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ORIGINAL



Effects of The Caregiver Pathway intervention on symptoms of post-intensive care syndrome among family caregivers to critically ill patients: long-term results from a randomized controlled trial

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Abstract

Purpose: A long-term evaluation of *The Caregiver Pathway*, a model to follow up family caregivers on Post-intensive Care Symptoms among Family (PICS-F).

Methods: A single-center non-blinded randomized controlled trial including 196 family caregivers to critically ill patients randomized to intervention ($n = 101$) or control group ($n = 95$). *The Caregiver Pathway* intervention consists of: (1) a digital assessment followed by a conversation with a nurse in the first days at the ICU, (2) a supportive card when leaving the ICU, (3) an offer to receive a phone call following patient transfer to a step-down unit, and (4) a follow-up conversation within 3 months after discharge. Outcome measures were collected at 6 and 12 months, including symptoms of post-traumatic stress disorder (PTSD), anxiety, depression, Health-related Quality of Life (HRQoL), hope, and self-efficacy.

Results: *The Caregiver Pathway* was associated with a significant effect for symptoms of PTSD after 6 months compared with controls, mean IES-R score: 25.8 [95% CI 21.9–29.7] versus 30.9 [95% CI 26.7–35.0], $p = 0.009$, and a trend toward an effect after 12 months: IES-R score: 25.0 [95% CI 21.3–28.7] versus 28.4 [95% CI 24.1–32.7], $p = 0.057$. Subgroup analyses at 12 months showed a significant intervention effect among family caregivers of patients who survived compared to controls for PTSD, IES-R score: 19.8 [95% CI 15.3–24.2] versus 29.1 [95% CI 23.5–34.6], $p = 0.001$, and anxiety, HADS-A score: 4.3 [95% CI 3.1–5.4] versus 6.8 [95% CI 5.2–8.4], $p = 0.003$.

Conclusions: *The Caregiver Pathway* has the potential to reduce the symptoms of PICS-F, especially among family caregivers whose patient has survived.

Introduction

Family caregivers of critically ill patients are in a challenging situation. Their experience can be traumatic, and they often feel scared, helpless, and vulnerable. They are therefore at risk of developing symptoms of post-traumatic stress disorder (PTSD), anxiety, depression, and prolonged grief, symptoms also known as Post-intensive Care Symptoms-Family (PICS-F) [1]. Advice

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on how to support family caregivers has been presented in the Patient and Family Centered Care guidelines [2]. Attempts to diminish the negative long-term consequences for family caregivers have included information leaflets [3], diaries [4], participation in patient care [5], communication facilitators [6, 7], condolence letters [8] and an online information tool about PTSD [9], all with varying success and impact [10, 11]. Actual models to support family caregivers of critically ill patients are therefore called for [12, 13].

The Caregiver Pathway model was developed with an emphasis on individual and structured follow-up from ICU admission until after homecoming [14]. A randomized controlled trial (RCT) evaluation of the model after 3 months (i.e., short term) showed no overall significant differences between the intervention and control groups [15]. However, family caregivers of patients who survived the ICU stay and received the intervention had significantly fewer symptoms of PTSD, anxiety, and depression, and reported higher Health-Related Quality of Life (HRQoL) for physical functioning and hope compared to controls [15].

The current study sought to evaluate 6 and 12 months (i.e., long-term) effects of *The Caregiver Pathway* intervention through a continuation of the ongoing RCT [15]. Symptoms of PTSD, anxiety, and depression (i.e., primary outcomes) and HRQoL, hope, and self-efficacy (i.e., secondary outcomes) were measured.

Methods

Study design

This study was designed as a single-center RCT and approved by the Regional Committee for Medical Research Ethics South-East Norway (199,446) and the Institutional Review Board equivalent at Oslo University Hospital (Personvernombudet 21/03594). This study was registered in ClinicalTrials.gov (NCT04839406) prior to inclusion. Results are reported in line with the CONSORT Non-pharmacological Treatments guidelines [16] (electronic supplementary material 1).

Participants and recruitment

Family caregivers were recruited from an Intensive Care Unit (ICU) at a university hospital in Norway from April 2021 to August 2023. Inclusion criteria were: The patient was expected to be on invasive ventilation for at least 48 h; the family caregivers were able to understand and speak Norwegian and were between 18 and 70 years old. Up to 3 family caregivers were eligible to participate for each patient. Bedside ICU nurses provided information about the study and asked if the family caregivers were interested in participating. The first author, an ICU nurse herself, then provided additional study information by

phone or while at the ICU to those interested. An email with a link to a secure informed consent form and baseline measures was sent to family caregivers willing to participate.

