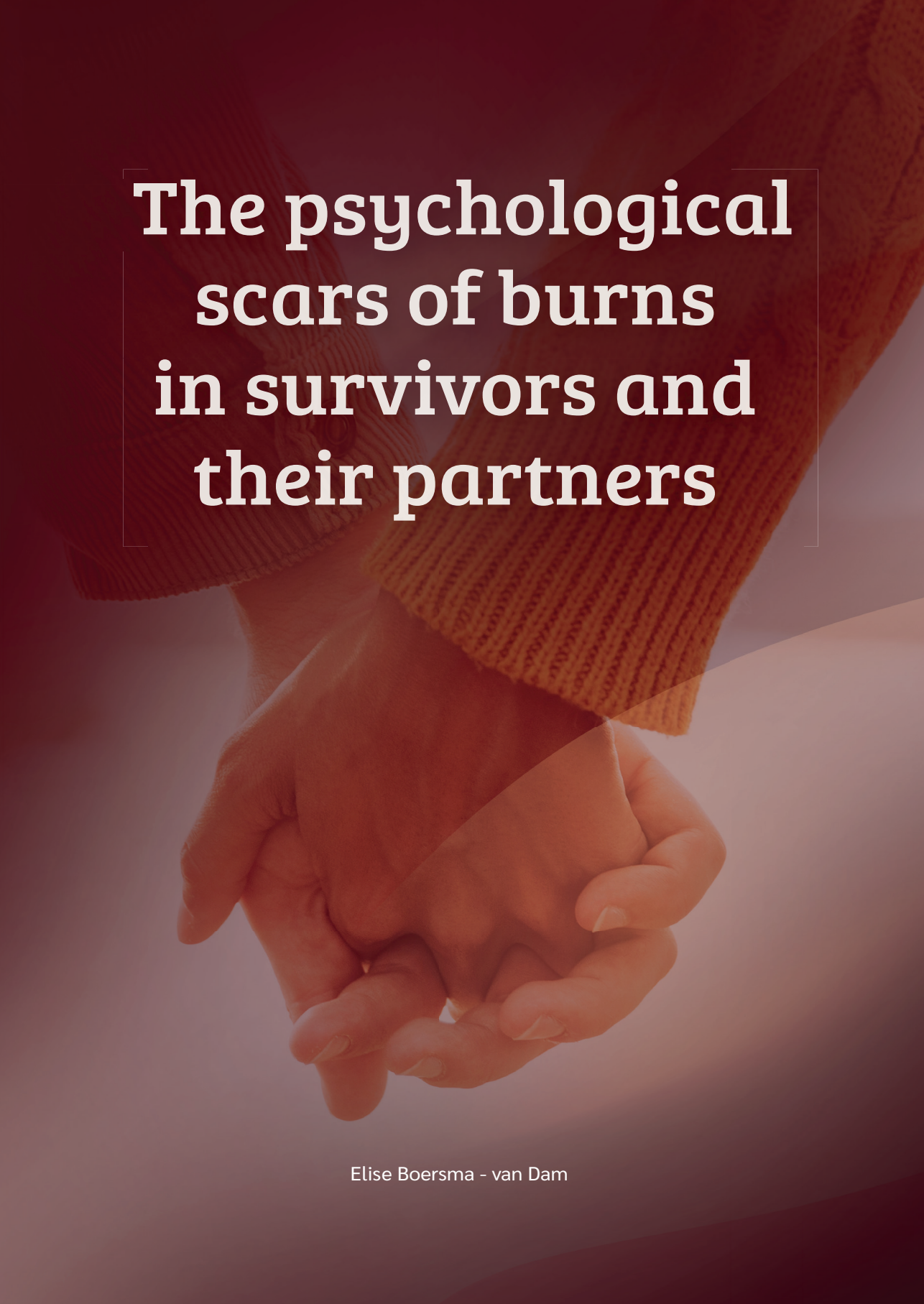
The psychological scars of burns in survivors and their partners



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The psychological scars of burns in survivors and their partners

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(met een samenvatting in het Nederlands)

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Contents

CHAPTER 1

1

General introduction

Burns are among the most traumatic injuries, eliciting severe inflammatory and neuropathic pain, emotional distress, and a changed appearance due to scarring. The injury and subsequent admission to a burn center can be a traumatic experience for both the survivor and their family. It disrupts family life, may cause profound distress in family members, and – for a shorter or longer time – changes partners' roles in the family. To better understand the potentially traumatic impact of adult burn injuries from a couple's perspective, the inclusion of the uninjured partners in research is essential. The current dissertation focuses on post-traumatic stress symptoms in couples and the impact of post-traumatic stress on survivor's general wellbeing. In the present chapter, a general background to this subject is provided and the aims and outline of the studies comprising this dissertation are presented.

Burn injuries

Epidemiology

In the Netherlands, each year approximately 92,000 persons visit the general practitioner with burns (van Zoonen et al., 2022), about 3,800 are treated at an emergency department (VeiligheidNL, 2022), about 1,100 are admitted to a hospital (Centraal Bureau voor de Statistiek, 2020), and about 900 are admitted to one of the three burn centers located in Groningen, Beverwijk, and Rotterdam (The Dutch Burn Repository Group, 2019; Van Yperen et al., 2022). Of those admitted to a burn center, about two-thirds comprise adults and one-third are pediatric patients. Most burn injuries are caused by scalds (39%) or flames (33%), followed by other causes, such as hot oil, contact with a hot surface, or chemicals.

Burn severity

The severity of a burn injury primarily depends on the depth and the extent of the tissue damaged by the burns. In terms of depth, burns are classified according to the layers of skin that are damaged. Epidermal burns, such as sunburns, are superficial and do not damage the skin, therefore they are not taken into account when determining the extensiveness of a burn wound. Partial-thickness burns affect the epidermis and dermis and can be further classified as superficial or deep. Superficial partial-thickness burns have the potential to heal spontaneously within 1-2 weeks with no or minimal scarring. Contrary, deep partial-thickness burns often require surgical interventions to close the wounds, because spontaneous healing may take too long and may result in worse scarring. Finally, full-thickness burns damage all layers of skin as deep as the subcutaneous fat

layer and do not heal spontaneously, but require surgical skin grafting and usually result in permanent scarring.

The extent of burn wounds is indicated by the percentage of the total body surface area (TBSA) that is affected by partial- and full-thickness burns. To visualize, the surface of the hand palm with closed fingers equals approximately 1% TBSA. Not every burn requires specialized burn care. Dutch guidelines for referral of adults to a burn center include a TBSA of ≥10% or ≥ 5% deep burns, burns in specific body areas, electrical or chemical burns, inhalation injury, age 75 or older, and (suspicion of) non-accidental burns (Nederlandse Verening voor Heelkunde, 2020).

Physical consequences and treatment

Burns typically trigger the acute release of inflammatory mediators (Jeschke et al., 2011; Mulder et al., 2020) that are crucial for wound healing and removal of dead tissue and bacteria, but, if uncontrolled, can result in systemic inflammation with severe or life-threatening complications such as organ failure. At the same time, the hypothalamic-pituitary-adrenal (HPA) axis is activated, triggering the release of stress hormones, such as cortisol, resulting in a profound and sustained stress response, which also play a key role in the emergence and maintenance of trauma-related symptoms (Josephs et al., 2017).

Therefore, treatment of severe burns in the first days is aimed at controlling the blood and fluid circulation and the nutritional balance, as well as preventing and treating infections. Treatment of acute burns further involves daily wound care procedures including removal of dressings, wound cleaning, disinfection, debridement of dead tissue, and applying new dressings. The burns and the wound care procedures can cause severe pain, necessitating additional pain management. About half of all burn patients admitted to Dutch burn centers need surgical procedures to transplant skin from healthy parts of the body to the burn site to acquire wound closure of deep wounds (Dokter et al., 2014; The Dutch Burn Repository Group, 2019). Burn treatment may take several days, weeks, or months, depending on wound healing and potential complications. In 2019, the length of stay in a burn center could take up to multiple months, but the median was 3 days (The Dutch Burn Repository Group, 2019). A multidisciplinary team provides treatment during the stay at the burn center, including, but not restricted to, doctors, nurses, surgeons, physiotherapists, social workers, and psychologists. In case of suspected mental health problems in survivors or their family members, medical professionals can involve a clinical psychologist, or survivors may request a consultation themselves.

Rehabilitation

After discharge from the burn center, follow-up visits to the outpatient clinics are planned to monitor wound and scar evolution and general well-being. The scars that often follow burns take up to 2 years to mature. While scars are preferably flat, pliable, and with only slight discoloration, hypertrophic, i.e. thick, non-pliable, scars may develop, which are often painful and itchy (Finnerty et al., 2016). Also, scar contractures may occur, causing limited flexibility and restriction of movement. Therefore, multiple reconstructive surgeries may be necessary to improve functioning and esthetics throughout the life span. The changes in appearance that result from scarring can be difficult to accept for both the burn survivor and their environment and may result in body image dissatisfaction (Cleary et al., 2020) and social challenges, such as stares or inquisitive questions from strangers (Martin et al., 2017). These difficulties are part of a broad range of mental challenges that burn survivors may face, including reduced quality of life and depressive and post-traumatic stress symptoms (Giannoni-Pastor et al., 2016; Spronk, Legemate, Oen, et al., 2018; Thombs et al., 2006). Estimates from the United Kingdom are that about one-third of burn survivors need additional psychological support in any form during their follow-up visits (Potter et al., 2023).

A trauma perspective on burn injuries

Although burn injuries are a potentially traumatic event, fortunately, most survivors and their family members do not develop persistent psychological difficulties (Nilsson et al., 2019). Still, a burn injury can elicit post-traumatic stress symptoms in both the survivor and other family members, irrespective of their presence at the burn event. In the first month post-burn, acute stress disorder (ASD) can occur, and in a subgroup of survivors and partners, symptoms may persist and develop into post-traumatic stress disorder (PTSD).

A formal diagnosis of PTSD requires the presence of symptoms in each of four clusters, with a duration of at least one month and with related impairment in functioning or personal suffering (American Psychiatric Association, 2013). The first cluster comprises symptoms of intrusions, including 'recurrent, involuntary, intrusive distressing memories' and 'dissociative reactions, (e.g. flashbacks)'. The second cluster comprises symptoms of avoidance, including 'avoidance of distressing memories, thoughts and feelings related to the trauma', and 'avoidance of external reminders (places, activities, objects)'. Third, negative alterations in cognitions and mood need to be present, such as 'persistent and exaggerated negative beliefs out oneself, others, or the world', and 'feelings of detachment or estrangement from others'. Fourth, marked alterations in arousal and reactiv-

ity need to be present, such as 'irritability or anger outbursts', 'hypervigilance', and 'sleep disturbances'.

To better understand the potentially traumatic impact of burns on the survivor, the uninjured partner, and the couple as a whole, the research in the current dissertation was guided by the cognitive model of PTSD (Ehlers & Clark, 2000) and the socio-interpersonal model of PTSD (Maercker & Hecker, 2016; Maercker & Horn, 2013).

The cognitive model of PTSD

While PTSD symptoms are a common reaction to traumatic events in the first weeks, the cognitive model of PTSD (Ehlers & Clark, 2000) explains why in a significant subgroup PTSD develops and persists. The model suggests that PTSD becomes persistent when the trauma is processed in a way that leads to a sense of ongoing serious threat, which arises as a consequence of two mutually reinforcing cognitive processes.

First, excessive negative appraisals of the trauma or its aftermath may occur if individuals are unable to see the trauma as a time-limited event without global negative implications for their future. For example, a person experiencing intrusive recollections of the trauma may think they are 'going mad' or will never get over it. These overgeneralizing and exaggerating appraisals elicit negative emotions (e.g. anxiety, depression, or anger) and maintain a sense of current threat.

The second cognitive process comprises a disturbance of autobiographical memory. This manifests as having difficulty with intentionally retrieving complete memories of the traumatic event, while at the same time experiencing a high number of involuntarily vivid intrusive memories and associated sensations. This is thought to result from poor elaboration and contextualization of the trauma memory, together with strong associative learning and perceptual priming by triggers in the environment.

Individuals try to control the sense of threat that results from these processes, by engaging in maladaptive strategies that maintain symptoms and prevent change in the appraisals and trauma memory. These strategies include thought suppression, avoidance of reminders of the trauma, safety behaviors, and rumination about the trauma and its consequences. While the cognitive theory by Ehlers and Clark (2000) has received much empirical support, it focuses mainly on intra-individual processes.

The socio-interpersonal model of PTSD

The socio-interpersonal model of PTSD (Maercker & Hecker, 2016; Maercker & Horn, 2013) comprises a broad social perspective on PTSD, including the trauma survivor, their close others, and the more distal social and cultural influences. The socio-interpersonal model states that the individual is nested in three levels of social contexts (Figure 1).

The first (inner) level is the individual level including social affective thoughts and feelings that relate to other people or communities, and include shame, guilt, and anger. Such social emotions are often reported by burn survivors and their family members (Egberts et al., 2020; Van Loey et al., 2008), and intrapersonal models, such as the cognitive model of Ehlers & Clark (2000) show how these emotions may contribute to the persistence of PTSD.

The second level comprises trauma-related interactional processes in close relationships with family members and friends, such as disclosure, social support, or negative exchanges (e.g. social exclusion or 'blaming the victim'). Interpersonal theories can be integrated at this level, such as the Cognitive-behavioral interpersonal theory (Monson et al., 2010), which states that partners' (well-intended) caretaking behaviors can serve to promote or maintain avoidant behavior and thereby PTSD. For example, a wife may take over all shopping-related chores, because crowded shops serve as PTSD-related triggers for her husband. Such behavioral accommodation can lead to less engagement in mutually reinforcing activities (e.g. dining out), constriction of affective expression, and avoidance of trauma-related conversation and disclosure, which not only serve to maintain PTSD but also contribute to diminished relationship satisfaction. On the other hand, trauma disclosure during an encouraging and supportive interaction with one's partner can aid the development of a more accurate and complete trauma narrative and processing of traumatic memories (Ehlers & Clark, 2000; Monson et al., 2010).

