



E-ICU/Communication

## Sharing intimacy in “open” intensive care units



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### ABSTRACT

**Purpose:** Opening intensive care units (ICUs) is particularly relevant because of a new Swiss law granting the relatives of patients without decision-making capability a central role in medical decisions. The main objectives of the study were to assess how the presence of relatives is viewed by patients, health care providers, and relatives themselves and to evaluate the perception of the level of intrusiveness into the personal sphere during admission.

**Material and methods:** In a longitudinal and prospective design, qualitative questionnaires were submitted concomitantly to patients, relatives, and health care providers consecutively over a 6-month period. The study was conducted in the 4 ICUs of the public hospitals of Canton Ticino (Switzerland).

**Results:** The questionnaires collected from patients, relatives, and health care providers were 176, 173, and 134, respectively. The analysis of the answers of 120 patient–relative pairs showed consistent results ( $P < .0001$ ), whereas those of health care providers were significantly different ( $P < .0001$ ), regarding both the usefulness of opening ICUs to patient relatives and what was stressful during admission.

**Conclusions:** Relatives in these “open” ICUs share a great deal of intimacy with the patients. Their presence and the deriving benefits were seen as very positive by patients and relatives themselves. Skepticism, instead, prevailed among health care providers.

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## 1. Introduction

Liberalization of intensive care unit (ICU) visiting policies is still a subject of debate [1,2] and is a topic of particular relevance following the implementation of the new Swiss law, which grants the relatives of patients who no longer have decision-making capacities a central role in medical decisions [3]. The law establishes the physician's obligation to respect the previously stated wishes of the patients and the opinion of the surrogates in the decision-making process [4]. An “open ICU” is conceived as a unit in which visiting policies allow a better interaction between patients, relatives, and health care providers [5]. Various studies have shown that the opening up of ICUs has the advantage of improving communication with relatives [6–9], which is essential for an effective cooperation in the decision-making process as well as beneficial for both patients and family [10–13]. Opening up the units and cooperating with relatives are 2 practices that are regarded as a guarantee of the respect of the patients' autonomy and of the quality of care [10,14,15]. On the other hand, other articles have also highlighted a

persistent reluctance on the part of health care providers to the opening up of ICUs [16–19], the need for an organizational and psychological preparation for the liberalization of visiting hours [8–10,20], and the difficulties that the greater participation of relatives in the treatment process causes to all parties involved [7,21,22]. These factors may explain why—despite numerous international recommendations and guidelines suggesting a liberalization of visiting hours—both in Western Europe and in the United States, most ICUs continue to adopt a restrictive visiting policy [23–26,17,27]. Swiss ICUs have less restrictive visiting policies as compared with other Western countries and United States, but only few Swiss ICUs have unrestricted visiting hours [28].

Our study aimed, firstly, at assessing how the presence of relatives is viewed by patients, health care providers, and relatives themselves and, secondly, at evaluating the perception of the level of intrusiveness into the patient's personal sphere during ICU admissions. Finally, we intended to compare the assessments provided by patients, relatives, and health care providers regarding relational aspects.

To explore these aspects, we chose for our survey the term *intimacy*, intended as a close personal relationship based on exchange of feelings and emotions [29]. The reason for this choice is to go beyond the concept of confidential information (privacy) to include aspects that are in effect more emotional and linked to the personal sphere of

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the patients [30,31] and in relation to which relatives can have a representative role. The hypothesis tested in our study is that, in ICUs, the safeguarding of the intimacy of the patients can be better achieved through the mediation of relatives, who are more capable than health care providers of sharing patients' personal values during hospitalization.

## 2. Materials and methods

### 2.1. Setting

Our study, longitudinal and prospective, was carried out at the 4 ICUs of the hospitals belonging to the Ente Ospedaliero Cantonale (EOC), which is made up of the public hospitals of Canton Ticino, the Italian-speaking part of Switzerland (population 340 000 people as of 2012). These mixed ICUs located in the towns of Bellinzona, Locarno, Lugano, and Mendrisio have a total of 34 beds and treat about 3200 adult patients per year. Among the 159 nurses (with various degrees of occupation), 70% are critical care registered, whereas the remaining ones are registered nurses on specific training. Patient to nurse ratio is usually 1.5:1 during daytime and 2:1 during the evening and night shifts. The practice of involving patient relatives in the decision-making process has been in operation for a number of years in the ICUs of the hospitals belonging to the EOC group. In these ICUs, formal access is allowed for 8 hours during the day; but in fact, visits are allowed during 24 hours and particular attention is paid for relatives' participation in the care process. In this context, a meeting with family members is organized as soon as possible at the time of admission and at regular intervals during hospitalization, with a variable frequency depending on the patient's clinical conditions and their evolution. The discussions involve the intensivist, the nurse in charge of the patient, and the specialist consultant involved in patient care (eg, neurosurgeon, surgeon, nephrologist). The interviews are documented in the patient folder. The nursing team, subsequently, has the task of answering questions that family members pose during their stay at the bedside and of organizing further meetings to clarify any doubts and provide them with more information and updates. This practice is intended to establish a relationship of trust and sharing between the ICU staff and family members, regardless of the need to make decisions with respect to the continuation of care [32,33].