Procedures

A computerized program (R-tool: RNGCryptoServiceProvider in Microsoft.net, Block size: 10) was used by the first author for randomization. If more than one family caregiver per patient was included, these were allocated to the same group. All participants were informed they could call a study phone at any time if needed, and all family caregivers received standard care (see electronic supplementary material 2). Family caregivers in the intervention group, in addition, received *The Caregiver Pathway*, offered by one of 11 dedicated ICU nurses 1–3 days after randomization. Details about the intervention and group allocation were not known by the other health-care providers in the ICU. The 11 ICU nurses received an introduction course and participated in regular meetings for education and support. They were trained in communication skills as described in the mnemonic VALUE: Value family contribution, Acknowledge emotions, Listen, Humanity, and Eliciting of information [17].

Intervention group

The Caregiver Pathway model consists of 4 steps [14]. *Step 1*, within the first days at the hospital, the family caregivers are offered a get-to-know conversation where they can mark their needs, concerns, and preferences through a digital assessment tool. The assessment tool generates a summary to be used in a subsequent conversation with an ICU nurse. *Step 2* is a card containing information and support, handed out upon patient discharge from the ICU or death. *Step 3* is a text message offering a phone call a few days after discharge to clarify any questions, concerns, or needs for information. *Step 4* is an individual follow-up conversation offered within 3 months after the hospital stay. This conversation is semi-structured, and the family caregivers are encouraged to talk about their experiences and process situations if necessary. If considered beneficial or needed, a physician who knew the patient from the admission is invited to participate.

Through the model, the family caregivers are also informed about available resources locally or nationally if considered appropriate and beneficial. See Fig. 1 for a model overview and electronic supplementary material 2 for details.

The individual approach ensures appropriate adjustments based on the situation at hand. For example, if the patient is deemed close to death shortly after ICU



admission, Step 1 would not be offered. Also, Step 3 is not offered for bereaved caregivers.

Data collection

Demographic questions (e.g., age, education, relationship to patient, patient age, gender, and reason for ICU admission) were collected at baseline, and study variables at baseline, 3 (i.e., reported elsewhere [15]), 6, and 12 months, and submitted through a secure server (i.e., Services for Sensitive Data, University of Oslo).

Study variables

Primary outcomes

Symptoms of PTSD were assessed using the 22-item Impact of Event Scale-Revised (IES-R) [18], a 3 subscales measure of: Intrusion (8 items), Avoidance (8 items), and Hyper-arousal (6 items). Score range is 0–4 with a total score of 0–88. Scores above 24 [19] indicate clinical concern, and scores above 30 [19] or 33 [20, 21] are considered high-risk PTSD. Symptoms of PTSD were not assessed at baseline, as the participants were in the middle of the critical incident [1, 22]. Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS) [23, 24], a 14-item measure of psychological distress with 2 subscales: anxiety (7-item HADS-A) and depression (7-item HADS-D). Score range is 0–21 for each subscale. Scores below 8 are considered non-clinical, and scores above 11 are probable for anxiety or depression mood disorder [23].

Secondary outcomes

HRQoL was measured using the Short Form 12-Item Health survey RAND-12 [25]. Score range: 0–100 for all 12 items, with subscales mental (MCS 12) and physical (PCS 12). Lower scores indicate more disability. Hope was measured by the Herth Hope Index (HHI) [26], a 12-item scale constructed to evaluate hope related to cognitive and affective factors and interconnectedness with self and others. Total score range 12–48 (global score), with higher scores indicating a higher level of hope. Self-Efficacy was measured using the General Self-Efficacy Scale (GSE) [27], a 10-item scale measuring optimistic self-beliefs in coping with life demands. Summary score range 10–40 (global score). Higher scores indicate higher perceived general self-efficacy.

All scales have been used in Norwegian samples, and reliability and validity are established for all outcome measurements [28–33].

Sample size

To detect a mean difference of 6 points between groups on IES-R [4], assuming high variation in data with a standard deviation (SD) of 13 for both groups, statistical power of 0.80 and a significance level alpha of 5%, a sample size of 75 in each group was required. Due to the challenging situation for caregivers, a drop-out rate of 30% was assumed, and the final estimated number of participants required is hence 196.

Statistical analysis

All variables were analyzed for outliers and unusual observations. Baseline socio-demographic and background characteristics were presented as means and SDs for normally distributed variables and counts and percentages for categorical data. Chi-square and independent t-tests were used to assess potential crude between-group differences for demographics and background variables at baseline.

To explore potential between-group differences of outcome measures, data were analyzed using generalized linear models (GLM) for repeated measures with time (measurement points), group (intervention vs. comparison group), and interaction term (group*time) as covariates.

