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Research paper

Impact of a nurse-led family support intervention on family members' satisfaction with intensive care and psychological wellbeing: A mixed-methods evaluation

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ABSTRACT

Background: Families of critically ill persons face uncertainty and experience distress during and after their close other's stay in an intensive care unit (ICU). Proactive nurse engagement and support is recommended to meet families' needs in the ICU, but little is known about its impact on quality of family care. We introduced a family support intervention that consisted of an interprofessional family support pathway and a new role of an advanced practice family nurse.

Objectives: The aim of the study was to examine the effect of an advanced practice nurse-led family support intervention on family members' satisfaction, wellbeing, and psychological distress.

Methods: We conducted a quasi-experimental before-and-after study with embedded qualitative interviews in a Swiss University Hospital from March 2018 to July 2019 using a questionnaire (Family Satisfaction in the ICU-24 Survey, Hospital Anxiety and Depression Scale, and Impact of Event Scale-Revised-6) and qualitative interviews (n = 19) after patient discharge.

Results: Families in the intervention group (n = 75) showed a trend for increased overall satisfaction (difference of 5.544, 95% confidence interval [CI]: –0.11 to 11.20), a statistically significant increase in satisfaction with decision-making (7.258, 95% CI: 0.89 to 13.63), and a nonsignificant increase in satisfaction with care (4.178, 95% CI: –1.53 to 9.89). Psychological distress was higher in the intervention group, with depression reaching statistical significance (difference of 1.706, 95% CI: 0.16 to 3.25), which may be explained by longer ICU stays and higher proportion of deaths in the intervention group. Families receiving the intervention reported to be feeling cared for, well informed, and better able to cope. Data integration suggests that early onset, fit to need, and quality of intervention were the most important intervention characteristics impacting family wellbeing.

Conclusions: Our study found that family members experience a nurse-led support intervention as beneficial for their wellbeing. It increased their satisfaction, but was unable to demonstrate a favourable impact on psychological distress.

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1. Introduction

Families of critically ill persons face uncertainty and considerable psychological distress during and after their close other's stay in an intensive care unit (ICU).^{1–4} Families report to be worried, sad, and nervous and to have trouble sleeping and concentrating.^{5,6} About one-third of the family members of ICU survivors, and about 50% of those who are bereaved, experience

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post-traumatic stress syndrome.^{7–9} Poor communication with families, insufficient shared-decision making, and inadequate emotional support have been found to negatively affect family members' experience and mental health.^{10–12}

To increase quality of family care, professional guidelines recommend proactive family engagement and support in the ICU, such as family presence and involvement in care, structured information, communication and support for families, or the use of specific consultations or roles.^{13–15} In recent years, several studies have investigated the effects of structured communication and family support interventions,^{16–18} which often included a family navigator role.^{19–22} These studies report a positive effect on the length of ICU stay, quality of communication, and satisfaction with care.^{16,17,19,23,24} Findings on psychological distress, such as stress, depression, or anxiety, however, remain inconclusive.^{19,21,23} Despite these promising results, best practice around family engagement and support in the ICU remains inconsistently and insufficiently implemented.^{25,26} More knowledge around the effectiveness of family support intervention in the ICU is needed. Hence, to increase quality of family care and reduce psychological distress, we introduced a family support intervention as part of a quality improvement initiative that aimed to address families' needs for relational engagement, consistent and constant communication, and emotional and practical support during critical illness. The aim of the study was to examine the intervention's impact on family members' satisfaction with care, which was the primary outcome, their sense of wellbeing, and post-ICU psychological distress. To increase understanding of the intervention effectiveness, we explored patterns and associations between the intervention's characteristics and family member outcomes.

2. Methods

2.1. Design

We conducted a prospective, quasi-experimental before-and-after study with embedded qualitative interviews.²⁷ The use of both quantitative and qualitative data is recommended for the evaluation of complex interventions as it allows for a comprehensive understanding of an intervention's effectiveness and of families' experience with the intervention.^{28,29} Data were collected in two sequential phases, before (control phase, March–August 2018) and after introduction of the nurse-led family support intervention (intervention phase, October 2018–July 2019).

2.2. Setting, participants, and procedures

The study took place in a 12-bed surgical and transplant ICU at a major Swiss University Hospital. The unit has more than 600 admissions a year and predominantly serves a highly critically ill patient group. Family members were defined as close others from the patient's perspective, as noted in the clinical record. They were eligible to take part when they were at least 18 years old, cognitively able to understand and participate in the study, and capable to fill in the German language questionnaire. In addition, family members in the intervention group had to have at least 5 min of intervention dose. No exclusion criteria were defined.

A consecutive sampling strategy was used. Potential family member participants were identified in the clinical record (control phase) or by the advanced practice nurse (APN) delivering the intervention (intervention phase). Their contact information was communicated to the research team. A research assistant sent out the study information pack together with the paper-and-pencil questionnaire one to two weeks after patient ICU discharge. If necessary, family members were followed up by phone or by mail 4

and 8 weeks after the questionnaire had been sent out. Family members of the intervention group were invited by the APN to take part in an interview. If they agreed, the researcher contacted families to explain the purpose of the interview, to obtain oral consent, and to arrange an interview date and location.

Because this study was designed to investigate the effects of an intervention that was introduced as part of a quality improvement initiative, no sample size/power calculation was performed in advance of the study.

2.3. Family support intervention

The family support intervention targeted families of patients who were admitted in life-threatening conditions, with an expected length of stay of 2 days or longer, or families with a complex psychosocial situation or symptoms of acute crisis. It consisted of a family support pathway and a new advanced practice family nursing (APN) role that was integrated into the ICU team. The family support intervention was grounded in a family systems nursing approach^{30–32} and built on guideline-based strategies and recommendations around ICU care to families.^{14,33} A family systems approach proposes that critical illness affects families' affective, cognitive, and behavioural functioning, requiring therapeutic relational nurse–family engagement, including relationship-focused and psychoeducational interventions to support management of illness in families and to alleviate their suffering. Hence, the family support intervention was designed to entail APN-delivered therapeutic conversations with families over time, in close collaboration with and in addition to the care provided by ICU nurses and physicians along the clinical patient pathway (Box 1).²⁷ Points of contact between the APN and the family included a family meeting within the first 72 h after admission, regular APN follow-up and interprofessional family meetings as needed, a family discharge meeting, and a follow-up call within 1 week after discharge or around 6 weeks after death. The number of intervention contacts varied based on family needs, course and duration of ICU stay, and availability of the APN. The APN was a certified ICU nurse with

Box 1

APN intervention activities with families.

