Post-Traumatic Stress Disorder in Caregivers

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Post-traumatic stress disorder (PTSD) is a mental disorder typically occurring after the exposure, both direct and indirect, to a traumatic event, and is characterized by the onset and persistence of a series of clinical symptoms that can often be profoundly incapacitating and tendentially chronic. In the past decades, increasing attention has been deserved to PTSD among caregivers of patients affected by severe medical conditions characterized by a risk for life, a severe impairment or a chronic course (e.g. cancer, severe injuries, type 1 diabetes and neurologic disorders) highlighting the potential traumatic role of such experiences.

Post-Traumatic Stress Disorder (PTSD) Caregiver mental health burden carers risk factors

1. Introduction

Caregiving burden is defined as the physical, psychological, social, or economic strain that caregivers may experience during the care of a loved one [1][2]. Caregivers are often overwhelmed in the early period of critical illness such that they struggle to understand even basic information about their loved one's diagnosis, treatment, or prognosis [3]. Additionally, the role of family caregiver can be extremely stressful and result in many adverse outcomes, ranging from mild psychological stress to an increased risk of death [4]. Indeed, family caregivers, while struggling to adjust to new responsibilities and roles [5], may experience negative psychological outcomes that include new or worsening depression, anxiety, and Post-Traumatic Stress Disorder (PTSD) symptoms [6]. Furthermore, the prevalence of psychiatric disorders in caregivers can be associated to psychological symptoms in the patient [7][8][9], virtually worsening the patient outcome.

Increasing evidence on psychiatric consequences on caregivers of patients with mental disorders are available, some of which is on PTSD [10][11][12][13][14][15][16][17], however less data are available on caregiving burden of patients affected by severe somatic illnesses, mostly reporting on anxiety or depressive symptoms [18][19][20][21]. However, in a public health perspective it is extremely relevant to investigate PTSD in such population. PTSD, in fact, is usually related to reduced quality of life, increased risk of other psychopathological conditions [22][23][24][25][26], substance abuse [27], and considerable costs for healthcare systems [28]. These data were also confirmed by the Authors of the European Study of the Epidemiology of Mental Disorders Survey (ESEMeD), who reported that this kind of traumatic event largely contributed to the European 12 months PTSD prevalence [29].

2. Risk Factors for PTSD.

For what concerns the risk factors for PTSD in caregivers, studies highlighted the role of sociodemographic and socioeconomic characteristics; familiar relationships; illness-related distress; exposure characteristics; and psychiatric symptoms and negative/maladaptive coping.

Sociodemographic and socioeconomic characteristics. Females resulted to be more affected by PTSD symptoms in many studies [30][31][32][33][34][35][36][37][38]. Younger caregivers also seemed to suffer from higher PTSD symptoms in three studies [39][40][41]. Other studies reported lower income as risk factor for developing PTSD symptoms [30][42]. Another study on 151 partners of patients coping with an acute coronary syndrome found that a lower level of education was associated to higher PTSD symptoms [43], and similar results emerged from another study [31]. Only one study on 103 family caregivers of neurologic intensive care unit (neuroICU) patients reported an association between being not married nor cohabitating and higher PTSD symptoms [36]. Andresen et al. [32] in a sample of 83 close relatives of ICU patients, found that older patient's age was associated to higher PTSD symptoms in relatives. This trend was shown up to patient's age of 62 years old, and then there was no more increase. Conversely, Hartog et al. [33], examining 84 relatives of ICU patients, found that younger patient's age was associated with higher PTSD symptoms.