The third level is the distant social level, which includes cultural and societal influences, such as collective trauma, feelings of injustice, societal acknowledgment as a trauma survivor, and societal values. Related to this level, a comparative burn study showed that a large proportion of survivors of a fire in a bar recovered to low levels of PTSD symptoms over time, whereas most survivors of an industrial fire maintained a high level of distress over time (Van Loey et al., 2012). This difference was attributed to the availability of community empowerment and companionship for the survivors of the bar fire, who lived in the same village, and whose questions concerning legal responsibility and financial compensa-

tion were solved adequately. On the contrary, survivors in the industrial fire comprised a diverse group of local workers and individual passers-by who did not have a shared supportive community and who got caught up in a lingering litigation process.

The studies in the current dissertation mainly tap into the first two levels of the socio-interpersonal model. The cognitive model of PTSD is used to explain the persistence of PTSD symptoms within (partners of) burn survivors at the individual level, and interpersonal theories are used to explain interpersonal processes in the couple at the second level.

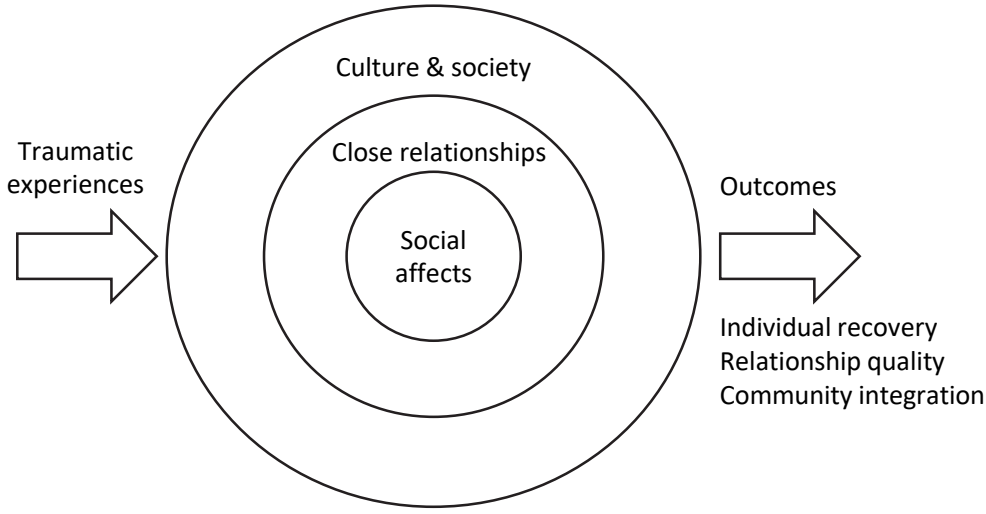

Figure 1. *The Socio-interpersonal model of PTSD*

Note. From "Broadening perspectives on trauma and recovery: a socio-interpersonal view of PTSD ", by A. Maercker and T. Hecker, 2016, *European Journal of Psychotraumatology*, *7*(29303). (doi: 10.3402/ejpt.v7.29303). CC BY 4.0

Post-traumatic stress and impact on partners

PTSD symptoms in burn survivors

A systematic review shows that the prevalence of ASD after a burn injury ranges between 2% and 30%. The prevalence of PTSD ranges between 3% and 35% during hospitalization, and between 10% and 45% one year post-burn (Giannoni-Pastor et al., 2016), suggesting that PTSD rates may increase during the first year post-burn. However, these estimates vary widely, and meta-analytic estimates, that can give more insight into the extent of the problem, are lacking.

With regard to risk factors for the development of PTSD, three broad categories have been studied, i.e. demographic factors, burn severity factors, and psychological factors. With regard to demographic variables, female gender and low socioeconomic status are related to higher levels of PTSD symptoms (Giannoni-Pastor et al., 2016; Hobbs, 2015).

With regard to the role of burn severity, the literature is inconsistent. While moderate effect sizes for TBSA and number of surgeries have been reported (Giannoni-Pastor et al., 2016), another review stated that a majority of studies report that burn injury characteristics are not associated with PTSD symptomatology (Hobbs, 2015). Even less is known about the role of more subjective scar-related factors, such as satisfaction with appearance and body image. Based on qualitative findings, It has been suggested that changes in appearance may act as a trigger for re-experiencing the trauma, which, – combined with social stigma, – may maintain a sense of current threat, leading to an intertwined relationship between appearance concerns and PTSD symptoms (Macleod et al., 2016). Further evidence suggests that body image dissatisfaction is related to survivors' PTSD symptoms (Dahl et al., 2016; Shepherd, 2015) and may mediate the relationship between burn severity and PTSD symptoms (Huang & Su, 2021).

Other psychological risk factors have also been identified, and a meta-analysis showed that the perception of life threat has the strongest association with the development of PTSD symptoms. Further, psychological predictors include the initial stress response, peri-traumatic emotions, pain severity, and premorbid or comorbid psychological problems (Giannoni-Pastor et al., 2016; Hobbs, 2015). Finally, coping is also an important factor, with avoidant coping being related to more PTSD symptoms (Bosmans et al., 2015; Su & Liang, 2022; Wiechman et al., 2020).

Psychological impact on the supporting partner

A burn event can profoundly affect the lives of family members of the injured person. Multiple qualitative studies have been undertaken to capture the (psychological) impact of burn injuries on the family. The initial reaction of family members, and especially partners is characterized by feelings of chaos and shock and a wide range of emotional responses such as worry, anxiety, grief, and helplessness (Bäckström et al., 2018; Bayuo & Wong, 2021; Phillips et al., 2007; Sundara, 2011). Up to 77% of partners of burn survivors showed heightened symptom levels of anxiety, depression, or PTSD shortly after admission to the burn center (Bond et al., 2017; Flannery et al., 2022). Family members often describe 'vicarious suffering', when witnessing pain in their loved one without

being able to relieve it and may try to contain their trauma to protect each other, disabling them from connecting emotionally (Gullick et al., 2014). At the same time, family members express the need to be close to and involved with the injured relative (Johnson et al., 2016).

From a more practical side, a burn injury often causes a change of roles in the family, increasing the uninjured partner's responsibility to manage the household, childcare, finances, and logistics needs of family members, while also providing emotional support to family members and managing social contacts with family and friends (Bäckström et al., 2018; Bayuo & Wong, 2021; Phillips et al., 2007; Sundara, 2011). As a result, they may feel overwhelmed and overburdened (Gullick et al., 2014).

Throughout burn care and rehabilitation, partners (and other family members) often experience a range of concerns, such as worry about and dealing with scars and changed appearance, concerns about how to take care of the survivor after discharge, both physically and emotionally, sexual concerns, and struggles to assist the survivor in the process of redefining their life (Gullick et al., 2014; Johnson et al., 2016; Phillips et al., 2007; Sundara, 2011).

Despite the evidence from these qualitative studies, few quantitative studies have been undertaken to substantiate the traumatic impact of burn injuries on partners and couples. Nevertheless, the literature shows that a burn injury can have impeding consequences beyond physical well-being, impacting the daily life and social functioning of both the burn survivor and their family.

Health-related quality of life after burns

PTSD symptoms may affect the survivor's functioning in a range of domains, including the ability to perform everyday activities, work, participate in family life, and connect to family and friends (Corry et al., 2010; Dyster-Aas et al., 2007). Not surprisingly, PTSD symptoms are an important predictor of health-related quality of life (HRQL) after burns (Spronk, Legemate, Dokter, et al., 2018). HRQL reflects an individual's perception of how their health condition affects their physical, psychological, and social well-being after an injury or disease (Testa & Simonson, 1996). As depicted in Figure 2, conceptual models state that HRQL is the result of a process in which changes in biological functioning, such as a burn, cause physical, emotional, or cognitive symptoms, and impact functional status. The individual integrates these components into general health perceptions, resulting in a general sense of well-being. During this process, both individual

and environmental characteristics interact with all of its components (Ferrans et al., 2005; Wilson & Cleary, 1995).

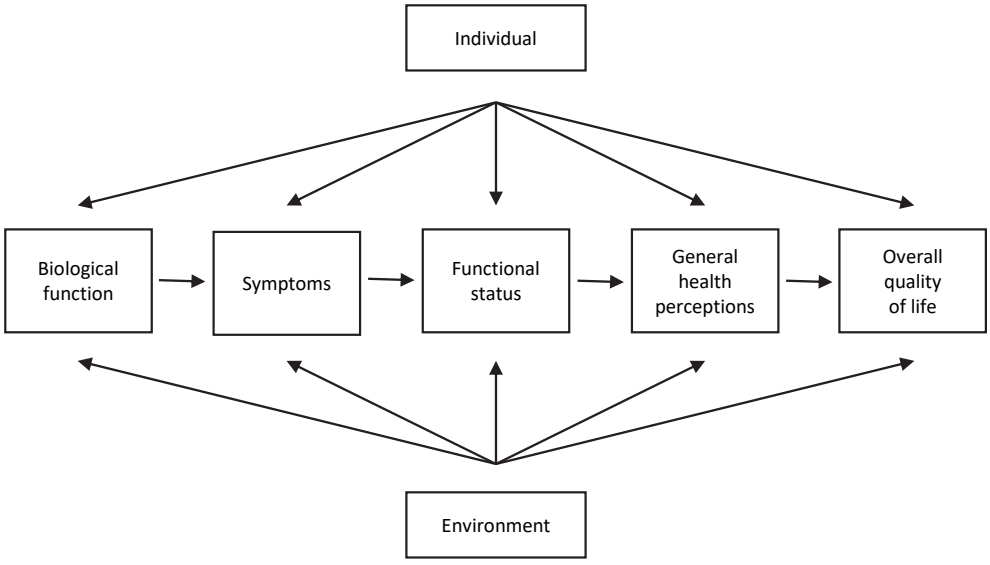

Figure 2. *Conceptual model of HRQL.*

Adapted from "Conceptual Model of Health-Related Quality of Life", by C. E. Ferrans et al., 2005, *Journal of Nursing Scholarship*, *37*(4), p. 338 (doi: 10.1111/j.1547-5069.2005.00058.x). Copyright 2005 by John Wiley & Sons. Adapted with permission. Based on the original model of Wilson and Cleary (1995).

HRQL is generally impaired shortly after burns, with large improvements in the first six months, followed by a steady improvement up to 18 months, when HRQL stabilizes around general population norms in those with mild and moderate burns, and below the norms in those with major burns (Spronk et al., 2020). Although functioning in most physical domains recovers over time, a delayed or lacking recovery is often observed with regard to role functioning, mental well-being, and pain. With regard to individual characteristics that may hamper recovery of HRQL, poorer HRQL is generally found in those with more severe burns, depressive or post-traumatic stress symptoms, avoidance coping, low social support, high neuroticism, post-burn unemployment, and female gender (Spronk, Legemate, Dokter, et al., 2018; Spronk et al., 2020).

Although a general pattern of impairment and recovery of HRQL has been established, less is known about individual patterns of change in HRQL from pre-burn to (long-term) post-burn. While generally known trajectories for PTSD symptoms (i.e. resilient, recovery, late-onset, and chronic) have been established in burn

survivors (Sveen et al., 2011), no such attempts have been undertaken for HRQL. Recently, as many as seven different HRQL trajectories were identified in a larger population of traumatic injuries (Visser et al., 2021). However, this large number of classes, combined with a lack of a pre-injury baseline measurement, makes it difficult to define and distinguish between trajectories. Therefore, a significant knowledge gap remains to exist with regard to meaningful HRQL trajectories after burns.

Benchmarking 'recovery'

When studying recovery, a proper benchmark has to be chosen to which the current health state can be compared, i.e. a prospective measurement of pre-burn health, a retrospectively (recalled) pre-burn health, or general population norms. Since prospective measurement of pre-burn HRQL is generally impossible, the use of retrospective recall of HRQL has been recommended among injury populations, preferably assessed in the first week post-injury (Polinder et al., 2010; Van Beeck et al., 2007), and has some advantages over the use of population norms or prospective measurements.

Individuals from the general population are unlikely to be representative of those from an injury population, and over- or underestimation may depend on the specific population (Scholten et al., 2017). In the case of burns, pre-burn HRQL may be lower than general population norms, because a substantial subgroup of people with burns has a history of psychopathology and healthcare utilization (Logsetty et al., 2016; Patterson et al., 2003). On the other hand, pre-burn HRQL may be higher than general population norms, as healthier people are more likely to participate in activities, increasing their risk of injuries (Watson et al., 2007). Nevertheless, it has been found that the health status of injured people who report full recovery, differs more from population norms than from recalled pre-injury status (Watson et al., 2007; Wilson et al., 2012), supporting the use of retrospective measurements instead of population norms.

However, obtaining a valid and reliable measurement of pre-burn HRQL is complicated because of the probable occurrence of response shift. *Response shift* refers to the idea that someone's internal standards, values, or conceptualization of HRQL may change between measurements (Howard & Dailey, 1979). Such a recalibration has also been found with regard to PTSD symptoms (Lommen et al., 2014), and may occur especially after a potentially traumatic injury, but also more generally during a recovery process (Haagsma et al., 2020). As a result, the answer to the same question by the same individual may not be comparable between measurements. Consequently, despite general preferences for pro-

spective data collection, it has been argued that retrospective post-injury measures may actually constitute a more accurate comparison because it is assessed through similar (changed) internal standards (Norman, 2003).

