

Psychological Effects of Remote-only Communication Among Reference Persons of ICU Patients During COVID-19 Pandemic

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Research

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Abstract

Background: During COVID-19 pandemic, visitations have been prohibited in most French ICUs. We aimed to assess psychological effects, for reference persons (RPs), of experiencing remote-only communication with both caregivers and the patient during COVID-19 pandemic.

Methods: All RPs of patients referred to ICU for COVID-19 were included. HADS, IES-R, and satisfaction were evaluated at admission, discharge/death and 3 months. At 3 months, an interview with a psychologist provided a qualitative description of RPs' psychological distress.

Results: Eighty-eight RPs were interviewed at patient admission and discharge, and 33 accepted the 3rd month-interview. Prevalence of anxiety and depression symptoms was 65% and 32% respectively at patient admission and 27% and 24% at discharge/death, with a significant decrease between ICU admission and discharge/death (23 [16;31] versus 16 [9;21] points, $p < 0.01$). At 3 months, lower HADS decrease was associated with patient death/continued hospitalization, and/or sleeping disorders in RPs ($p < 0.01$). Despite visit prohibition, 99% RPs felt the patient was safe (9 [7;10]/10 points, Likert-type scale). They also felt confident with caregivers, therapeutic decisions (10 [9;10]/10 points) and satisfied with the manner/frequency information was provided (10 [9;10]/10 points). All RPs stressed the specific-type of "responsibility" associated with being an RP in a remote-only context. The 3 salient themes turned out to be dichotomous variables: positive (9 RPs, 27%) vs. negative (24 RPs, 73%) subjective experience; wide (11 RPs, 33%) vs. narrow (22 RPs, 67%) information diffusion strategies: only a third chose to transmit the information to many relatives. Only 10 RPs (30%) related the situation to a prior traumatic experience.

Conclusion: In a distressing situation, remote-only communication allowed RPs to remain involved in decision processes and maintain contact with patient and caregivers.

Trial registration: NCT04385121. Registered 12 May 2020. <https://clinicaltrials.gov/>

Background

As of July 2020, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic (COVID-19) has led to over 12.7 million infections. About 25% of hospitalized patients required ICU admission for supportive care [1]. The rapid progression of COVID-19 and the dramatic escalation of cases have led to the lockdown of the population, as well as a strict limitation of access to hospitals and care facilities for relatives, in order to break the chain of transmission. Overnight, visits in our ICU have been prohibited by hospital policy. Before this unexpected crisis, our intensive care unit (ICU) was organized on a "24/7 open Unit" model with unrestricted visiting policy, as recommended by critical care societies [2].

Having a beloved or a family member hospitalized in ICU is a stressful event [3]. Relatives are suddenly immersed in "another world", oscillate between fear and hope, and experience extreme vulnerability and helplessness. Twenty-five to 50% of the relatives would subsequently develop significant anxiety, depression and stress symptoms [2] called "post-intensive care syndrome-family" (PICS-F) [3–7]. Taking

time to provide clear information, listening to them, involving them in decision process and care, giving families full access to the ICU, may help reduce the prevalence of post-traumatic stress disorder [8, 9]. Particularly, unrestricted visits in ICU decrease anxiety and psychological disorders, allow for a better adherence to medical decisions, and improve satisfaction on both impression of safety and quality of care for patients and relatives [6, 10].

Having to find a new way to communicate with and inform relatives, we committed to call families every day before 6 pm, and at any time in case of acute problem. We asked them to choose a Reference Person (RP) in order to facilitate communication [11]. The call was conducted by either a resident or a senior doctor, and included daily news from the patient. As soon as possible after the patient woke up (even if still intubated), the phone was put on speaker so that the RP could speak to him/her; alternately, a tablet was used in Visio. Yet, we felt that the total restriction of visits represented a significant additional psychological burden for relatives, likely to increase their potentially traumatic feeling of helplessness [12–14] - all the more in the context of high mediatization and generalized fear. We thus decided to address the psychological suffering of relatives specific to this novel type of remote-only communication. To that effect, we focused on RPs, with whom all remote communications took place: the novel context of the pandemic gave this status a specific significance in need of examination. While most work on the responsibility and distress associated with being a reference person focuses on decision making [15], being an RP in the context of the COVID-19 pandemic chiefly meant having to be the sole, designated intermediate between ICU caregivers and the rest of the family and/or close ones. To our knowledge, this hasn't been explored in published literature.

