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ORIGINAL

Effects of an online information tool on post-traumatic stress disorder in relatives of intensive care unit patients: a multicenter double-blind, randomized, placebo-controlled trial (ICU-Families-Study)

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Abstract

Purpose: Intensive care unit (ICU) hospitalization is challenging for the family members of the patients. Most family members report some level of anxiety and depression, sometimes even resulting in post-traumatic stress disorder (PTSD). An association has been reported between lack of information and PTSD. This study had three aims: to quantify the psychological burden of family members of critically ill patients, to explore whether a website with specific information could reduce PTSD symptoms, and to ascertain whether a website with information about intensive care would be used.

Method: A multicenter double-blind, randomized, placebo-controlled trial was carried out in Austria and Switzerland.

Results: In total, 89 members of families of critically ill patients (mean age 47.3 ± 12.9 years, female n = 59, 66.3%) were included in the study. 46 relatives were allocated to the intervention website and 43 to the control website. Baseline Impact of Event Scale (IES) score was 27.5 ± 12.7. Overall, 50% showed clinically relevant PTSD symptoms at baseline. Mean IES score for the primary endpoint (~ 30 days after inclusion, T1) was 24 ± 15.8 (intervention 23.9 ± 17.9 vs. control 24.1 ± 13.5, $p = 0.892$). Hospital Anxiety and Depression Scale (HADS - Deutsch (D)) score at T1 was 12.2 ± 6.1 (min. 3, max. 31) and did not differ between groups. Use of the website differed between the groups (intervention min. 1, max. 14 vs. min. 1, max. 3; total 1386 "clicks" on the website, intervention 1021 vs. control 365). Recruitment was prematurely stopped in February 2020 due to coronavirus disease 2019 (COVID-19).

Conclusion: Family members of critically ill patients often have significant PTSD symptoms and online information on critical illness did not result in reduced PTSD symptoms.

Keywords: Families, Family-centered care, Post-traumatic stress disorder, Information, Intensive care, Communication, Online

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Introduction

Intensive care unit (ICU) hospitalization of critically ill patients is particularly challenging for their family members. The families experience anxiety, depressive feelings, poor sleep, and symptoms of acute stress and post-traumatic stress disorder (PTSD) [1–3]. Twenty to sixty percent of family members subsequently experience adverse mental health outcomes [4, 5]. However, the presence of family is important for patients, either in person or via virtual contact [6, 7]. This contact is equally vital for the family members themselves, as it enables them to cope with the difficult situation [8]. Family members need ongoing, clear, and consistent information and communication about their significant other's condition [9, 10]. Information and communication are important in determining their ability to cope. An association has also been reported between lack of information and symptoms of PTSD [11].

Lautrette et al. showed that combining a proactive end-of-life conference with a brochure reduced PTSD symptoms by 30% [12]. Mistraletti et al. studied use of an online website with a brochure and found that the intervention was associated with a significantly lower incidence of PTSD symptoms [13]. However, these additional tools are rarely implemented in the ICU setting [14]. Tabah et al. showed that only 67% (n = 64) of all Australian and New Zealand ICUs offer information booklets [14]. Such tools must fulfil some essential criteria: simple, appropriately translated information in language accessible to lay persons [15], options for feedback and interaction, and instructions for use.

Face-to-face communication with healthcare professionals often suffers from the lack of time for deep conversations and restrictions on visits. The increasing digitization and mobility of society combine to reinforce the importance of tools such as brochures, websites, apps, and virtual communication in the ICU and after discharge [14, 16].

Little research has studied whether or how often family members use supplementary tools in addition to face-to-face information and communication in a crisis. To date, few studies have investigated the use of these supplementary tools by family members in the ICU and their effects.

This study therefore has the following objectives: (1) to quantify the psychological burden of having a loved one in the ICU, (2) to explore whether a website with specific information could reduce PTSD symptoms, and (3) to ascertain whether a website with information about intensive care would be used by family members.