Focus of APN intervention activities

- Proactive engagement: Building relations and interacting with families.
- Family assessment: Getting to know the family and learn about their structure, functioning, emotions, needs, and preferences.
- Relationship-focused interventions: Creating a safe and supportive space for families to reflect, to increase mutual understanding, and to mobilise resources that enable families to live through the situation together.
- Psychoeducational interventions: Offering education and counselling around critical illness and its impact on individual and family health to support self-management and family management of the illness.
- Transition and follow-up support: Being present with families over time and into the post-ICU phase.
- Liaison and coordination activities: Liaising between the family and the ICU team to promote communication and coordination of care.

graduate education in family nursing. Regular reflection and clinical supervision by the first and last author were used to ensure quality of family interventions.

2.4. Data collection

Quantitative data were obtained using a written questionnaire with several self-report measures after patient discharge. Half of the family members (49.6%) returned the questionnaire within the first month after their close other's ICU discharge or death, and another one-third (37.8%) of the family members did so between two and three months post-discharge. Return of the questionnaire was taken as informed consent. Semistructured, qualitative interviews were held with a subsample of families in the intervention phase. Interview participants signed a written informed consent. Intervention delivery was recorded in a structured log.

2.4.1. Quantitative measures

2.4.1.1. Family satisfaction in the ICU. To measure family members' satisfaction with ICU care, which was the primary outcome, the validated, 24-item German version of the Family Satisfaction in the ICU (FS-ICU-24) questionnaire was used^{34,35} (<https://fsicu.org>). The FS-ICU-24 assesses on a 5-point Likert scale the satisfaction with care (FS-ICU-care, 14 items) and satisfaction with involvement in decision-making (FS-ICU-dm, 10 items). A standardised score of 0–100 is calculated for the total score and the two subscores, whereas 100 indicates maximal satisfaction. The FSC-ICU has excellent psychometric properties,³⁶ with a Cronbach's alpha of 0.95 for satisfaction with care and 0.87 for decision-making subscales.³⁵ In our data, values were similar, with $\alpha = 0.93$ and $\alpha = 0.92$, respectively.

2.4.1.2. Hospital Anxiety and Depression Scale. Psychological distress was measured using the widely used and well-validated German version of the Hospital Anxiety and Depression Scale (HADS).^{37,38} It rates on a 4-point Likert scale overall psychological burden (total score = 0–42), anxiety (HADS-A, seven items, score = 0–21), and depression (HADS-D, seven items, score = 0–21), wherein higher scores indicate worse symptoms. Cronbach's alpha levels of the German version are higher than .80.³⁷ In our data, Cronbach's alpha levels were 0.92 for the total, 0.86 for the anxiety, and 0.89 for the depression scale.

2.4.1.3. Impact of Event Scale-Revised-6. Stress was assessed using the six-item short form of the German version of the IES-R.^{39,40} The Impact of Event Scale-Revised-6 (IES-R-6) measures severity of subjective stress on a 5-point Likert scale (score from 0 to 24, with a high score indicating post-traumatic stress). The IES-R-6 is a valid measure (Cronbach's alpha = 0.80) that correlates highly with the IES-R.⁴⁰ Cronbach's alpha in our sample was satisfactory with 0.75.

2.4.1.4. Advanced Practice Nurse – Care Quality Questionnaire. To measure the quality of the APN-delivered family interventions, the 19-item Advanced Practice Nurse – Care Quality Questionnaire (APN-BQ) was used for family members of the intervention group.^{41,42} Seven of the 19 items were slightly reworded to fit family members' situation. The APN-BQ assesses quality, that is, structural (i.e., nurses' knowledge, skill, and relational competencies), process (participatory interaction, shared decision-making), and outcome (empowerment, self-care ability) quality of APN-delivered interventions on a 4-point Likert scale, yielding a score from 0 to 57 (high quality). Examples include “The nurse was very knowledgeable” (structure), “I was able to determine the topics and course for the conversations” (process), or “I was able to apply the coping strategies that I have acquired during the conversations in

my daily life” (outcome). The APN-BQ holds excellent internal consistency (current sample Cronbach's alpha = 0.97).

2.4.1.5. Intervention log. The APN recorded frequency (number of interventions lasting ≥ 5 min), intensity (duration, standardised as mean time of intervention per length of time), mode (face-to-face, phone), and activity (type of APN intervention) in a structured documentation format.

2.4.1.6. Demographics. The patient's age, gender, and length of stay were extracted from the clinical record. Other patient characteristics, data on family situation, and family member demographics were obtained from family members using a structured form that was part of the questionnaire.

2.4.2. Qualitative interviews

To learn about families' perception of the intervention's impact on their wellbeing, semistructured, evaluative interviews⁴³ were conducted by the first author using an interview guide with families of the intervention group. Interviews are a particularly suitable approach to data collection when individual and dyadic perspectives and views are of interest. We were interested to learn about family members' perception of potential impact of the intervention on their sense of wellbeing and their self-management and family management of the critical illness situation. Questions included: “How was the support given by the family nurse helpful to you and your family during and after your close other's critical illness?”, “How did it impact on your and your families' wellbeing and ability to cope with critical illness?”, or “What part of the intervention has been most helpful and what was less relevant to you?”. The interviews also aimed to assess experience with, including usefulness and acceptability of, the intervention from families' perspective, which have been reported elsewhere.²⁷

Interviews were carried out with a total of 19 family members who belonged to 16 patients (two family members participated for three patients). They took place between 29 and 157 days (median = 101.5) after ICU discharge or death, at a place of their choice (five at home, three at the hospital, two in a public space, six on the phone), and had a median length of 26 min (range from 16 to 51). Interviews were audiotaped and transcribed verbatim by a professional transcriptionist. All except one interview participant had previously filled in the questionnaire.

2.5. Ethical considerations

The study was reviewed by the Ethics Committee of the Canton of Zurich (Req-2018-00107), which waived the need for approval as the study was judged to not fall under the jurisdiction of the ethics commission based on national law.

2.6. Data analysis

Data analysis was performed using R version 3.6.3 (R Core Team, 2020, www.R-project.org). To reduce the imbalance of potential confounding variables between the control and intervention groups, propensity score matching was applied. Because the unit of treatment in this study is the cluster of family members associated with a particular patient (>one family member participated for 14 patients), we decided to match patients and then to consider family members of the same patient as repeated measurements, accounting for the dependence of these repeated measurements. Propensity scores were estimated by logistic regression, using the patient characteristics in Table 1 (except the patient outcome variables, length of stay and death) as explanatory variables. Using R package Matching,⁴⁴ all 58 patients whose family members

received the intervention were successfully matched 1:1 to 58 control patients. The covariate balance of the original and matched samples was then inspected using R package *cobalt*.⁴⁵ After matching, the absolute standardised mean difference was <0.1 for all variables (Supplementary file 1). To estimate the treatment effect of intervention vs. control, we joined the patient-level data of the matched set with data on the family members from the same set of patients. Outcome variables were analysed using linear mixed-effects models with a random intercept per patient. As explanatory variables in the model, we used the family member characteristics' relationship with the patient: age, gender, and civil status.