We therefore aimed to assess the psychological effects, for a reference person, of experiencing remote-only communication with both caregivers and the patient. We evaluated reference persons' depression and anxiety symptoms, and their satisfaction, during the ICU stay (admission and discharge) and at 3 months. During the 3-months assessment, we also examined additional elements: what it felt like to be the reference person in this remote context, the manner in which they transmitted the information, and the coping strategies they used to manage the(ir) situation. We then assessed the extent to which these additional elements could account for their anxiety and depression, during or after hospitalization.

Methods

Study Participants

Relatives of all patients hospitalized in an ICU from a French tertiary hospital for a severe form of COVID-19 were included in a prospective study. Only one relative per patient - the reference person designated by other family members - was included in the study and asked for consent to 3 phone interviews: at admission and discharge or patient death, by an ICU physician, and 3 months after ICU admission by a clinical psychologist. Independently of their participation in this study, a daily phone call was given by ICU physicians to inform the RP of the patient's clinical evolution. Non-inclusion criteria were the refusal to

participate to the study and insufficient mastery of French language. The local ethical committee approved the study (NCT04385121).

Interviews and measurements

Considering the context of COVID-19, all interviews were conducted by phone, by an ICU physician for daily calls during ICU stay and for the interviews at admission and discharge/death; at 3 months, the interview was conducted by a clinical psychologist experienced in working with ICU patients and families (incl. RPs) during the COVID pandemic.

During these interviews, the following were completed: Hospital Anxiety and Depression Scale (HADS) at admission, ICU discharge or patient death, and 3 months; Impact of Events Scale-Revised (IES-R) at 3 months [16, 17]. The HAD scale was used to screen for anxiety and depressive disorders. It has 14 items, rated from 0 to 3. Seven questions are related to anxiety (total HADS-A) and seven others to depression (total HADS-D), thus providing 2 scores (maximum score for each subscale = 21 points). For the depression and anxiety subscales (HADS-D and HADS-A), scores of 11 or more were used for definite cases [16]. The revised version of the Impact of Event Scale (IES-R) has seven additional questions and a scoring range of 0 to 88. Scores exceeding 24 on IES-R scale were considered as indicating a post-traumatic stress disorder [17]. Responses to open-ended questions (supplementary methods), including alcohol/tobacco consumption, sleep quality, level of satisfaction, feeling of security and confidence in caregivers, were also evaluated on a 5 or 10 points Likert-type scale at ICU discharge/death and 3 months, so that the respondent could complete the answer with their own words or thoughts.

In addition, during the 3rd month interview, after the clinical psychologist helped RPs complete the questionnaires, she interviewed them in an open-ended semi-directive fashion about their experience of the situation [18]: that is, of being an RP in a context of remote-only, doctor-mediated communication. When necessary, she referred them to professional counselling. In this sequence, she asked two questions: “Q1. *How did you experience being a reference person in this context, i.e. being an intermediate between the ICU and the rest of the family and/or close ones?* Q2. *How did you cope with being in that position?*”

With Q1, we wanted to explore how the person experienced the specific responsibility associated with the context, and more generally how they handled communication with the rest of the family. With Q2, we sought to highlight the variety of coping strategies.

