# Scoping literature review on psychosocial factors associated with the psychological outcomes in family caregivers of patients hospitalized in the intensive care unit

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Master thesis

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### **Abstract**

**Background:** The aim of this scoping review was to explore factors which protect family members from developing PICS-F and risk factors involving the patients and the ICU context which contribute to the development of PICS-F **Method**: A scoping review was performed. Relevant studies were retrieved from Scopus, PsychINFO and PubMed. In total, 898 titles and abstracts were reviewed from which 17 were included to the current review. Results: The review revealed that the most studied preventive factors were the relative-related. The found protective factors for PICS-F were resilience, higher education, satisfaction with the ICU care and participating in the care for the patient as well as building skills (Coping, mindfulness and self-efficacy). Furthermore, the retrieved patient-related factors revealed that the feeling of uncertainty and helplessness of family members about the state of the patient (e.g., if he will survive, is he in pain, etc.) contributed to the development of PICS-F. The ICU related risk factors were namely, lack of information, ICU environment and rules, privacy issues, which can cause distress in family members and foster the development of PICS-F. Additionally, coping strategies negatively associated with PICS-F are "focus on the positive" (humour, acceptance and positive re-evaluation), large social network, self-distraction, optimism, spirituality, religion, social support, coping self-efficacy and planning. Coping strategies used by people who have experienced PTG are religion, spirituality, focus on the problem, acceptance, hope and positive reframing. Conclusions: The factors and coping strategies found by this scoping review could be used to make interventions which deal with the acute stress experienced by family members in the initial admission of the patient and build skills which can make help them to cope with the situation. The results of this review showed that there is a need for further research of patient- and ICU-related risk factors. Future research should focus on exploring new risk and protective factors instead of confirming already known factors. Furthermore, future research should explore more coping strategies with an experimental design and their impact on family members in the ICU. Additionally, PTG in the context of family members requires more longitudinal research.

Keywords: review, PICS-F, PTG, coping strategies

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### Introduction

Every year, many people get admitted to the intensive care unit (ICU). In the Netherlands in 2019, 73.979 people got admitted to the ICU with a duration from 1 to 4.6 days for patients who survive and 1.7 to 2.9 days for patients who do not survive. As a result of these unforeseen event, some of their relatives experience considerable psychological burden (Kentish-Barnes et al., 2009). This burden consists of adverse psychological outcomes such as posttraumatic stress, depression, anxiety and complicated grief. A stakeholder conference was held to improve such long-term outcomes by discussing different strategies to reduce the negative experience of family members in the ICU. This cluster of psychological consequences for family members was named post-intensive care syndrome-family (PICS-F; Needham et al., 2012). The adverse psychological outcomes for family members could be present for one to more than four years or longer (Rodríguez et al., 2005; Needham et al., 2012; Davidson et al., 2012). For example, one year after the patient discharge, between 15 % and 24 %, 22.8 % and 44 % and 31.7 % to 80 % of the family members had anxiety, depression and PTSD respectively (van Beusekom et al., 2016). In contrast, the one-year prevalence for the general population is 2.9% for generalized anxiety disorder, 7% for major depression disorder and 3.5% for PTSD (American Psychiatric Association, 2013, pp. 165-276). These psychological impairments may be even greater in family members than in the (former) ICU patients themselves (Young et al., 2005; Fumis et al., 2015). Previous reviews exploring these problems have identified patient, relative and ICU related risk factors which contribute to PICS-F (Gay et al., 2009; Serrano et al., 2019). Yet there are no reviews which combines these three types of factors together.

In the last decade, there was a gradual paradigm shift from the negative consequences to positive consequences after a trauma (Teixeira & Pereira, 2013). Previous literature reviews focus on modifiable risk factors which could potentially reduce PICS-F symptoms when efforts are put into changing them. By way of illustration, Zante and colleagues (2020) showed in their

literature review different interventions such as providing information through brochures, family conferences, educational programmes, family-authored diaries and so forth, which are ineffective or have a small effect on PICS-F symptoms. With the current paradigm shift, PICS-F could be approached by focusing on modifiable factors which have a protective function and connect them to modifiable risk factors which could be influenced by changing these protective factors. That could be done not only to reduce the currently experienced PICS-F symptoms by family members but potentially prevent them from experiencing them for a longer time and to a greater extent. Protective factors are defined as a psychological characteristic that can lower the likelihood of PICS-F symptoms to have severe and longer effects or reduce the influence of the risk factors on the adverse outcomes. Additionally, these factors are modifiable because measures could be taken to change them in comparison to non-modifiable factors. As an outcome, most reviews focus on the characteristics and factors of family members and no other review tries to combine factors involved with the ICU, the patient and the family members in order to understand PICS-F better. Particularly, it is the key to understanding which interpersonal factors protect family members from PICS-F and which patient- and ICU-related factors can contribute to the development of symptoms. The focus of this review is to investigate modifiable protective factors which not only reduce the psychological burden of family members but reduce the probability of risk factors involving the patient and the ICU to have an impact on the severity and longevity of PICS-F symptoms.