To investigate the associations between intervention characteristics and family member outcomes in the intervention group, we also used linear mixed-effects models with a random intercept per patient. Explanatory variables in the model were characteristics of the APN-F intervention, i.e., the total number of intervention contacts, the intensity of the intervention as minutes per day in the ICU, and the quality of care (APN-BQ).

Qualitative data were analysed using inductive content analysis, which is a well-established qualitative analysis method that uses a systematic process to identify patterns of meaning in the data.^{46,47} Anonymous and checked transcription files were entered into NVivo 12 (<https://www.qsrinternational.com/>)

Table 1
Participant and family member characteristics.

Characteristics	Control ^a	Intervention	p-value ^b	Matched control ^a	ASMD unadjusted ^c	ASMD adjusted ^c
Patients	n = 135	n = 58		n = 58		
Age (years), mean (SD)	59.87 (16.79)	63.09 (16.66)	0.223	66.57 (16.67)	0.19	0.03
Female gender, n (%)	56 (41.5)	26 (44.8)	0.785	25 (43.1)	0.06	0.03
Civil status, married/partnered, n (%)	86 (63.7)	37 (63.8)	1.000	38 (65.5)	0.01	0.04
Having children, yes, n (%)	93 (69.4)	40 (69.0)	1.000	38 (65.5)	0.01	0.07
Living situation, n (%)						
With a spouse/partner	72 (53.3)	29 (50.0)		31 (53.4)	0.07	0.07
With family members (>2)	24 (17.8)	12 (20.7)		12 (20.7)	0.07	0.00
Alone/with someone else	39 (28.9)	17 (29.3)	0.872	15 (25.9)	0.02	0.08
Cause of admission, n (%)						
Unplanned	50 (37.0)	27 (46.6)		25 (43.1)	0.20	0.07
Transfer from other ICU	10 (7.4)	10 (17.2)		9 (15.5)	0.26	0.05
Elective surgery	50 (37.0)	8 (13.8)		9 (15.5)	0.68	0.05
Organ transplant	25 (18.5)	13 (22.4)	0.006	15 (25.9)	0.09	0.08
Length of stay ^d , median (IQR)	3.0 (2.0, 6.0)	11.0 (5.0, 20.0)	<0.001	3.5 (2.0, 6.75)	–	–
Death in the ICU ^d , n (%)	13 (9.6)	25 (43.1)	<0.001	7 (12.1)	–	–
Family members	n = 139			n = 62		
Age (years), mean (SD)	55.27 (15.56)	51.54 (15.68)	0.100	56.34 (16.21)		
Female gender, n (%)	99 (71.2)	49 (65.3)	0.462	45 (72.6)		
Relation, n (%)						
Spouse/partner	73 (52.5)	24 (32.0)		33 (53.2)		
Child	25 (18.0)	32 (42.7)		10 (16.1)		
Parent	19 (13.7)	9 (12.0)		7 (11.3)		
Other family members	22 (15.8)	10 (13.3)	0.001	12 (19.4)		
Cohabiting, n (%)	84 (60.4)	35 (46.7)	0.074	38 (61.3)		
Frequency of contact ^e , n (%)						
Several times a week	32 (59.3)	23 (57.5)		13 (54.2)		
Once a week	15 (27.8)	11 (27.5)		6 (25.0)		
Once a month	5 (9.3)	2 (5.0)		5 (20.8)		
<Once a month	2 (3.7)	4 (10.0)	0.572	0 (0.0)		
Previous ICU experience, n (%)	61 (44.2)	20 (26.7)	0.018	26 (41.9)		
Distance from home to hospital, n (%)						
Same city as the hospital	24 (17.3)	6 (8.0)		12 (19.4)		
Outside city	52 (37.4)	27 (36.0)		28 (45.2)		
Outside canton	63 (45.3)	42 (56.0)	0.126	22 (35.5)		
Civil status, n (%)						
Married, partnered	103 (74.1)	51 (68.9)		44 (71.0)		
Divorced, separated	8 (5.8)	4 (5.4)		2 (3.2)		
Single	19 (13.7)	16 (21.6)		11 (17.7)		
Widowed	9 (6.5)	3 (4.1)	0.466	5 (8.1)		
Highest degree, n (%)						
No vocational training	8 (5.8)	0 (0.0)		4 (6.5)		
Vocational training	70 (50.4)	31 (42.5)		37 (59.7)		
Diploma	37 (26.6)	27 (37.0)		12 (19.4)		
Bachelor's degree	7 (5.0)	5 (6.8)		2 (3.2)		
Master's or doctoral degree	17 (12.2)	10 (13.7)	0.142	7 (11.4)		

SD = standard deviation; ICU = intensive care unit; ASMD = absolute standardised mean difference.

^a The column "Control" contains all control patients or family members of control patients, whereas the column "Matched control" contains the matched control patients or family members of the matched controls only.

^b P-values are calculated using a t-test for continuous variables, Wilcoxon rank-sum test for ordinal-level data, and chi-square test for categorical variables.

^c ASMD unadjusted is the absolute standardised mean difference before matching, whereas ASMD adjusted is the adjusted ASMD after matching, only displayed for those variables used for matching.

^d Length of stay and death were considered patient outcome variables and therefore not included in the propensity score matching.

^e Only for family members who are not cohabiting with the critically ill person (n = 55, control group; n = 40, intervention group, n = 24, matched control group).

nvivo), a qualitative data analysis software. First, the data were read and reread. Relevant sentences or paragraphs that carried meaning in relation to the research question were identified and coded by one researcher. Next, two researchers reviewed the codes and grouped similar codes into categories. Interpretive and reflective writing occurred at each analytical step, which helped to refine the findings' structure and capture interpretive insights. Finally, the findings' structure was verified with the data.