More family caregivers were living together with the patient in the control group compared to the intervention group, which is a risk factor for PICS-F [34, 35]. The variable was therefore included in the analysis as a possible confounder. As patient survival during the ICU stay can impact outcomes [15, 35], this variable was also included as a possible confounder in the model. Possible dependencies within individuals were controlled for using an unstructured covariance matrix. The GLM analysis was adjusted for clusters as 1–3 family caregivers could belong to the same patient. All measured time points for outcome variables were considered. All analyses were conducted according to intention to treat principles, independent of how many steps of the intervention participants received. Between-group differences for symptoms of PTSD (IES-R) were calculated at 6 and 12 months. For outcomes with baseline measures, between-group differences are reported as the intervention group change from baseline to 6 and 12 months, minus the control group change from baseline.

To explore how patient survival during the ICU stay impacted outcomes at 6 and 12 months, GLM models described above were fitted separately for family caregivers of patients who survived or died. The customary significance level alpha of 0.05 was used for all statistical analyses, and $p < 0.05$ was considered statistically significant. Analyses were conducted using SPSS (version 29 (SPSS Inc.)) and STATA/SE (version 18).

Results

See Fig. 2 for participant inclusion, follow-up, and analysis. The participants were primarily female (127/196, 65%) and mean 47 (range 18–70) years old. See Table 1 for demographics of family caregivers and patients. Drop-out analyses revealed no significant differences in demographic characteristics between completers and non-completers at 6 and 12 months. ICU nurses spent, on average, 75 min plus 15 min administrative time

carrying out *The Caregiver Pathway* per family caregiver. In addition, 7 family caregivers received a conversation with a physician.

Between-group differences

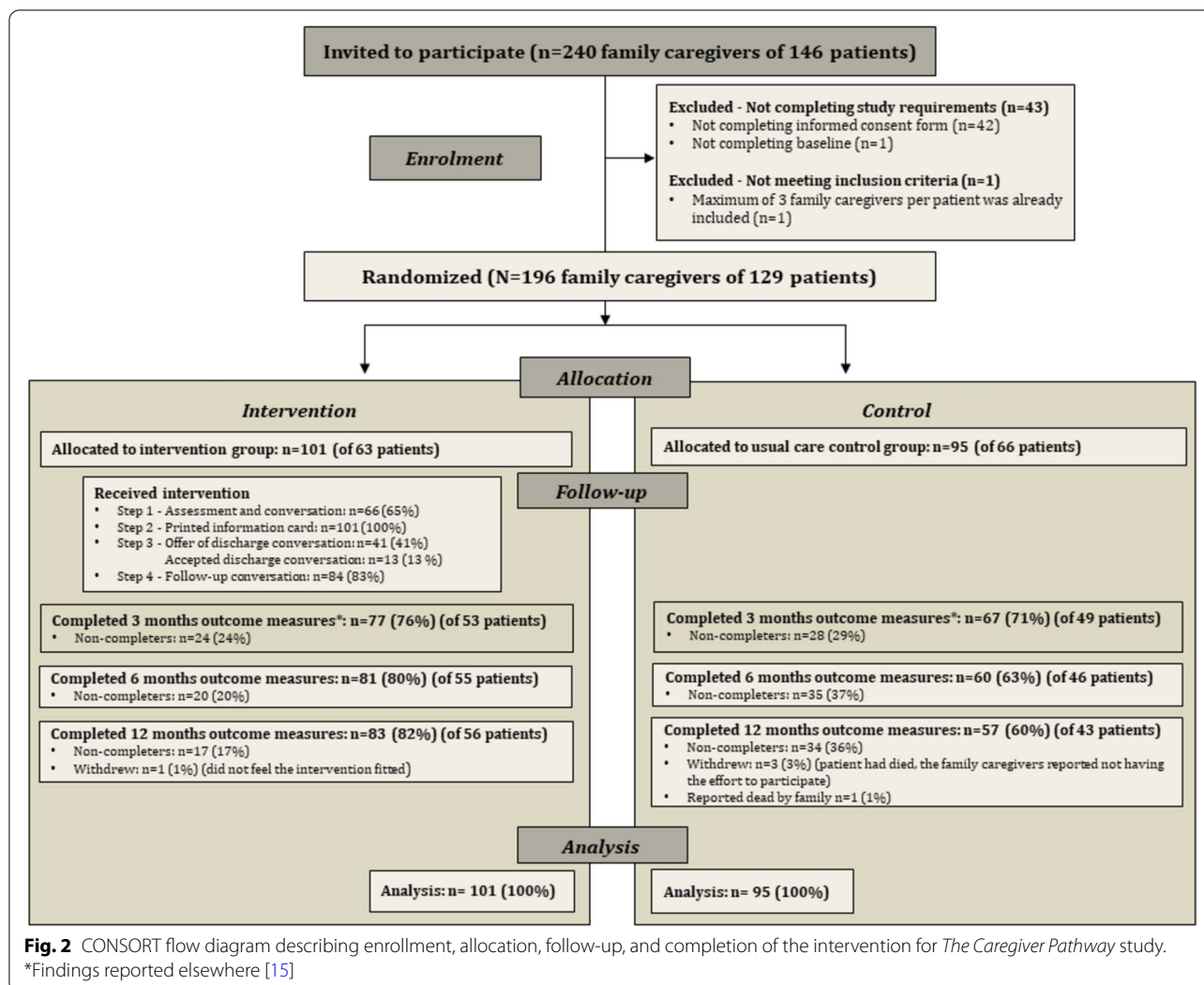
Both groups had a decrease in scores related to PTSD, anxiety, and depression during the study. See Table 2 for details. Including all time points in the linear mixed model, a statistically significant between-group difference at 6 months in favor of the intervention group was identified for the primary outcome of symptoms of PTSD, IES-R mean difference (MD) – 6.8, (intervention group 25.8 [95% CI 21.9–29.7], control group 30.9 [95% CI 26.7–35.0], $p = 0.009$). See Table 2 for details. Mean IES-R total score remained low for the intervention group from 6 to 12 months. At 12 months, there was a trend toward statistical significance between-group differences for symptoms of PTSD in favor of the intervention group, IES-R MD – 5.0, intervention group 25.0 [95% CI 21.3–28.7] versus control group 28.4 [95% CI 24.1–32.7], $p = 0.057$. No significant between-group differences were found for anxiety, depression, HRQoL, or hope, though a trend toward effect for self-efficacy, GSE MD 1.2 [95% CI – 0.0; 2.4], $p = 0.056$ was detected.