Methods

First, a pilot study was set up in the centers to measure the first baseline data on psychological symptoms in family members of critically ill patients (ICU families) in a prospective multicenter study [17]. The current study is a multicenter double-blind, randomized, placebo-controlled trial (ICU Families Study) in Austria and Switzerland. This study was performed in four independent ICUs in Graz, Vienna, Innsbruck (Austria), and Bern (Switzerland). It was approved by the Medical University of Graz Ethics Committee (approval no: 27-317 ex 14/15), the Ethics Committee Vienna (approval no: 1910/2016), the Ethics Committee Innsbruck (approval no: 1025/2019), and the Swiss Ethics Committee in Bern (approval no: 2017-00318).

Take-home message

The results of this multicenter double-blind, randomized, placebo-controlled trial (ICU-Families-Study) show that half of the family members of critically ill patients have severe symptoms of post-traumatic stress disorder (PTSD). An informative website did not result in reduced PTSD symptoms.

Setting

Two mixed ICUs (11 beds and 10 beds), one cardiology ICU (9 beds) and one gastroenterology and hepatology ICU (7 beds) in Austria and one mixed ICU (37 beds) in Switzerland participated in this study. Each of the ICUs was part of a university hospital. The data was collected from 2017 to 2020 by trained investigators (registered critical care nurses with > 10 years of professional experience, doctorate, master's degree, or other special training or research experience) at each study site.

Participants

The study population comprised family members (relatives by blood or very close friends) of critically ill patients. Only one family member per patient was included in the study. This person was the patient's primary support person and was invited by the investigators to take part in the study. The inclusion criteria were: minimum age of 18 years, primary residence in the same country as the study site, and expected duration of the related patient's stay in the ICU of at least ≥ 72 h, as predicted by the intake ICU clinician (physician or critical care nurse). Exclusion criteria were: insufficient German language skills; impaired reading ability or vision; imminent death (i.e., the patient was expected to die within five days, as estimated by the independent treating ICU physician). Family members of dying patients were not to be subjected to additional stress.

Selection, recruitment, and procedure

Family members were invited to take part in the study on the day the critically ill patient was admitted to the ICU

and up to two days afterwards. The family members provided written informed consent. The baseline data (T0) were measured within two days of the patient's admission to the ICU; the second time (T1) was 30 days after T0. The baseline data were collected using face-to-face interviews, and T1, T2 (90 days after admission), and T3 (365 days after admission) data were collected by telephone or by a paper-based questionnaire. The first participant was enrolled in September 2017. Recruitment was prematurely stopped in February 2020, at the beginning of the coronavirus disease 2019 (COVID-19) pandemic, when visiting restrictions for family members were declared in Austria and Switzerland and funding resources ended.

Study measurements

Impact of event scale (IES)

The symptoms of PTSD were measured using the Impact of Event Scale (IES), per Lautrette et al. [12, 18]. The IES is a screening tool for individuals who might benefit from more formal tests for symptoms of PTSD [19]. The score has 15 items that are assigned to either intrusion or avoidance during assessment. Each item is assessed on a scale of 0 to 5 points for individual statements. Total scores from 0 to 8 are interpreted as insignificant, scores from 9 to 26 indicate an event with an impact (individuals may be affected by symptoms of PTSD), scores from 27 to 43 indicate a strong impact (individuals are certain to be affected by symptoms of PTSD), and scores from 44 to 75 indicate serious effects that compromise the individual's ability to function. The present study used scores higher than 27 as clinically relevant. A score of 35 and above was the cut-off point for a possible diagnosis of PTSD. The German version in our study was translated by the study team and demonstrates good face validity [20]. The scale has been used in other studies of family members of critically ill patients [12, 21, 22].

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS-Deutsch (D)) by Zigmond & Snaith [23] serves to record anxiety and depression in patients with physical illnesses or (possibly psychogenic) physical complaints. The screening scale, in the form of a self-assessment questionnaire, consists of two subscales, the HADS-D/A (anxiety scale) and the HADS-D/D (depression scale). The scale consists of a total of 14 items. The values are interpreted as follows: 0–7 unremarkable, 8–10 suspect, and > 10 conspicuous [23]. This scale has been successfully used in ICU settings [24, 25]. In the present study we used the German version by Hans Huber Bern (1995/2003, order number 0306903).

