

Caregiving and Caring: Times and Tools of Connection in Intensive Care Unite



The Caregiver's Perspective



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Introduction

“The success of Intensive Care should not be measured by survival statistics alone, as if every death were a medical failure. It must be measured by the quality of lives preserved or restored, and by the quality of deaths of those for whom it is preferable to die, and by the quality of human relationships involved in each death.”

The humanization of care is expressed, in the context of Intensive Care, by this sentence in which the importance of taking care of the person as a whole rather than of the individual disease is evident. In this process, a fundamental step was to open the physical and mental doors of the Intensive Care Unit which brought benefits for patients and their families rather than disadvantages.

It emerges from numerous studies that one of the fundamental needs expressed by patients in the ICU is the need to have significant people beside them, not only in terms of emotional support, but for the trust placed in these people in the face of the need to exercise their rights and will in a time of great dependence. It is also well documented that the proximity of loved ones produces beneficial effects on the clinical course, reduction of cortisol levels, reduction of the need for physical restraint and sedation and does not constitute a danger at all, e.g. from an infectious point of view.

In this perspective, the "Patient's Diary in Intensive Care" joins traditional aids as a typical tool of narrative medicine; placing itself as a new and necessary space and an opportunity to tell, listen, honor the story of the other. The first diary experiences were made in the 80s in Denmark and subsequently the use spread to Scandinavian countries, the UK and Northern Europe.

It is a document containing simple level information on what happens to the patient during hospitalization, written voluntarily and freely by both relatives and health personnel. The participatory and collective sharing of this tool testifies to the common will to take care of the subject. It also gives proof of both the presence of the patient's loved ones and the promptness of the healthcare personnel. Finally, numerous studies have shown that the diary is a useful tool during the patient's recovery phase, helping reduce Post Traumatic Stress Disorder. An event as significant as hospitalization in the ICU can make people miss "some beats" of their life path, giving rise to feelings such as anxiety and terror. Reliving the facts through the diary can help understand and accept what happened and move forward, reworking the lived experience as much as possible.