Subgroup analyses

Subgroup analyses comparing family caregivers of patients who survived the stay at the ICU revealed significant between-group differences in favor of the intervention group. For symptoms of PTSD at 6 and 12 months, intervention group caregivers of patients who survived scored on average 10 points lower compared to the control group (IES-R MD 6 months – 10.3 [95% CI – 16.3; – 4.3], $p = 0.001$; IES-R MD 12 months – 9.9 [95% CI – 15.8; – 4.0], $p = 0.001$). See Table 3 for details. Between-group differences from baseline to 6 and 12 months were also statistically significant for symptoms of anxiety at 6 and 12 months and for depression at 6 months (Table 3). Regarding secondary outcomes, this study revealed significant between-group differences with increased levels of hope and HRQoL, sub-score physical functioning after 6 months, and increased levels of mental functioning and hope after 12 months for intervention group caregivers of patients who survived (Table 4, electronic supplementary material 3). No such effects were detected for bereaved family caregivers (Table 3 and Table 4, electronic supplementary material 3).

Discussion

This study shows how *The Caregiver Pathway* can be associated with long-term effects in terms of reduced symptoms of PTSD for family caregivers of critically ill patients over the course of 12 months. No significant



between-group differences were found for anxiety, depression, HRQoL, or hope, but a trend was detected toward significance for self-efficacy.

For family caregivers whose patients survived, the significant decrease in symptoms of PTSD and anxiety (i.e., 6 and 12 months) and in symptoms of depression (i.e., 6 months), along with an increase in HRQoL, sub-score physical functioning (i.e., 6 months), mental functioning, and hope (i.e., 12 months) underlines the potential effect and importance of *The Caregiver Pathway* for this group of caregivers. The findings also reveal a sustainability of the previously published 3-month results [15].

The reduction of PICS-F symptoms seen may have a vital impact for family caregivers as well as their patients as the patient is often in need of support from the family caregivers in the process of recovery [14, 36, 37]. While a number of studies have described attempts to reduce the symptoms of PICS-F, few have proven successful. For

example, use of diaries has shown some indications of reducing symptoms of PTSD [4], whereas a family participation program [5], nurse facilitators [7] or an online information tool about PTSD has not been able to establish effect on psychosocial outcomes [9].

The strength of *The Caregiver Pathway* may be in the emphasis on individual and structured follow-up from admission to after discharge. The model starts by paying attention to the family caregivers by listening, showing empathy, acknowledging emotions, and enabling them to articulate their concerns and process situations if needed (Step 1). This is an acknowledged approach [38–41], with talking about frightening situations potentially reducing anxiety and diminishing fear, which in turn might reduce symptoms of PTSD [22]. The model continues with including a supportive card (Step 2) and offering a discharge conversation (Step 3), both underlining the importance of caring. In the follow-up conversation (Step

Table 1 Demographics of family caregivers (N= 196) and patients (N= 129)