Finally, a source of concern in retrospectively collected data is *recall bias*, meaning that survivors remember their previous health condition differently than they experienced it at that time (Blome & Augustin, 2015). Memory is in fact closer to reconstruction than reproduction and inconsistencies may occur as a function of survivors' current state (Engelhard & McNally, 2015). Such recall bias can be either non-directional ("recollection error" or "noise") or directional. For example, recalled pre-injury HRQL in injury survivors tends to be consistently higher than population norms (Scholten et al., 2017), suggesting directional recall bias may be present. However, recall bias can be minimized by assessing the pre-burn health within the first weeks after the injury (Terwee et al., 2007).

Proxy reporting

Although a retrospective measurement of pre-burn HRQL is recommended to benchmark recovery, a second informant, such as a parent or partner, may be included in research to obtain a more complete idea of a survivor's pre-burn HRQL. This second informant is often called a 'proxy', and is quite common in research with children (Sherifali & Pinelli, 2007) or in the elderly with cognitive difficulties (Hutchinson et al., 2022). Proxy assessments can constitute a substitute for the primary participant or a complementary assessment. Such a complementary view on the survivor's HRQL is referred to as the proxy-proxy perspective, assessing the survivor's health from the proxy's own perspective which may diverge from the survivor's perspective (Pickard & Knight, 2005).

While a complementary perspective may be especially useful for obtaining the most accurate pre-burn HRQL assessment, a substitute assessment may also be of interest in the burn population in cases where medical status prevents timely self-reporting by the survivor. In that case, proxies can help to reduce missing data and avoid systematic non-participation of more severely burned survivors (Van Beeck et al., 2007). For this purpose, assessment with the proxy-patient perspective is most suitable, in which the proxy assesses the survivors' health as the proxy thinks the survivor would rate him/herself (Pickard & Knight, 2005).

Despite the difference between substitute and complementary perspectives, systematic reviews have included either perspective and showed that proxies and patients are generally concordant in more observable HRQL domains of physical functioning, but differ in their view of the more emotional and psychological

aspects of HRQL (Roydhouse & Wilson, 2017; Sneeuw et al., 2002). Nevertheless, proxy-patient concordance regarding HRQL has not been studied in the adult burn population, necessitating agreement studies before such a measure can be reliably used.

Fatigue

A specific element of quality of life, fatigue, is often mentioned as an impairment by burn survivors (Holavanahalli et al., 2016; Kool et al., 2017), but it has not been extensively studied. In the post-acute phase, fatigue is often attributed to the inflammatory and hypermetabolic responses that are triggered by the burns (Jeschke et al., 2011; Sommerhalder et al., 2020). Inflammatory mediators signal the brain via neuronal pathways to care for the ill body and increase energy expenditure. Ultimately, the brain responds by setting illness-related behavioral priorities, for example, reduced social exploration, loss of appetite, and fatigue, that contribute to survival and repair (Dantzer et al., 2014). When the body heals, these behavioral priorities change again, and fatigue levels normalize. Little is known about the mechanisms and factors that explain why fatigue levels do not normalize in all burn survivors, despite wound healing. Recently, it has been suggested that prolonged dysregulation of the HPA-axis may play a role in maintaining fatigue (Stanculescu et al., 2021), indicating that the psychological aftermath may play a role. Therefore, more insight is needed in predictors of both short-term and long-term fatigue, to help understand this phenomenon and provide clues for prevention and treatment of protracted fatigue.

Research aims

The overall aim of this dissertation is to increase our understanding of the impact of the potentially traumatic experience of a burn injury on the psychological well-being of burn survivors and their partners over time. In the first part of the dissertation, the aim was to delve into a new area of research, the psychological well-being of partners and the dynamic interplay between partners and burn survivors. In the second part of the dissertation, we studied the impact of trauma (symptoms) on fatigue and HRQL in the context of recovery to pre-burn functioning. By adopting a longitudinal perspective, we aim to identify early predictors of problematic long-term outcomes. Hence, the results of this dissertation inform clinical practice of (early) signs that indicate which burn survivors and partners may need extra monitoring or support to deal with the traumatic impact of the burns.

The specific aims of the thesis were to:

- Model the development of PTSD symptoms in partners of burn survivors and examine early risk factors related to its development and persistence.
- Investigate how expressions of avoidance and approach between couple members interact with survivor's and their partner's PTSD symptoms over time.
- Examine the relationship of PTSD symptoms with (change in) HRQL and specifically fatigue after burns
- Explore the prevalence of different individual recovery trajectories of HRQL, and investigate the use of a retrospective pre-burn measure in survivors and partner-proxies as a potential benchmark for survivors' recovery.

Outline of the dissertation

Chapters 2 and 3, present two studies on PTSD symptoms. On the individual level, **Chapter 2** examines the course and predictors of PTSD symptoms in partners of burn survivors up to 18 months post-burn. Turning to the interpersonal level, **Chapter 3** focuses on the interaction between survivors and partners in relation to their PTSD symptom levels over time. The aim of this chapter is to determine PTS-related intra- and interpersonal processes with two complementary interpersonal constructs.

Chapters 4 and 5 present two studies on HRQL. In **Chapter 4**, we explore different trajectories of change in HRQL from pre-burn until 18 months post-burn. In a second analysis, the study focuses on early predictors of recovery and non-recovery, including PTSD symptoms. **Chapter 5** focuses on the retrospective measurement of pre-burn HRQL, investigating the agreement between burn survivors and their partners who served as proxies in this study. A comparison with population norms is made, and possible sources of (dis)agreement are studied. In **Chapter 6**, we turn to symptoms of fatigue in burn survivors. Using a biopsychological perspective, we studied the course and predictors of fatigue over time, with special attention to predictors of long-term problems with fatigue. **Chapter 7** presents a summary and general discussion of the main findings.

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CHAPTER 2

2

Prevalence and course of posttraumatic stress disorder symptoms in partners of burn survivors

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Abstract

Background: Partners of burn survivors may develop posttraumatic stress disorder (PTSD) symptoms in response to the potential life threatening nature of the burn event and the burn survivor's medical treatment.

Objective: This longitudinal study examined the prevalence, course and potential predictors of partners' PTSD symptoms up to 18 months post-burn.

Methods: Participants were 111 partners of adult burn survivors. In a multi-centre study, PTSD symptoms were assessed with the Impact of Event Scale-Revised during the acute phase and subsequently at 3, 6, 12 and 18 months post-burn. Partners' appraisal of life threat, anger, guilt and level of rumination were assessed as potential predictors of PTSD symptoms in an exploratory piecewise latent growth model.

Results: Acute PTSD symptoms in the clinical range were reported by 30% of the partners, which decreased to 4% at 18 months post-burn. Higher acute PTSD symptoms were related to perceived life threat and higher levels of anger, guilt, and rumination. Over time, mean symptom levels decreased, especially in partners with high levels of acute PTSD symptoms, perceived life threat and rumination. From three months onward, PTSD symptoms decreased less in partners of more severely burned survivors. At 18 months post-burn, higher levels of PTSD symptoms were related to higher acute PTSD symptoms and more severe burns.

Conclusions: One in three partners reported clinical levels of acute PTSD symptoms, of which the majority recovered over time. Perceived life threat, feelings of anger and guilt, and rumination may indicate the presence of acute PTSD symptoms, whereas more severe burns predict long-term PTSD symptom levels. The results highlight the need to screen for acute PTSD symptoms and offer psychological help to partners to alleviate acute elevated stress levels if indicated.

Background

Admission to a burn centre may be distressing for the partner of the patient and may affect psychological wellbeing. Besides the potential life threat of the burn event, sources of distress entail for example monitoring of the patient's vital symptoms, mechanical ventilation and the patient may be unrecognizably bandaged. Studies in partners of survivors of critical illness show that posttraumatic stress disorder (PTSD) symptoms in response to these medical applications may occur (Gawlytta et al., 2020; Petrinec & Daly, 2016). Furthermore, family members, especially partners, are an important source of support for patients with burns, both during the acute phase and after discharge from the hospital, when partners may take on the role of caretaker of the patient (Bäckström et al., 2018; Bayuo & Wong, 2021). It is therefore important to investigate partners' psychological state, for both their own wellbeing and because it may affect their capacity to support the patient in this process.

The burns literature shows that PTSD symptoms in patients occur in up to 30% (Hobbs, 2015). But also their partners are at risk of developing PTSD. A study in spouses and close relatives of burn survivors reported acute PTSD symptoms prevalence rates of 29% at admission to the burn centre in 31 spouses and 15% at discharge in 20 spouses (Bond et al., 2017). In the longer term, a prevalence rate of 65% in 37 spouses was reported (Zheng et al., 2020). In the intensive care unit (ICU) literature, prevalence rates of acute PTSD symptoms in partners and close relatives ranged between 14% and 72%, decreasing to 23.6% to 36.2% at 12 months and 14% at 24 months (Alfheim et al., 2019; Kentish-Barnes et al., 2015; Kulkarni et al., 2011; Pillai et al., 2010; Pillai et al., 2006). However, to our knowledge, no longitudinal burn or ICU studies document PTSD symptom trajectories exclusively in partners. Treating partners and other relatives as a homogeneous group may leave specific patterns or predictors unnoticed. Indeed, differences in PTSD symptom levels between partners, parents and other relatives have been reported (Alfheim et al., 2019; Bond et al., 2017; Petrinec & Daly, 2016). Therefore, focussing specifically on partners may add unique insights into PTSD symptom trajectories and may assist the identification of specific predictive factors for partners in need of psychological support.

With respect to potential predictors of PTSD symptoms, a meta-analysis in a variety of samples showed that demographic variables were predictive in some populations but not in other (Brewin et al., 2000), which supports the necessity to study homogeneous populations. Previous research in family members of burn survivors and patients at the ICU showed that women and younger fam-

ily members had higher PTSD symptom levels (Alfheim et al., 2019; Bond et al., 2017; Petrinec & Daly, 2016), a finding supported by the broader PTSD literature (Brewin et al., 2000). Furthermore, burn related factors such as facial burns, length of hospital stay, ventilated days and total body surface area (TBSA) burned were not significantly associated with PTSD symptoms (Bond et al., 2017). However, in the paediatric burn literature, larger TBSA burned was related to higher levels of PTSD symptoms in parents (Bakker et al., 2013; Egberts et al., 2017). Consequently, we hypothesized an association between burn severity and PTSD symptoms in partners.

Stronger and more robust effects were found for cognitive factors such as trauma appraisals. The cognitive model (Ehlers & Clark, 2000) posits that when the trauma is processed in a way that produces a sense of current threat, people are vulnerable to persistent PTSD. In the DSM-5, appraised life threat is part of Criterion A, indicating one of the factors that can elicit PTSD (Ursano et al., 2004). When life threat is not appraised as a time-limited event and with global negative implications, it may maintain PTSD symptoms (Ehlers & Clark, 2000). Although one study found no association between perceived life threat of partners and close relatives with acute PTSD symptoms (Bond et al., 2017), a larger body of evidence points towards a detrimental impact of life threat in PTSD occurrence after injury (Timmer-Murillo et al., 2020). Therefore, it is hypothesized that perceived life threat predicts more PTSD symptoms in partners.

Negative appraisals of the trauma and/or its aftermath are proposed to maintain PTSD by producing negative emotions (Ehlers & Clark, 2000). Trauma-related emotions, such as anger and guilt, are associated with PTSD symptoms in various trauma-exposed samples (Lommen et al., 2014; McLean & Foa, 2017; Orth & Wieland, 2006), but have not been studied often in partners of critically ill patients. Guilt, and, to a lesser extent anger, are common reactions to burns in family members (Kornhaber et al., 2018; Rossi et al., 2005). Guilt relates to a negative evaluation of a person's specific behaviour (McLean & Foa, 2017); parents of children with burns may feel guilty because they were unable to prevent the burn event (Egberts et al., 2017; Hawkins et al., 2019), but guilt may also occur in partners of critically ill patients (Gawlytta et al., 2020). Anger, a negative emotional state related to specific cognitive distortions and physiological changes (McLean & Foa, 2017) was reported by burn survivors and parents of children with burns and was shown to be related to PTSD symptoms (Egberts et al., 2017; Van Loey et al., 2008). However, the occurrence and extent to which these emotions constitute risk factors for PTSD symptoms in partners should

also be known to assess whether these emotions are relevant to screen for in partners.

Dysfunctional coping strategies, for example rumination, are also presented as a factor that maintains PTSD through negative appraisals (Ehlers & Clark, 2000; Seligowski et al., 2015). Rumination involves a recurrent focus on the causes and consequences of the trauma and related 'what-if' questions (McLaughlin & Nolen-Hoeksema, 2011) and may be a way to avoid thinking about traumatic memories and associated thoughts and feelings (Bishop et al., 2018; Michael et al., 2007), thereby maintaining PTSD (Ehlers & Clark, 2000; Szabo et al., 2017). Negative emotions such as guilt have been linked to rumination in parents of children with burns, underscoring the relevance to investigate this maladaptive coping style in family members of burn survivors (Kornhaber et al., 2018).

The aim of the current longitudinal study was to investigate both acute PTSD symptoms in partners of burn survivors in the acute phase and chronic PTSD symptoms up to 18 months post-burn. Based on the extant literature, it was expected that symptoms would be relatively high during the acute phase, but would subsequently decrease over time. Furthermore, we hypothesized that demographic variables, burn severity, perceived life threat, higher levels of anger, guilt, and rumination would predict PTSD symptoms in partners over time.

Methods

Inclusion

Data from this study were part of a larger project in three Dutch and three Belgian burn centres that focused on the social impact of burns. Previous work described patients' PTSD symptoms and quality of life (Boersma-van Dam et al., 2020). Patients and their partners were recruited between October 2013 and October 2015 and followed for 18 months. Inclusion criteria for patients were: hospital stay of >24 h following the burn event, age of 18 years or older and proficiency in Dutch. The latter two criteria also applied to partners. Exclusion criteria were: psychiatric problems that interfere with the comprehension of questionnaires (e.g. psychosis, cognitive problems).