# **PICS-F Symptoms**

The experience of family members who see their loved ones in the ICU is traumatic. One of the definitions of trauma is witnessing or learning about a traumatic event (e.g., actual or threatened death, or a serious injury) in a family member or a close friend (American Psychiatric Association, 2013). This traumatic event could cause symptoms of depression,

anxiety and PTSD in family members (American Psychiatric Association, 2013; Harding et al., 2014).

Depression, anxiety and PTSD are interconnected and there are earlier signs which could help with identifying family members who are more prone to them. For example, history of mental health issues or sleep disturbance could be a precursor of developing PICS-F symptoms (Kao et al., 2016; Serrano et al., 2019). Furthermore, in the study of Paparrigopoulos and colleagues (2006) 81% of family members were at risk for PTSD. In their study, they measured PICS-F symptoms one week after admission and two days before the discharge of the patient. They found that trait anxiety was a significant predictor for the development of PTSD and the severity of depression at both time points. Next to that, state anxiety was a significant predictor of PTSD at the second time point. These results showcased the intertwined connection between PICS-F symptoms. The ability of anxiety to predict PTSD could be explained by the overlap of the symptomology with PTSD (American Psychiatric Association, 2013; Koopman et al., 1995). An earlier indicator of PTSD is Acute Stress Disorder (ASD) which is a nest of symptoms that ensued from a traumatic event that could occur immediately or within four weeks after the event (Koopman et al., 1995). The ASD is characterized by symptoms such as poor concentration, difficulty with sleeping and other anxiety-related symptoms; avoidance of thoughts and feelings; flashbacks of their experiences and so forth. The ASD signs can be used as predictive factors which help with the earlier identification of family members who are prone to certain symptoms and then can be helped by modifying protective factors which are negatively associated with the same symptoms.

# **Posttraumatic Growth**

With respect to the paradigm shift that has occurred, due to the negative consequences of a traumatic event, people could experience positive psychological change. This positive change is defined as *posttraumatic growth (PTG)* which is the result of a struggle with a highly

challenging life situation (e.g., traumatic event; Tedeschi & Calhoun, 1996, 2004). The manifestation of this change is the changed world view of the person. More specifically: a greater appreciation of life, change of priorities, more interpersonal relationships, richer spiritual life and an increased sense of personal strength (Tedeschi & Calhoun, 2004). The growth following the traumatic event is related to factors such as optimism, self-worth, the severity of the trauma, satisfaction with the social support and coping strategies (Linley & Joseph, 2004). It was shown that PTG could reduce PICS-F symptoms and PTSD symptoms are predisposing factors for PTG, meaning people who experience early PTSD symptoms could benefit from PTG interventions (Dekel et al., 2011; Wu et al., 2019). That was further supported by a meta-analysis that finds a positive association between PTSD and PTG (Linley & Joseph, 2004). There are no reviews summarizing coping strategies which are used by family members of former ICU patients who had PTG.

# **Coping Strategies**

Furthermore, based on the model of Lazarus and Folkman (1974) which posits that the experience of stress is based on primary appraisal (i.e. appraisal of the significance of the situation) and secondary appraisal (i.e. the abilities of the person to meet the challenges of the situation). They defined coping as the cognitive and behavioural efforts to deal with the challenges of the situation. Coping is separated into three categories: problem-based, emotion-based and avoidance-based strategies. it was shown that different coping styles and strategies reduce PICS-F symptoms, except avoidant-coping (Chan et al., 2007; Nadig et al., 2016). As well, the model of Tedeschi and Calhoun (1996, 2004) indicates that different problem- and focus-based coping strategies contribute to PTG which was later confirmed (Danhauer et al., 2013; Senol-Durak & Ayvasik, 2010; Teixeira & Pereira, 2013). There are no reviews which connect used coping strategies of family members who had PTG with the coping strategies used by them while in the ICU or after discharge.

### Aim

The goal of this literature review is to identify factors that protects family members from developing PICS-F and risk factors involving the patients and the ICU context which contribute to the development of PICS-F. Furthermore, the current review examines which coping strategies are used by family members who had experienced PTG and which coping strategies are used by them during their stay in the ICU.

This review will try to answer the following research questions:

- 1. Which factors (relative-related, patient-related, or ICU-related) are described in literature as being a protective or risk factor for the development of PICS-F symptoms?
- 2. Which coping strategies are associated to PICS-F symptoms?
- 3. Which coping strategies are associated to PTG in family members of former patients?

### **Methods**

To identify the key factors of PICS-F, a scoping review was conducted. This type of a review looks into a large amount of literature to identify key points around a newer concept to answer questions which could not be answered by systematic reviews. Essentially, it retrieves and uses large amount of literature to answer the research question (Munn et al., 2018).