Characteristics	Total (N= 196)	Intervention group (n= 101)	Control group (n= 95)	p value
<i>Family caregivers</i>				
Age, mean (SD)	46.8 (13.5)	46.7 (13.3)	46.9 (13.8)	0.942
Gender, n (%)				0.444
Female	127 (64.8)	68 (67.3)	59 (62.1)	
Male	69 (32.5)	33 (32.7)	36 (37.9)	
Education, n (%)				0.729
Elementary/high school	73 (37.2)	37 (36.6)	36 (37.9)	
University/college ≤ 4 years	67 (34.2)	37 (36.6)	30 (31.6)	
University/college > 4 years	56 (28.6)	27 (26.7)	29 (30.5)	
Household annual income, (NOK ^a), n (%)				0.419
< 399.000	17 (8.6)	12 (11.9)	5 (5.3)	
400.000–599.000	27 (13.8)	14 (13.9)	13 (13.7)	
600.000–799.000	32 (16.3)	13 (12.9)	19 (20.0)	
800.000–1.000.000	29 (14.8)	13 (12.9)	16 (16.8)	
> 1000.000	67 (34.2)	35 (34.7)	32 (33.7)	
Do not wish to answer	24 (12.2)	14 (13.9)	10 (10.5)	
Employment status, n (% ^b)				0.802
Full-time work/student	123 (62.8)	66 (65.3)	57 (60.0)	
Part-time work	21 (10.7)	9 (8.9)	12 (12.6)	
Disability, retired, rehab, other	37 (18.9)	19 (18.8)	18 (18.9)	
Sick leave	15 (7.7)	7 (6.9)	8 (8.4)	
Relation to the patient, n (%)				0.377
Partner, spouse	45 (23.0)	20 (19.8)	25 (26.3)	
Parent	32 (16.3)	14 (13.9)	18 (18.9)	
Child	79 (40.3)	43 (42.6)	36 (37.9)	
Sibling	26 (13.3)	14 (13.9)	12 (12.6)	
Other	14 (7.1)	10 (9.9)	4 (4.2)	
Living situation, n (%)				
Living alone	28 (20.4)	16 (20.0)	12 (21.1)	0.880
Living with the patient	57 (29.1)	20 (19.8)	37 (38.9)	0.003
<i>Patient-related details</i>				
Patient's age, n (%)				0.163
16–30 years	28 (14.3)	10 (9.9)	18 (18.9)	
30–60 years	70 (35.7)	36 (35.6)	34 (35.8)	
60 years and older	98 (50.0)	55 (54.5)	43 (45.3)	
Patient's gender, n (%)				0.609
Female	57 (29.1)	31 (30.7)	26 (27.4)	
Male	139 (70.9)	70 (69.3)	69 (72.6)	
Patient's diagnosis, n (% ^c)				
Autoimmune disease	18 (9.2)	10 (9.9)	8 (8.4)	0.720
Sepsis	25 (12.8)	11 (10.9)	14 (14.7)	0.420
COVID-19	29 (14.8)	12 (11.9)	17 (17.9)	0.236
Drowning, accident, unknown	10 (5.1)	6 (5.9)	4 (4.2)	0.749 ^d
Cerebral injury/attack	17 (8.7)	6 (5.9)	11 (11.6)	0.161
Heart failure/attack	40 (20.4)	28 (27.7)	12 (12.6)	0.009
Liver failure	14 (7.1)	4 (4.0)	10 (10.5)	0.097 ^d
Respiratory failure	45 (23.0)	20 (19.8)	25 (26.3)	0.279
Neurological disease	9 (4.6)	3 (3.0)	6 (6.3)	0.320 ^d
Renal failure	25 (12.8)	11 (10.9)	14 (14.7)	0.420

Table 1 (continued)

Characteristics	Total (N = 196)	Intervention group (n = 101)	Control group (n = 95)	p value
Acute poisoning	8 (4.1)	2 (2.0)	6 (6.3)	0.160 ^d
Psychiatric suffering	5 (2.6)	2 (2.0)	3 (3.2)	0.675 ^d
Suicidal attempt	19 (9.7)	11 (10.9)	8 (8.4)	0.559
Do not wish to answer	1 (0.5)	1 (1.0)	0 (0.0)	1.00 ^d

^a NOK = 10 NOK is approximately 0.9 USD; approximately 0.8 Euro (spring 2025)

^b Percentages not 100 due to rounding

^c Patients could have several diagnoses

^d Fisher's exact test

4), the family caregivers can receive support in processing the experiences from the ICU if needed. Processing, along with exposure to the circumstances associated with the traumatic event, could be therapeutic in terms of symptoms of PTSD [42].

The high symptoms of PTSD, anxiety, and depression for the bereaved family caregivers in the intervention group underline the need for palliative care and follow-up. The European Society of Intensive Care Medicine has outlined guidelines for care and future research concerning palliative care at the ICU [43]. End-of-life care has, for example, shown to be improved by communication facilitators [6] conversations following a template, and including a bereavement leaflet [17], and a three-step support strategy with special awareness of the family caregiver's needs and reactions [44]. Further support at the ICU and a broader collaboration with external agencies and organizations, for example, through religious support, could also be beneficial [45].

