agrees on the restitution of the diary, which takes place in the context of a broader post-discharge assessment of the outcomes and the patient's needs. On this occasion the Follow-Up team returns the diary to the patient. If the patient refuses the diary, it is kept for 12 months and if unclaimed it is destroyed. In case of death, after about three months the family/caregiver is contacted with a proposal to give the diary back, if this is not accepted the diary is destroyed.

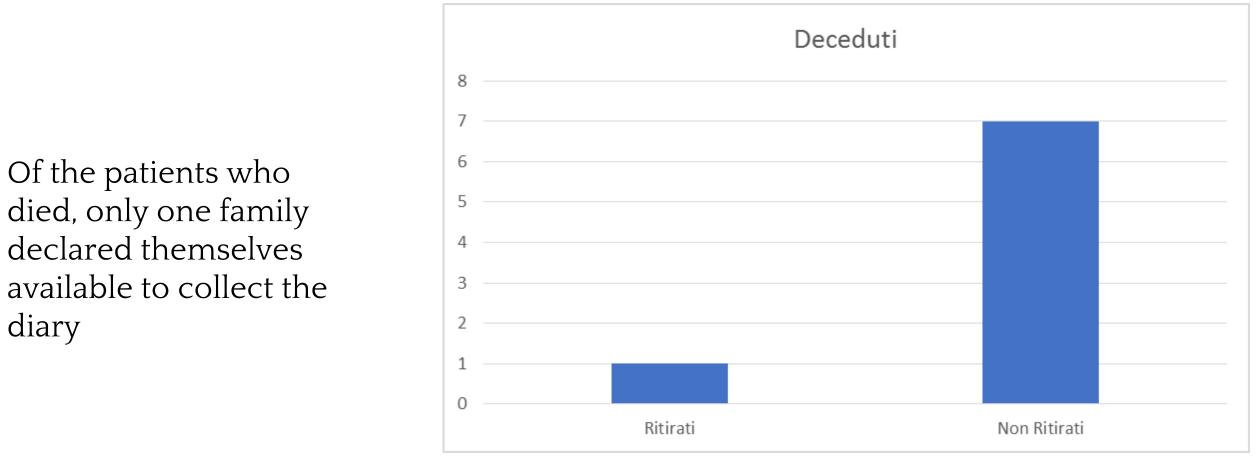
Individual diary writing days were a low of 0, a high of 72 with an average of 21.



The return of diaries took place as part of the Follow Up activity.

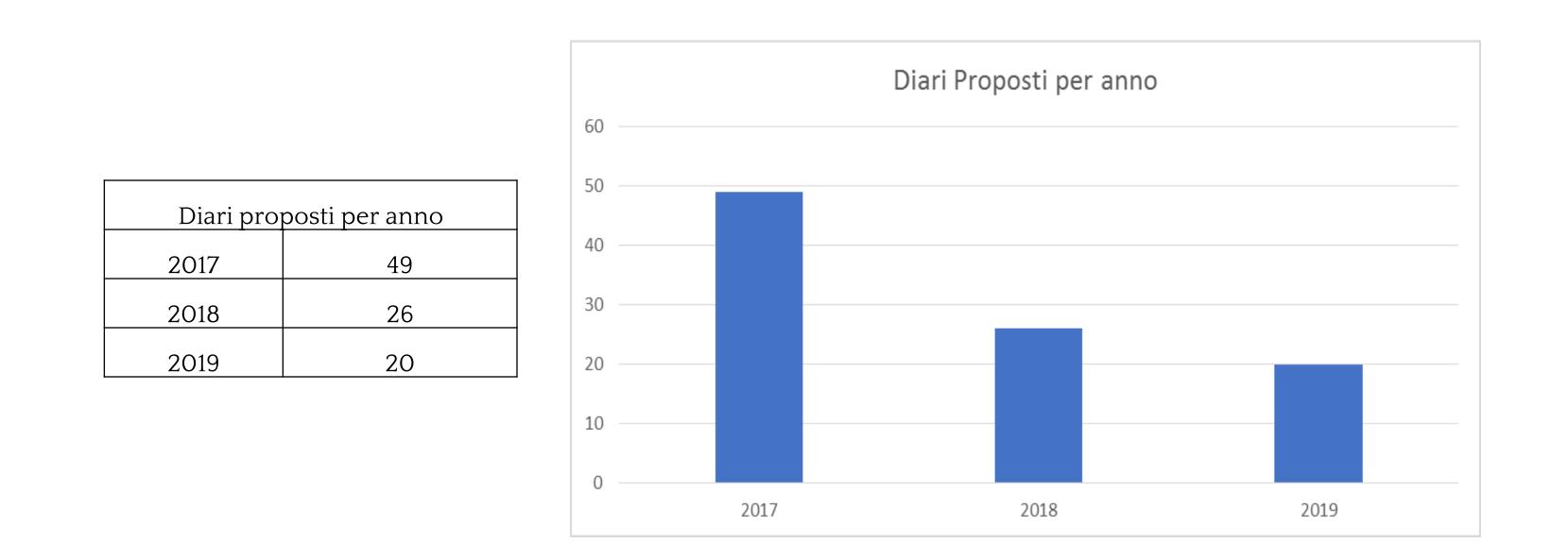
Of the patients who died, only one family declared themselves