Familiar relationships. Having a closer relationship with patients (i.e., being spouse or parent) was a factor related to PTSD symptoms in a study on 163 family caregivers of adult patients with acute leukemia [44]. Another study on 31 spouses and 25 close relatives of hospitalized patients with acute burns found that spouses had significantly higher levels of PTSD symptoms than close relatives [36]. Similarly, Hartog et al. [33] found that spouses were more prone to have higher PTSD symptoms in comparison to children and other relatives. Some other studies have examined the role of family relationships. Two studies have shown that having a lower bond or a poor relationship with the patient increased the risk of developing PTSD symptoms in the caregivers [40][45]. Teixeira and Pereira [34], analyzing a sample of 214 adult children caregivers of cancer patients, found that having a more enmeshed and chaotic family functioning predicted higher PTSD symptoms.

Illness-related distress. Many disease-related factors have been found to enhance PTSD symptoms. The uncertainty related to disease and the family strain have been related to PTSD symptoms in a study on 333 caregivers of hematopoietic cell transplant recipients [46]. Richardson et al. [47] found that in 78 caregivers of patients with head and neck cancer, having perceptions of low benefits from treatment and the presence of many patient symptoms, increased the risk of experiencing symptoms of PTSD in caregivers. Another study on 214 adult children caregivers of cancer patients highlighted that the perception of higher patient dependency was associated to higher PTSD symptoms [48]. Similarly, caregiving burden and caregiving strain have been stressed as a potential risk factors for PTSD in other studies [40][49][50]. Rumpold et al. [49] in a prospective study on 80 family caregivers of advanced cancer patients, found that caregiver subjective burden at baseline was significantly associated with PTSD symptoms at 9 months follow-up. Another study on 36 caregivers of ICU patients found that caregiving strain, represented by emotional adjustment, social issues, and physical and financial strain, was associated to increased PTSD symptoms [50]. Some authors [32], investigating a sample of 83 close relatives of ICU patients,

found a relationship between patient's Acute Physiology and Chronic Health Evaluation (APACHE) II score, an ICU scoring system used to classify the severity of disease, and PTSD symptoms in caregivers. Indeed, when the patient's APACHE II score rose from 7 to 20, there was an increase in PTSD symptoms in caregivers, even though afterward the trend flattened. Other studies found an association between a greater severity of the disease [31], more days of hospitalization [32], persistent patient's pain [42], and the levels of PTSD symptoms. Another study on 82 family members of ICU patients found that being caregivers of ICU patients with a traumatic brain injury (TBI), rather than of ICU patients without TBI, was a risk factor for experiencing more PTSD symptoms [51]. Furthermore, Dew et al. [40] examined 190 family caregivers to heart transplant recipients and found that in the first year post-transplant, caregivers presented higher PTSD symptoms. A more recent study on informal caregivers of adult hematopoietic cell transplant recipients showed that a shorter time since transplant was associated with greater PTSD symptoms in caregivers [46]. Moreover, Teixeira and Pereira [48] found that a shorter disease and caregiving duration were associated with a poorer outcome in terms of PTSD symptomatology, while Carek et al. [41], examining 51 caregivers of recent stroke survivors, found that an increased time since the event, with consequently more chronic stressors related to the sequelae of the medical event, was related to higher PTSD symptoms. Finally, Norup and Elklit [31] found that also the subjective evaluation of severity of illness may have enhanced PTSD symptoms.

Exposure characteristics. In a study on 41 family members of patients in the neuroICU, researchers found that having had more frequent visits in the aftermath of the event, which implied more time spent at bedside, was related to greater PTSD symptoms [42]. Having accompanied the patient during the drive to the Intensive Cardiac Care Unit (ICCU) after witnessing the medical event also was found to be a risk factor for PTSD, in a study on 143 female partners of acute coronary event patients [52]. Finally, in a prospective study on 102 relatives of patients with chronic obstructive pulmonary disease who survived an ICU stay, peritraumatic dissociation was related to higher PTSD symptoms at 90 days post-discharge [53].