# **Search Strategy**

Three databases (PsychInfo, PubMed and Scopus) were used to identify relevant research papers related to the psychological outcomes of family members of former ICU patients through March and April 2021. The search range was set for the past ten years. The search strategy used title, abstract and keyword searches. Three separate search strings were created

The following combination of search terms was used based on the research questions of this review, keywords and terms from previous studies and the search string of van Beusekom and collegues (2016):

("ICU" OR "intensive care unit" OR "intensive care" OR "critical care unit" OR "critical care" OR "critical care" OR "critical care" OR "post-traumatic stress disorder" OR "post-traumatic stress" OR "PTSD" OR acute stress") OR ("post-intensive care syndrome family" OR "PICS-F")] AND [("coping styles" OR "coping strategies" OR "coping mechanisms") OR ("PTG" OR "posttraumatic growth")] AND ("family member" OR "relative" OR "spouse").

See Appendix A for the search sequence for one research question in Scopus. The same procedure was applied to the rest research questions across all three databases.

### **Inclusion and Exclusion Criteria**

Inclusion criteria were 1) targeted at family members of patients admitted to ICU, 2) psychological outcomes were reported, 3) at least one protective or risk factor was examined, 4) empirical studies, 5) English articles and 6) published between 2011 and 2021 since previous reviews already have covered the preceding years.

Exclusion criteria were 1) outcomes were not measured in an ICU context, 2) longitudinal design (except of two articles), 3) in the context of pediatric, oncological and rehabilitation care, 4) reviews, 5) not having a sufficient information for the research question, 6) specification of how PICS-F symptoms were affected (they conducted a study about PICS-F, but they did not reported any outcomes).

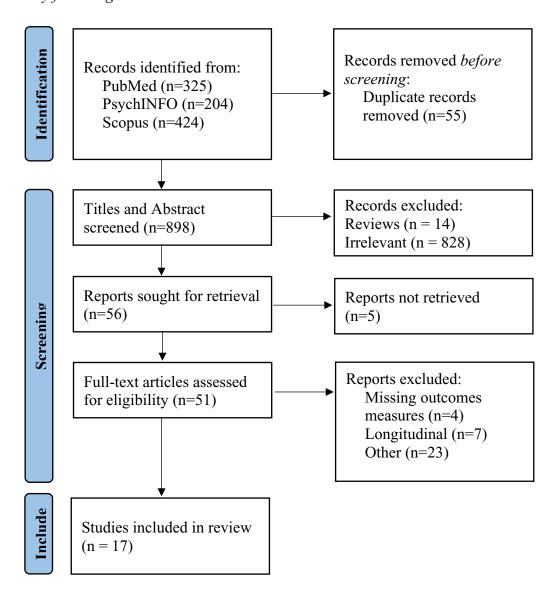
# **Study Screening**

Any duplicates were removed. The titles and abstracts of all retrieved articles from the databases were reviewed by one coder. If they fulfilled the inclusion criteria their whole text was acquired. The retrieved full-text articles were read and screened by one person.

### **Data Extraction**

From all the articles which fulfilled the inclusion criteria, all relevant information was extracted in Table 1. The extracted data included: The Author, the study characteristics, relative-related factors, patient-related factors, ICU-related factors, quantitative and qualitative results, coping strategies used by family members of ICU patients. Under Figure 1, it can be found the study flow diagram which depicts the course of the study.

Figure 1
Study flow diagram



### **Results**

In total 17 studies were used for this review and several studies contribute to different parts of this review. Ten studies addressed *relative-related* protective factors (1; 2; 3; 4; 5; 6; 11; 13; 15; 16). Two studies addressed *patient-related* risk factor (4; 13). Two studies addressed *ICU-related* risk factor (12; 13). Four studies addressed *coping strategies* used in the ICU by family members (9; 10; 14; 17). Two studies addressed *PTG* coping strategies (7; 8). The results will be discussed in the following order *relative-related factors, patient-related factors, ICU-related factors, coping strategies* and *PTG*. Under Table 1, the relative-, patient-and ICU-related factors can be found.

**Table 1**Protective and risk factors

Factor	Factor specification	Study	Study characteristics	Quantitative and qualitative results
		Nadig et al., 2016 <i>(2)</i>	(2) $N=56$ Age $\leq 45=18$ $46-64=28$ $\geq 65=10$ Gender  Female= $45$ Design  Multi-center, cross-sectional, observational study.	(2). Resilience and optimism were negatively associated with HADS total score ( $\beta$ = -4.82, 95% CI= -8.53 to - 1.11; $\beta$ = -3.80, 95% CI= -1.63 to -5.96) respectively and resilience with PTSS score ( $\beta$ = -4.00, 95% CI= -0.98 to -7.01).
Relative- related factors	Resilience	Sottile et al., 2016 (3)	(3) $N=170$ Age $49 \pm 15$ Gender  Female= -  Design  Multi-center, cross-sectional survey	(3). Resilient families had lower PICS-F symptoms compared to non-resilient families, anxiety (14.2% vs 43.6%, p<0.001, n=155), depression, (14.1% vs 44.9%, P< 0.001. n=156), and acute stress (12.7% vs 36.3%, p=0.001).
		Komachi & Kamibeppu, 2018 (16)	(16) <i>N</i> = 77 <i>Age</i>	(16). Resilience was significantly associated with acute stress scores

$$\leq$$
45= 16  
46-55= 24  
56-65= 23  
 $\geq$ 66= 14  
Gender  
Female= 53  
Male= 24  
Design  
Cross-sectional study

(B=-11.98, 
$$\beta$$
=-0.27,  $t$ = - 2.65;  $p$ < .01).