Qualitative and quantitative data were integrated in two ways: (i) by contrasting and comparing families' experience of benefit with self-report measures around satisfaction and psychological distress and (ii) by mixing data around intervention characteristics with interview findings to discern a typology of family need, service responsiveness, and self-perceived outcomes.⁴⁸

3. Results

3.1. Patient and family member characteristics

The participant flow is displayed in Fig. 1. A total of 139 family members from the control group (response rate = 50.0%) and 75 family members from the intervention group (response rate = 52.4%) participated in our study. The sample characteristics of patients and family members are listed in Table 1. The intervention group had a greater number of unplanned admissions, longer length of stays, and higher mortality than those in the control group (Table 1). Family members did not differ much between the two groups except in their distribution of family relationship and proportion of previous ICU experience. The propensity score-matched set contained a total of 116 patients with 137 family members, i.e., all 58 patients and 75 family members from the intervention group and 58 matched control patients with 62 family members.

A total of 19 persons (42% daughters, 21% parents, 16% spouses, 11% siblings, 10% others) representing 16 families were interviewed. They were predominantly women (79%) and married (63%), had a median age of 52.5 (range: 51; minimum–maximum = 34–74), and held a diploma (56%) or bachelor's degree (22%). One-third lived in the same household as the patient ($n = 7$). Half of the families ($n = 8$) experienced the loss of their close other during the ICU stay.

3.2. Intervention characteristics

Two-thirds of the APN intervention contacts ($n = 371$) with families of the intervention group were delivered face-to-face (69%), most often during the patients' ICU stay, followed by follow-up calls (23%). A majority of contacts included different intervention activities, most frequently family assessment (94% of APN contacts), psychoeducational interventions (90%), relationship-focused interventions (85%), and relating and interacting (74%). Transition support (39%) and liaison and coordination activities (37%) occurred in just more than one-third of the contacts.

Families in the intervention group received on average 4.5 (standard deviation [SD] = 3.2) APN interventions, with a mean length per ICU day of 10.9 (SD = 11.1) minutes. Family members ($n = 66$) rated the quality of the APN interventions (APN-BQ) on average with a score of 43.8 (SD = 9.9, mode = 57, score = 0–57). One-third ($n = 22$) of them appraised the quality of the intervention to be higher than a score of 50.

3.3. Satisfaction with care

As expected, families receiving the intervention demonstrated higher levels of satisfaction with ICU care in the matched analysis. The family support intervention showed a trend for an increase in family members' overall satisfaction with intensive care (FS-ICU-24 total differed by 5.544, 95% confidence interval [CI] from –0.11 to 11.20, $p = 0.055$), a statistically significant increase in satisfaction with involvement in decision-making (FS-ICU-dm differed by 7.258, 95% CI from 0.89 to 13.63, $p = 0.026$), and a nonsignificant increase in the satisfaction with care (FS-ICU-care differed by 4.178, 95% CI from –1.53 to 9.89, $p = 0.15$) (Table 2). In the unmatched sample, FS-ICU single questions about satisfaction with end-of-life care showed that a higher proportion of family members receiving the intervention ($n = 30$) found that their close other died calmly or very calmly (43.8% before vs. 58.6% after). They felt supported or very supported by the ICU team (75.1% before vs. 100% after) in comparison with the control group ($n = 16$).

3.4. Psychological distress

Contrary to our expectation, levels of post-ICU psychological distress, including depression, anxiety, and post-traumatic stress,

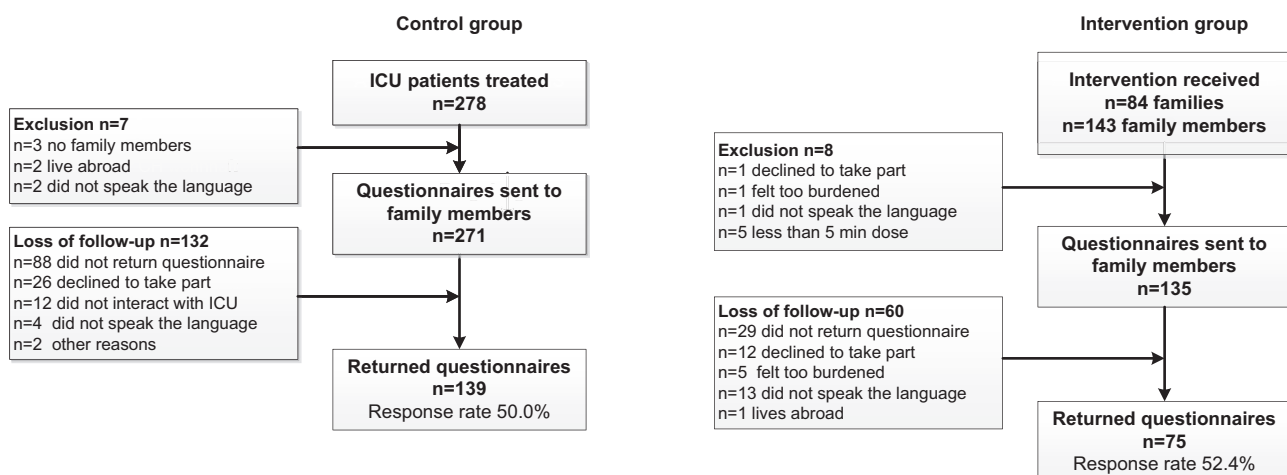


Fig. 1. Participant flow. ICU = intensive care unit.

Table 2
Impact of intervention on satisfaction.

Model term	FS-ICU-total satisfaction			FS-ICU-care			FS-ICU-decision-making		
	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value
(Intercept)	69.848	61.25–78.44	<0.0001	70.551	61.86–79.27	<0.0001	69.301	59.54–79.06	<0.0001
Intervention	5.544	-0.11–11.20	0.055	4.178	-1.53–9.89	0.15	7.258	0.89–13.63	0.026
Age	0.062	-0.15–0.28	0.55	0.059	-0.16–0.28	0.57	0.061	-0.18–0.30	0.60
Female gender	0.772	-5.50–7.05	0.79	1.575	-4.77–7.92	0.60	-0.564	-7.68–6.56	0.87
Civil status, married/partnered	-1.858	-8.67–4.95	0.57	-2.608	-9.47–4.26	0.43	-0.782	-8.43–6.87	0.83
Child	-0.518	-8.85–7.82	0.90	-1.900	-10.34–6.54	0.63	1.122	-8.27–10.51	0.80
Parent	4.968	-4.82–14.76	0.29	3.073	-6.85–12.99	0.52	7.570	-3.45–18.59	0.16
Other family member	5.605	-3.30–14.51	0.20	5.179	-3.66–14.02	0.23	6.399	-3.63–16.43	0.19

FS-ICU = Family Satisfaction in the ICU.