Methods

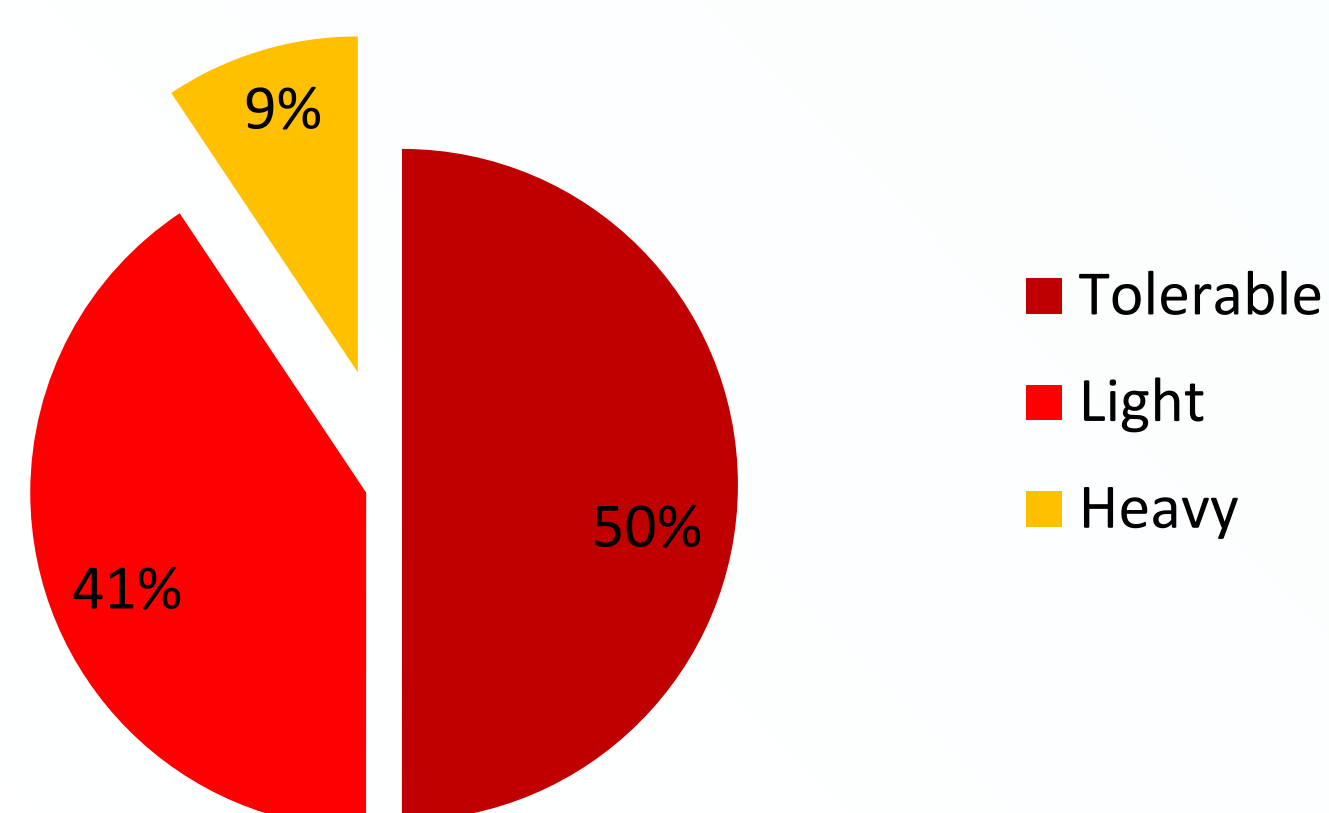
A qualitative research was performed on questionnaires relating to the period 02/06/2017-07/06/2018 to bring out the perceptions and experiences of the caregiver. Consent to the use of the diary was expressed by the caregivers as their loved one was hospitalized in an unconscious state at that time.

The questionnaire was delivered to the caregiver during a dedicated follow-up meeting, at least 3 months after the patient's discharge from the ICU. The questionnaire proposed to the caregiver was filled in using a special Google form during the meeting, while the patient was interviewed and visited with the follow-up team. The questionnaire was made up of open questions and structured closed questions and it was compiled and analyzed anonymously.