Gil-Juliá et al., 2021 *(4)*.

(4). Higher education showed a negative correlation with anxiety on a state level (r=-.45, p<.009), and depression assessed by HADS (r=-.38, p<.000), as well as BDI (r=-.49, p<.004), in addition, the same results were valid for family members own perception of depression (r=-.30, p<.007).

Educational level

Kao et al., 2016 *(5)* 

(5) N=200 Age  $45.0 \pm 12.6$  GenderFemale= 118 Male= 82 DesignCross-sectional, descriptive correlational design

(5). Education had a significant effect on depressive symptoms after the estimation of the mediating effects of learned resourcefulness and sleep disturbance (b= -.15, p<0.1).

Bastian Matt et al., 2017 *(13)* 

(13). Having a higher education predicted lower post-traumatic stress symptoms (B= -.52, p< .003, n=143) in family members.

(11) N=214Age  $53.95 \pm 15.67$ Gender
Female= 148
Male= Design
Single-center observational
study

Naef et al., 2021 (11)

(11). Satisfaction with care was negatively associated with depression ( $\beta$ = -.064, 95% Cl from -.11 to -.02, p< .01), anxiety ( $\beta$ = -.063, 95% Cl from -.11 to -.02, p=.01) and PTS ( $\beta$ = -.054, 95% Cl from -.10 to -.00, p<.04).

Satisfaction Yoo & Shim, with care 2020 (15)

(15)  $N= \exp = 28$ ; control=

28

Age

Exp.=  $51.0 \pm 12.7$ ; control=

49.0 ± 11.0

Gender

Female exp.= 18; control=

16

Male exp= 10; control= 12

Design

Quasi-experimental with a nonequivalent control group

and pretest/posttest study.

(15). In the open visitation and participation programme it was found that family members satisfaction grew from 75.71 to 89.59 points after the intervention (t= 8.62, p<.001, n=28) compared to the control group with 73.47 to 77.80 points (t= 4.24, p<.001, n=28). The anxiety scores reduced for both the experimental group (t=-17.05, p<.001) and the control group (t=-12.94, t=-1001).

Participating in the care for the patient

Amass et al., 2020 (6)

(6) N= exp.= 226; control= 226 Age Exp.= 51.0; control= 52.8 Gender (6). Family members who participated in the care for the patient had less PTSD symptoms (*B* = 27.1%, 95% CI = 19.2–35.1%, n=129) compared to family

Female exp.= 151; control=

148

Male= 
Design

Multicenter, multinational,
before-and-after intervention
trial.

members who did not participate (B = 39.2%, 95% CI= 30.7–47.4%, n=130) at 90-day follow-up. Additionally, family members who participated had significant decrease in anxiety symptoms from enrollment to 90-day follow-up (B= -35.7%, 95% CI= -45.1% to -26.3%, p< .019) compared with family members who did not (B= -19.3%, 95% CI= -29.2% to -9.4%, p< .019).

Building skills

Bannon et al., 2020 (1)

(1) N= exp.= 7; control= 9
Age
Exp.= 56.7; control= 51.7
Gender
Female exp.= 4; control= 5
Male= Design
RCT

- (1) Family members who participated in the study had lessened symptoms of anxiety, depression and PTSD (*d*= -1.25, *d*= -.41 and *d*= -.83, respectively) compared to the control group which had an increase in their symptoms (*d*=.44, .98 and .68, respectively). Additionally, the increase of self-efficacy, mindfulness and perceived coping had small to large effect size (*d*= .07-.85).
- (4). The family members in this study (n=89) experience *feelings of uncertainty* (i.e., something can happen to the patient (n=91.8%) or he/she can die (n=85%); unexpected ICU admission (n=75.7%); the patient is in pain (n=68.7%) or the medicine does not influence the pain (n=73.7%); uncertainty for the upcoming operation (n=65.7%) and unknowing what the disease is (n=60.3%).
- (13). Feelings of uncertainty or helplessness, severity of illness, inability of the patient to speak and the unexpected illness of the patient.