Further background information (age, gender, living situation) was recorded from the family members.

Use of the website

The hope was that use of the website would lead to an improvement in the well-being of the family member. We recorded frequency and times of website use, as well as the specific content accessed. We assumed that frequent use of the website indicated that it met information needs or provided some other benefits for the family members.

Interventions

The intervention was either an "intervention website" or a "control website" (placebo). Both websites had the same structure and were developed by the framework Groovy on grails in the German language. Both contained basic information about the participating ICUs (i.e., contact address, description of the department, visiting times, etc.). This information was already available prior to the study. The intervention website also included the following content (please see box below): chat with ICU experts, videos (e.g., about the ICU, hand hygiene, stress reduction measures), detailed descriptions of different ICU topics (e.g., monitoring, medication, processes), stories of critically ill patients and their families, information on stress and anxiety reduction, information for children with videos and a picture story, and a glossary.

Intervention website	Control website (placebo)
Basic information (e.g., contact address, description of the department, visiting times, etc.)	Basic information (e.g., contact address, description of the department, visiting times, etc.)
Chat with ICU experts—supervised by the study team in a multidisciplinary manner	
Videos (e.g., about the ICU, hand hygiene, stress reduction measures)	
Detailed descriptions of different ICU topics (e.g., monitoring, medication, processes)	
Stories of critically ill patients and families, information on stress and anxiety reduction	
Information for children with videos and a picture story	
Glossary	

The structure was the same for both websites, to avoid accidental unblinding, and all information was formulated in lay language. The usability of the control (placebo) website was the same as that of the intervention website, but with less content.

The intervention website was developed using content from a cross-sectional survey of critically ill patients, nurses, and physicians (Hoffmann et al. [26]). A second study by Hoffmann et al. tested the intervention website to determine usability, design, and content [27]. The website was tested among lay people and experts according to the Think Aloud Method [28].

Outcomes

The primary outcome was IES score on day 30 (T1) in family members. We expected a reduction in symptoms of PTSD through targeted information management for relatives of patients in the ICU. As a secondary outcome, the following points were examined: anxiety and depression in family members of critically ill patients, use of an interactive information platform, and development of a German-language interactive information platform for family members of critically ill patients. Specifically, these are a reduction in the HADS-D score in the intervention group vs. the control group and use of the intervention website vs. the control website (user statistics).

Sample size

Based on a previous study by Lautrette et al. [12], symptoms of PTSD (as measured by the IES) were expected to improve by 30% as a result of the intervention. Assuming a group difference in the IES score of 12 at day 30 (T1) and common standard deviation of ± 18, a two-sided t-test with a Type I error of 0.05 requires n = 49 per group to achieve a power of 90%. Considering a drop-out of approximately 10%, a total of 110 family members of 110 critically ill patients needed to be included in the study (55 family members per group).

Randomization

For group allocation, the interactive web response system "Randomizer" (www.randomizer.at) was used. Randomization was carried out in a 1:1 ratio, stratified by center and gender using a minimization algorithm with preferred treatment probability of 0.9. The randomization was carried out by trained investigators directly after inclusion in the study.

Blinding

This was a double-blinded study. Neither the investigators nor the study participants knew the assigned group of any participant. Before study start, an independent programmer prepared access codes for either the intervention or the control website. The access codes were linked based on the blinding list generated via the randomization tool. Relatives were randomized after inclusion and given an envelope with the relevant access code. Each family member had access to only one website. Only the independent programmer and statistician responsible for the randomization tool had access to the blinding table.

Statistical methods

Continuous variables were summarized as means or median, standard deviation, minimum, and maximum, and categorical data as frequencies and relative frequencies.

To compare the IES score and the HADS-D between the intervention and control group at the different time points, linear mixed models including treatment, visit time (T0, T1, T2, T3), treatment-visit interaction, and gender as fixed effects were used. An unstructured covariance structure for the repeated measurements and site as a random effect was modelled. P-values for group differences and for changes over time within the groups were obtained via least square-means.