Coefficient estimates from a linear mixed-effects model on family member outcomes to estimate the effect of the intervention using the propensity score–matched data set and covariate adjustment for characteristics of the family members. A random intercept was modelled per patient. A total of 132 family members from 113 patients were included in the FS-ICU-total, 133 family members from 114 patients were included in the FS-ICU-care, and 131 family members from 112 patients were included in the FS-ICU-decision-making model.

^a 95% confidence interval.

were higher in the intervention group, which faced statistically significantly more often an unplanned admission to and longer stays in the ICU as well as the death of their critically ill family member. The effect of the intervention was significant for depression (HADS-D differed by 1.706, 95% CI from 0.16 to 3.25, $p = 0.03$) and nonsignificant for overall psychological distress (HADS total differed by 2.202, 95% CI from -0.66 to 5.07, $p = 0.13$), anxiety (HADS-A differed by 0.463, 95% CI from -1.15 to 2.08, $p = 0.57$), and post-traumatic stress (IES-R-6 differed by 0.965, 95% CI from -0.75 to 2.68, $p = 0.27$) (see also [Supplementary file 2](#)).

3.5. Associations between intervention characteristics and family member outcomes

A positive association was observed between APN intervention quality (APN-BQ) and family satisfaction with ICU care (FS-ICU total and subscores) and between APN intervention quality and post-traumatic stress (IES-R-6), whereas a negative association was observed between the APN-BQ score and depression (HADS-depression) (Table 3). Associations of the outcomes with the number of APN interventions and the mean length of interventions per ICU day were only weak and inconsistent between outcomes.

Table 3
Associations between intervention characteristics and family member outcomes.

Model term	FS-ICU-total satisfaction			FS-ICU-care			FS-ICU-decision-making		
	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value
(Intercept)	75.010	71.45–78.57	<0.0001	73.311	69.31–77.32	<0.0001	77.262	73.46–81.06	<0.0001
No of intervention contacts	0.139	-0.90–1.18	0.78	-0.055	-1.18–1.07	0.92	0.444	-0.69–1.58	0.41
Intervention dose per LoS ^b	-0.165	-0.46–0.13	0.25	-0.265	-0.60–0.07	0.11	-0.055	-0.37–0.26	0.71
Intervention quality ^c	0.889	0.53–1.25	0.0002	0.910	0.54–1.29	0.0002	0.901	0.49–1.31	0.0004

Model term	HADS total			HADS-Depression			HADS-Anxiety			IES-R-6 Stress		
	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value	Estimate	CI ^a	p-value
(Intercept)	11.612	9.13–14.09	<0.0001	5.108	3.71–6.50	<0.0001	6.517	5.23–7.80	<0.0001	12.418	11.25–13.58	<0.0001
No of intervention contacts	-0.191	-0.85–0.47	0.54	-0.060	-0.43–0.31	0.73	-0.143	-0.49–0.21	0.39	0.120	-0.22–0.46	0.46
Intervention dose per LoS ^b	0.009	-0.19–0.21	0.93	0.013	-0.10–0.13	0.81	-0.002	-0.11–0.10	0.97	-0.021	-0.12–0.07	0.64
Intervention quality ^c	-0.138	-0.35–0.07	0.18	-0.144	-0.26–0.03	0.017	-0.001	-0.11–0.11	0.99	0.133	0.01–0.25	0.036

FS-ICU = Family Satisfaction in the ICU; HADS = Hospital Anxiety and Depression Scale.

Coefficient estimates from a linear mixed-effects model on family members are from the intervention group only. A random intercept was modelled per patient. A total of 66 family members from 51 patients were included in the model. A total of 66 family members from 51 patients were included in the models for FS-ICU-total, FS-ICU-care, FS-ICU-decision-making, HADS-Anxiety, and IES and 65 family members from 50 patients were included for HADS total and HADS-Depression.

^a 95% confidence interval.

^b LoS = length of ICU stay.

^c As measured using the Advanced Practice Nurse – Care Quality Questionnaire (APN-BQ), the score ranges from 0 to 57 (high quality).

Interview and intervention log data revealed a typology around family needs, service responsiveness and fit to needs, and impact on families' sense of wellbeing (Table 4). Qualitative data indicated that family needs together with early onset were the most important determinant of families' experience of the intervention as beneficial for their wellbeing. Intervention log data on service delivery affirmed the typology.

3.6. Qualitative findings on sense of wellbeing

Interview participants indicated that the APN-delivered support intervention was beneficial for their wellbeing in two ways.

Being recognised and cared for

The availability of a family nurse made families feel recognised, acknowledged, and looked after, as one family member said, “I took it to be a continuous process, which means that everyone is looked after. Not only my aunt, but me too.” (ID 549). Families highly appreciated to have a person to turn to, which meant that they felt more in control of the situation and capable to seek and get support if needed, as one spouse explained, “... a trustworthy person to turn to who coordinates everything. I knew I could turn to her no matter

what. (...). I have ALWAYS felt that I have leverage in getting to the things I need. I knew that I was not alone.” (ID 527).

Interactions with the APN enabled a healthful focus on family wellbeing. Regular conversations meant that families could voice their fears and talk about difficult emotions, ask questions that they might not want to pose in front of the critically ill family member, and reflect on the ways the critical illness affected them. One daughter explained, “When someone takes the time to look at you and to ask: ‘How are you?’ Then you slowly start to ask yourself: ‘How am I?’ You’re only functioning, really. And when you have someone who specially comes to see you asking how you are, then you start to reflect on it.” (ID 567). The relational interactions with the APN created a safe space for families in which they could talk and listen to each other and devise self-care strategies while also acting upon their need to be present and supportive to their critically ill family member.

Being supported as an individual and a family

Families described that the support helped them to live through the critical illness and the aftermath. The critical illness was often an utterly unfamiliar, disruptive, incisive, and extremely stressful experience for which they felt ill prepared. Ongoing communication and dialogue with the APN meant that they were more knowledgeable and better informed about their critically ill family member: “It is really awful when you don’t understand what is happening and she always told me what is happening, and why. Explained it in detail. I do believe that it would have turned out extremely different and very upsetting for me (if she hadn’t).” (ID 574). Families reported that the APN support instilled a sense of comfort and confidence in their capacity to live through critical illness, as another daughter said, “It was helpful to hear her say: ‘Well, you give him strength and courage, you are doing a great job’. How should I put it: she created hope in a hopeless situation.” (ID 565). Families felt that they received guidance on how to mobilise their resources, access additional support, and work together as a family that stretched into the post-ICU phase, as one bereaved daughter illustrated, “You go to the hospital, (...), you go home, things circle in your head. You’ve received no strategy at all how to cope with

the whole situation, but we have, and it had a lasting impact. She helped my mother to figure out how to endure the time that follows. You’re supported during ICU, and it lingers.” (ID 524).