Procedure

The study was approved by ethics boards in the Netherlands and Belgium (NL44682.094.13 and B670201420373). Patients and their partners were invited

to participate in the study by a local researcher during hospitalization. After they received oral and written study information, they provided written informed consent. Partners completed T1 in the acute phase (*M* = 21 days post-burn; *Mdn* = 15 days post-burn) and the follow-ups at 3, 6, 12 and 18 months post-burn (T2 to T5) by postal mail (with *Mdn* = 99, 198, 379, 562 days post-burn for the respective time points).

Sample and missing data

Of the 266 patients included in this study, 71 reported they had no partner and eight patients had missing data. Of the remaining 187 patients with a partner, 120 (64.2%) partners enrolled in the study and 111 (59.4%) completed the predictor measures and PTSD symptoms measures at T1 and were included in the analyses. Comparing the 111 participating partners with the 76 that did not participate or had missing values, partners of male patients were more likely to participate in the study (*n* = 89/138, 64.5%) than partners of female patients (*n* = 22/49, 44.9%), χ^2 (1) = 5.76, *p* = .02, but no statistically significant differences (*p* > .05) were found with respect to TBSA burned, number of surgeries and age of the patient.

The number of partners that completed (at least 19 of the 22 items of the) PTSD measures at T2 – T5 was 94 (84.7%), 90 (81.1%), 76 (68.5%) and 79 (71.2%) respectively. Sixty-nine (62.2%) partners completed all five measurements. Respondents lost to follow-up were significantly younger (*M* = 39.0) than those with complete data (*M* = 45.8), *t* (109) = -2.36, *p* = .02, but no statistically significant differences (*p* > .05) were found with respect to gender, the patient's number of surgeries, patient's TBSA burned, and acute PTSD symptoms at T1. Little's Missing Completely At Random (MCAR) test in the final sample showed that missing data were random, χ^2 (72) = 81.63, *p* = .21.

Measures

Posttraumatic stress disorder symptoms.

The Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997) was used to asses partners' PTSD symptoms. The IES-R is a 22-item self-report questionnaire that measures three symptom clusters of PTSD, that is, intrusion, avoidance and hyper-arousal symptoms, in the past week. Answers were given on a 5-point Likert scale and summed to obtain a total score, with scores ≥ 33 indicating a possible diagnosis of PTSD (Creamer et al., 2003). If at least 19 of the 22 items were completed, sum scores were calculated based on the mean of the completed items. The IES-R was validated in Dutch trauma populations and showed

good psychometric properties (Olde et al., 2006). Reliability of the IES-R in the current study was excellent, with Cronbach's alphas from .94 to .96, at the five measurements. Partners' PTSD symptoms were assessed in the acute phase, and at 3, 6, 12 and 18 months post-burn.

Subjective appraisal of life threat and emotions

Partners reported their appraisal of the life-threatening nature of the injury through the question: "At any time, did you think your partner would not survive the burn event?" (yes/no). And if so, at what time? Previous studies have supported the validity of the measure (e.g. Kassam-Adams et al., 2009). Emotions directly related to the burn event were assessed with the following question: 'To what extent do the following emotions apply when you think about the accident that caused the burn?'. From the assessed emotions (fear, sadness, horror, shame, guilt, anger), guilt and anger were evaluated in the latent growth model, because these emotions were deemed most relevant in previous burn research in parents (Bakker et al., 2013; Egberts et al., 2017) and thereby enable a comparison of the results in partners and parents. Answers were rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (a lot) during the acute phase of the burn injury.

Rumination

The rumination scale of the Cognitive Emotion Regulation Questionnaire (CERQ; Garnefski & Kraaij, 2007) was used to assess the partners' level of rumination. The rumination scale comprises four items, for example 'I am preoccupied with what I think and feel about what I experienced'. Answers were rated on a 5-point Likert scale ranging from 1 '(hardly) ever' to 5 '(hardly) always'. The Dutch version of the CERQ demonstrated good factorial validity and reliability (Cronbach's α = .83) in the general population (Garnefski & Kraaij, 2007). Cronbach's alpha in this study was .87. Partners' rumination was assessed during the acute phase of the burn injury.

Burn characteristics

Number of surgeries, total body surface area (TBSA) burned, length of stay in the hospital, and mechanical ventilation (yes/no) were recorded from the patient's medical file. Number of surgeries indicates the number of skin graft procedures that was required to cover the wounds and is considered an indicator of burn severity. TBSA burned is the estimated percentage of the body covered with partial and full thickness burns. Presence at the burn event was self-reported by the partner.

Statistical analysis

Descriptive analyses were conducted in IBM SPSS v24. Potential predictors were correlated with PTSD symptom scores at each time point. Longitudinal trajectories of PTSD symptoms among partners were estimated using latent growth modelling (LGM) in Mplus 8.3 (Muthén & Muthén, 1998-2017). Full information maximum likelihood (FIML) was used to handle missing data in the main analyses, because Little's MCAR test showed that data were missing completely at random. To account for the non-normality of some of the variables, Maximum Likelihood (ML) estimation with bootstrapped confidence intervals was used with 10,000 draws.

To find a model that best described the data, the adequacy and model fit of different growth models was evaluated. The slope growth factors represented the timing of the measurements since the burn event. Because a standard growth model with a single intercept plus linear slope did not fit the data well, and, to our knowledge, this was the first study to apply such a model to data on partners, we decided to explore a series of models to identify the best fitting curve. A complete overview of the consecutively evaluated models can be found in an additional file, including model fit, warnings and conclusions for each model. Because of the explorative nature of our approach, model replication is warranted.

The predictors included in the model were gender, number of surgeries, perceived life threat, anger, guilt and rumination. Age was not included in the model, because addition of this variable yielded bad fit indices (see Additional file 1, models 8 – 12). Anger, guilt and rumination were grand mean centred to aid interpretation of intercept and slope estimates. Model fit was evaluated with the comparative fit index (CFI), the Tucker-Lewis Index (TLI), and the root mean square error of approximation (RMSEA). TLI and CFI > 0.90 and RMSEA < 0.08 indicate an acceptable model fit; TLI and CFI values > 0.95 and RMSEA values < 0.05 indicate good fit to the data (Kline, 2011).

To evaluate the association of the predictors with PTSD symptoms at T5, a multiple regression analysis was performed in two steps. In the first step, all predictors were added to the regression. In the second step, to evaluate prediction of the baseline-adjusted change of PTSD symptoms, PTSD symptoms at T1 was additionally included.

Results

Descriptive analyses

The 111 partners were mostly women (*n* = 89, 80.2%) and the mean age was 43.8 years (*SD* = 14.0, range: 19 – 76). The burn survivor's mean TBSA burned was 10.4% (*SD* = 11.4, range: 1.0 – 75.0), mean length of hospital stay was 20.2 days (*SD* = 23.6, range: 1 – 175), and 16 burn survivors (14.4%) needed mechanical ventilation. Figure 1 shows the means of the IES-R subscales and total sum score over time.

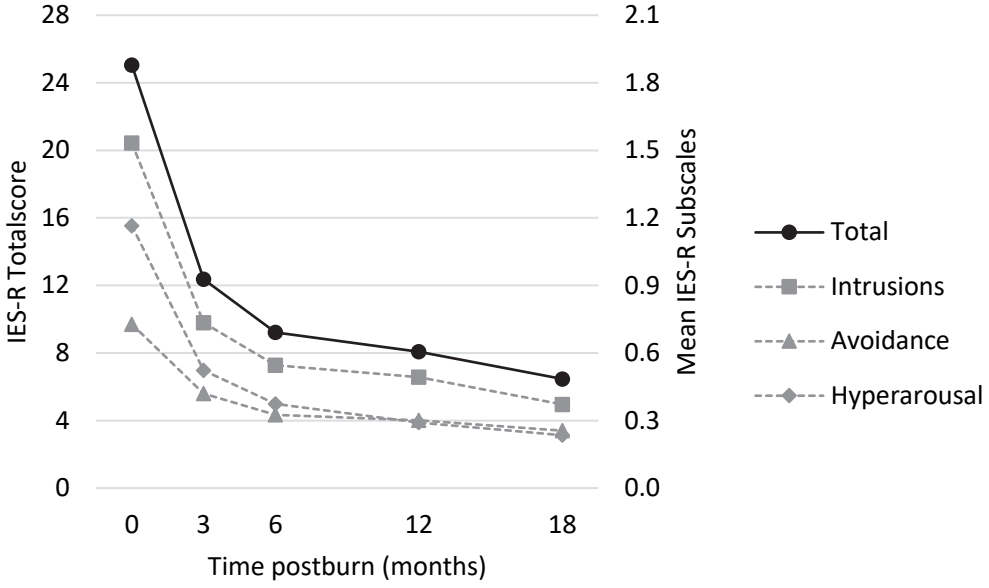

Figure 1. *Observed Total Score and Mean Levels of Intrusions, Avoidance and Hyperarousal Symptoms over Time, assessed with the Impact of Event Scale-Revised (IES-R).*

At T1, 29.7% of the partners experienced PTSD symptoms within the clinical range, which gradually decreased to 10.6%, 7.8%, 3.9% and 3.8% at T2 – T5. Mean symptom scores were highest at T1, roughly halved at T2, and further decreasing over time. Of the three subscales, mean levels of intrusions were higher than mean levels of avoidance and hyper-arousal over time, Wilks' Lambda = .48, F (10, 260) = 11.51, p < .001.

Table 1 presents descriptive statistics of partners' emotions. The majority experienced fear, sadness and anger. Horror was reported by half of the partners, and guilt and shame were reported by a minority. Twenty-seven participants

(24.3%) had perceived their partner's life to be in danger at some point (e.g. the moment the patient was on fire, learning that the patient was exposed to a burn event or was admitted to a dedicated burn centre, or during the ICU period). Perceived life threat was associated with mechanical ventilation, χ^2 (1) = 20.04, p < .001; 69% of the partners of mechanically ventilated burn survivors perceived life threat. Thirty nine percent of the partners were present at the moment of the burn event. Partners who were present reported higher levels of rumination (t (103) = 2.11, p = .04) and guilt (t (103) = 2.11, p = .04), but did not show more acute PTSD symptoms or anger (p > .05).

Table 1. *Descriptives of partner's emotions during hospitalization*

	N	Mean	*SD*	Median	% >0*
Fear	110	2.2	1.3	2	88.2
Sadness	111	2.6	1.3	3	94.6
Horror	108	1.0	1.3	0	46.3
Anger	111	1.5	1.4	1	69.4
Shame	111	0.2	0.7	0	13.5
Guilt	111	0.7	1.1	0	36.9

*percentage scoring ≥1 on a scale from 0 (not at all) to 4 (a lot)

Correlations between PTSD symptoms and predictors are shown in Table 2. Age showed low correlations with PTSD symptoms. Notably, the correlations of number of surgeries with PTSD symptoms were low, but reached statistical significance at 18 months. Anger was moderately correlated up to T2. Guilt was only significantly correlated to PTSD symptoms at T1. Rumination showed moderate to high correlations with PTSD symptoms across the time span and was also related to anger. Partners who perceived life threat, had on average higher scores than partners who did not for PTSD symptoms (Cohen's d ranged from 0.74 to 1.30), anger (d = 0.7), rumination (d = 0.7), and patient's number of surgeries (d = 0.5).

Table 2. *Descriptives and Bivariate Pearson Correlation Matrix of Study Variables*

	1	2	3	4	5	6	7	8	9	10
1 Age										
2 Surgeries	.08									
3 Anger T1	.12	.06								
4 Guilt T1	.02	.03	.18							
5 Rumination T1	-.02	.12	.22*	.13						
6 PTSD T1	.10	.14	.40**	.27**	.61**					
7 PTSD T2	.24*	.09	.47**	.20	.60**	.74**				
8 PTSD T3	-.01	.15	.36**	.07	.43**	.55**	.68**			
9 PTSD T4	.17	.17	.23*	.16	.35**	.43**	.58**	.70**		
10 PTSD T5	.12	.25*	.17	.01	.32**	.51**	.59**	.58**	.75**	
n	111	111	111	111	111	111	94	90	76	79
Mean	43.8	1.2	1.5	0.7	2.2	25.0	12.4	9.2	8.1	6.5
SD	14.0	2.1	1.4	1.1	0.9	17.9	13.8	11.3	11.3	10.1
Median	45.0	1.0	1.0	0.0	2.0	21.0	7.5	5.0	4.0	2.0

* $p < .05$; ** $p < .01$

PTSD = Post-traumatic Stress Disorder symptoms; T1 = acute phase, T2 = 3 months, T3 = 6 months, T4 = 12 months, T5 = 18 months post-burn.

Latent growth modelling

A 'simple' growth model with a single linear slope and without predictors did not fit the data well (χ^2 (10) = 92.57, $p < .001$; RMSEA = .273; CFI/TLI = .648), so a series of models were tested to explore which model had the best fit to the data (see Additional file 1). These series included models with quadratic and cubic effects, but a piecewise linear growth model fitted the data best. This piecewise growth model for partners' PTSD symptoms consisted of an intercept, one slope modelling the change between T1 and T2, and a second slope modelling the change between T2 and T5. The 'knot' for the two slopes was set at T2: Mean PTSD symptoms showed a steep decline between T1 and T2 and a smaller decline afterwards (see Figure 1). The piecewise growth model without predictors showed mixed results with regard to model fit, χ^2 (6) = 20.89, $p = .002$; RMSEA = .150; CFI = .936; TLI = .894. The addition of predictors yielded an acceptable model fit, χ^2 (18) = 32.09, $p = .021$; RMSEA = .084; CFI = .958; TLI = .907 (Table 3). This final model explained 70% of the variance in acute PTSD symptoms, 36% of the variance in the first three months, and 42% of the variance after T2. A significant negative correlation between the intercept and slope 1 indicated that higher acute PTSD symptom levels were associated with a steeper decline in PTSD symptoms between T1 and T2.