No imputation for missing values was performed. The analysis is based on the intention to treat principle. A p-value $p < 0.05$ indicates statistical significance. The analysis was carried out with SAS software version 9.4 (SAS Institute, Cary, NC).

Data management

Data collection took place via the program ClinCase (https://clincase.com/), based on the electronic Case Report Form, which lists all the data to be collected in chronological order. Excluded from this are identifying data such as name, date of birth, and address. This data is stored separately in the source data sheet. No data entered in ClinCase allows direct conclusions to be drawn about the study participants.

Results

In total, 89 family members of critically ill patients (female: n = 59, 66.3%) were included (mean age 47 ± 13 years, range 19–75), mean patient age 58.5 ± 14.7, range 20–81). Most relatives were spouses (n = 36, 40.4%) or children (n = 31, 34.8%) of the critically ill patient. Most patients were male (n = 62, 69.7%). At T1 follow-up there were 38 patients in the intervention group and 36 in the control group (see Fig. 1). Relative and patient characteristics are presented in Table 1.

The study was stopped at the start of the COVID-19 pandemic in 2020, due to the visiting ban in ICUs for family members and the withdrawal of funding resources. We randomized 89 relatives at T0: 46 family members were allocated to the intervention website and 43 to the control website. At T1, we interviewed 74 relatives (intervention 38, control 36); at T2; we interviewed 59 (intervention 29, control 30); at T3, one year after study inclusion, we interviewed 48 family members

(intervention 24, control 24). Median time for visit T1 (day 30) was 37 days (25–92 days); for visit T2 (day 90), 98 days (61–169 days); and for T3 (365 days), 376 days (329–444 days). A detailed description of the course of the study can be found in Fig. 1.

The baseline IES score was 27.5 ± 12.7, with 44 of 88 (50%) family members showing clinically relevant symptoms of PTSD (IES score > 27) at baseline (T0). At 30 days (the primary endpoint; T1), the mean IES score was