Statistical Analysis

Descriptive analyses were performed indicating median and IQR for numeric variables, and frequencies for categorical variables. Inferential analysis investigating the relations between our variables were performed in accordance with the type of variables considered. Linear regressions were used when both the dependent and independent variables are continuous, and the dependent variable normally distributed. When the dependent variable has a natural left bound and can be considered as a count variable, Poisson regression was employed. In case the independent variable is categorical and binary,

Student T test were performed. Finally, we used Chi-2 test when both the dependent and independent variables were categorical. All analyses were performed using R software version 4.0.2. (R Core Team, 2020). For qualitative analysis, we used a thematic approach, in line with previous studies [19, 20]; details can be found in supplementary methods.

Quantitative and qualitative data integration: We tried to operationalize emerging themes as qualitative (categorical) variables, under a format allowing us to statistically relate them with quantitative HADS and IESR scores by drawing on the statistical procedures described in the above section.

Results

Quantitative analysis of RP characteristics

Eighty-eight RPs were included in the study. Most RPs were women ($n = 57, 65\%$). Eighty-one RPs (92%) were first-degree relatives of the patient; table 1 describes their demographic characteristics, and scores to the different numeric scales administered. All the 88 RPs completed the interview at admission and ICU discharge / patient death. Among them, 33 RPs accepted to complete the long interview at 3 months; 9 did not honor their rendezvous, and 9 interviews were quite poor: 3 were extremely short, and 6 RPs had important language difficulties. The rest declined, most frequently because of painful mourning, or subsequent unwillingness to partake in the interview without further motive. This subgroup of 33 was considered as representative of the whole sample, since age, gender, relationship, and mortality, did not differ whether the participant accepted to complete the interview or not.

Supplementary table 1 describes the mortality rate for the patients and their ICU length of stay.

Prevalence and evolution of anxiety and depression symptoms after ICU admission

Prevalence of anxiety and depression symptoms was 65% and 32% respectively at patient admission and 27% and 24% respectively at patient discharge/death.

Median HADS was significantly decreased between ICU admission and discharge/death, with both a decrease in anxiety and depression symptoms ($p < 0.01$ for all comparisons) (Fig. 1). During the first 3 months, lower HADS decrease was associated with patient death or the patient being still hospitalized at 3 months and sleeping disorders in RPs ($p < 0.01$). Neither the type of relationship (romantic [spouse or significant other] vs. familial), nor the fact of being also diagnosed with COVID-19 or having other relatives with COVID-19 influenced HADS evolution. The evolution of anxiety symptoms was neither influenced by the feeling of security, nor by confidence in caregivers and level of satisfaction. Depression symptoms were higher if the patient has died and/or the RP suffered from sleeping disorders ($p < 0.01$), and were associated with increased tobacco consumption ($p < 0.05$).

Feeling of security, confidence, satisfaction

Despite visit prohibition, the vast majority of RPs (n = 87, 99%) felt that the patient was safe (9 [7; 10] points /1–10 Likert scale). They also felt confident with caregivers, therapeutic decisions and information provided (10 [9; 10] points /1–10 Likert scale) and were satisfied with the manner and frequency with which information was provided (10 [9; 10] points /1–10 Likert scale) (Fig. 2).

Qualitative analysis of the interviews

Qualitative variables (themes) were not patterns across the data, but mostly remained within the answer to each question. We thus present thematic results below each question. All these results and detailed verbatim excerpts of Themes from Q1 and Q2 can be found in supplementary material (Results section).

As could be expected with Q1 (*How did you experience being a reference person in this context, i.e. being an intermediate between the ICU and the rest of the family and/or close ones?*), all RPs stressed the specific type of “responsibility” associated with being an RP in a remote-only context. Interestingly, the 3 most salient themes turned out to be dichotomous variables, which tell us whether each theme was addressed or not by each participant:

Theme 1: Of all 33 RPs, 9 (27%) had an *overall positive* vs. 24 (73%) an *overall negative subjective experience* of being the intermediate between the ICU and the rest of the relatives.

Theme 2: About one third of RPs adopted a *wide information diffusion strategy* (11 RPs, 33%), while 22 RPs (67%) adopted a *narrow* one, restricting the array of contacted relatives to a very few and/or only contacting them rarely.

Theme 3: Only 10 RPs (30%) spontaneously related the situation to a *prior traumatic experience*, while 23 (70%) didn't.