4. Discussion

This quasi-experimental study with embedded qualitative interviews revealed a potentially beneficial effect of a family support intervention on families’ satisfaction with care, in particular in regard to decision-making and end-of-life care, and their ICU support experience. The intervention combined an interprofessional family support pathway with a specific family nursing role, which included therapeutic family nursing interventions and coordination activities to increase interaction and communication with the ICU team over time. Families reported to be feeling acknowledged, cared for, well informed, and supported and strengthened in living through critical illness, loss, and bereavement. Although a statistically significant increase was observed in satisfaction with decision-making, overall levels of satisfaction, while improved, did not reach statistical significance. Research to date has shown that different forms of family-centred interventions in the ICU increase family satisfaction with care and sense of wellbeing.^{17,24,49–51} White et al.,²³ who investigated a nurse-facilitated family support pathway for surrogate decision-makers, found a statistically significant increase in quality of communication and perception of person-centredness, but did not investigate satisfaction with care. Our study, together with others, suggest that information support, communication over time, and a facilitator role are associated with satisfaction with ICU care,^{24,52,53} but more research is needed to tease out the mechanisms through which a particular intervention or component thereof increases satisfaction with care and family wellbeing.

Our intervention failed to demonstrate a reduction in post-ICU psychosocial distress, which is consistent with previous trials investigating family support interventions that entailed a specific family navigator role.^{21,23} Contrary to our expectation, family members in the intervention group demonstrated higher levels of depression, anxiety, and post-traumatic stress than those in the control group, although only depression reached statistical

Table 4
Family needs—service responsiveness—family outcomes typology.

Dimensions	Constituting factors	Pattern 1: low and met needs, high responsiveness (n = 3)	Pattern 2: high and met needs, high responsiveness (n = 10)	Pattern 3: high and unmet needs, low responsiveness (n = 3)
Family needs (interviews)	Nature and dynamic of illness	A challenging family experience. Close other survives critical illness.	A family crisis, with a high degree of uncertainty and unpredictability. Family experiences prolonged illness and/or loss of close other.	A family crisis, with a high degree of uncertainty and unpredictability. Loss of the close other.
	Inner-family resources	Family draws on inner-family resources and manages together.	Family draws on inner-family resources but struggles to live through the situation together.	Family draws on inner-family resources but struggles to live through the situation together.
	Family health literacy	Family is knowledgeable about illness or health care.	–	–
Service responsiveness (interviews, APN-BQ ^a , intervention log)	Onset	Early onset (median LoS ^b to discharge = 4 days)	Early onset (median LoS ^b to discharge/death = 6 days)	Late onset (median LoS ^b to death = 1 day)
	Dose	Sufficient dose (median frequency of 2, range = 3; median dose/LoS ^b = 16 min)	Sufficient dose (median frequency of 3, range = 5; median dose/LoS ^b = 13 min)	Insufficient dose (median frequency of 1, range = 0; median dose/LoS ^b = 9.5 min)
	Quality	Fit to need, high quality (median APN-BQ ^a of 53, range of 4, 100% >50).	Fit to need, high quality (median APN-BQ ^a of 54, range of 22, 64% >50).	Lack of fit to need, moderate quality (median APN-BQ ^a of 35, range of 22, 0% >50).
Family wellbeing (interviews)	Benefit	Being recognised and cared for	Being recognised and cared for Being supported as an individual and a family	No tangible benefit

ICU = intensive care unit.

^a Advanced Practice Nurse – Care Quality Questionnaire: the score ranges from 0 to 57 (high quality).

^b LoS = length of ICU stay.

significance. Comparison between groups shows that a higher proportion of patients in the intervention group was admitted to the ICU unexpectedly, stayed longer, and died more often in the ICU, which are factors associated with symptoms of post-traumatic stress, depression, and anxiety in family members.^{2,54} In our own data, we also found a statistically significant positive relationship between the patient's death and depression levels of family members.⁵⁵ In addition, a lower proportion of families in the intervention group held previous ICU experience. As the intervention targeted those most in need for support, it is not surprising that patients' critical illness course tended to be more prolonged and precarious in the intervention group. Nonetheless, the group differences warrant attention. One explanation for these differences is that we treated length of the stay and the patient's death as outcome variables and did not include them in the statistical matching of the groups. Group differences may also have occurred owing to the fact that family members of all patients admitted to the ICU were invited to take part in the study during the pre-implementation, control phase, whereas during the intervention phase, only those with a stay of 2 days and longer who received the intervention were eligible to take part. These differences may conceal the true effect of the intervention. It can only be speculated that the intervention, while not decreasing psychological distress, might have buffered against more profound symptoms of distress. It has been previously pointed out that families of patients at high risk of dying might benefit most from support interventions.^{18,19,56} However, controlled trials are needed to further investigate the impact of such family support interventions on family members' mental health.^{57,58}

Our study found that early, proactive onset of the family support intervention (as reported in interviews) and family members' appraisal of the family interventions as fitting their needs and using a strength-oriented, participatory approach (as measured using the APN-BQ) determines the extent to which the intervention is experienced as beneficial for individual and family wellbeing. High quality of APN intervention was positively associated with satisfaction with care and negatively associated with depression, but not with anxiety or psychological distress. The positive association with post-traumatic stress is difficult to interpret. One possible explanation might be that those families who experienced highest levels of post-traumatic stress, potentially owing to the course of the critical illness itself, had experienced the quality of the intervention as positive. Findings around the frequency and dose of intervention contacts remain somewhat inconclusive, but our data indicate that at least two intervention contacts are needed in order for the intervention to start having an impact, particularly for families experiencing prolonged illness and/or the loss of their close other. This is consistent with other research that suggests that families of persons at a high risk of dying have particular support needs.^{18,59} Nonetheless, more research is needed to better understand the mechanisms through which the interventions become beneficial and effective.

4.1. Study limitations and strengths

This study is not without limitations. Although the use of qualitative and quantitative data allows for a more comprehensive understanding of the impact of the intervention from families' perspective and enabled us to shed light on the "working" of the intervention itself, the lack of randomisation and a parallel control design clearly limits the validity of our findings. The differences in patient characteristics between the two study groups warrant careful consideration when interpreting the results, particularly in relation to psychological distress. Clearly, our study is limited by lack of randomisation and the ensuing differences at baseline

between the study groups. As this study was designed to investigate the effects of an intervention that was introduced as part of a quality improvement project, no sample size calculation was performed at the outset. Data were collected only once, and questionnaires were completed by family members at varying time points during the first three months after ICU discharge. While using self-report measures, we used well-established and psychometrically sound instruments that are widely used outcome measures when investigating family support interventions in the ICU and recommended for operationalising postintensive care syndrome–family.^{3,60} The use of qualitative interviews enabled us to learn about families' experience with the intervention and their perception of benefit that complements the insight gained from the before-and-after study.