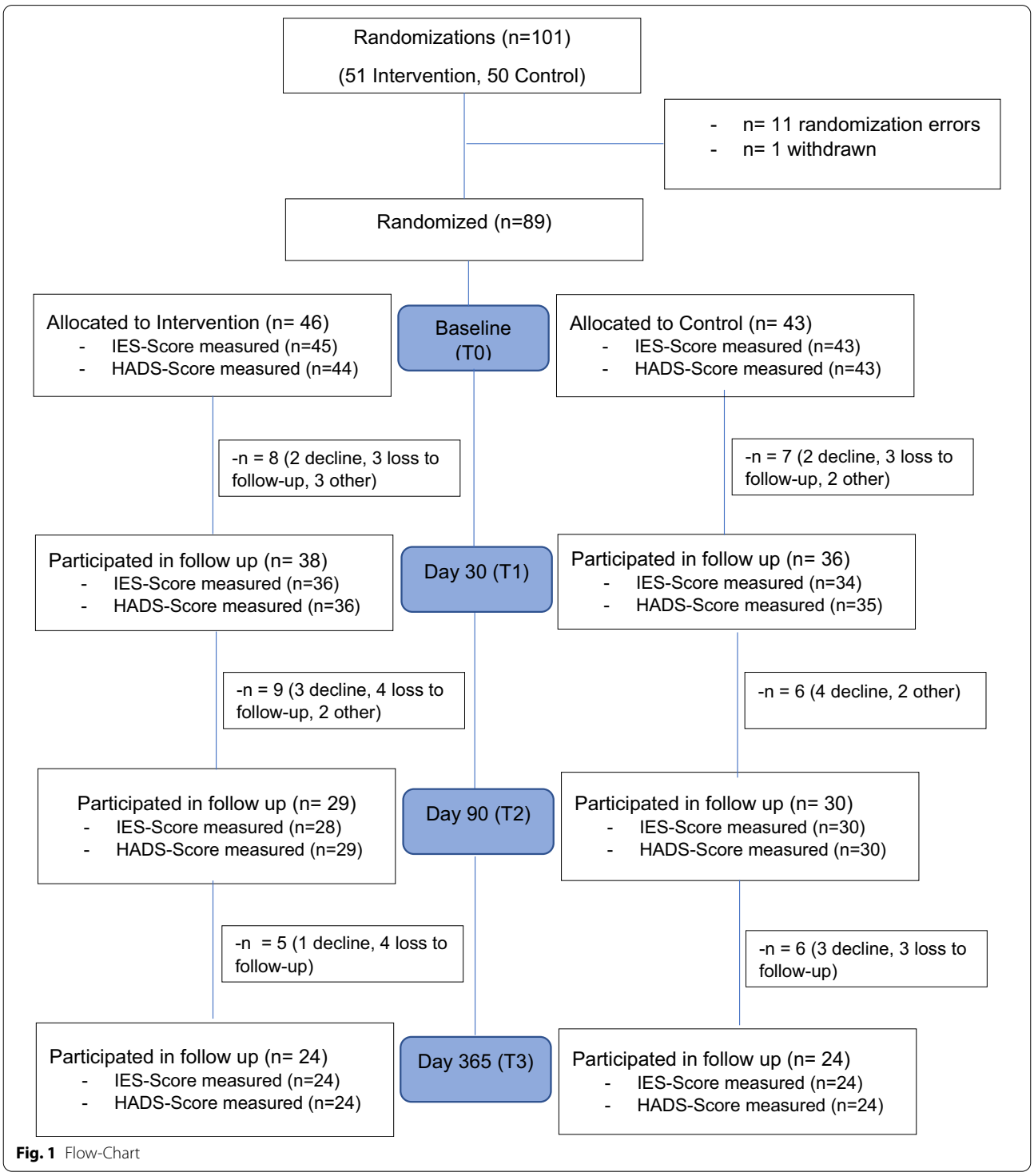

Fig. 1 Flow-Chart

Table 1 Baseline characteristics of the study participants

Relatives	Description	All (*n*, %)	Control (*n*, %)	Intervention (*n*, %)
Gender	Male	30 (33.7%)	14 (32.6%)	16 (34.8%)
	Female	59 (66.3%)	29 (67.4%)	30 (65.2%)
Site	Site 1	58 (65.2%)	28 (65.1%)	30 (65.2%)
	Site 2	13 (14.6%)	6 (14%)	7 (15.2%)
	Site 3	6 (6.7%)	2 (4.7%)	4 (8.7%)
	Site 4	12 (13.5%)	7 (16.3%)	5 (10.9%)
Education	Secondary school/compulsory school	7 (7.9%)		7 (15.2%)
	Completed apprenticeship/university entrance qualification	46 (51.7%)	26 (60.5%)	20 (43.5%)
	College/University	34 (38.2%)	15 (34.9%)	19 (41.3%)
	Other	2 (2.2%)	2 (4.7%)	
Lives with the patient	Yes	48 (53.9%)	25 (58.1%)	23 (50%)
	No	41 (46.1%)	18 (41.9%)	23 (50%)
Relative has children under the age of 18	Yes	24 (27%)	13 (30.2%)	11 (23.9%)
	No	65 (73%)	30 (69.8%)	35 (76.1%)
Relation to patient	Spouse/Partner	36 (40.4%)	20 (46.5%)	16 (34.8%)
	Child	31 (34.8%)	12 (27.9%)	19 (41.3%)
	Parent	8 (9%)	3 (7%)	5 (10.9%)
	Brother/Sister	9 (10.1%)	5 (11.6%)	4 (8.7%)
	Other	5 (5.6%)	3 (7%)	2 (4.3%)
Lives in a city (> 50.000 residents)	Yes	27 (30.3%)	13 (30.2%)	14 (30.4%)
	No	62 (69.7%)	30 (69.8%)	32 (69.6%)
Working/Employed	Yes	67 (75.3%)	28 (65.1%)	39 (84.8%)
	No	22 (24.7%)	15 (34.9%)	7 (15.2%)
	Part time	20 (29.9%)	7 (25%)	13 (33.3%)
	Full time	47 (70.1%)	21 (75%)	26 (66.7%)
Was present at the event that led to the patient's ICU admission	Yes	33 (37.1%)	14 (32.6%)	19 (41.3%)
	No	56 (62.9%)	29 (67.4%)	27 (58.7%)
Patients				
Gender	Male	62 (69.7%)	29 (67.4%)	33 (71.7%)
	Female	27 (30.3%)	14 (32.6%)	13 (28.3%)
Admission diagnosis	Surgical	27 (30.3%)	14 (32.6%)	13 (28.3%)
	Non surgical	62 (69.7%)	29 (67.4%)	33 (71.7%)
Surgical				
	Elective	8 (29.6%)	4 (28.6%)	4 (30.8%)
	Emergency	19 (70.4%)	10 (71.4%)	9 (69.2%)
Mechanical ventilation	Yes	85 (95.5%)	40 (93%)	45 (97.8%)
	No	4 (4.5%)	3 (7%)	1 (2.2%)
Vasopressors	Yes	72 (80.9%)	31 (72.1%)	41 (89.1%)
	No	17 (19.1%)	12 (27.9%)	5 (10.9%)
Katz Activities of daily life (n, mean ± SD)	T0	88	43, 4.2 (± 2.6)	45, 4.2 (± 2.6)
	T1	52	26, 3.9 (± 2.5)	26, 3.2 (± 2.9)
	T2	38	21, 4.4 (± 2.2)	17, 5.2 (± 2)
	T3	31	16, 5.9 (± 0.3)	15, 5.6 (± 1.5)
Karnofsky Index (n, mean ± SD)	T0	89	43, 90.7 (± 17.6)	46, 86.5 (± 22.2)
	T1	65	32, 39.4 (± 30)	33, 42.1 (± 32.7)
	T2	45	22, 59.5 (± 28.2)	23, 55.2 (± 41.5)
	T3	33	16, 78.8 (± 19.6)	17, 82.9 (± 32)