With Q2 (*How did you cope with being in that position?*), we sought to collect the variety of coping strategies; all respondents understood the question in this way. It is interesting to note that in a subset of the 33 RPs, a gap can be observed between their scores at the standardized scales and their spontaneous recollection of the painful stay of their relative in the ICU. This is partial evidence of the relevance of semi-structured, open-ended qualitative methods to complete quantitative scales. We could hypothesize that open-ended questions tend to bring about more spontaneous answers, which could be closer to people's actual behaviors and attitudes, while standardized scales might induce a more distanced perspective, further from « the heat of the moment ».

There was also a significant link between having an overall negative subjective experience and preferring narrow diffusion strategies ($p < 0.01$). All RPs who negatively experienced the situation also employed a restraint diffusion strategy (100%). Conversely, the majority of RPs who had an overall positive experience of being an RP used a wide diffusion strategy (82%). On the basis of the interviews, we could assume that the wide diffusion strategy partially explains overall positive experience: wide diffusion strategies were often described as a way to feel less powerless.

At the end of the interview, 8/33 relatives (24%) were referred to professional counselling support.

Mixed quantitative-qualitative analysis

Supplementary table 2 describes the mortality rate for the 33 RPs who completed the interview, the presence of COVID-19 symptoms in the RP or in his/her family members, the numeric scores obtained at the IES-R, and the three qualitative variables obtained from the interviews.

For the subgroup of 33 respondents, HADS evolution on the three measurement occasions (admission, discharge or death, interview 3 months later) is depicted on Fig. 3. For the subgroup who completed the 3rd month interview, median HADS was 12 [9; 18] points. A repeated-measures ANOVA revealed that HADS significantly decreased with time ($p < 0.01$). Post-Hoc analysis with Bonferroni correction revealed a difference between ICU admission and ICU discharge or death ($p < 0.01$), and no difference between ICU discharge or death and 3 months later ($p = 0.71$).

Relations between qualitative and quantitative variables

Figure 4 depicts the relations between the quantitative variables - HADS and IES-R score – and the qualitative variables obtained from the interview analysis – subjective experience, diffusion strategy, and prior traumatic experience. Median HADS at 3 months was 12 [9; 18] points in this subgroup, and was higher in RPs who had a negative experience of the ICU stay ($p < 0.01$; median 16 vs. 11 points). HADS was not influenced by the diffusion strategy employed ($p = 0.67$), nor by the explicit mention of a prior traumatic experience ($p = 0.80$).

Prevalence of PTSD at 3 months was 64% in the subgroup of 33 RPs, with a median IES-R of 28 [19; 42] points. Median IES-R was higher in RPs who had a negative experience of the ICU stay ($p < 0.01$; median 35 vs. 23) and who did not develop a wide diffusion strategy ($p < 0.01$; median 34 vs. 29). IES-R scores were not influenced by the explicit correlation of the situation with a prior traumatic experience ($p = 0.92$).

Discussion

Herein, we describe the psychological effects of remote-only communication among reference persons of ICU patients during COVID-19 pandemic. The rapid progression of COVID-19 pandemic and the massive influx of patients in our hospital have indeed led to ICU visit prohibition overnight. To face this exceptional situation, a chosen relative (the RP) was called daily by the medical team to provide daily information, and preserve the link between all relatives and the caregivers. This major change in the usual communication channels with families warranted a specific examination - even more so since it cannot be ruled out that diseases leading to this type of remote-only communication will happen again in the future.

We chose to implement daily calls to try and make both RPs and other relatives feel less overwhelmed and helpless. Despite these exceptional measures, our results (median HADS-A > 11 points) show that RPs experienced massive psychological distress: anxiety and depression, overall negative experience of

the situation (requiring a variety of coping strategies) which can plausibly be traced back to the specific type of distress caused by the forced remoteness and the prohibition to even see and/or touch one's relative.