5. Conclusion

Our study suggests that family members experience a specific family nursing role that offers supportive interventions and facilitates interaction and communication with the ICU team as beneficial for their wellbeing, but only if it is initiated shortly after ICU admission, it is responsive to their unique needs and is perceived to be of high quality. Although our study demonstrated a trend towards an increased satisfaction with ICU care, in particular with decision-making and end-of-life care, it did not mitigate family members' symptoms of depression, anxiety, or stress after critical illness. In contrast, we found increased levels of psychological distress, which may be due to the more serious course of critical illness and death in the intervention group. Controlled, multicentre trials are needed to establish intervention effectiveness and to confirm that the differences in psychological distress are truly attributable to the discrepancies in patient groups. Future research should also attend to cost utility and address questions of implementation and scalability of such a guideline-based family support interventions in the ICU.

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CRedit authorship contribution statement

Rahel Naef: Conceptualisation, Methodology, Investigation, Formal analysis, Writing – original draft, Funding acquisition. **Stefanie von Felten:** Formal analysis, Writing – original draft. **Heidi Petry:** Conceptualisation, Supervision, Writing – review & editing. **Jutta Ernst:** Investigation, Project administration, Data curation, Writing – review & editing. **Paola Massarotto:** Conceptualisation, Funding acquisition, Writing – review & editing.

Conflict of interest

No conflict of interest has been declared by the authors.

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Appendix A. Supplementary data