T0: Baseline data, T1: 30 days, T2: 90 days, T3: 365 days

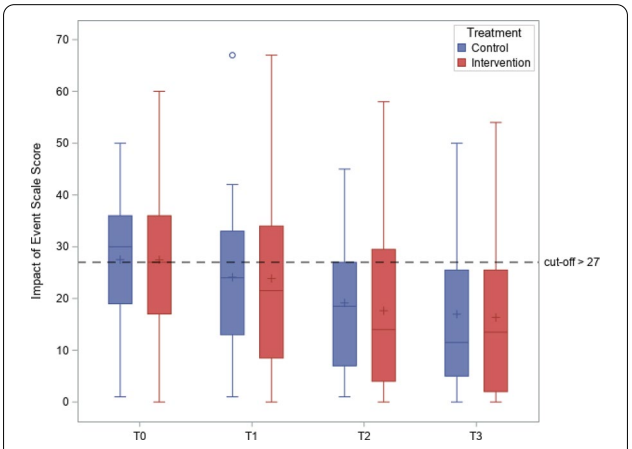

Fig. 2 Impact of Event Scale Score over time. T0: Baseline data, T1: 30 days, T2: 90 days, T3: 365 days

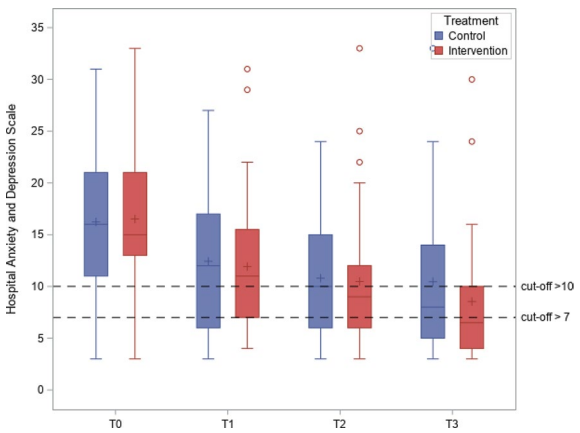

Fig. 3 HADS Score over time. T0: Baseline data, T1: 30 days, T2: 90 days, T3: 365 days

similar between groups (intervention 23.9 ± 17.9 vs. control 24.1 ± 13.5, $p = 0.892$).