Psychiatric symptoms and negative/maladaptive coping. Alfheim et al. [39], analyzing a sample of 211 family caregivers of ICU patients, found that having more comorbidities, such as depression or pain, was predictive of having more PTSD symptoms. Presenting higher levels of anxiety [45][54], depression [53], or both depression and anxiety symptoms [31][35] were all found to be related to a higher severity of PTSD symptoms. As concerns the prior psychiatric history, having a history of depression [35][37], depressive and anxiety disorders [40], or more generically a personal positive history for psychiatric illness [30] were associated with increased PTSD symptoms. Even the presence of psychiatric symptoms in patients was found to be a risk factor for some authors, particularly patient's PTSD symptoms in three studies [44][46][55] and panic disorder symptoms in another study on 168 caregivers of advanced cancer patients [56]. Negative coping styles have been related to greater PTSD symptoms severity in a study on 86 family members and friends of patients who have suffered spontaneous subarachnoid hemorrhage [57]. Another two studies have highlighted the importance of maladaptive coping strategies, such as avoidance, denial, behavioral disengagement and use of humor, in predicting caregivers' PTSD symptoms [40][47]. Finally, a study on 101 relatives of out-of-hospital cardiac arrest patients found that caregivers' perception of patient's therapy as insufficient was related to higher PTSD symptoms [37].

3. Protective Factors for PTSD.

Social status, familiar relationships, support, and positive coping resulted the most important factors related to lower PTSD symptoms in caregivers of severely ill adult patients.

Social status. Alfheim et al. [39] found that being on sick leave was a risk factor for PTSD and suggested that continuing to work reduced PTSD symptoms in caregivers. Also having higher educational levels was associated with fewer PTSD symptoms [32].

Familiar relationships. Being the parent of the patient, instead of the spouse or a friend [39] was found to be related to a better outcome in PTSD symptoms. Moreover, Stukas et al. [30], examining a sample of 142 family caregivers of heart transplant recipients, found that having a higher level of family cohesiveness reduced PTSD symptomatology.

Support. The importance of support has been highlighted by many studies [30][31][35][44][48][58]. Norup and Elklit [31], examining 614 partners of people with epilepsy, found that a high level of social support decreased PTSD symptoms, and similar findings were highlighted in another study on 39 partners of head and neck cancer survivors [35]. Another study on 306 surrogate decision makers of patients with chronic critical illness found that perceptions of clinician support and communication reduced PTSD symptoms [58].

Positive coping. A positive coping style [36] and mindfulness [36][45] were both shown to reduce PTSD symptoms. Indeed, Choi et al. [45], on a sample of 99 caregivers of patients admitted to a neuroICU, found that caregivers with higher levels of mindfulness were more likely to have lower PTSD symptoms. Having feelings of hope [39] or a perceived sense of mastery in the situation [40] were also associated with a reduction in PTSD symptoms.

Table 1. Characteristics of included studies.

Study	Year	Study Type	Sample	Quality Rating	Assessments	PTSD Rates	Risk Factors	Protective Factors
Alfheim et al. [39]	2018	Longitudinal	211 family caregivers of intensive care unit patients	Good	IES-r	PTSD: 54% (at enrolment); 24% (at 12 months)	-Younger -Having more comorbidities (e.g., pain, depression.) -Being on sick leave	-Being the parent of the patient (than spouse or friend) -Increased levels of hope

							-Working
Andresen et al. [32]	2015	Prospective	83 caregivers of ICU patients assessed at admission (time I), at 2 to 4 days (time II) and 60 days (time III).	Fair	PCLS	PTSD: 22.89%	-Older patient's age, up to 62 years old -Greater severity of disease from APACHE II level of 7 up to 20 -More days of hospitalization -Female	-Educational level
Bambauer et al. [56]	2006	Longitudinal	168 patient–caregiver dyads (Advanced cancer patients and their primary, informal, non-paid caregivers)	Fair	SCID IV	PTSD: 4.17%	-Patient psychiatric disorders	
Bond et al. [38]	2017	Prospective	31 spouses and 25 close relatives of hospitalized patients with acute burns	Good	Modified PTSD Symptom Scale	PTSD: 23.21% at admission, 8.33% at discharge	-Women -Spouses	
Carek et al. [41]	2010	Cross-sectional	51 informal caregivers of	Poor	PDS; PTCI	PTSD: 20%	-Younger -Increased time since stroke	