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References

- [1] Alfheim HB, Hofso K, Samstuen MC, Toien K, Rosseland LA, Rustoen T. Post-traumatic stress symptoms in family caregivers of intensive care unit patients: a longitudinal study. *Intensive Crit Care Nurs* 2019;50:5–10.
- [2] McAdam JL, Puntillo K. Symptoms experienced by family members of patients in intensive care units. *Am J Crit Care* 2009;18(3):200–9. quiz 210.
- [3] Davidson JE, Jones C, Bienvenu OJ. Family responses to critical illness: post-intensive care syndrome – family. *Crit Care Med* 2012;40(2):618–24.
- [4] Turner-Cobb JM, Smith CP, Ramchandani P, Begen FM, Padkin A. The acute psychobiological impact of the intensive care experience on relatives. *Psychol Health Med* 2016;21(1):20–6.
- [5] Alfheim HB, Rosseland LA, Hofso K, Smastuen MC, Rustoen T. Multiple symptoms in family caregivers of intensive care unit patients. *J Pain Symptom Manag* 2018;55(2):387–94.
- [6] Minton C, Batten L, Huntington A. A multicase study of prolonged critical illness in the intensive care unit: families' experiences. *Intensive Crit Care Nurs* 2019;50:21–7.
- [7] Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. *J Gen Intern Med* 2008;23(11):1871–6.
- [8] Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005;171(9):987–94.
- [9] Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, Prigerson HG. Psychiatric illness in the next of kin of patients who die in the intensive care unit. *Crit Care Med* 2008;36(6):1722–8.
- [10] Carlson EB, Spain DA, Muhtadie L, McDade-Montez L, Macia KS. Care and caring in the intensive care unit: family members' distress and perceptions about staff skills, communication, and emotional support. *J Crit Care* 2015;30(3):557–61.
- [11] Khalaila R. Patients' family satisfaction with needs met at the medical intensive care unit. *J Adv Nurs* 2013;69(5):1172–82.
- [12] Hwang DY, Yagoda D, Perry HM, Tehan T, Guanci M, Ananian L, et al. Assessment of satisfaction with care among family members of survivors in a neuroscience intensive care unit. *J Neurosci Nurs* 2014;46(2):106–16.
- [13] Brown SM, Rozenblum D, Aboumatar H, Fagan MB, Milic M, Lee BS, et al. Defining patient and family engagement in the intensive care unit. *Am J Respir Crit Care Med* 2015;191(3):358–60.
- [14] Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross KE, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med* 2017;45(1):103–28.
- [15] Harvey MA, Davidson J. Long-term consequences of critical illness: a new opportunity for high-impact critical care nurses. *Crit Care Nurs* 2011;31(5):12–5.
- [16] Lee HW, Engelberg RA, Curtis JR, Hough CL, Kross EK. Intensive care unit length of stay is reduced by protocolized family support intervention: a systematic review and meta-analysis. *Intensive Care Med* 2019;45(8):1072–81.
- [17] Goldfarb MJ, Bibas L, Bartlett V, Jones H, Khan N. Outcomes of patient- and family-centered care interventions in the ICU: a systematic review and meta-analysis. *Crit Care Med* 2017;45(10):1751–61.
- [18] Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. *Chest* 2011;139(3):543–54.
- [19] Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, et al. Randomized trial of communication facilitators to reduce family distress and autonomy of end-of-life care. *Am J Respir Crit Care Med* 2016;193(2):154–62.
- [20] Shelton W, Moore CD, Socaris S, Gao J, Dowling J. The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit. *Crit Care Med* 2010;38(5):1315–20.
- [21] Torke AM, Wocial LD, Johns SA, Sachs GA, Callahan CM, Bosslet GT, et al. The family navigator: a pilot intervention to support intensive care unit family surrogates. *Am J Crit Care* 2016;25(6):498–507.
- [22] White DB, Cua SM, Walk R, Pollice L, Weissfeld L, Hong S, et al. Nurse-led intervention to improve surrogate decision making for patients with advanced critical illness. *Am J Crit Care* 2012;21(6):396–409.
- [23] White DB, Angus DC, Shields AM, Buddadhumaruk P, Pidro C, Paner C, et al. A randomized trial of a family-support intervention in intensive care units. *N Engl J Med* 2018;378(25):2365–75.
- [24] Moore CD, Bernardini GL, Hinerman R, Sigond K, Dowling J, Wang DB, et al. The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. *Crit Care Nurs Q* 2012;35(4):378–87.
- [25] Kleinpell R, Heyland DK, Lipman J, Sprung CL, Levy M, Mer M, et al. Patient and family engagement in the ICU: report from the task force of the world Federation of Societies of intensive and critical care medicine. *J Crit Care* 2018;48:251–6.
- [26] Penrod JD, Pronovost PJ, Livote EE, Puntillo KA, Walker AS, Wallenstein S, et al. Meeting standards of high-quality intensive care unit palliative care: clinical performance and predictors. *Crit Care Med* 2012;40(4):1105–12.
- [27] Naef R, Massarotto P, Petry H. Families' and health professionals' experience with a nurse-led family support intervention in ICU: a qualitative evaluation study. *Intensive Crit Care Nurs* 2020;61:102916. <https://doi.org/10.1016/j.iccn.2020.102916>.
- [28] Craig P, Dieppe P, McIntyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *Br Med J* 2008;337:a1655.
- [29] Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman C, et al. Process evaluation of complex interventions: Medical Research Council guidance. *BMJ* 2015;350:h1258.
- [30] Wright LM, Leahey M. *Nurses and families: a guide to family assessment and intervention*. 6th ed. Philadelphia, PA: F.A. Davis; 2013.
- [31] Doane GH, Varcoe C. *Family nursing as relational inquiry: developing health-promoting practice*. Philadelphia: Lippincott Williams & Wilkins; 2005.
- [32] Hartmann M, Bazner E, Wild B, Eisler I, Herzog W. Effects of interventions involving the family in treatment of adult patients with chronic diseases: a meta-analysis. *Psychother Psychosom* 2010;79(3):136–48.
- [33] International Family Nursing Association. *Position statement on advanced competencies for family nursing*. 2017. Available from: <https://internationalfamilynursing.org/2017/05/19/advanced-practice-competencies/>.
- [34] Harrison DA, Ferrando-Vivas P, Wright SE, McColl E, Rowan KM, Investigators FS. Psychometric assessment of the family satisfaction in the intensive care unit (fs-icu-24) questionnaire among family members of patients admitted to adult general icus in the United Kingdom. *Intensive Care Med* 2015;3(Suppl 1):A152.
- [35] Stricker KH, Niemann S, Bugnon S, Wurz J, Rohrer O, Rothen HU. Family satisfaction in the intensive care unit: cross-cultural adaptation of a questionnaire. *J Crit Care* 2007;22(3):204–11.
- [36] van den Broek JM, Brunsvelde-Reinders AH, Zedlitz AM, Girbes AR, de Jonge E, Arbous MV. Questionnaires on family satisfaction in the adult ICU: a systematic review including psychometric properties. *Crit Care Med* 2015;43(8):1731–44.
- [37] Herrmann-Lingen C, Buss U, Snaith RP. *Hospital anxiety and depression scale – Deutsche version (HADS-D)*. Manual. Bern: Hans Huber; 2011.
- [38] Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002;52(2):69–77.
- [39] Maercker A, Schützwohl M. *Erfassung von psychischen Belastungsfolgen: die Impact of Event Skala-revidierte Version*. Diagnostica 1998;44:130–41.
- [40] Thoresen S, Tamsb K, Hussain A, Heir T, Johansen VA, Bisson JI. Brief measure of posttraumatic stress reactions: impact of Event Scale-6. *Soc Psychiatr Psychiatr Epidemiol* 2010;45(3):405–12.
- [41] Petry H, Suter-Riederer S, Kerker-Specker C, Imhof L. Quality of advanced practice nurse counseling in home care settings (APN-BQ): psychometric testing of the instrument. *Pflege* 2014;27(6):393–403.
- [42] Hediger H, Mahrer Imhof R. *Qualität einer pflegegeleiteten Beratung für Angehörige älterer Menschen*. Pflegewissenschaft 2018;9(10):377–85.
- [43] Patton MQ. *Qualitative research and evaluation methods: integrating theory and practice*. 4th ed. Thousand Oaks, CA: Sage; 2014.
- [44] Sekhon JS. Multivariate and propensity score matching software with automated balance optimization: the matching package for R. *J Stat Software* 2011;42:1–52.
- [45] Greifer N. *Cobalt: covariate balance tables and plots*. R package version 3.9.0. 2019. Available from: <https://CRAN.R-project.org/package=cobalt>.
- [46] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105–12.
- [47] Erlingsson C, Brysiewicz P. *A hands-on guide to doing content analysis*. Afr J Emergency Med 2017;7(3):93–9.
- [48] Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs – principles and practices. *Health Serv Res* 2013;48(6):2134–56.
- [49] Blom H, Gustavsson C, Sundler AJ. Participation and support in intensive care as experienced by close relatives of patients – A phenomenological study. *Intensive Crit Care Nurs* 2013;29(1):1–8.
- [50] Hinkle LJ, Bosslet GT, Torke AM. Factors associated with family satisfaction with end-of-life care in the ICU: a systematic review. *Chest* 2015;147(1):82–93.
- [51] Kleinpell R, Zimmerman J, Vermoch KL, Harmon LA, Vondracek H, Hamilton R, et al. Promoting family engagement in the ICU: experience from a national collaborative of 63 ICUs. *Crit Care Med* 2019;47(12):1692–8.
- [52] Kodali S, Stamatz RA, Bengier CA, Clarke DN, Layon AJ, Darer JD. Family experience with intensive care unit care: association of self-reported family conferences and family satisfaction. *J Crit Care* 2014;29(4):641–4.
- [53] Bailey JJ, Sabbagh M, Loiselle CG, Boileau J, McVey L. Supporting families in the ICU: a descriptive correlational study of informational support, anxiety, and satisfaction with care. *Intensive Crit Care Nurs* 2010;26(2):114–22.
- [54] Haines KJ, Denehy L, Skinner EH, Warrillow S, Berney S. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. *Crit Care Med* 2015;43(5):1112–20.

- [55] Naef R., Von Felten S., Ernst J. Factors influencing post-ICU psychological distress in family members of critically ill patients: a linear mixed-effects model. *BioPsychoSocial Med.* In press.
- [56] Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007;356(5):469–78.
- [57] Seaman JB, Arnold RM, Buddadhumaruk P, Shields A-M, Gustafson RM, Felman K, et al. Protocol and fidelity monitoring plan for four supports. A multicenter trial of an intervention to support surrogate decision makers in intensive care units. *Ann Am Thorac Soc* 2018;15(9):1083–91.
- [58] Mitchell ML, Coyer F, Kean S, Murfield J, Dwan T. Patient, family-centred care interventions within the adult ICU setting: an integrative review. *Aust Crit Care* 2016;29(4):179–93.
- [59] Bloomer MJ, Morphet J, O'Connor M, Lee S, Griffiths D. Nursing care of the family before and after a death in the ICU—an exploratory pilot study. *Aust Crit Care* 2013;26(1):23–8.
- [60] Kentish-Barnes N, Lemiale V, Chaize M, Pochard F, Azoulay E. Assessing burden in families of critical care patients. *Crit Care Med* 2009;37(10 Suppl): S448–56.