However, it is likely that restricted visitation policies, as well as COVID-19 pandemic itself, and the impact of lockdown and related frustrations have led to additional burden for RPs and therefore represent independent confounding factors for the prevalence of depression and anxiety symptoms among RPs of ICU patients that cannot be fully individually isolated - in spite of the partial correlation highlighted above between quantitative and qualitative variables (namely, IES-R scores and negative experiences of being an RP + narrow diffusion strategies).

Interestingly, even though symptoms of anxiety and depression increased with the death of the patient, the impression of security and the RPs' level of satisfaction and confidence in the healthcare team remained high. Even in cases of fatal evolution, RPs and relatives were thankful and satisfied with the daily contact and the global care. This communication model, in a French COVID-19 epicenter during the hard times of the pandemic, seems to effectively preserve a reassuring link between caregivers and RPs and relatives of ICU patients. However, all of us experienced difficult situations where patients did not survive while the family couldn't reach the hospital in time. Ethical dilemmas were not rare during the COVID-19 pandemic [21]. To the best of our knowledge, it's the first time that a fully remote communication model consisting in virtual meetings, without direct telehealth implications, has been used in an ICU for such a long period and with such a high number of severe patients. The results are promising and seem to prevent a possible worsening of psychological distress of ICU patients RPs. These results also warrant the use of mixed methods to feed clinical practice: while adding a qualitative approach allows for inductive exploration (required in novel clinical contexts), the qualitative production of relevant categories can be signs of distress (measurable by IES-R). Therefore, being sensitive to the type of diffusion strategy and to the negative or positive overall experience in informal exchanges can help caregivers have a grasp of such distress.

We consider our approach as potentially contributing to help caregivers provide adequate global therapeutic support to relatives [15] and, in particular, RPs. In such remote-only contexts, the determinants and modalities of such a support largely remain to be devised: this present paper was also meant as an initial contribution to this emerging field of research.

The main limitations to our study include a monocentric and observational design and the lack of a comparison group, and therefore the impossibility to formally relate the anxiety and depression symptoms to remote communication. Furthermore, the month-3 follow-up could be performed in only 33 RPs, due to a high rate a refusal of the longer interview at 3 months. HAD-S and IES-R data at 3 months are therefore underpowered. However, a comparison group of RPs experiencing only remote communication would be hardly acceptable from an ethical perspective.

Further study will therefore be necessary to comfort and/or refine our results.

Conclusions

An extraordinary situation needs creative workarounds. New communication skills and habits had to be integrated in everyday practice overnight. Taking care of relatives is essential to caregiver duty, particularly during a critical situation like an ICU stay. Human beings need social contact. Having to disallow relatives - and even reference persons - who might also be infected with SARS-CoV-2 (and therefore contagious), to visit a close one in a highly critical situation is a painful ethical position to hold. To manage these ethically and medically difficult situations, a daily contact with reference persons - even remotely, by phone - allowed partial reassurance and promoted a higher level of confidence in the healthcare's team. Further studies about the communicational and relational skills required by this type of remote daily contact should motivate institutional or even national recommendations in times of exceptional crisis, in order to encourage clinicians to also care for the relatives, and in particular RPs, who stand in-between caregivers and the rest of the family.

Abbreviations

- HADS
- Hospital Anxiety and Depression Scale
- ICU
- intensive care unit
- IES-R
- Impact of Events Scale-Revised
- PICS-F
- post-intensive care syndrome-family
- PTSD
- posttraumatic stress disorder
- RP
- reference person
- SARS-CoV-2
- severe acute respiratory syndrome coronavirus 2

Declarations

Ethics approval and consent to participate: Yes

Consent for publication: Not applicable

Availability of data and material: All data generated or analysed during this study are included in this published article [and its supplementary information files].

Competing interest: The authors have no conflicts of interest to declare.