IES scores did not differ between groups at day 90 (T2) (intervention 17.6 ± 15.4 vs. control 19.1 ± 12.5, p = 0.814) or after one year (T3) (intervention 16.3 ± 15.9 vs. control 17.0 ± 15.6, $p = 0.824$) (see Fig. 2).

At day 30 (T1), patient survival status was available for 72 critically ill patients. In total, 22 (30.6%) patients died before day 30 (n = 10 (37.8% in the control group and n = 12 (33.3%) in the intervention group). Significant differences were observed for the family members' IES scores at T1 (patient deceased: 31.3 ± 16.7 vs. patient alive: 20.9 ± 14.5, $p = 0.009$) (see Fig. 2).

Baseline HADS-D score was 16.4 ± 6.6 (min 3, max. 33). HADS-D score at T1 was 12.2 ± 6.1 (min. 3, max. 31); at T2, 10.6 ± 6.3 (min. 3, max. 33); at T3, 9.5 ± 7.1 (min. 3, max. 33). The HADS-D scores did not differ between groups (see Fig. 3).

In the whole cohort, significant reductions from baseline to follow-up were observed in IES at T2 and T3 and in HADS-D at T1–T3.

Women had significantly higher IES scores than men at T0 (30.8 ± 12.2 vs. 20.7 ± 11.2, $p < 0.001$) and at T1 (27.4 ± 15.3 vs. 17.9 ± 15.2, p = 0.008). The scores for men and women were comparable at T2 (19.8 ± 13.3 vs. 16 ± 14.9, p = 0.250) and T3 (18.8 ± 15.9 vs. 13.4 ± 14.9, $p = 0.567$).

At T0, women also had higher HADS-D scores (17.6 ± 6 vs. 13.8 ± 7.2, $p = 0.008$) than men. At T1 (12.3 ± 5.2 vs. 12 ± 7.7, p = 0.552), T2 (10.7 ± 6.1 vs. 10.5 ± 6.8), p = 0.849), and T3 (9.8 ± 7.2 vs. 9 ± 7), p = 0.583), HADS-D scores for women and men were comparable.

Family members who were present at the event that led to the respective patients' ICU admissions had significantly higher IES and HADS-D values at later time points (IES: T2 and T3; HADS-D: T2).

We recorded time, frequency, and content accessed on the website (login intervention mean 2.4 ± 2.6, min. 1, max. 14, vs. control mean 1.5 ± 0.8, min. 1, max. 3; total 1386 "clicks" on the website pages, intervention 1021 vs. control 365).

Discussion

This Austrian/Swiss multicenter double-blind, randomized, placebo-controlled trial showed a substantial psychological burden on family members of patients in the ICU, both at ICU admission and even after one year. IES scores as well HADS-D scores were significantly higher among family members that were present at the event that led to the respective patients' ICU admission. The connection to this phenomenon was already evident in the pilot study for this randomized controlled trial [17]. However, the intervention website did not lead to a significant improvement in the intervention over the control groups.

Our results are confirmed by other studies which have assessed the psychological burden of relatives in other countries [1, 3, 22]. The development of acute stress disorders during ICU stays and the question of whether there are possible approaches for alleviating this burden remain open in most studies [22].

Other studies have shown that female gender is a risk factor for symptoms of PTSD [29]. In our study, women had significantly higher IES scores than men at T0 and at T1, but the scores for men and women were comparable at T2 and T3. This shows that women and men react differently in similar situations. It may also imply a need for

differential gender-based support in acute settings. This knowledge could be directly considered when caring for female family members.

Mistraletti et al. studied an online website and a brochure and found that the intervention was associated with a significantly lower incidence of PTSD symptoms [13]. Our intervention website was unable to reduce the psychological burden compared to a control website with less information. This may be because the sample was too small, because the intervention was inappropriate, or because of differing concepts in family-centered care, communication and information practices, or follow-up management [6]. Family members encounter varied beneficial and hindering factors over the course of the ICU stay when dealing with information needs and psychological burdens [30–32].