diary



Results

Between 2017 and 2019, a total of 95 diaries were proposed and accepted. In 2019, this activity came to an halt with the onset of the Covid pandemic which led to the closure of the ICU departments.

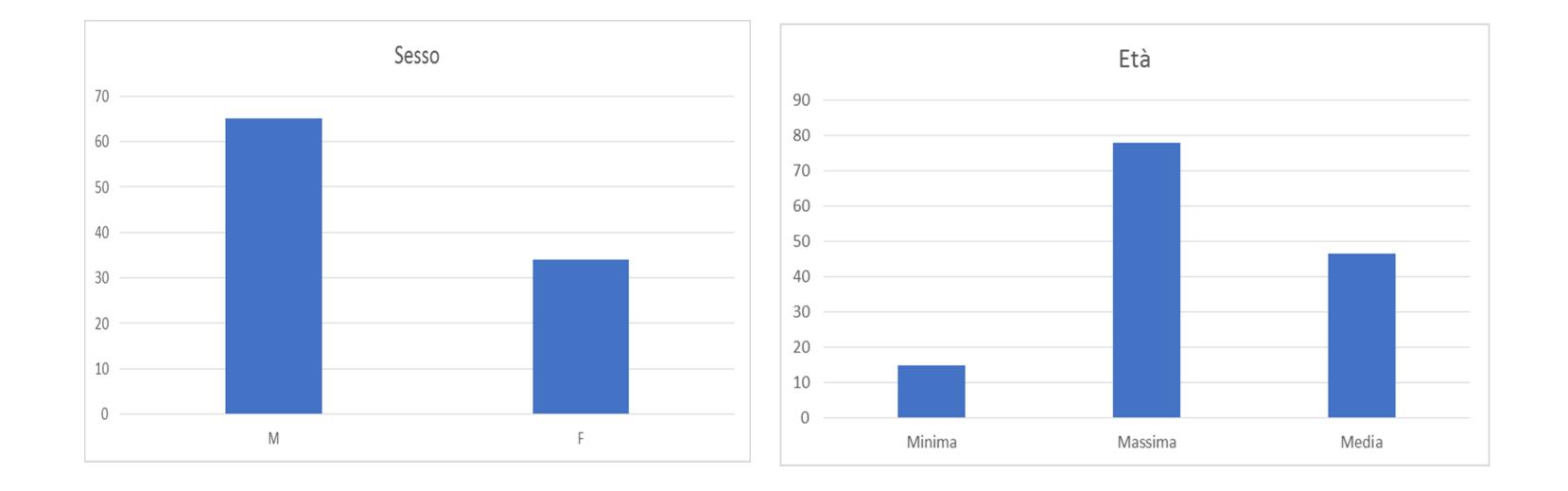


Conclusions

In line with the most recent literature, the patient's diary proves to be an important acquisition as a treatment tool (Tavares et al. 2019) and its implementation in the ICU is an important initiative in the patient's long-term recovery path. The diary returned in the follow up meetings, fulfils the "need to know" and becomes an important tool in restoring the memory of the days of hospitalization (Barreto et al. 2019). Moreover, the diary can be seen as an open space and a continuous opportunity for exchanging points of view. For this reason, For this reason, the diary strengthens the relationship between caregivers, increasing the sense of teamwork and making the relationship between family members and the hospital staff more participatory, aware and active.

Finally, the diary has been a rich and multifaceted source of data that can concretely contribute to the clearer identification of needs and to the definition of good ward practices, with an impact both on the variety and quality of services offered to patients and families, and on the modalities of care coordination and improvement of interaction between team members.

The information that revealed by the analysis of the diaries allowed us to identify the critical



Diaries were distributed to 65 males and 34 females with a minimum age of 15, a maximum of 78 and an average of 47.

aspects of our organization, leading us to planning improvement projects and training events. Furthermore, the feedback that emerged after the reset of the data favoured the empowerment of the working group.

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