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Tables

Table 1
Characteristics of reference persons

		N = 88
Age	median, SD	57 (15)
Gender: Female	n (%)	57 (65)
Relationship to patient: first degree	n (%)	81 (92)
Spouse/partner		51 (58)
Grown child		22 (25)
Parent		5 (6)
Sister/brother		3 (3)
Other		7 (8)
Professional occupation	n (%)	
Working/studying		44 (50)
Unemployed		24 (27)
Retired		19 (22)
Sleep quality	10 points Likert-type scale	6 [4; 8]
Security feeling	10 points Likert-type scale	9 [7; 10]
Confidence feeling	10 points Likert-type scale	10 [9; 10]
Satisfaction feeling	10 points Likert-type scale	10 [9; 10]
Comprehension	10 points Likert-type scale	10 [8; 10]
Increased smoking*	5 points Likert-type scale	4 [3; 4]
Increased alcohol consumption*	5 points Likert-type scale	4 [3; 4]
HADS / ICU admission	numeric score	13[9; 16]
Anxiety / admission	numeric score	10[7; 13]
Depression / admission	numeric score	23[16; 31]
HADS / ICU discharge	numeric score	8[5; 12]

For count variables: sum and percentage. For numeric score variables and Likert-type scale variables: Median [IQR].

*1 point: completely agree ; 2 points: somewhat agree ; 3 points: somewhat disagree; 4 points: completely disagree; 5 points: no advice.

		N = 88
Anxiety / ICU discharge	numeric score	7[3; 11]
Depression / ICU discharge	numeric score	16[9; 21]
For count variables: sum and percentage. For numeric score variables and Likert-type scale variables: Median [IQR].		
*1 point: completely agree ; 2 points: somewhat agree ; 3 points: somewhat disagree; 4 points: completely disagree; 5 points: no advice.		

Figures

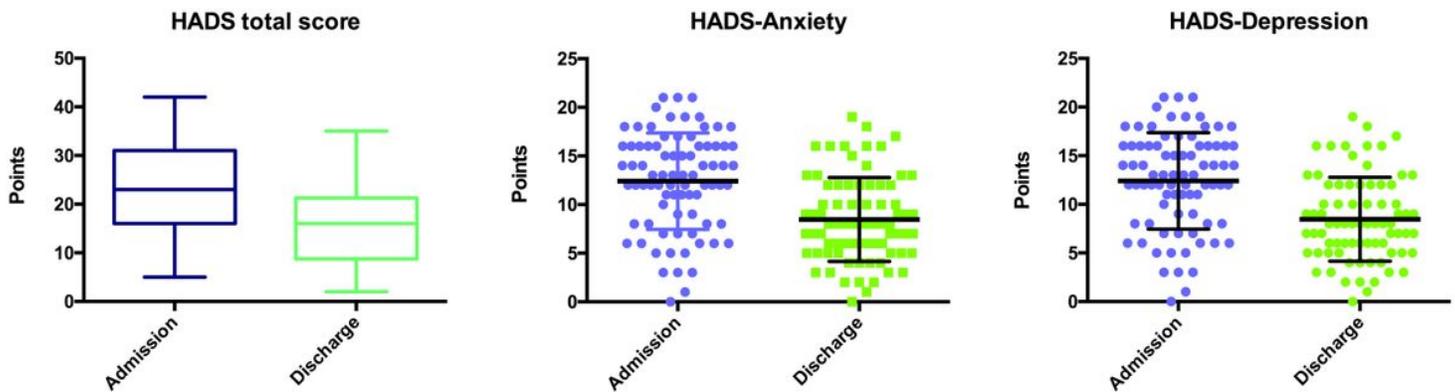


Figure 1

HADS evolution between ICU admission and discharge or death. Total HADS, HADS Anxiety, HADS Depression. HADS: Hospital Anxiety and Depression Scale.