### 2.2. Procedures

For this study, we designed an anonymous questionnaire with 21 multiple-choice questions on a Likert-4 scale with 3 different versions for patients (P), relatives (R), and health care providers (H). The survey questions were defined during an explorative phase that involved health care providers from different ICUs in Europe. The questions included in the final version of the questionnaire cover 2 pages and are preceded by a personal data section (see Supplementary Materials 1, 2, and 3 presenting the 3 questionnaires and relevant accompanying letters). The first 9 questions concern an overall evaluation of the presence of relatives in the ICUs. The following 12 questions investigate the issue of respect of the intimacy in the ICUs. In addition, relevant data including age, sex, length of stay, and Simplified Acute Physiology Score II were collected for all patients included in the study.

All patients admitted to the ICUs between December 2011 and May 2012 and their relatives were screened for enrollment. For each admitted patient, 2 prestamped and numbered envelopes containing the questionnaires for the patient and 1 relative, respectively, were prepared. The contact nurse proposed the study to patients and relatives (identified as the most frequent accompanying person) during the first 48 hours of hospitalization in the ICU. The only exclusion criterion for patients was the inability to fill in the questionnaire. No exclusion criteria were defined for relatives. The questionnaire for health care providers was filled in by each physician, nurse, and care assistant who was

on duty during the study period. No exclusion criteria were defined for health care professionals.

The study was approved by the Cantonal Ethics Committee, and patients and relatives were requested to sign a written informed consent.

### 2.3. Data collection

In the study period (6 months), 349 completed questionnaires were received from the 4 ICUs involved, corresponding to 173 patients and 176 relatives, with a response rate for patients, depending on the unit, ranging between 18.2% and 28.1% (mean, 23.5%) and for relatives ranging between 16.4% and 26.7% (mean, 24.1%). Among health care providers, 134 questionnaires were returned, corresponding to a response rate, depending on the unit, ranging between 51% and 90.6% (mean, 68.7%: physicians,  $n = 13$ ; nurses,  $n = 108$ ; care assistants,  $n = 13$ ).

The 2011 data on all patients admitted to the 4 ICUs were comparable to those of the study population, with the exception of the Simplified Acute Physiology Score II [34,35], which was lower in the study subjects ( $27.2 \pm 11.3$  in the study population vs  $32.7 \pm 17.4$  in the 2011 general population,  $P < .010$ ). One hundred and twenty dyads of patients and relatives were consecutively enrolled, and this sample is representative of the patients usually admitted in the 4 ICUs with a less severe clinical state and their relatives. The relatives designed by patients were in most cases spouses or partners (51.0%), children (23.8%), and parents (14.3%). Brothers and sisters (5.4%), friends (1.4%), and others classes (4.1%) were less represented. The relatives of patients who were either unconscious or incapable of responding ( $n = 14$ ) were also included in the study; because of their limited number, these cases have not been analyzed separately. The 3 groups of patients, relatives, and health care providers could be compared because the same measuring instrument was used.

### 2.4. Statistical analysis

All statistical analyses were performed with the IBM SPSS Statistics 20 software. The comparison of categorical data among groups was performed with the  $\chi^2$  test or, in the case of aggregated groups with small frequency, with the Fisher exact test. Bonferroni correction was applied for multiple testing of pairs of groups. In addition, a logistic regression model was used to include age and sex as covariates in the analysis. Spearman rank correlation coefficient was used to analyze the relationship with ordinal variables. For the comparison of continuous variables, *t*-tests were used. Statistical significance was declared if the corrected rounded 2-tailed *P* value was  $< .05$ .

## 3. Results

First of all, an important observation was that patients and relatives tended to answer in similar ways, whereas the answers of health care providers differ significantly from those of patients and relatives in all cases except one (Figs. 1, 2, and 3 and Supplementary Materials 1, 2, and 3). In addition, we tested the explanatory power on the answers of age, sex, severity, and duration of the period spent in hospital in all questions; and a statistically significant difference was found only for age in some questions. However, as age varied in the patients, relatives, and caregivers group, to understand if differences in perceiving intimacy were driven by age, a logistic regression was used including age as a confounder; and it was found that differences were better explained by the group variable than by the age.

### 3.1. Sharing of medical information regarding therapeutic procedures

The first questions in the questionnaire evaluated the perceived medical information, presence of relatives, and their influence on the

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