			recent stroke survivors					
Choi et al. [45]	2018	Prospective, observational	99 caregivers of patients admitted to neuroICU assessed during admission (baseline), three months, and six months post-hospitalization	Good	PCLS	PTSD: 16% (baseline); 22% (at six months)	-Fearful/anxious profile during admission -Negative relationship with patient	-Strong positive relationship with patient -Mindfulness
Cornelius et al. [52]	2020	Longitudinal	143 female partners of acute coronary event patients four months after the event	Fair	PDS-5	PTSD symptoms: 74.1%	-Accompanying the patients during the drive to the hospital, than only witnessing the emergence of symptoms.	
De Miranda et al. [53]	2011	Prospective multicenter	102 informal caregivers of patients with chronic obstructive pulmonary disease	Fair	IES	PTSD: 29.8% (on day 90)	-Peritraumatic dissociation at ICU discharge -Depressive symptoms	
Dew et al. [40]	2004	Prospective	190 caregivers to heart transplant	Good	CIDI	PTSD-T: 22.5% (cumulative rates 3 years post-transplant)	-Younger -Lower bond with patient	-Higher sense of mastery

			recipients evaluated at 2, 7, 12, and 36 months post-transplant				-Caregiver burden -First year post-transplant -History of depressive and anxiety disorders -Maladaptive coping	
Fait et al. [43]	2016	Cross-sectional	151 partners of patients with acute coronary syndrome 2 to 6 months after patients' hospitalization	Poor	PC-PTSD	CDI-PTSD symptoms: 11%	-Lower level of education	
Hartog et al. [33]	2015	Prospective observational	84 relatives od ICU patients interviewed by phone after 90 days after patients had died or were discharged	Fair	IES	PTSD: 51%	-Younger patient age -Female -Spouses (with respect to children and other relatives)	
Jia et al. [44]	2015	Cross-sectional	163 caregivers of adult patients with acute leukemia	Poor	PCL-C	PTSD symptoms: 36.8%	-Closer relationship with patients (e.g., spouses)	-Higher levels of perceived social support

							-Higher levels of patients' PTSS	
Liang et al. [46]	2019	Cross-sectional	333 caregivers of adult hematopoietic cell transplant recipients	Poor	PCL-5	PTSD: 6.6%	-Shorter time since hematopoietic cell transplant. -PTSD in patient -Higher cancer-related distress	
McPeake et al. [50]	2016	Cross-sectional	36 caregivers of ICU patients	Poor	IES	PTSD:53%	-Caregiving strain	
Meyers et al. [36]	2020	Longitudinal prospective cohort	103 family caregivers of neuroICU patients at baseline and 3- and 6-month follow-up	Good	PCL-Specific Stressors	PTSD symptoms: 16% baseline; 14% at 6 months	-Female -Not married/cohabitating	-Higher baseline mindfulness -Positive coping
Moschopoulou et al. [35]	2018	Cross-sectional	39 partners of head and neck cancer survivors	Fair	PCL-C	PTSD: 12.8%; PTSD symptoms: 25.7%	-Prior history of depression -Female -Symptoms of depression and anxiety	-Social support
Noble and Schenk [57]	2008	Cross-sectional	86 family members	Fair	PDS	PTSD: 25.6%	-Maladaptive coping strategies	