With regard to the intercept, perceived life threat, more anger, guilt or rumination was associated with higher acute PTSD symptom levels. With regard to slope 1, perceived life threat was associated with a sharper decline of PTSD symptoms between T1 and T2 and a trend was shown for rumination ($p = .08$). The results for slope 2 showed that more severe burns were associated with a smaller reduction in PTSD symptoms, and, more rumination was associated with a sharper decline in PTSD symptoms after T2.

Table 3. *Piecewise Linear Growth over Time: Predictors of PTSD Symptoms*

	Estimate	*SE*	95% CI	*p*	R^2
Correlations					
Intercept with Slope 1	-.63	0.13	[-0.88; -0.38]	<.001	
Intercept with Slope 2	-.08	0.30	[-0.66; 0.50]	.79	
Slope 1 with Slope 2	-.09	0.48	[-1.04; 0.85]	.85	
Regression estimates					
Intercept	19.05	2.53	[14.08; 24.01]	.00	.70
Gender[1]	3.34	2.82	[-2.19; 8.87]	.24	
Surgeries	-0.18	0.56	[-1.27; 0.91]	.75	
Life threat T1	14.51	3.76	[7.14; 21.88]	<.001	
Anger T1	1.86	0.94	[0.03; 3.69]	.05	
Guilt T1	3.33	1.01	[1.35; 5.32]	.001	
Rumination T1	8.68	1.52	[5.71; 11.66]	<.001	
Slope 1[2]	-40.50	10.14	[-60.37; -20.63]	.00	.36
Gender[1]	1.31	11.36	[-20.96; 23.58]	.91	
Surgeries	0.12	1.73	[-3.28; 3.51]	.95	
Life threat T1	-27.79	12.73	[-52.74; -2.84]	.03	
Anger T1	0.28	3.68	[-6.93; 7.50]	.94	
Guilt T1	-5.40	4.49	[-14.20; 3.41]	.23	
Rumination T1	-10.13	5.75	[-21.41; 1.14]	.08	
Slope 2[3]	-1.66	1.62	[-4.84; 1.51]	.31	.42
Gender[1]	-2.72	1.85	[-6.35; 0.91]	.14	
Surgeries	0.59	0.30	[0.002; 1.18]	.05	
Life threat T1	0.23	2.39	[-4.45; 4.91]	.92	
Anger T1	-1.10	0.71	[-2.49; 0.29]	.12	
Guilt T1	-0.85	1.06	[-2.93; 1.24]	.42	
Rumination T1	-2.80	1.03	[-4.82; -0.78]	.01	

PTSD = Post-traumatic Stress Disorder; T1 = acute phase ; [1] male is the reference category; [2] 0-3 months postburn; [3] 3-18 months postburn.

Multiple Regression of PTSD symptoms at 18 months

To investigate the relevance for long-term PTSD symptoms, a regression analysis of early predictors of PTSD symptoms at 18 months was performed (Table 4). Without controlling for acute PTSD symptoms, perceived life threat and more severe burns predicted higher PTSD symptoms at T5. A trend for rumination was shown (p = .07). Corrected for acute PTSD symptoms (step 2), only number of surgeries predicted a lower reduction of PTSD symptoms.

Discussion

Table 4. *Multiple Regression Results Predicting PTSD Symptoms at 18 Months Post-burn (n = 79).*

Variable	Estimate	*SE*	95% CI	*p*
Step 1				
Gender[1]	-0.63	2.74	[-6.01; 4.74]	.82
Surgeries	0.82	0.36	[0.11; 1.53]	.02
Life threat T1	7.05	3.05	[1.07; 13.04]	.02
Anger T1	0.24	0.89	[-1.51; 1.99]	.79
Guilt T1	0.02	1.01	[-1.97; 2.00]	.99
Rumination T1	2.24	1.25	[-0.22; 4.69]	.07
Step 2				
Acute PTSD symptoms T1	0.26	0.13	[0.01; 0.51]	.04
Gender[1]	-1.02	2.74	[-6.39; 4.35]	.71
Surgeries	0.72	0.34	[0.04; 1.39]	.04
Life threat T1	3.78	3.29	[-2.66; 10.22]	.25
Anger T1	-0.37	0.97	[-2.27; 1.54]	.71
Guilt T1	-0.54	1.20	[-2.89; 1.81]	.65
Rumination T1	-0.44	1.73	[-3.83; 2.94]	.80

PTSD = Post-traumatic Stress Disorder; T1 = acute phase; R^2 for the model is .31; [1] male is the reference category.

To our knowledge, this is the first study that examined the level, course and predictors of PTSD symptoms exclusively in partners of burn survivors with an 18-month follow-up. Results showed that 30% of the partners reported PTSD symptoms within the clinical range in the acute phase. Perceived life threat, more anger and guilt, and higher levels of rumination were related to more acute PTSD

symptoms. Within the first three months, PTSD symptoms decreased on average, especially if initial stress was high and/or partners perceived life threat. Partners who showed initially more rumination, showed a higher decrease in PTSD symptoms after three months. Acute PTSD symptoms and burn severity, indicated by number of surgeries, predicted higher PTSD symptoms in the longer term.

About one in three partners experienced acute PTSD symptoms. These rates dropped to 11% after three months, and 4% at 12 and 18 months. The prevalence rate in the acute phase fits with earlier findings in partners of burn survivors (Bond et al., 2017), but the chronic rates are lower than reported in the ICU literature (Petrinec & Daly, 2016).

However, ICU studies comprised a heterogeneous group of partners, parents and other family members, and PTSD cut-offs varied (e.g. Alfheim et al., 2019; Petrinec & Daly, 2016) which may partly explain the difference in prevalence rates. A significant correlation between mechanical ventilation (indicative of ICU status) and perceived life threat may suggest that life threat may be more frequent in ICU populations, inducing PTSD symptoms in more partners. In line with the broader psychological trauma literature (Galatzer-Levy et al., 2018), our study showed that over time, most partners recovered from initial PTSD symptoms or were resilient.

The results of the piecewise growth model indicated a minor role of gender in PTSD symptoms of partners, whereas the burn and ICU literature described associations with female gender (Alfheim et al., 2019; Bond et al., 2017; Zheng et al., 2020). However, our predominantly female sample may be underpowered to find significant effects of gender. Burn severity, indicated by number of surgeries, was not associated with PTSD symptoms in the acute phase, but in the longer term, predicted a lower decrease in PTSD symptoms over time, in agreement with earlier research (Attoe & Pounds-Cornish, 2015; Bond et al., 2017). More severe burns likely cause more scars and functional limitations, affecting quality of life (Boersma-van Dam et al., 2020), which may hamper the recovery of PTSD symptoms in partners. Future studies may investigate the content of intrusive memories (e.g. what event is represented in intrusive memories) to reveal whether scars may act as reminder to the burn event.

The results indicate the relevance of appraisal of life threat, and also anger and guilt, as indicators of PTSD symptoms in partners of burn survivors. Perceived life threat was related to more acute PTSD symptoms and a stronger decrease in PTSD symptoms over time. After the acute phase, when life threat has abated

for virtually all cases, PTSD symptoms may decrease accordingly. Perceived life threat predicted higher PTSD symptom levels at 18 months post-burn, but not after controlling for acute PTSD symptoms. This suggests an indirect long-term effect of life threat through acute stress symptoms. This assumption is consistent with Ehlers and Clark's (2000) model, which states that PTSD symptoms can become persistent when trauma processing leads to negative appraisals of the trauma and/or its sequelae (e.g. overestimating the probability of future harm) and from poor elaboration or contextualization of the trauma memory. The findings fit with earlier studies showing that perceived life threat is a predictor of PTSD symptoms (Giannoni-Pastor et al., 2016; Kassam-Adams et al., 2009; Timmer-Murillo et al., 2020), and that peri-traumatic processes indirectly affect long-term PTSD symptoms through acute PTSD symptoms (Engelhard et al., 2003).

About two in three partners reported anger, whereas about one in three partners reported guilt. Compared to mothers of children with burns, the prevalence rate of anger in partners is comparable, but the prevalence of guilt was around 45% lower (Egberts et al., 2020). This may be explained by partners feeling less responsible for the burn event than mothers. Guilt was more common in partners who were present during the burn event. Possibly, they felt more helpless and may evaluate their behaviour more negatively, which is related to guilt feelings (McLean & Foa, 2017). This points to the relevance to consider guilt in partners who witnessed the event. Higher levels of anger and guilt in partners were related to higher levels of acute PTSD symptoms but were not related to the rate of decline in PTSD symptoms. These findings confirm previous studies indicating that the presence of early trauma-related emotions not necessarily predicts chronic PTSD and that persistent anger was longitudinally associated with PTSD symptoms (Egberts et al., 2020), in concert with DSM-5 criteria pointing to the risk of persistent emotions (American Psychiatric Association, 2013). In sum, the current study reveals differences across trauma-populations in the extent to which specific emotions occur and its contextual factors.

This study supports the concurrent link between rumination and acute PTSD symptoms. Rumination was earlier found to be associated with a higher frequency of intrusions and overall PTSD (Laposa & Rector, 2012; Szabo et al., 2017). As posited by Ehlers and Clark (2000), rumination in response to intrusions may prevent change in the trauma memory and inhibits modification of trauma appraisals. No evidence was found for a lasting effect of initial rumination on PTSD symptoms, which may be an indication of state rumination. As reported by Szabo et al (2017), trait rumination may be a more powerful predictor of PTSD

symptoms and suggests that measuring rumination at a later time point may yield more predictive power. Future research may investigate whether persistent rumination is associated with long-term PTSD symptoms in partners.

Strengths of the present study include the focus on partners, the longitudinal design, and assessment of emotional and cognitive factors relatively shortly after the burn event, which makes it unlikely that these reports were affected by retrospective bias or changes in the interpretation of the event (e.g. Engelhard & McNally, 2015). However, some limitations of this study should be noted. First, the model construction was performed in an exploratory way. Therefore, model replication is warranted. Second, the sample size was relatively small considering the complex statistics which may affect statistical power, and the inclusion of more male partners would have increased the generalizability of the findings to men. Third, rumination was measured in general and shortly after the burn event. An assessment at a later time might have increased predictive power. Last, pre-existing psychological problems were not reported, nor did we inquire after social support or professional psychosocial support received by the partner post-burn. Considering the multi-centre study design, professional support may have differed across the study locations.

This study yields some potential clinical implications. First, it shows that partners were particularly affected during the early phase, and also three months later, when one in ten partners experienced PTSD symptoms. Early interventions and psychoeducation in partners with acute PTSD symptom levels may improve stress management and emotion regulation (Ursano et al., 2004). For instance, online education and interventions may be considered for partners (Gawlytta et al., 2020). Future research may study interpersonal processes between burn survivors and partners, as dyadic associations have been reported in survivors of critical illness and their partners (Rosendahl et al., 2013).

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Additional file 1

This is supplementary information to the following article: Prevalence and course of posttraumatic stress disorder symptoms in partners of burn survivors.

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Description

This additional file shows an overview of the model development process that was followed in Mplus to come to the final piecewise growth model that described and predicted the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn. Table A lists the growth models that were subsequently tested, and, for each model, it provides information on the modelfit statistics, errors and warnings it produced, and a note on the conclusion about the model and the next step in the process. The model printed in Bold (model 13) was the final model that is described in the article.

Table A. *The model development process for a growth model that describes the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn (N = 111)*

Nr	Type	Mplus model	X^2 (*p*)	*df*	RMSEA	CFI	TLI	Errors / Warnings	Notes
1	growth	is | m1@0 m2@.3 m3@.6 m4@1.2 m5@1.8	92.57 (<.001)	10	.273	.648	.648		Bad modelfit --> add quadratic term
2	growth	isq | m1@0 m2@.3 m3@.6 m4@1.2 m5@1.8	47.68 (<.001)	6	.250	.822	.704	Warning: The residual covariance matrix (theta) is not positive definite (Negative residual m5)	Warning and bad modelfit --> add cubic term
3	growth	isqc | m1@0 m2@.3 m3@.6 m4@1.2 m5@1.8	5.29 (.02)	1	.197	.982	.817	Warnings: 1) The residual covariance matrix (theta) is not positive definite (Negative residual m5). 2) The latent variable covariance matrix (psi) is not positive definite (involving Q).	Warnings and bad modelfit --> try equal time intervals between all measurements
4	growth	isqc | m1@0 m2@.3 m3@.6 m4@.9 m5@1.2	1.24 (.27)	1	.046	.999	.990	Warnings: 1) Warning: The residual covariance matrix (theta) is not positive definite (Negative residual m5). 2) The latent variable covariance matrix (psi) is not positive definite (involving C).	Good modelfit, but warnings --> try simpler model without cubic term
5	growth	isq | m1@0 m2@.3 m3@.6 m4@.9 m5@1.2	24.25 (<.001)	6	.166	.922	.870	Warning: The residual covariance matrix (theta) is not positive definite (Negative residual m5)	Bad modelfit --> for completeness try model without quadratic term

Table A. *The model development process for a growth model that describes the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn (N = 111) (continued)*