Results

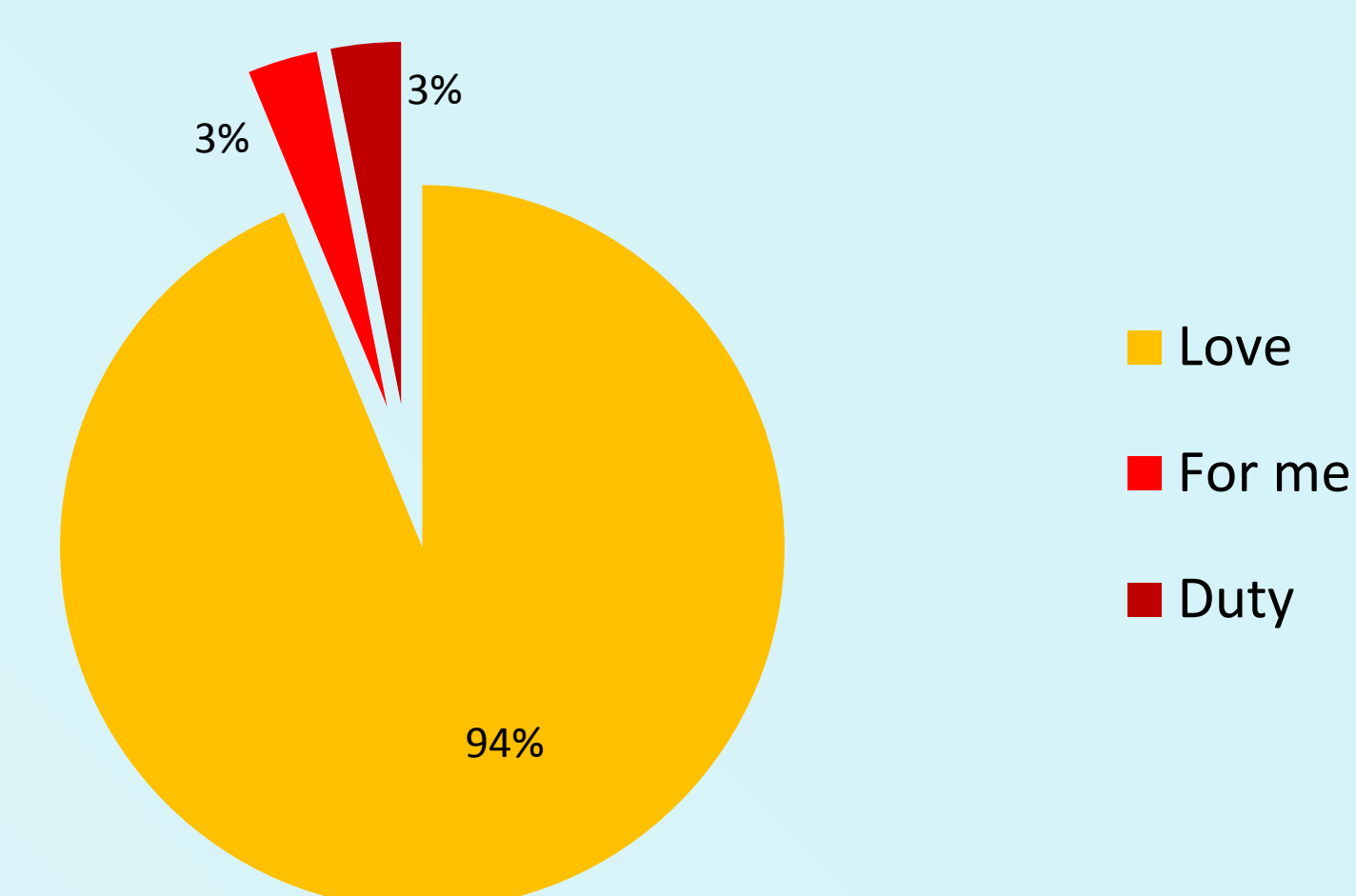
32 caregivers participated in the study. 75% were women. Most of the subjects were aged between 36 and 65 years (69%) and had a permanent job (53%). 100% of caregivers were relatives of the patient, the predominant link being spouse-partner (47%).