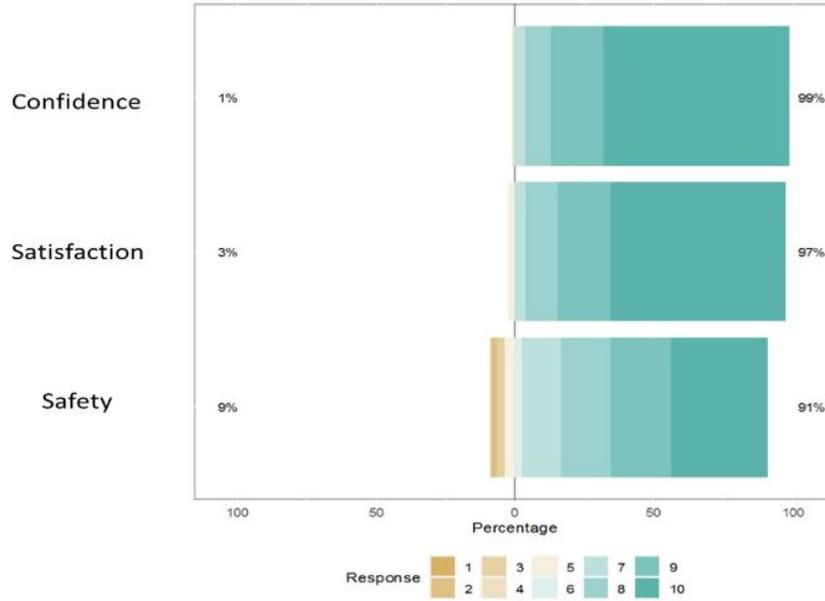


Figure 2

Confidence in ICU caregivers, therapeutic decisions and information, Satisfaction towards ICU care and information modalities, and Feeling of safety. Descriptive statistics on Confidence, Satisfaction, and Safety on a 10-points Likert scale. ICU: intensive care unit.