The Caregiver Pathway model was led by ICU nurses during this RCT. More than 40% of ICU professionals report high levels of burnout [46], and recognized programs supporting healthcare providers are unfortunately currently lacking [43]. Adding new tasks to their workload must therefore be thoroughly deliberated. However, follow-up of patients and family caregivers has also been found to be rewarding for the ICU staff [47]. Considering the potential impact of caregiver support programs such as *The Caregiver Pathway*, it does however appear crucial for hospital management to, while encouraging the ICU nurses to manage family caregiver follow-up, also provide the necessary support, time, and resources for such support [48, 49]. Short- [15] and long-term findings from this RCT indicating reduction in symptoms of PTSD underline the importance of such care. *The Caregiver Pathway* has been recognized as showing distinct promise [50] and is currently being implemented into regular care at the hospital ICU of project initiation.

Limitations

This study has some limitations. First, ICU nurses only forwarded information about those family caregivers interested in the intervention, resulting in somewhat limited information about the potential eligibility of family caregivers and reasons for not becoming involved. Second, while blinding was attempted, and *The Caregiver Pathway* content was kept confidential among the nurses delivering the intervention, other ICU staff could have become aware of group allocation based on their presence at the ICU. Caregivers included may also have realized the difference between intervention and standard care follow-up. Third, differences in standard care could have been present, potentially impacting group differences, as standard care for family caregivers in the ICU might vary depending on the physicians and ICU nurses present. The nurses delivering the intervention also provided standard care to participants in the control group, which could have impacted the delivery of standard care. Fourth, the lower participation at 12 months in the control group (60%) compared to the intervention group (82%) may also have impacted the outcomes, and findings should be interpreted with caution due to the limited number of bereaved family caregivers completing final measures in the control group. Similarly, while drop-out analyses revealed no significant differences in demographic characteristics between completers and non-completers, most bereaved caregivers in the intervention group managed to complete the study, while several bereaved participants in the control group did not. This difference in group participation may also have impacted the results and potentially the intervention effect. Finally, further process evaluation of *The Caregiver Pathway*, including experiences from ICU nurses and family caregivers to better understand the feasibility and acceptability of the intervention, could provide vital information for future implementations.

Table 2 Effects of The Caregiver Pathway at 6 and 12 months

	Intervention group ^a (n = 101)			Control group ^a (n = 95)			Between-group differences ^b		
	n	M	[95% CI]	n	M	(95% CI)	MD	(95% CI)	p value
PTSD (IESR) total									
6 months	81	25.8	[21.9; 29.7]	60	30.9	[26.7; 35.0]	- 6.8	[- 11.8; - 1.7]	0.009
12 months	83	25.0	[21.3; 28.7]	57	28.4	[24.1; 32.7]	- 5.0	[- 10.2; 0.2]	0.057
IESR intrusion									
6 months	81	10.5	[9.0; 12.1]	60	12.8	[11.0; 14.6]	- 2.5	[- 4.7; - 0.4]	0.020
12 months	83	10.4	[8.8; 12.0]	57	11.8	[10.0; 13.6]	- 1.9	[- 4.1; 0.2]	0.077
IESR avoidance									
6 months	81	9.2	[7.7; 10.7]	60	11.0	[9.5; 12.5]	- 2.7	[- 4.6; - 0.9]	0.004
12 months	83	8.9	[7.6; 10.3]	57	10.2	[8.7; 11.7]	- 1.8	[- 3.7; 0.0]	0.055
IESR hyper-arousal									
6 months	81	6.0	[4.8; 7.2]	60	7.1	[5.7; 8.5]	- 1.2	[- 2.9; 0.4]	0.142
12 months	83	5.6	[4.5; 6.7]	57	6.4	[5.0; 7.8]	- 1.0	[- 2.6; 0.6]	0.235
Anxiety (HADS-A)									
Baseline	101	9.9	[8.9; 10.8]	95	10.5	[9.5; 11.5]			
6 months	81	5.3	[4.3; 6.2]	60	7.1	[5.9; 8.3]	- 1.07	[- 2.4; 0.3]	0.125
12 months	83	5.2	[4.3; 6.2]	57	6.7	[5.4; 8.0]	- 0.80	[- 2.3; 0.7]	0.286
Depression (HADS-D)									
Baseline	101	7.2	[6.3; 8.0]	95	7.9	[6.9; 8.8]			
6 months	81	3.5	[2.7; 4.2]	60	4.1	[3.1; 5.0]	0.3	[- 1.0; 1.6]	0.652
12 months	83	3.2	[2.4; 3.9]	57	3.9	[3.0; 4.7]	0.0	[- 1.3; 1.4]	0.950
HRQoL (RAND-12)									
Physical functioning									
Baseline	101	75.0	[70.6; 79.3]	95	71.5	[66.5; 76.6]			
6 months	81	75.6	[70.2; 81.0]	60	69.9	[62.7; 77.0]	2.5	[- 4.4; 9.5]	0.473
12 months	83	78.3	[73.6; 83.0]	57	73.1	[65.8; 80.5]	2.5	[- 4.5; 9.5]	0.484
Mental functioning									
Baseline	101	54.6	[50.0; 59.1]	95	51.5	[46.0; 57.0]			
6 months	81	64.4	[58.9; 69.9]	60	60.2	[53.7; 66.6]	3.5	[- 5.4; 12.4]	0.447
12 months	83	68.6	[63.4; 73.7]	57	62.4	[55.8; 68.9]	4.9	[- 3.5; 13.2]	0.252
Hope (HHI)									
Baseline	101	38.0	[37.0; 39.0]	95	36.5	[35.5; 37.6]			
6 months	81	38.0	[36.7; 39.2]	60	36.4	[35.1; 37.7]	0.9	[- 0.5; 2.3]	0.218
12 months	83	38.3	[37.0; 39.5]	57	37.4	[36.0; 38.9]	- 0.4	[- 1.9; 1.1]	0.618
Self-efficacy (GSE)									
Baseline	101	31.3	[30.4; 32.2]	95	30.5	[29.5; 31.4]			
6 months	81	31.8	[30.8; 32.9]	60	30.6	[29.2; 32.0]	1.2	[- 0.1; 2.4]	0.069
12 months	83	32.3	[31.2; 33.4]	57	30.7	[29.6; 31.8]	1.2	[- 0.0; 2.4]	0.056