Nr	Type	Mplus model	X^2 (*p*)	*df*	RMSEA	CFI	TLI	Errors / Warnings	Notes
6	growth	is | m1@0 m2@.3 m3@.6 m4@.9 m5@1.2	75.33 (<.001)	10	.243	.721	.721		Bad modelfit. A sharp decline in mean PTSD symptoms between m1 and m2 and a small decrease after m2 is observed. Two options were considered: 1) a growth model without m1; and 2) a piecewise growth model. We choose option 2 to be able to retain all data.
7	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.9 m5@1.5;	20.89 (.002)	6	.150	.936	.894	No convergence. Number of iterations exceeded.	Fixed: Iterations increased to 3000 Bad modelfit --> try equal time intervals
7x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9;	15.01 (.02)	6	.116	.962	.936		Modelfit better, but still not for all indicators. --> Try adding the predictors and explore both with actual time intervals and with equal time intervals
8	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.9 m5@1.5; all predictors: age, gender, surgeries, life threat, anger, guilt, rumination	45.83 (<.001)	20	.108	.926	.834	No convergence. Number of iterations exceeded. Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Fixed: Iterations increased to 40000 Warning and bad modelfit

Table A. *The model development process for a growth model that describes the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn (N = 111) (continued)*

Nr	Type	Mplus model	X^2 (*p*)	*df*	RMSEA	CFI	TLI	Errors / Warnings	Notes
8x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; all predictors: age, gender, surgeries, life threat, anger, guilt, rumination	40.19 (.005)	20	.095	.942	.870	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1)	Warning and bad modelfit --> try a model with less predictors (first only age, gender, surgeries) to explore which predictor(s) cause the warnings.
9	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.6 m4@.9 m5@1.5; predictors: age, gender, surgeries	38.41 (<.001)	12	.141	.894	.780	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1)	Warning and bad modelfit
9x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; predictors: age, gender, surgeries	32.15 (.001)	12	.123	.919	.832	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Warning and bad modelfit
10	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.6 m4@.9 m5@1.5; predictors: age, gender	37.39 (<.001)	10	.157	.890	.779	No convergence. Number of iterations exceeded. Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Fixed: Iterations increased to 40000 Warning and bad modelfit

Table A. *The model development process for a growth model that describes the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn (N = 111) (continued)*

Nr	Type	Mplus model	X^2 (*p*)	*df*	RMSEA	CFI	TLI	Errors / Warnings	Notes
10x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; predictors: age, gender	31.49 (<.001)	10	.139	.913	.827	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Warning and bad modelfit
11	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.6 m4@.9 m5@1.5; predictors: age, surgeries	32.58 (<.001)	10	.143	.908	.817	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Warning and bad modelfit
11x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; predictors: age, surgeries	25.46 (.005)	10	.118	.937	.874	Warning: The residual covariance matrix (theta) is not positive definite (negative residual m1).	Warning and bad modelfit
12	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.6 m4@.9 m5@1.5; predictors: gender, surgeries	25.85 (.004)	10	.119	.934	.867		No warnings --> age seems to cause the warnings
12x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; predictors: gender, surgeries	20.58 (.02)	10	.098	.956	.911		Next step: add the other predictors to see if no further warnings occur

Table A. *The model development process for a growth model that describes the trajectory of Post-traumatic stress symptoms in partners of burn survivors during 18 months post-burn (N = 111) (continued)*

Nr	Type	Mplus model	X^2 (*p*)	*df*	RMSEA	CFI	TLI	Errors / Warnings	Notes
13	**piece-wise growth**	**i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.6 m4@.9 m5@1.5; final predictors: gender, surgeries, life threat, anger, guilt, rumination**	**32.09 (.02)**	**18**	**.084**	**.958**	**.907**		**Modelfit acceptable, no warnings. This is the final model and results are reported in the article**
13x	piece-wise growth	i s1 | m1@0 m2@.3 m3@.3 m4@.3 m5@.3; i s2 | m1@0 m2@0 m3@.3 m4@.6 m5@.9; final predictors: gender, surgeries, life threat, anger, guilt, rumination	27.59 (.07)	18	.069	.971	.937		Modelfit acceptable, no warnings. Although the modelfit is slightly better than for model 13, the difference is not large enough to select this model as the final model. Also, model 13 is preferred, as it describes actual time intervals.

Estimator = Maximum Likelihood with 10,000 bootstraps for all models

CHAPTER 3

3

Posttraumatic stress symptoms and interpersonal processes in burn survivors and their partners

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EBvD, RvdS, IE, and NVL designed the study. EBvD analysed the data under supervision of RvdS and NVL. EBvD drafted the initial article. All authors critically reviewed and revised the article and read and approved the final manuscript.

Abstract

Background: A burn event can elicit symptoms of posttraumatic stress disorder (PTSD) in survivors and their partners and may impact the way these couple members interact with each other. They may try to protect each other from further emotional distress by avoiding talking about the burn event, but they may also show concern towards each other.

Objective: The aim of this study was to investigate bidirectional relationships between survivor's and partner's PTSD symptoms and two interpersonal processes: partner-oriented 'self-regulation', which is avoidance-oriented, and 'expressed concern', which is approach-oriented.

Method: In this longitudinal multi-centre study, 119 burn survivors and their partners participated. Measures of PTSD symptoms, self-regulation, and expressed concern were administered in the acute phase following the burns, and follow-ups took place up to 18 months postburn. Intra- and interpersonal effects were examined in a random intercept cross-lagged panel model. Exploratory effects of burn severity were also investigated.

Results: Within individuals, survivor's expressed concern predicted later higher levels of survivor's PTSD symptoms. In their partners, self-regulation and PTSD symptoms reinforced each other in the early phase postburn. Between the two couple members, partner's expressed concern predicted later lower levels of survivor's PTSD symptoms. Exploratory regression analyses showed that burn severity moderated the effect of survivor's self-regulation on survivor's PTSD symptoms, indicating that self-regulation was continuously related to higher levels of PTSD symptoms over time within more severely burned survivors, but not in less severely burned survivors.

Conclusion: PTSD symptoms and self-regulation reinforced each other in partners and possibly also in more severely burned survivors. Partner's expressed concern was related to lower levels of survivor's PTSD symptoms, whereas survivor's expressed concern was related to higher levels of survivor's PTSD symptoms. These findings emphasize the importance of screening for and monitoring PTSD symptoms in burn survivors and their partner and of encouraging couple's self-disclosure.

Introduction

A burn event can be distressing for both the burn survivor and their partner. Given the potentially traumatic nature of the event, it may be unsurprising that elevated acute stress levels are found in about 30% of survivors and partners (Bond et al., 2017; Giannoni-Pastor et al., 2016). Also, posttraumatic stress disorder (PTSD) symptoms may develop, which may persist and have a long-term impact on quality of life (Spronk et al., 2018). Thus far, it is largely unknown how interpersonal processes and posttraumatic stress interact within couples after a burn event, and whether burn severity affects these processes. Burns often result in scarring and changes in the physical appearance or functioning, which may trigger intrusive recollections of the trauma and constitute a struggle with acceptance for both survivors and partners (Gullick et al., 2014; Phillips et al., 2007), thereby interfering with adequate (dyadic) coping (Ehlers & Clark, 2000; Falconier & Kuhn, 2019). A deeper understanding of these processes and contributing factors may inform health care practice to provide better support for burn survivors and their partners.

To cope with a distressing event, couples may engage in an avoidance-oriented interpersonal process (Stroebe et al., 2013). According to the cognitive-behavioural interpersonal model (Dekel & Monson, 2010; Monson et al., 2010), avoidance is one of the primary coping mechanisms that contributes to both the maintenance of PTSD symptoms and relationship difficulties. In an attempt to protect the survivor or the partner from further suffering, an avoidance-oriented interpersonal process manifests when one couple member tries to remain strong or holds negative feelings and thoughts from the other (Bäckström et al., 2018; Gullick et al., 2014), which may be triggered by seeing the scars (Macleod et al., 2016). Such an avoidance-oriented process was operationalized by Stroebe et al. (2013) as 'partner-oriented self-regulation' (hereafter referred to as 'self-regulation'), and resembles concepts in the PTSD literature, such as protective buffering (Coyne & Smith, 1991), partner accommodation (Fredman et al., 2014), expressive suppression (Seligowski et al., 2015), holding back (Manne et al., 2015), or reluctance to talk (Pielmaier & Maercker, 2011). All these avoidance-oriented interpersonal processes have in common that they require continuous efforts to regulate the self, a depleting capacity (Baumeister et al., 2018) that may interfere with processing, habituation, and reduction of threat perception, thereby maintaining PTSD symptoms (Ehlers & Clark, 2000; Seligowski et al., 2015).

Regardless of its specific form, the empirical literature shows support for an intrapersonal effect of avoidance-oriented interpersonal processes, increasing one's own distress (Chen et al., 2021; Langer et al., 2009; Manne et al., 2015; Manne et al., 2007; Stroebe et al., 2013) and PTSD symptoms (Pielmaier, 2011). There is also support for an interpersonal effect, in which avoidance-oriented processes displayed by one couple member are related to higher levels of their partner's distress (Chen et al., 2021; Manne et al., 2007; Stroebe et al., 2013) and PTSD symptoms (Fredman, 2014; Pielmaier, 2011). In burn research, avoidant coping (though not in an interpersonal context) has been related to higher levels of PTSD symptoms (Bosmans et al., 2015; Lawrence & Fauerbach, 2003; Su & Chow, 2020; Wiechman et al., 2020). Although the effect in the reverse direction, of PTSD symptoms on interpersonal avoidance, has been less intensively studied, it was found that interpersonally, PTSD symptoms and grief predict higher levels of interpersonal avoidance in one's partner over time (Allen et al., 2021; Stroebe et al., 2013). Moreover, a review shows that over time, PTSD symptoms appear to spur interpersonal difficulties rather than vice versa (Campbell & Renshaw, 2018).

Another interpersonal process is approach-oriented and may occur when a couple member expresses concern about the emotional well-being of their partner or encourages the partner to disclose feelings (Stroebe et al., 2013). By showing sensitivity, interest, acceptance and understanding one partner is responsive to the needs of the other (Maercker & Horn, 2013; Reis & Clark, 2013). Such responsivity can enhance emotional self-disclosure (Ruan et al., 2020), which may facilitate the processing of a traumatic event by promoting habituation and integration of trauma-related emotions and memories and challenging dysfunctional cognitions (see Frattaroli, 2006). Even the non-injured partner may feel supported when they can discuss strains with the burn survivor (Bäckström et al., 2018). This approach-oriented interpersonal process was operationalized by Stroebe et al. (2013) as 'expressed concern', and it comes close to concepts in the PTSD literature such as social (crisis) support (Engelhard et al., 2003; Wang et al., 2021; Zalta et al., 2021), intimacy (Leifker et al., 2015), and (perceived) partner responsiveness (Canevello et al., 2016). A partner's support and expressed concern may compensate for the depletion of self-regulatory strength through promoting adaptive processes like self-efficacy (Pietromonaco et al., 2022; Warner et al., 2015).

Research on approach-oriented interpersonal processes has primarily focused on the interpersonal effect of (perceived) social support on the survivor's well-being. Meta-analyses of risk factors for PTSD after other types of traumatic

events, as well as burn research, showed that higher levels of social support are related to lower levels of PTSD symptoms (Brewin et al., 2000; Lawrence & Fauerbach, 2003; Ozer et al., 2003; Su & Chow, 2020; Sveen et al., 2011; Wang et al., 2021; Zalta et al., 2021). Furthermore, intrapersonally, a more complex relation between approach processes and PTSD symptoms is found. One study showed that higher levels of PTSD symptoms were related to providing less support to the partner (Hanley et al., 2013), and another study showed that veterans' tendency to experience concern towards others was related to their own higher levels of PTSD symptoms (Siegel et al., 2021).

Currently, few studies have examined the (bidirectional) effects of PTSD symptoms on both avoidance- and approach-oriented interpersonal processes, or included both intra- and interpersonal effects, and none have studied these effects in the burn population. Consequently, the general aim of this study was to investigate intra- and interpersonal bidirectional relations between an avoidance-oriented interpersonal process (i.e. self-regulation) and PTSD symptoms, and between an approach-oriented process (i.e. expressed concern) and PTSD symptoms in burn survivors and their partners over time. Specifically, we hypothesized bidirectional effects between self-regulation and expressed concern on the one hand and PTSD symptoms on the other hand, both within and between couple members. Furthermore, the possible effect of burn severity on these relationships was explored.

Methods

Inclusion

Data from this study were part of a larger project in three Dutch and three Belgian burn centres that focused on the social impact of burns. Previous work described burn survivor's quality of life in relation to PTSD symptoms and described partner's PTSD symptoms (Boersma-van Dam et al., 2021; Boersma-van Dam et al., 2020). Survivors and their partners were recruited between October 2013 and October 2015 and were followed for 18 months. Inclusion criteria for survivors were: hospital stay of >24 h following the burn event, age of 18 years or older, and proficiency in Dutch. The last two criteria also applied to partners. Exclusion criteria were: psychiatric problems that interfere with the comprehension of questionnaires (e.g. psychosis, cognitive problems).

Procedure

The study was approved by ethics boards in the Netherlands and Belgium. Survivors and their partners were invited to participate in the study by a local researcher during hospitalization. After receiving oral and written study information, they provided written informed consent and completed the first measurement (T1; $M_{survivor}$ = 22 days postburn, *SD* = 22.8; $M_{partner}$ = 24 days, *SD* = 24.0 days postburn). Follow-up measures were sent at 3 (T2), 6 (T3), 12 (T4), and 18 (T5) months postburn by postal mail.

Sample and missing data

In this cohort study, 187 survivors (out of a total of 266 patients) indicated they were involved in a romantic relationship, 120 of whom had partners who agreed to participate in the study. One survivor did not complete any measure. For the 119 couples comprising the final sample, each member had completed at least one measurement of PTSD symptoms and one measurement of either self-regulation (*n* = 118) or expressed concern (*n* = 117). Using t-tests and chi-square difference tests, no statistically significant differences emerged between the 119 participating couples and the 68 not participating couples, with respect to T1 measures of survivors' PTSD symptoms, self-regulation, expressed concern, TBSA burned, number of surgeries, gender and age (*p*'s > .05).