HADS total score

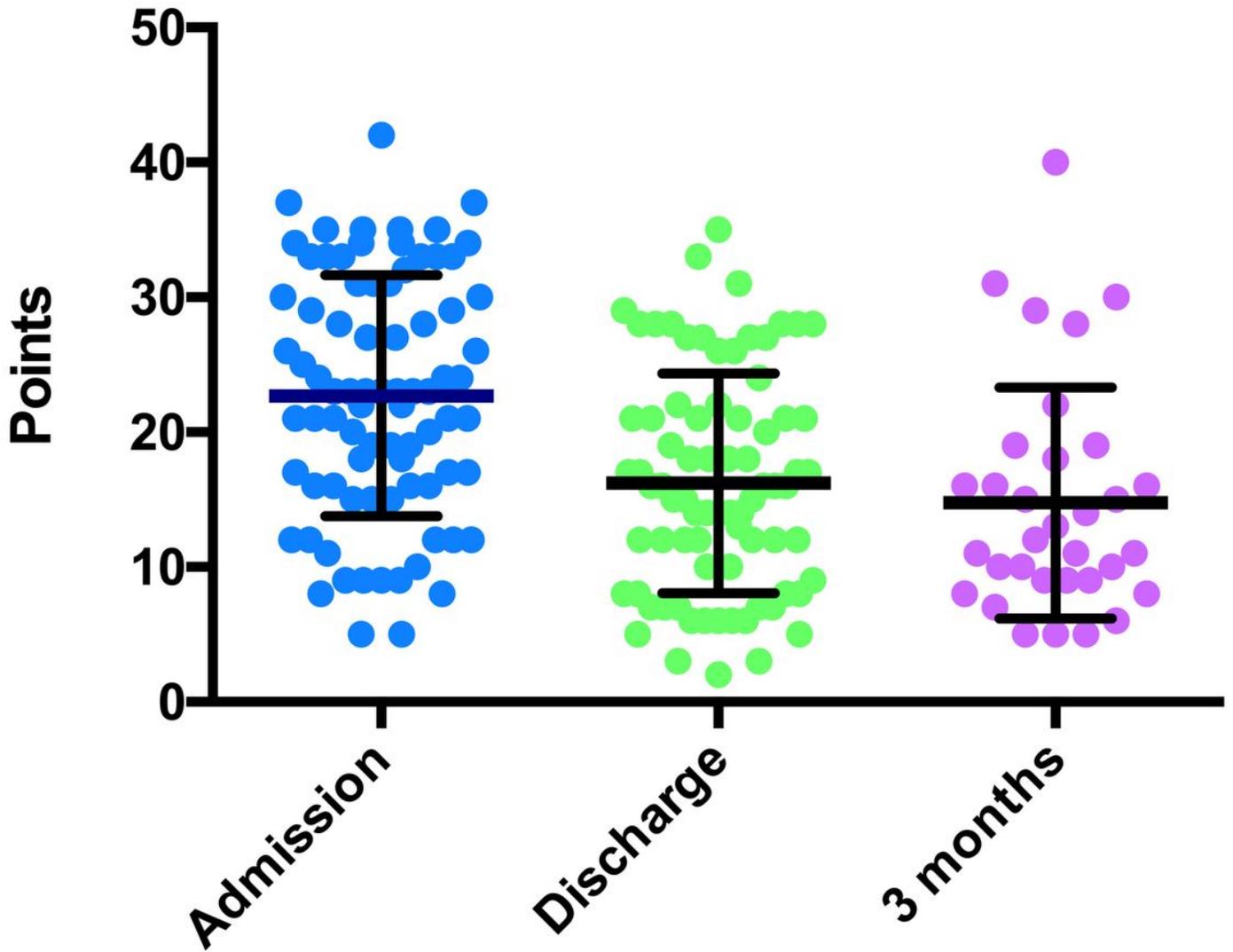


Figure 3

HADS evolution between admission, discharge/death, and 3 months later. HADS: Hospital Anxiety and Depression Scale.

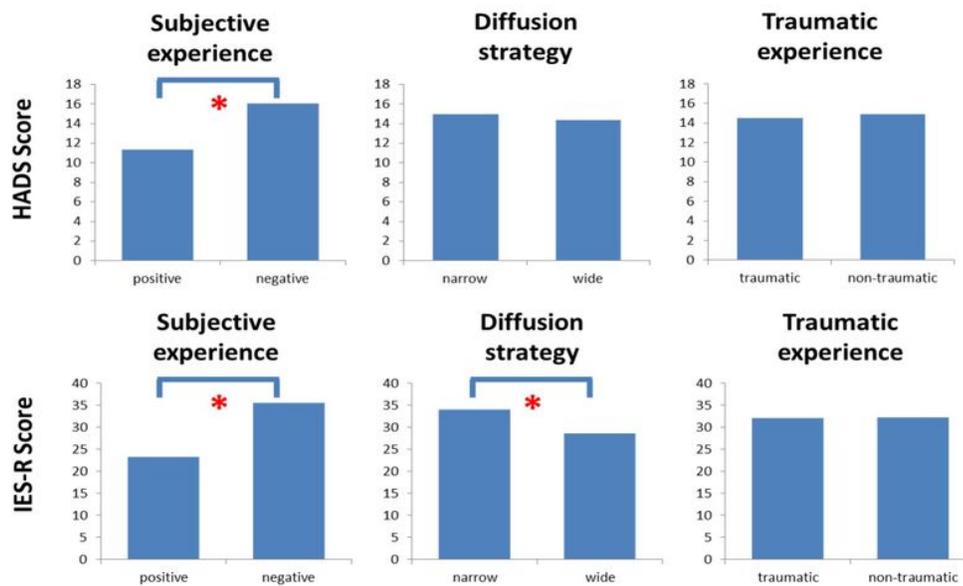


Figure 4

Relations between the quantitative variables - HADS and IES-R – and the qualitative variables obtained from the interview analysis – subjective experience, diffusion strategy, and traumatic experience. * $p < 0.01$. HADS: Hospital Anxiety and Depression Scale; IES-R: Impact of Event Scale – revised.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Supplementarytable2.docx](#)
- [SupplementaryTable1.docx](#)
- [Supplementarydata.docx](#)
- [VAarticlefamilies.tiff](#)
- [STROBEchecklistv4combined.docx](#)