Previous studies report on the immense information needs of family members [11, 33]. This is also shown by the results of our study. The intervention website was used three times as often as the control website. Paper-based or online information services, which can be used regardless of staff availability, can help family members. Hofmann et al. [27] recommended the use of a website based on evidence-based medical principles with easily understandable information about ICUs (including videos, information on hygiene, delirium, rehabilitation, and mental health). Such information should be specifically developed for family members and critically ill patients, enabling them to find relevant information both during and after the ICU stay [33]. The advantage of online information lies in its easy access, the amount of information that can be provided, the easy evaluation of the website, and the low cost. However, the exclusion of family members with little affinity for modern information technology (IT) is a clear disadvantage.

All individuals bear a heavy burden during and after ICU admission. What can be done in the future? Bohart et al. concluded that clinical staff need to equip patients and family members to cope within the unit; staff also need to provide specific support that enables family members to fulfill their roles as advocates and supporters of the patient [33]. This requires active involvement, when desired by family members, communication, and information sharing. Available approaches emphasize the ways in which new media and social media can help people to cope with the stress [16]. Cherak et al. reported in a review that there are potential benefits for caregivers of the critically ill, but more robust and clinically relevant studies are required to identify effective social media strategies to use among caregivers for the critically ill [16].

A revised version (based on feedback of participants and our own critical revision) of the intervention website can now be found at www.intensivstation.jetzt. The continuation of the project was supported by the scientific societies (ÖGIAIN, DIVI, etc.) because of its usefulness for patients, family members, and ICU experts, and in 2022, a non-profit association was founded.

Limitations

This study has several limitations. First, the recruitment targets were not achieved (primary endpoint n = 74 out of n = 98, 75.5%). The reasons for this were underfunding of the study and the unanticipated visit bans caused by the COVID-19 pandemic. The study therefore had lower power than required. Second, despite several contact efforts by telephone and e-mail, some family members were lost to follow-up over the long study period of 365 days. As a result, interviews were conducted at different time points and were sometimes carried out later than planned. Third, in addition to the low number of family members, there was a larger proportion of female participants. Furthermore, we used the original IES by Horowitz et al. (1979) [18], which was also used in Lautrette's study, and not the newer IES-R version [34]. The IES was originally used to estimate symptoms after a traumatic event. Nevertheless, we used the IES only with face validity during the traumatic event related to the ICU hospitalization to better compare symptoms and monitor their progression during and after the traumatic event. This should be taken into account when interpreting the results. Finally, only family members with a certain IT literacy could take part in the study. For the reasons mentioned above, it is not possible to generalize the results.

Conclusion

Our multicenter randomized interventional study showed that half of the family members of critically ill patients exhibited considerable psychological symptoms at ICU admission, and female relatives and those present at the critical event had a higher symptom burden. No difference in IES scores between intervention and control groups was found in the course of the study. Long-term follow-up indicated that many family members have symptoms of PTSD up to one year later. Measurements to record psychological stress and to determine optimal support services for family members of critically ill patients seem warranted in ICU routine care. Further research is needed to determine ways to improve the difficult situation for relatives.

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Author contributions
MH and KA designed the study. HB developed and maintained the study website. M-MJ, JCS, DL, NV, PH, AB, and PE recruited participants. RR analyzed data. MH, JCS, DL, NV, PH, AB, HB, PE, RR, AKH, GS, and TRP supported data interpretation. TP, GS, and KA supervised the project. MH and M-MJ wrote the letter and manuscript.

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Availability of data and materials
The data that support the findings of this study are available on request from the first author MH.

Declarations

Conflicts of interest
All authors declare that they have no competing interests.

Ethics approval
This study was approved by the Austrian Medical University of Graz Ethics Commission (27–317 ex 14/15).

Consent to participate
All participants gave their informed consent.

Consent for publication
All authors listed have given their consent to publication.

ICU families study group
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