The number of couples for which at least one of the members completed a measure of PTSD, self-regulation or expressed concern was 119 (100%) at T1, 107 (89.9%) at T2, 102 (85.7%) at T3, and 90 (75.6%) at both T4 and T5. In total, 38 couples (31.9%) had complete data for all measurements of PTSD symptoms, self-regulation and expressed concern, 35 (29.4%) had missing data for one dyad member, and 46 (38.7%) had missing data for both dyad members. Comparing specifically survivors with complete (*n* = 57) and incomplete (*n* = 62) data yielded no significant differences with regard to T1 measures of PTSD symptoms, self-regulation, expressed concern, TBSA burned, number of surgeries, partner's presence at the burn event, gender and age (*p*'s > .05). However, comparing specifically partners with complete (*n* = 54) and incomplete (*n* = 65) data showed significantly higher levels of survivor's self-regulation (T1) for partners with incomplete data (*M* = 6.25 , *SD* = 2.78) than for partners with complete data (*M* = 5.15, *SD* = 1.90), t (109.5) = 2.53, p = .01.

Measures

Posttraumatic Stress Disorder Symptoms. The Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997) was used to assess PTSD symptoms. It is a 22-item self-report questionnaire that measures three symptom clusters of PTSD

symptoms in the past week: intrusions, avoidance, and hyper-arousal. Answers were given on a 0 – 4 Likert scale and summed to obtain a total score, with scores ≥ 33 indicating a possible diagnosis of PTSD (Creamer et al., 2003). If at least 19 of the 22 items were completed, sum scores were calculated based on the mean of the completed items. The IES-R was validated in Dutch trauma populations and showed good psychometric properties (Olde et al., 2006). The reliability of the IES-R in the current study was excellent at the five measurements, with Cronbach's alphas ranging from .95 to .97 for survivors and .93 to .97 for partners.

Partner-oriented self-regulation. The partner-oriented self-regulation scale (Stroebe et al., 2013) was designed to examine self-regulation of feelings in order to protect a partner in a bereavement situation, but we applied it to the burn event. It consists of three items: 'I stay strong for my partner', 'I try to spare my partner's feelings', and 'I hide my feelings for the sake of my partner'. Answers were rated on a 5-point Likert scale ranging from 1 'not at all' to 5 'very much' by both partners. The scale has not been validated in the burn population, but in line with Stroebe et al (2013), Cronbach's alphas ranged from .69 to .76 for survivors and from .72 to .84 in partners over time.

Expressed concern. Expressed concern was measured with the 'concern for the partner' scale (Stroebe et al., 2013), that was designed to measure approach-oriented behaviour in the bereavement situation, but we applied it to the burn event. Expressed concern was measured with three items: 'I encourage my partner to talk about his/her feelings', 'I ask my partner how he/she feels',and 'I show interest in what my partner is going through'. Answers were rated on a 5-point Likert scale ranging from 1 'not at all' to 5 'very much' by both partners. The scale has not been validated in the burn population, but in line with Stroebe et al. (2013), Cronbach's alphas ranged from .84 to .88 in survivors and from .81 to .87 in partners over time.

Burn characteristics. The number of surgeries, total body surface area (TBSA) burned, length of stay in the hospital, and mechanical ventilation (yes/no) were recorded from the survivor's medical file. Presence at the burn event was self-reported by the partner. The number of surgeries indicates the number of skin graft procedures required to cover the wounds and is considered an indicator of burn severity. TBSA burned is the estimated percentage of the body covered with partial and full-thickness burns.

Statistical analyses

Descriptive analyses were conducted in IBM SPSS v28. To analyse missing data patterns, t-tests and chi-square difference tests were performed. Longitudinally, intra- and interpersonal effects between self-regulation and PTSD symptoms, and between expressed concern and PTSD symptoms, were examined in two random intercept cross-lagged panel models (RI-CLPM; Hamaker et al., 2015) in Mplus 8 (Muthén & Muthén, 1998-2017). Full Information Maximum Likelihood (FIML) was used to handle missing data in SEM. To account for the non-normality of some of the variables, Robust Maximum Likelihood (MLR) was used.

Unlike the traditional CLPM, the RI-CLPM separates the within-dyad level from the between-dyad level by including a random intercept, thereby accounting for time-invariant, trait-like stability between dyads (Hamaker et al., 2015). Figure 1 displays the RI-CLMP model for self-regulation, but an identical model was tested for expressed concern. On the between-level, correlations between the random intercepts represent overall between-couple effects (Figure 1(a)). On the within-level, positive cross-lagged regression paths indicate, for example, that time points when a survivor scored above their expected score on PTSD symptoms were followed by time points when this survivor scored above their expected score on self-regulation (Figure 1(b)).

A RI-CLPM with time-varying estimates was too complex for the data. Therefore, the parameters in each model were constrained to be equal across time points without evaluation of this assumption with a formal chi-square difference test. Next, in a stepwise procedure, it was tested whether the paths for survivors and partners could be constrained to be equal, resulting in two identical final models, one for self-regulation and one for expressed concern. Model fit of these models was evaluated with the comparative fit index (CFI), the Tucker-Lewis Index (TLI), and the root mean square error of approximation (RMSEA). TLI and CFI > .90 and RMSEA < .08 indicated an acceptable model fit (Kline, 2011).

An additional aim of the study was to explore the effect of burn severity on the above relations. However, model complexity in relation to the sample size prevented to add this variable as a moderator to the RI-CLPM. Therefore, cross-sectional multiple regression analyses were performed within survivors and within partners at each time point. Specifically, the survivor's PTSD symptoms were cross-sectionally predicted by the survivor's self-regulation, number of surgeries, and the interaction between these variables. This analysis was repeated using expressed concern as a predictor instead of self-regulation. Similarly, survivor's self-regulation and expressed concern were each regressed on number of

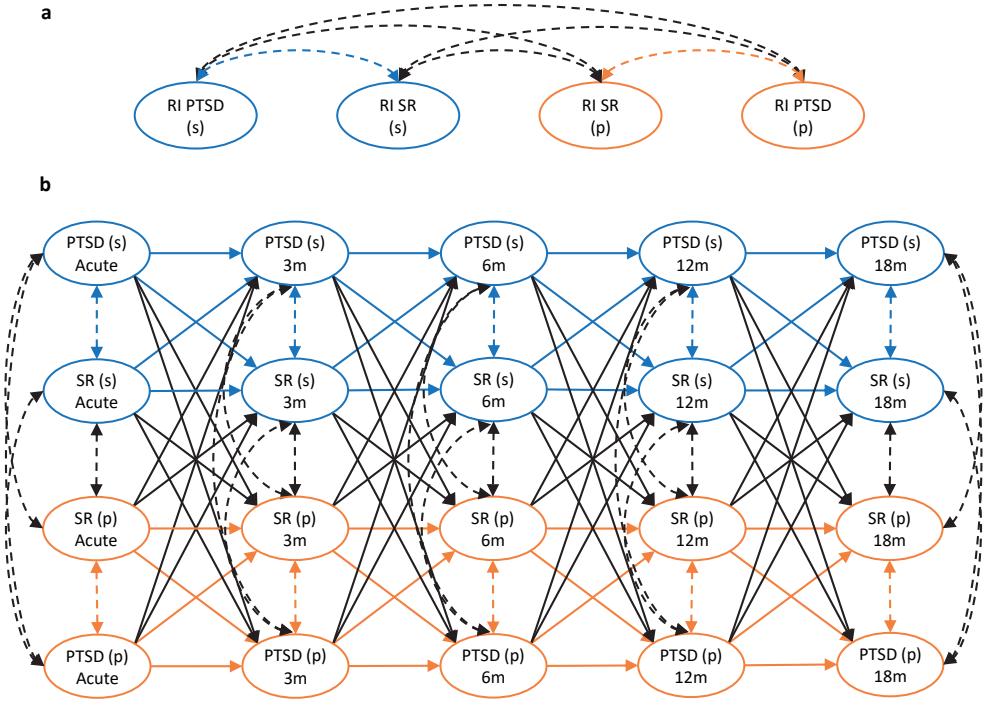

Figure 1

Simplified path model of the random-intercept cross-lagged panel model without estimates, with **(a)** *representing the correlations between the four random intercepts and with* **(b)** *representing the relations between the person-mean centered variables over time. ← - → = correlations; → = regression coefficients; Blue colors indicate effects within survivors; Orange colors indicate effects within partners; Black colors indicate interpersonal effects between survivors and partners; RI = random intercept; PTSD = post-traumatic stress disorder symptoms; SR = partner-oriented self-regulation; S = survivor; P = partner; m = months postburn*

surgeries, survivor's PTSD symptoms, and the interaction term. These analyses were repeated for the partner, resulting in a large number of analyses. To correct for multiple-testing in all analyses, only p-values ≤ .01 were deemed significant in all analyses.

Results

Descriptive analyses

The 119 couples consisted of 92 (77.3%) male burn survivors with a female partner and 27 (22.7%) female survivors with a male partner. The mean age was

45.7 (*SD* = 15.1, range 18 – 77) in survivors, and 44.5 (*SD* = 14.5, range 19 – 78) in partners. The burn survivor's mean TBSA burned was 10.3% (*SD* = 11.1, range: 1 – 75) and the median number of surgeries was 1 (range 0 – 14). For further analyses, this variable was recoded into 'no surgeries' (*n* = 53; 44.5%), and 'one or more surgeries' (*n* = 66; 55.5%). Among the partners, 44 (39.6%) were present at the burn event, 67 (60.4%) were not present, and 8 had missing data.

Figure 2 depicts the mean scores for total PTSD symptoms, self-regulation, and expressed concern of burn survivors and partners over time (see also Appendix 1 in the Supplementary material). PTSD symptom levels of both survivors and partners decreased over time, and the percentage that showed clinically high levels of PTSD symptoms decreased from 18% (acute) to 6% (18 months) in survivors and from 30% (acute) to 5% (12/18 months) in partners. Levels of self-regulation and expressed concern were approximately stable in survivors but decreased over time in partners. In the acute phase, partner's PTSD symptoms, self-regulation, and expressed concern were significantly higher than those of survivors, and at 18 months postburn expressed concern was significantly higher in survivors than in partners.

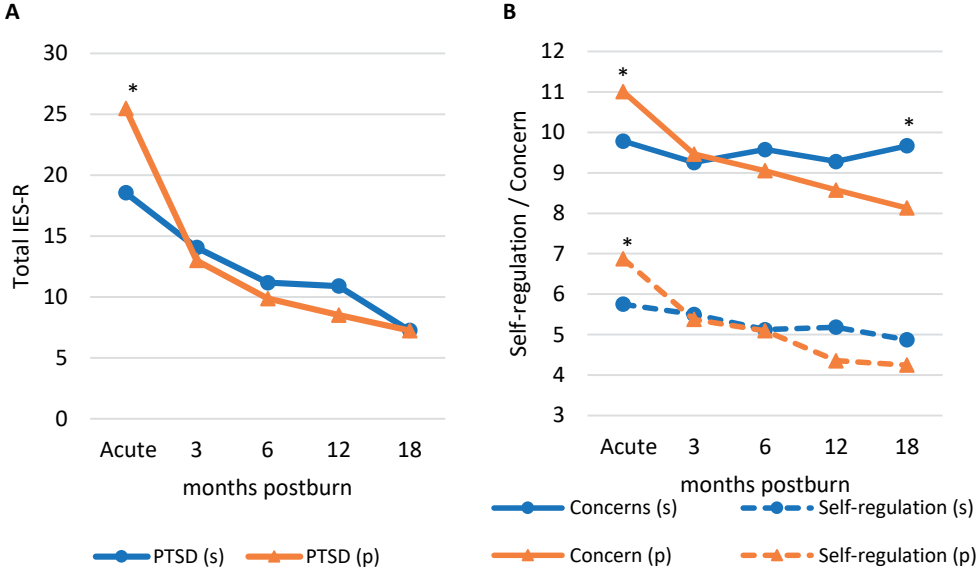

Figure 2

*Survivors' and partners' levels of PTSD symptoms (a), self-regulation (b), and concern (b) over time. PTSD = Posttraumatic stress symptoms; s = survivor; p = partner. *At this measurement time, the means of survivors and partners differ significantly with p ≤ .01*

Tables 1 and 2 present the bivariate correlations of respectively self-regulation and expressed concern with the study variables. Within individuals, associations between PTSD symptoms and self-regulation were, generally, moderately-strong over time, whereas associations between expressed concern and PTSD relations were small-moderate in partners, and unrelated or small in survivors. Interpersonally, associations between self-regulation of one dyad member and PTSD symptoms of the other were not consistently found across all time points, and were weaker for expressed concern with PTSD symptoms.

Remarkably, all significant correlations between expressed concern and PTSD symptoms were positive. Burn severity was significantly related to PTSD symptoms of both dyad members, but not to self-regulation and expressed concern.

RI-CLPM

A stepwise method was used to arrive at the most parsimonious RI-CLPM by testing whether identical paths between survivors and partners could be constrained to be equal (see Appendix 2 in the supplementary material). In the within-part of the final models, identical autoregressive paths and correlations were constrained to be equal, while the paths of most interest, the cross-lagged effects, could not be constrained and were estimated freely in survivors and partners. The model fit of the final models was acceptable for self-regulation, χ^2 (158) = 244.29, $p < .001$, RMSEA = .07, CFI = .91, TLI = .90, and expressed concern, χ^2 (158) = 229.90, $p < .001$, RMSEA = .06, CFI = .93, TLI = .91.