Patientrelated factors Uncertainty and helplessness about the condition of the patient

(13) ^

**(4)** ^

ICU-related factors	Disturbing ICU environment	Nadig et al., 2021 <i>(12)</i>	(12)¶ $N$ = if patient is: admitted= 43; transferred= 39 Age	transferred patient suffered higher psychological stress ( $\beta$ = 5.1, 95% CI= .35 – 10.03).
		(13) ^	admitted= 56.6 ± 12.4; transferred= 53.9 ± 13.2 Gender Female admitted= 32; transferred= 29 Male= - Design Cross-sectional observational study.	(13). Quality of the information (i.e., lack or contradictory information), quality of care (i.e., critique or doubts about it; transfer from the intensive care), life organization and traveling to the hospital; ICU rules and environment (i.e., restricted possibility to visit the patient, privacy issues, waiting time, threatening ICU environment) and lack of empathy or respect from the staff.

(12)

The family members of

*Note.* (n) denotes the citations before them.  $\P$  refers to family members of patients who were admitted or transferred to the ICU.  $^{\land}$  indicates already characterized studies.  $n \pm n$  represent the mean age and the standard deviation.

### **Relative-related factors**

The relative-related factors which were found are *resilience*, *educational level*, *satisfaction* with care, participating in the care for the patient and building skills (building intimate bonds between patient and spouse, coping skills, mindfulness, and self-efficacy). Three studies found an association between having *higher education* and reduced symptoms of anxiety, depression and PTS symptoms (4; 5; 13). In one descriptive study, it was found that education level was negatively correlated with anxiety, depression and stress experience (4). Meaning that people who had a university diploma were less likely to develop PICS-F symptoms. Similar findings were established in a cross-sectional study where people with higher education had lower levels of anxiety and depression, but this study did not include stress measures (5). In the third study, it was found that higher education significantly reduces PTS

symptoms but nothing was mentioned about the relationship between education, depression and anxiety (13). The one study used HADS, STAI and BDI to measure anxiety and depression (4) and the other one used STAI and CES-D (5) which could indicate the reliability of these findings, although it is hard to compare the measurements from different instruments.

Several studies found *resilience* as a protective factor of PICS-F symptoms (2; 3; 16). After studying the patients and their family members from two teaching hospitals it was established that resilient families were less vulnerable to PTSD symptoms than less resilient families as it was measured with IES-R (16). A multi-center, cross-sectional study had similar findings where they measured acute stress with PTSS and showed that lower scores were associated with higher resilience scores, including hope and optimism, as well it was negatively associated with depression and anxiety which were measured with HADS (2). Furthermore, in another multicentral, cross-sectional study, similarly, it was found that resilience is a protective factor of depression, anxiety and acute stress (3).

Moreover, two studies found that that *satisfaction with ICU care* contributes to fewer PICS-F symptoms as measured with HADS and IES-R-6 (11; 15). In one of the studies, it was found that if family members were satisfied with the care, then they experience less anxiety, depression and PTS symptoms (11). As well, the other study was an intervention that tried to involved family members in the daily care of the patient. They found that anxiety scores were reduced after the intervention, although that happened for both the experimental and control group, even though the experimental group benefited more (15).

One study was found which indicated that *participating in the care for the*patient helped family members with the disturbing situation they were in (6). In this

multicenter study, the before-and-after intervention trial involved the performance of family

care rituals in the ICU where family members were empowered to take care of the patients.

As a result, the PTSD and anxiety scores were significantly reduced at the 90-day follow-up (6).

Finally, in a dyad's intervention, it was found that when the caregiver *builds skills* such as mindfulness, interpersonal bond with their partner and self-efficacy, symptoms of anxiety, depression and PTSD are significantly reduced (1).

All the above-mentioned factors contribute to reduced experience of PICS-F symptoms. The *participating in the care for the patient* and *satisfaction ICU care* factors were put in the relative-related factors instead of ICU-related factors because they emphasize the point of view and action of the relative themselves. They do depend on the ICU policies of the hospitals, but the perception of the family member is more important because the policies could be stiff and the relative could be still satisfied and participate in some way in the care for the participation irrelevant of how small it is. While the ICU-related factor would induce distress in almost all cases regardless of how the relative sees it but that will be further elaborated.

### **Patient-related factors**

The patient-related factors which were found are uncertainty and helplessness about the condition of the patient and they are modifiable. Here, it is important to note that the uncertainty and helplessness are experienced by the family members due to the situation of the patient. From a qualitative perspective, feelings of uncertainty or helplessness can occur due to the severity of the illness, the unexpected condition of the patient and the inability for the patient to communicate (13). Other factors are the experienced pain by the patient or ineffective pain medicine, uncertainty for the upcoming operation and not knowing what the disease is. From a quantitative perspective, many people experience uncertainty due to what can happen to the patient (the condition of the patient can worsen), the possibility of dying and unexpected ICU

admission (4). Other factors are the experienced pain by the patient or ineffective pain medicine, uncertainty for the upcoming operation and not knowing what the disease is.

# **ICU-related factors**

Two studies identified the same ICU-related factors involved with the development of PTS/PTSD symptoms (12; 13). It was found that a *disturbing ICU environment* could cause higher psychological stress (12). From a qualitative standpoint, it was found that lack of information, changing contact person or contradictory information, doubts about the quality of care, transfer from ICU with negative consequences; commuting to the hospital, restricted hospital visit, privacy issue and lack of respect or empathy of staff can be disturbing for family members (12; 13).