			and friends of patients with spontaneous subarachnoid hemorrhage					
Norup and Elklit [31]	2013	Cross-sectional	614 partners of people with epilepsy	Poor	HTQ	full PTSD: 7.7%; partial PTSD: 43.9%	-Female -Less years of education -Objective and subjective epilepsy severity -Anxiety and depression	-Social support
Richardson et al. [47]	2016	Prospective	78 caregivers of patients with head and neck cancer at diagnosis and 48 caregivers six months later	Good	PSSSR	PTSD: 19%	-Perceived little benefit from treatment -Many cancer symptoms -Denial and/or behavioral disengagement at diagnosis	-Use of humor at diagnosis
Rumpold et al. [49]	2016	Prospective	80 family caregivers of advanced cancer patients at baseline and	Good	IES-r	PTSD: 19.5% (baseline); 12.5% (follow-up)	-Caregiver subjective burden	

			at 9 months follow-up					
Stukas et al. [30]	1999	Prospective	142 family caregivers of heart transplant recipients	Good	CIDI	PTSD: 7.7%	-Female -Younger -Lower income -Personal history of psychiatric disorder -Lower friend support	-Higher family cohesiveness
Sundararajan et al. [54]	2014	Cross-sectional	63 family members of ICU patients	Fair	IES-r	PTSD symptoms: 41.2%	-Anxiety symptoms	
Teixeira and Pereira [48]	2012	Cross-sectional	214 adult children caregivers of parents with cancer	Poor	IES-r	Not reported	-Female -Perception of higher parental dependency -Shorter disease and caregiving's duration	-Social support
Teixeira and Pereira [34]	2016	Cross-sectional, comparative	214 adult children caregivers of cancer patients and 78 adult children of	Poor	IES-r	Not reported	-Female -Enmeshed or chaotic family functioning	

			nonchronically ill parents					
Trevick and Lord [42]	2017	Prospective cohort	41 caregivers of neuroICU patients at baseline, 26 at 1 month and 23 at 6 months	Fair	IES-r	PTSD: 7.7% at 1 month and 17% at 6 months	-Lower income -More frequent visits at 1 month -Persistent pain at 6 months	
Warren et al. [51]	2016	Longitudinal	40 family members of ICU patients with traumatic brain injury (TBI) and 42 of non-TBI ICU patients, assessed at baseline and 3 months	Good	PC-PTSD	PTSD symptoms: 24.3%	-ICU patients with TBI vs. ICU patients without TBI	
Wendlandt et al. [58]	2019	Randomized controlled	306 surrogate decision makers of patients with chronic critical illness 90 days post-randomization	Good	IES-r	Not reported		-Support and communication
Wintermann et al. [55]	2019	Cross-sectional	70 partners of chronically critically ill patients	Fair	PTSS-10	PTSD symptoms:18.6%	-Patient's PTSS	

Zimmerli et al. [37]	2014	Observational	101 relatives of out-of-hospital cardiac arrest patients	Good	IES-r	PTSD: 40%	-Females -History of depression -Family perception of patient's therapy as insufficient

APACHE II, Acute Physiology And Chronic Health Evaluation II; CIDI, Composite International Diagnostic Instrument; HTQ, Harvard Trauma Questionnaire; ICU, Intensive Care Unit; IES, Impact of Event Scale; IES-r, Impact of Event Scale-Revised; PCL-5, PTSD Checklist for the Diagnostic and Statistical Manual of Mental Disorders 5th edition; PCL-C, PTSD Checklist-Civilian Version; PCLS, Post-traumatic stress disorder checklist, version S; PC-PTSD, Primary care-PTSD screening questionnaire; PDS, Post-traumatic Diagnostic Scale; PDS-5, Post-traumatic Diagnostic Scale for DSM-5; PSSSR, Post-Traumatic Stress Disorder Symptom Scale; PTCI, Post-traumatic Cognitions Inventory; PTSD, Post-Traumatic Stress Disorder; PTSD-T, Post-Traumatic Stress Disorder related to the Transplant; PTSS, Post-Traumatic Stress Symptoms; PTSS-10, Post-traumatic Stress Scale; SCID-IV, Structured Clinical Interview for DSM-IV.

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