IESR Impact of Event Scale-Revised, HADS-A Hospital Anxiety and Depression Scale-Anxiety subscale, HADS-D Hospital Anxiety and Depression Scale-Depression subscale, HRQoL Health-Related Quality of Life measured by RAND-12: a 12-Item scale, HHI Hertz Hope Index, GSE General Self-Efficacy Scale, M mean, CI confidence interval, MD mean difference

^a Observed values

^b Between-group differences estimated from generalized mixed models, controlled for baseline values (exception: IESR), living together with the patient (yes/no), patient survival (yes/no) during the ICU stay and adjusted for clusters (i.e., family unit)

Table 3 Effects of The Caregiver Pathway on family caregivers based on patient survival

Family caregivers to patients surviving the ICU stay									
	Intervention group ^a			Control group ^a			Between-group differences ^b		
	<i>n</i>	<i>M</i>	[95% CI]	<i>n</i>	<i>M</i>	[95% CI]	MD	[95% CI]	<i>p</i> value
PTSD (IESR) total									
6 months	55	19.8	[15.0; 24.5]	47	28.8	[23.1; 34.4]	- 10.3	[- 16.3; - 4.3]	0.001
12 months	57	19.8	[15.3; 24.2]	45	29.1	[23.5; 34.6]	- 9.9	[- 15.8; - 4.0]	0.001
IESR intrusion									
6 months	55	8.0	[6.2; 9.9]	47	12.1	[9.7; 14.6]	- 4.0	[- 6.5; - 1.4]	0.002
12 months	57	8.1	[6.3; 9.9]	45	12.2	[10.0; 14.3]	- 4.0	[- 6.4; - 1.6]	0.001
IESR avoidance									
6 months	55	6.8	[5.2; 8.4]	47	9.8	[7.9; 11.6]	- 3.6	[- 5.7; - 1.4]	0.001
12 months	57	7.3	[5.6; 8.9]	45	10.1	[8.2; 12.1]	- 3.0	[- 5.2; - 0.8]	0.007
IESR hyper-arousal									
6 months	55	4.9	[3.4; 6.4]	47	6.9	[5.0; 8.8]	- 2.5	[- 4.4; - 0.6]	0.012
12 months	57	4.4	[3.0; 5.7]	45	6.8	[4.9; 8.6]	- 2.6	[- 4.4; - 0.7]	0.007
Anxiety (HADS-A)									
Baseline	69	9.8	[8.2; 11.4]	64	10.4	[8.8; 12.0]			
6 months	55	4.2	[3.1; 5.4]	47	6.4	[4.8; 8.0]	- 2.2	[- 3.7; - 0.6]	0.006
12 months	57	4.3	[3.1; 5.4]	45	6.8	[5.2; 8.4]	- 2.5	[- 4.1; - 0.8]	0.003
Depression (HADS-D)									
Baseline	69	7.0	[5.6; 8.3]	64	7.8	[6.2; 9.4]			
6 months	55	2.7	[1.8; 3.7]	47	3.5	[2.4; 4.5]	- 1.5	[- 2.7; - 0.2]	0.021
12 months	57	2.1	[1.3; 3.0]	45	4.0	[2.8; 5.1]	- 1.0	[- 2.1; 0.1]	0.087
Family caregivers to patients who died during the ICU stay									
	Intervention group ^a			Control group ^a			Between-group differences ^b		
	<i>n</i>	<i>M</i>	[95% CI]	<i>n</i>	<i>M</i>	[95% CI]	MD	[95% CI]	<i>p</i> value
PTSD (IESR) total									
6 months	24	34.6	[26.6; 42.6]	11	32.1	[25.4; 38.8]	4.6	[- 3.0; 12.2]	0.240
12 months	25	33.7	[26.3; 41.1]	12	26.0	[16.3; 35.5]	11.3	[2.4; 20.2]	0.013
IESR intrusion									
6 months	24	14.0	[11.1; 16.9]	11	13.4	[10.7; 16.1]	1.9	[- 1.2; 5.0]	0.225
12 months	25	13.7	[11.1; 16.4]	12	10.7	[6.7; 14.7]	4.9	[1.2; 8.5]	0.009
IESR avoidance									
6 months	24	13.0	[9.5; 16.4]	11	13.0	[9.6; 16.4]	- 0.7	[- 4.2; 2.9]	0.707
12 months	25	12.3	[9.0; 15.6]	12	10.4	[7.1; 13.7]	2.0	[- 1.6; 5.6]	0.273
IESR hyper-arousal									
6 months	24	7.7	[5.1; 10.2]	11	5.7	[3.4; 8.0]	3.0	[0.5; 5.4]	0.020
12 months	25	7.7	[5.6; 9.8]	12	4.8	[1.7; 7.9]	4.1	[1.3; 6.8]	0.004
Anxiety (HADS-A)									
Baseline	26	10.2	[8.4; 12.1]	15	10.1	[7.2; 13.0]			
6 months	24	6.0	[4.1; 7.9]	11	6.7	[4.5; 8.9]	2.3	[- 0.4; 5.0]	0.090