The relative-related factors have a protective role which means that family members who have these characteristics are less prone to develop PICS-F symptoms. The patient- and ICU-related factors are risk factors that contribute to the development of PICS-F symptoms.

# **Coping strategies**

Summarization of the coping strategies used by family members can be found under Table 2. Four studies identified coping strategies which are negatively associated with PICS-F symptoms (9; 10; 14; 17). In one predictive study, it was found that *self-efficacy* has a negative effect on depression and anxiety (17). Overall, *adaptive coping* was associated with reduced symptoms of depression and anxiety (9; 10; 14;). From qualitative perspective, family members find a helpful larger social support network when they need to cope with the situation of the patient (14). Moreover, it is helpful for family members when they have the mindset of accepting the situation and looking at it as an opportunity for personal growth (14). One quantitative study showed similar results where *focus on the positive* (acceptance, humour and

positive re-evaluation) was negatively associated with depression (9). Similarly, another study showed the acceptance, humour and planning was negatively associated with anxiety.

Table 2

Coping strategies

Coping strategy	Study	Study characteristics	Quantitative and qualitative results
Self-efficacy	Kynoch et al., 2019 <i>(17)</i>	$(17) N=170$ Age $50.31 \pm 19.4$ Gender  Female= 119  Male= 511  Design  Observational, correlational, and predictive study.	(17). Coping self-efficacy had a direct negative effect on anxiety $(\beta =40)$ and it was negatively correlated with depression $(\beta =33)$
	Rueckriegel et al., 2015 (9)	(9) $N=53$ Age $57.7 \pm 11.4$ Gender Female= 35 Male= 18 Design Standardized interviews	(9). In this study the use of <i>focus</i> on positive (i.e., humour, acceptance, positive re-evaluation) was negatively associated with depression ( $r$ =29, $p$ <.03).
Adaptive coping			
	Pérez-Cruz et al., 2019 <i>(10)</i>	(10) $N=198$ Age $58.2 \pm 12.8$ Gender  Female= 177  Male= 21	(10). Planning (partial r=18, p<04), acceptance (partial r=22, p<.01), humour (partial r= -20, p<.02) were negatively associated with anxiety.

Design Cross-sectional study

(14) N= 14

Age

Gender

Koukouli et al., Female= 
2018 (14)

Male= 
Design

Descriptive qualitative study.

(14). Family members who are seeking the social support of their relatives, accept the situation, see it as an opportunity for personal growth, rely on spirituality/religion and optimism helps them to overcome the stressful situation of having a relative in the ICU.

# PTG coping strategies

The retrieved PTG coping strategies can be found under Table 3. One study was found to contribute to the development of PTG. The study demonstrated the association of PTG and coping strategies less or more than 3.5 years to 9 years after the transplantation. They showed that people with high PTG used mostly religion and positive reframing, family members with medium levels of PTG used self-distraction the most and people who were low on PTG do not use either of these strategies (8). Indicating that self-distraction could be an adaptive coping strategy in acute stressful situations. All three groups use instrumental and emotional support, positive reframing, self-distraction, acceptance and religion. self-distraction Lastly, the most used coping strategies among family members who had PTG were religion and positive reframing (7). This study as well found that family members with a medium level of PTG use self-distraction in the short term (7). Further supporting that self-distraction could be looked like an adaptive coping strategy in the short-term or for acute situations.

**Table 3**PTG coping strategies

<b>Coping strategy</b>	Study	Study characteristics	Quantitative and qualitative results
Religion, positive reframing, self- distraction and social support	Turner-Cobb et al., 2016 (7)	(7) N= 6 Age 25-64 Gender Female= 2 Male= 4 Design Mixed methods	(7). Among the family member with the highest PTG, the most used strategies are religion ( $P$ = .000, $d$ =87) and positive reframing ( $P$ = .002, $d$ =56). Additionally, family members with medium level of PTG use self-distraction ( $P$ = .006, $d$ =52).
	Pérez-San-Gregorio et al., 2018 (8)	(8) $N=218$ $Age$ $53.07 \pm 12.62$ $Gender$ Female= 170 $Male= 48$ $Design$ A 3 x 3 factorial study $Male= 48$ $Design$ A 3 x 3 factorial study	(8). Seeking help from family members' social support network help them with the coping with the situation of the patient. Additionally, self-distraction was found to be an adaptive coping strategy when family members are confronted with acute stressful situation.