Caring for the family member



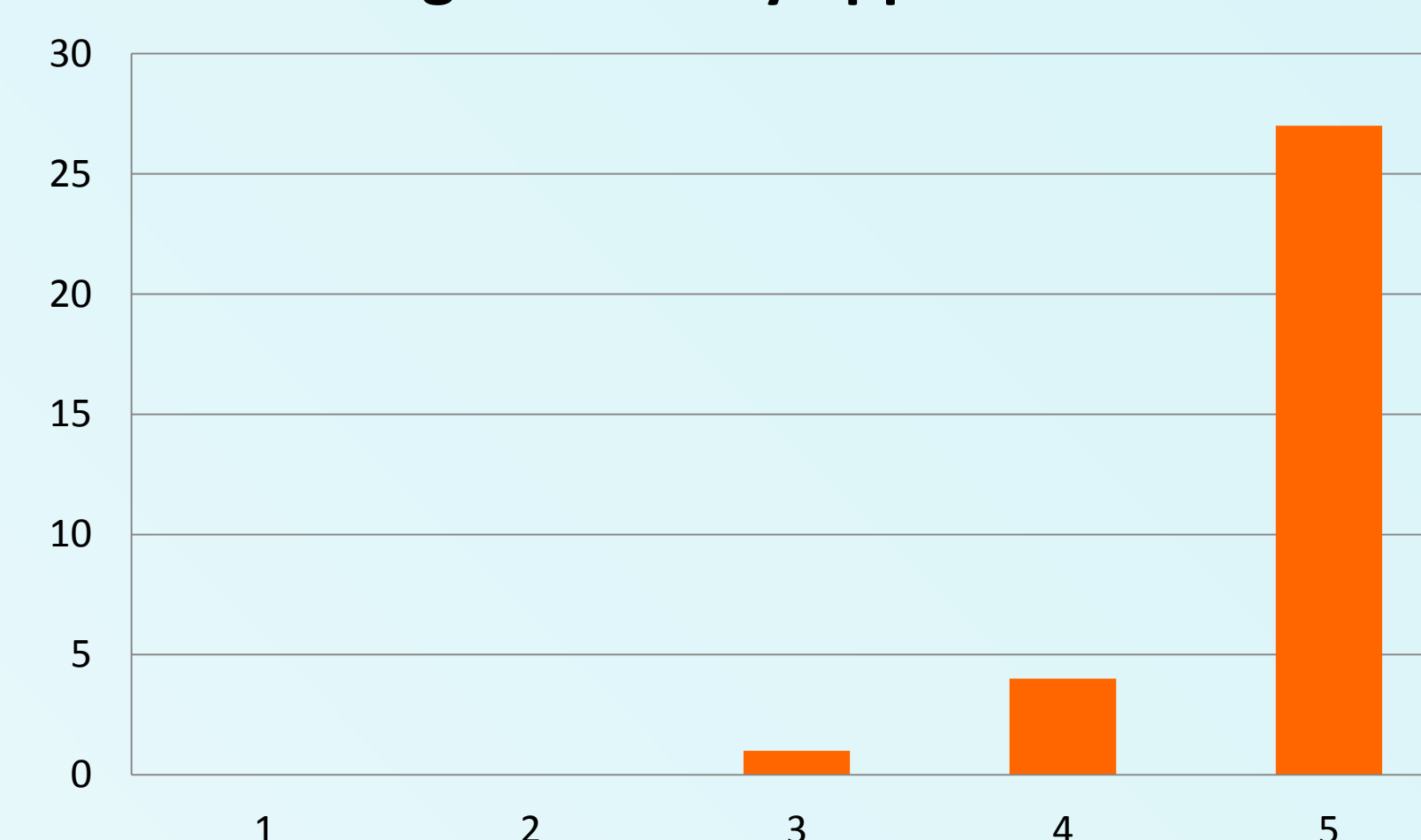
It is interesting to note that, despite the majority of caregivers dedicating at least 5-6 hours a day to their loved one, only 9.37% define the workload as "heavy". For the most part (90.62%) it is light-bearable. It is as if taking care of those we love never costs us sacrifice, despite the hours spent.

Reason that prompted you to write in the diary



93.75% of caregivers declare that they have decided to write the diary out of love for their loved one

Degree of diary approval



It is important to underline how, having available a score ranging from 0 to 5, no one has given a score lower than 3.

So the diary was not only appreciated by the 32 participants, but it was also defined as a useful method of venting for them and of help for the patient.

Conclusions

The objective of this part of the research project is to understand the effectiveness of the diary for the caregiver, either as a tool to relieve the stress experienced during the hospitalization of their family member or as a source of suggestions for improving the department climate and/or interactions between patients, relatives and ICU teamwork.

The results show that caregivers consider the diary useful, usable and easy to use.

Among the suggestions that emerged from the questionnaires, two in particular made us understand how taking care of the patient and his family is important for cementing the therapeutic alliance and optimizing the management of hospitalization and recovery:

“The diary is for me a fundamental element to fill the void that patients have and it is beautiful after some time to read it, it is exciting.”

“CONTINUE WITH DIARIES!»

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