12 months	25	6.8	[4.6; 9.0]	12	5.8	[3.0; 8.6]	0.3	[- 1.8; 2.5]	0.757
Depression (HADS-D)									
Baseline	26	7.9	[5.8; 9.9]	15	7.0	[5.4; 8.6]			
6 months	24	4.6	[2.7; 6.5]	11	4.0	[1.8; 6.2]	2.8	[0.7; 4.8]	0.008
12 months	25	4.9	[3.3; 6.5]	12	3.2	[1.2; 5.2]	1.2	[- 1.0; 3.4]	0.292

IESR Impact of Event Scale-Revised, HADS-A Hospital Anxiety and Depression Scale-Anxiety subscale, HADS-D Hospital Anxiety and Depression Scale-Depression subscale, *M* mean, *CI* confidence interval, *MD* mean difference

^a Observed values

^b Between-group differences estimated from generalized mixed models, controlled for baseline values (exception: IESR), and living together with the patient (yes/no)

Future directions

The most vulnerable family caregivers with complex issues might require even more intensive and prolonged types of support than the support given through *The Caregiver Pathway* [15]. Future studies and clinical care of family caregivers should take this aspect into consideration, perhaps particularly for family caregivers whose patients pass away [43]. *The Caregiver Pathway* also facilitates expansion of care when deemed necessary, for example through involvement from psychology/psychiatry, a notion that should be taken into account by future research. The emotional strain and resources demanded for ICU nurses should also be further explored [43, 48], as should the potential impact of such caregiver models on the participating ICU nurses themselves.

Conclusion

The Caregiver Pathway can contribute to reduced symptoms of PICS-F among family caregivers of critically ill patients, especially among family caregivers of patients who survive the ICU stay.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1007/s00134-025-08139-x>.

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Author contributions

SW, LSN, EH, ME, MH, and EB conceived the study and wrote the trial protocol. EB was awarded project funding to support the trial. The family caregivers were recruited by SW. Data analyses were performed by SW, MH, and EB. The first draft of the manuscript was written by SW. All authors revised and gave critical important contributions to the manuscript and approved the final manuscript.

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Data availability

Data sets from this study are not available for public sharing through public archives or repositories due to the nature of participant sensitive information. Deidentified data from this study will however be made available in accordance with institutional standards through contacting Elin Børøsund, eborosun@ous-hf.no

Declarations

Conflicts of interest

The authors have no potential conflicts of interest to disclose.

Ethical approval

This study was approved by the Regional Committee for Medical Research Ethics South-East Norway (199446) and the Institutional review board equivalent at Oslo University Hospital (Personvernombudet 21/03594).

Registration

The study was registered in Clinicaltrials.gov (NTC04839406) prior to the inclusion of participants.

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