### **Discussion**

The aim of this scoping review was to explore factors which protect family members from developing PICS-F and risk factors involving the patients and the ICU context which contribute to the development of PICS-F. Additionally, this review was to investigate which coping strategies are associated with PICS-F and which strategies were used by family members who had experienced PTG. The results revealed for the first research question five relative-related protective factors, one patient-related risk factor and one ICU-related risk factor. The relativerelated factors were: resilience, higher education, satisfaction with the ICU care and participating in the care for the patient and building skills. Furthermore, one patient-related factor was found which contributes to the development of PICS-F, namely the uncertain and helpless feeling of family members about the state of the patient (e.g., if he will survive, is he in pain, etc.). Additionally, one ICU-related risk factor was the disturbing ICU environment (e.g., lack of information, ICU environment and rules, privacy issue, etc.) can cause distress in family members. The second research question looked at coping strategies which were associated with PICS-F, they were: "focus on the positive" (humour, acceptance and positive re-evaluation), large social network, optimism, spirituality, religion, self-efficacy and planning. The third research question looked into which *coping strategies* were used by family members who had experienced PTG, they were religion, spirituality, self-distraction, acceptance, and positive reframing.

Higher-level education was proven to be a protective factor of depression, anxiety and PTSD (Paparrigopoulos et al., 2006; Van Pelt et al., 2010; Pillai et al., 2010). One possible reason for that could be that educated people seek more information to reduce their uncertainty about a situation which in turn reduces distress and anxiety (Brashers et al., 2002).

Furthermore, resilience was shown to have a protective role in family members of patients with depression (Ozawa et al., 2017), family members of patients with autism who

experience anxiety and stress (Bitsika et al., 2013) and in refuges who experience PTSD symptoms (Maree et al., 2013). In general, more resilient are less prone to experience psychopathological symptoms. With that in mind, it is not surprising that more resilient family members would not be affected severely and for longer a period of time by PICS-F symptoms.

Another protective factor of PICS-F symptoms is participation in the care for the patient (Amass et al., 2020; Hye Jin Yoo & Shim, 2021). That could be accounted to stressors such as uncertainty in the patient's prognosis, witnessing his resurrection or him suffering which could generate feelings of helplessness, restriction of visiting and perceived lack of empathy or respect from the staff which can contribute to a low sense of control and social support, and contribute to the development of PICS-F symptoms (Pochard et al., 2005; Rusinova et al., 2014; American Psychiatric Association, 2013; Cameron et al., 2016; Matt et al., 2017; Gil-Juliá et al., 2021).

Coping strategies which are associated with PICS-F and PTG are religion, spirituality, acceptance, and positive reframing. The experience of having a loved one in the ICU is a new experience for many, which could be quite stressful and contribute to negative psychological outcomes (Gil-Juliá et al., 2021). Similarly, the family members of patients who have chronic illnesses need to reexperience this traumatic event and contribute to PICS-F symptoms. In connection to such adverse experiences, the combination of acceptance and positive reframing coping strategies where the situation is cognitively redefined in a more acceptable variant could help to make the situation more manageable and generate feelings of security (Chui & Chan, 2007). Another, coping strategy that could have a supportive role towards building resilience is spirituality and religion, as it was shown that once this type of traumatic event occurs, people start looking for existential answers and once they acquire them, they can change their views and start "focusing on the positive" (Koukouli et al., 2018; Ozawa et al., 2017; Rzeszutek et al., 2017). Furthermore, it is interesting to see how self-distraction, which usually is taken as an

avoidant/maladaptive coping strategy, actually is found helpful by some family members (Pérez-San-Gregorio et al., 2018). As well, family members who experienced a traumatic event and have achieved posttraumatic growth use self-distraction (Turner-Cobb et al., 2016). These findings are inconsistent with previous studies of self-distraction where it was found to be positively associated with PTSD. One possible explanation is that self-distraction could be good for short-term acute stressors as Turner-Cobb and colleagues (2016) suggested, while it is harmful to the long-term (Radoš et al., 2018; Skeffington et al., 2016). At the same time, if that coping strategy is used for a longer period and it raises symptoms of PTSD, in the long-term that could facilitate posttraumatic growth.

This scoping review explored risk and protective factors related to the patient, the relative and the ICU. Additionally, it looked at coping strategies used by family members of ICU patient and the coping strategies used by family members after they went through PTG. The results provided information on these topics and showed a need for a further research. The quality of the included studies was not considered because it is not part of the methodology of scoping reviews. This scoping review had a scarce number of included papers compared to other reviews from this type. A reason for that is the type of research that was conducted on this topic, particularly there are many correlational studies that confirmed known factors but did not provide new information in relation to risk or protective factors. Furthermore, there was a lack of experimental research for coping strategies that assess which coping strategies can help family members and to what extent. Additionally, longitudinal research in relation to the PTG of family members of former patients and the strategies which these family members are using or how these changed over time are lacking.

### Limitations and future directions

The first limitation of this scoping literature review is the use of three databases and not looking into the grey literature such as presentation, conference proceedings and so forth. As a result, many articles which could have been valuable for the current review were not found and perhaps important information was missed. The second limitation was the inclusion criteria of studies only in English, published between 2011-2021 and had a full-text available. Both limitations restrict the coverage of this literature review which could have provided a better insight into the topic. As well, the use of different instruments should be taken into consideration when making reviews since when there is a difference, it is harder to make comparisons. The fourth limitation is that only one coder investigated the retrieved articles which could have led to missing some studies which are eligible for this review. Usually, due to a large number of articles, there is always more than one person when a scoping review is conducted. In future more research in that direction should be made, where a variety of coping strategies is assessed as part of longitudinal research. A study should be made where it establishes which coping strategies could help relatives in the short-term and later it is observed which strategies help in the long-term. Additionally, it should be estimated the extent to which family members experience PTG and which strategies helped people experience higher growth.

Nevertheless, the outcomes of the review could be used for the design of prospective interventions. As this review adds resilience, educational level, satisfaction with care, participating in the care for the patient and building skills as protective factors, some of them can be used to help family members of patients cope with the traumatic event. This type of intervention can have an educative component where resilience is built, they are taught coping strategies which can make them more resilient towards this traumatic event, as well as recognize when maladaptive coping strategies are used and what to do in this type of situation. These skills could be taught in some form of a game where the high

problem-solving capabilities of older people is utilized. That can be combined with goaldirected processing and positive re-appraisal, especially in the stage of acute stress. It will be suitable in that stage since this review showed self-distractions can reduce acute stress in combination with positive re-appraisal it can change the viewpoint of people towards acceptance and mindfulness. These elements can be part of the game with the help of specific goal-directed processing which in turn will increase the activity of the frontal cortex and as a result reduce the activation of the amygdala caused by the traumatic event they are experiencing (Blair et al., 2007). For example, short games which use cognitive abilities could be used in the waiting rooms to distract family members while they wait. games separate interventions for old and young adults can be made if resilience is used since older people are more resilient than young people, although they score lower on the social support scale (Gooding et al., 2012). As the results of the review showed resilience and building up skills have preventive characteristics towards PICS-F. For older people, it can be devised a group intervention where resilience and coping skills are built, while they are in a group with people similar to them in order to support and share their struggle. These skills could be taught in some form of a game where the high problem-solving capabilities of older people is utilized.

This scoping review revealed a need for more research. Particularly, the results of some papers confirm the same risk factors and most research papers do not look at what factors could protect family members from their adverse experience. Future research focus on risk factors further from what is known so far and should explore more factors which have a protective function. Furthermore, family members found coping strategies as useful. Currently, there is a limited number of coping strategies which were used and their efficacy. Future research could employ experimental designs which utilizes variety of coping strategies and explore the impact they have on family members. Moreover, there is a scarce

number of research which was performed on PTG in family members of former patients. Future research could explore further the impact of a variety coping strategies on the well-being of family members by using research with longitudinal designs.

### **Conclusion**

This review provided insight into protective relative-related factors, patient-related and ICU-related risk factors. Moreover, it showed which coping strategies are associated with PICS-F and PTG. The result showed education, resilience, satisfaction with care, building skills and family involvement in the care are protective against adverse psychological outcomes. The risk factors which were discovered in relation to the patient and the ICU environment were the experienced uncertainty and helplessness about the condition of the patient and disturbing ICU environment. Furthermore, it was shown that religion, spirituality, acceptance and positive reframing are coping strategies used by people who experienced PTG. This scoping review showed that more research is needed on how the patient and the ICU environment contribute to the development of PICS-F. Lastly, more experimental and longitudinal research is needed with more diverse coping strategies and how effective are they in relation to the PICS-F. Finally, the literature around the PTG of family members requires more research.

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Appendix A

Example of a search sequence

Number	Search string	Results
1	TITLE-ABS-KEY (ICU)	75,327
2	TITLE-ABS-KEY ("intensive care unit*")	226,408
3	TITLE-ABS-KEY ("critical	73,341
	care")	
4	#1+#2+#3	284,311
5	TITLE-ABS-KEY	4,150
	("psychological outcome")	
6	TITLE-ABS-KEY ({post-	20
	intensive care syndrome-	
	family}) OR TITLE-ABS-	
	KEY ( {PICS-F} )	
7	TITLE-ABS-KEY ("anxiety"	5,470
	) AND TITLE-ABS-KEY (	
	"depression") AND	
	TITLE-ABS-KEY ( "PTSD"	
	)	
8	TITLE-ABS-KEY ("PTS" )	300,252
	OR TITLE-ABS-KEY (	
	"post-traumatic stress	
	symptoms") OR TITLE-	

	ABS-KEY ("PTSD" ) OR	
	TITLE-ABS-KEY ( "post-	
	traumatic stress disorder")	
9	TITLE-ABS-KEY	31,252
	("protective factors")	
10	#5 OR #6 OR #7 OR #8	1,263,306
11	TITLE-ABS-KEY ("family	125,117
	members")	
12	TITLE-ABS-KEY ("relative"	2,310,228
	)	
13	#11 OR #12	2,424,495
14	#4 AND #10 AND #13	699
15	#4 AND #10 AND #13	357
	(LIMIT-TO: English, 2011-	
	2021; EXCLUDE: reviews)	