Table 1. *Pearson correlations for PTSD symptoms and self-regulation in survivors and partners over time*

	Survivors										Partners									
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Survivors																				
1 PTSDs Acute																				
2 PTSDs 3m	.72*																			
3 PTSDs 6m	.68*	.73*																		
4 PTSDs 12m	.61*	.62*	.82*																	
5 PTSDs 18m	.48*	.65*	.68*	.87*																
6 SRs Acute	.34*	.39*	.27*	.41*	.20															
7 SRs 3m	.34*	.53*	.39*	.40*	.26*	.55*														
8 SRs 6m	.37*	.49*	.59*	.58*	.55*	.41*	.55*													
9 SRs 12m	.29*	.43*	.49*	.55*	.44*	.57*	.58*	.76*												
10 SRs 18m	.28*	.40*	.47*	.53*	.48*	.48*	.48*	.67*	.80*											
Partners																				
11 PTSDp Acute	.24*	.38*	.33*	.29*	.38*	.22*	.19*	.24*	.21	.31*										
12 PTSDp 3m	.27*	.47*	.35*	.24*	.42*	.36*	.26*	.42*	.35*	.41*	.72*									
13 PTSDp 6m	.31*	.37*	.41*	.34*	.43*	.23*	.16	.36*	.33*	.38*	.57*	.72*								
14 PTSDp 12m	.24*	.31*	.36*	.33*	.51*	.22*	.14	.30*	.29*	.37*	.46*	.64*	.72*							
15 PTSDp 18m	.30*	.53*	.50*	.53*	.68*	.31*	.27*	.44*	.46*	.48*	.54*	.66*	.67*	.78*						
16 SRp Acute	.22*	.19	-.05	-.07	-.03	.13	.19	-.05	-.05	.02	.25*	.29*	.18	.08	.03					
17 SRp 3m	.19	.17	.11	.02	.10	.21*	.18	.23*	.13	.24*	.30*	.52*	.52*	.48*	.31*	.44*				
18 SRp 6m	.22*	.33*	.32*	.25*	.38*	.28*	.23*	.45*	.28*	.33*	.49*	.66*	.68*	.76*	.71*	.36*	.65*			
19 SRp 12m	.27*	.40*	.30*	.36*	.36*	.24*	.22*	.38*	.38*	.45*	.40*	.52*	.65*	.62*	.61*	.21	.38*	.65*		
20 SRp 18m	.23*	.28*	.19	.24*	.32*	.21	.11	.24*	.15	.31*	.41*	.38*	.47*	.64*	.51*	.32*	.47*	.67*	.68*	
Burn severity																				
21 Surgeries	.15	.24	.26*	.32*	.32*	.00	.11	.18	.19	.23	.23	.32*	.18	.27*	.36*	-.07	.07	.18	.26	.21

Note. PTSD = Posttraumatic stress symptoms; SR = self-regulation; m = months postburn; *$p < .01$.

Table 2. *Pearson correlations for PTSD symptoms and concern in survivors and partners over time*

	Survivors										Partners									
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Survivors																				
1 PTSDs Acute	-																			
2 PTSDs 3m	.72*	-																		
3 PTSDs 6m	.68*	.73*	-																	
4 PTSDs 12m	.61*	.62*	.82*	-																
5 PTSDs 18m	.48*	.65*	.68*	.87*	-															
6 CONCs Acute	.05	.00	.11	.19	.12	-														
7 CONCs 3m	.18	.07	.26	.26	.14	.40*	-													
8 CONCs 6m	.05	-.11	.00	.13	-.11	.47*	.57*	-												
9 CONCs 12m	.16	.16	.15	.16	.18	.63*	.49*	.67*	-											
10 CONCs 18m	.09	.09	.02	.02	.00	.46*	.48*	.68*	.64*	-										
Partners																				
11 PTSDp Acute	.24*	.38*	.33*	.29*	.38*	.09	-.04	-.07	.08	.04	-									
12 PTSDp 3m	.27*	.47*	.35*	.24	.42*	-.01	-.13	-.10	.07	-.01	.72*	-								
13 PTSDp 6m	.31*	.37*	.41*	.34*	.43*	.00	-.10	-.09	.09	.06	.57*	.72*	-							
14 PTSDp 12m	.24	.31*	.36*	.33*	.51*	.15	.12	.05	.22	.13	.46*	.64*	.72*	-						
15 PTSDp 18m	.30*	.53*	.50*	.53*	.68*	.06	.09	-.06	.18	.04	.54*	.66*	.67*	.78*	-					
16 CONCp Acute	.09	.11	.06	.07	.18	.27*	-.06	-.11	.08	-.01	.27*	.22	.21	.31	.25	-				
17 CONCp 3m	.19	.22	.11	.11	.11	.23	.24	.17	.16	.21	.31*	.24	.24	.32*	.18	.50*	-			
18 CONCp 6m	.24	.31*	.33*	.16	.33*	.22	.20	.00	.31*	.17	.30*	.38*	.42*	.39*	.32*	.40*	.47*	-		
19 CONCp 12m	.11	.22	.13	.07	.08	.09	.27	.13	.28	.31*	.23	.18	.30*	.35*	.23	.50*	.61*	.60*	-	
20 CONCp 18m	.16	.08	.09	.01	.03	.17	.38*	.29*	.35*	.44*	.14	.13	.28	.28	.18	.23	.41*	.63*	.78*	-
Burn severity																				
21 Surgeries	.15	.24	.26*	.32*	.32*	.03	.09	-.02	-.03	-.03	.23	.32*	.18	.27	.36*	.07	.11	.15	.22	.05

Note. PTSD = Posttraumatic stress symptoms; CONC = expressed concern; m = months postburn; *$p < .01$.

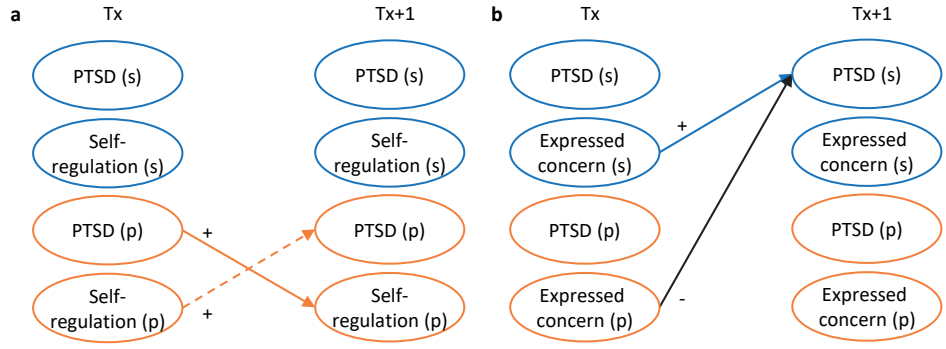

Figure 3. *Visual presentation of the statistically significant within-couple results (p ≤ .01) in a simplified path model for (a) self-regulation and (b) expressed concern. The full lines represent repeated significant effects over time, the dashed line represents a significant effect from T1 to T2. Blue colors indicate effects within survivors; Orange colors indicate effects within partners; Black colors indicate interpersonal effects between survivors and partners; PTSD = post-traumatic stress disorder symptoms; S = survivor; P = partner; Tx represents T1-T4*

Table 3 presents the standardized estimates for the RI-CLPMs for self-regulation and expressed concern and Figure 3 presents a graphical display of the significant cross-lagged paths in both models. In general, levels of self-regulation and PTSD showed significant within-person stability over time, whereas levels of expressed concern did not. Couple members' levels of PTSD symptoms were significantly correlated over time, both at the within-couple and the between-couple levels.

The results for self-regulation showed that, only within partners, PTSD symptoms predicted higher levels of later self-regulation. And, self-regulation predicted higher levels of later PTSD symptoms, although this trend was not significant after 3 months postburn (p-value ranged between .02 and .05). Between the two members of a couple, no significant effects emerged. At the between-couple level, a number of significant correlations between the random intercepts emerged, indicating that stable differences between couples were present.

With regard to expressed concern it was found that, within survivors, expressed concern predicted higher levels of later PTSD. In partners, we found a non-significant trend with higher PTSD symptoms predicted higher levels of later expressed concern (p-values ranged between .04 and .06). Between couple members, higher levels of expressed concern in partners were related to lower levels of later PTSD in survivors. At the between-couple level, significant correlations were found between partner's PTSD and expressed concern, and between both couple members' expressed concern.

Table 3 *Standardized path coefficients for the random-intercept cross-lagged panel model*

Parameter	Self-regulation (n = 118)					Expressed concern (n = 117)				
	Acute	3m	6m	12m	18m	Acute	3m	6m	12m	18m
Within-couple effects										
Survivor → Survivor										
PTSDs → PTSDs		.50**	.41**	.53**	.55**		.49**	.41**	.55**	.59**
IPs → IPs		.24**	.23**	.26**	.21**		.09	.16	.12	.11
IPs → PTSDs		-.04	-.04	-.05	-.06		.14**	.17**	.17**	.24**
PTSDs → IPs		.11	.09	.10	.08		-.01	-.01	-.01	-.01
Partner → Survivor										
PTSDp→ PTSDs		-.11	-.10	-.10	-.11		.15	.11	.12	.17
IPp→ IPs		.12	.09	.09	.08		.08	.11	.11	.09
IPp → PTSDs		.17	.12	.14	.19		-.14**	-.15**	-.19**	-.24**
PTSDp → IPs		.10	.09	.09	.07		-.10	-.10	-.09	-.09
Partner → Partner										
PTSDp → PTSDp		.56**	.47**	.41**	.47**		.57**	.49**	.40**	.48**
IPp → IPp		.23**	.30**	.29**	.24**		.11	.12	.13	.11
IPp → PTSDp		.21**	.24	.18	.16		-.05	-.06	-.06	-.06
PTSDp → IPp		.30**	.28**	.31**	.33**		.23	.17	.16	.16
Survivor → Partner										
PTSDs→ PTSDp		.07	.07	.07	.07		.03	.03	.03	.02
IPs→ IPp		.01	.02	.02	.02		.05	.07	.06	.05
IPs → PTSDp		-.01	-.01	-.01	-.01		-.02	-.03	-.02	-.03
PTSDs → IPp		-.01	-.02	-.02	-.02		.04	.03	.04	.03
Correlations										
PTSDs ↔ IPs	.17	.13	.13	.21	.29	.02	.05	.06	.10	.16
PTSDp ↔ IPp	.11	.10	.16	.19	.24	.02	.06	.07	.08	.09
PTSDp ↔ IPs	.17	.08	.09	.10	.11	.03	-.01	-.02	-.01	-.02

Table 3 *Standardized path coefficients for the random-intercept cross-lagged panel model (continued)*

Parameter	Self-regulation (n = 118)					Expressed concern (n = 117)				
	Acute	3m	6m	12m	18m	Acute	3m	6m	12m	18m
PTSDs ↔ IPp	.15	.05	.07	.13	.20	.04	-.01	-.01	-.02	-.03
PTSDs ↔ PTSDp	.12	.20**	.22**	.29**	.50**	.10	.15**	.17	.23**	.47**
IPs ↔ IPp	.14	.13	.18	.28	.27	.41**	.06	.09	.10	.10
Between-couple effects										
RI PTSDs ↔ RI IPs			.69**					.02		
RI PTSDp ↔ RI IPp			.75**					.36**		
RI PTSDp ↔ RI IPs			.51					-.01		
RI PTSDs ↔ RI IPp			.47**					.23		
RI PTSDs ↔ RI PTSDp			.68**					.63**		
RI IPs ↔ RI IPp			.39					.32**		

*Note. *p ≤ .01; PTSD = Posttraumatic stress symptoms; IP = Interpersonal process; m = months postburn; RI = Random Intercept; p = partner; s = survivor.*

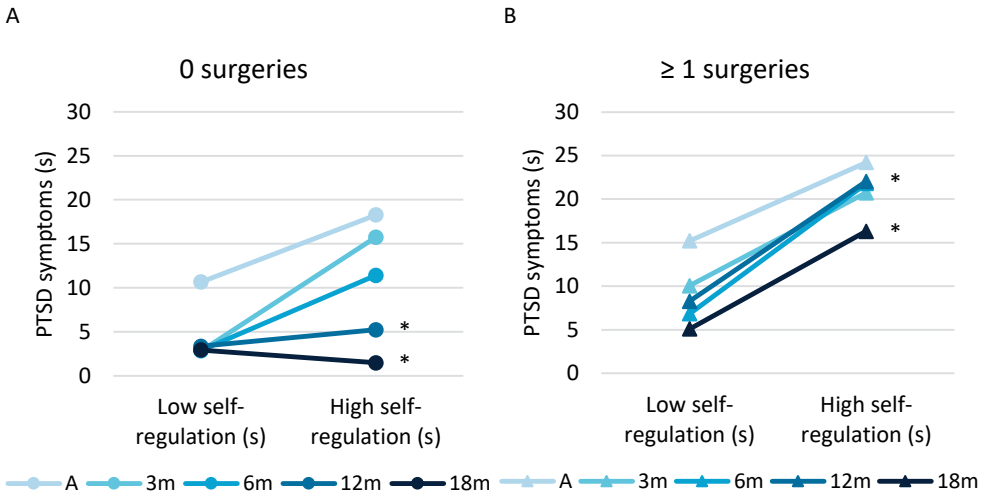

Figure 4

*Cross-sectional interaction effects of number of surgeries with self-regulation on PTSD of the survivor at each of the five measurement times. Predicted values for survivors without acute surgeries (A) and with at least 1 surgery (B) are shown. The 'low' and 'high' split for self-regulation was defined by the average median of the five measurement points. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; s = survivor; * p ≤ .01 for the interaction effect*

To explore the effect of number of surgeries on the above within-person relationships, cross-sectional interaction effects were evaluated at each measurement point. A significant interaction effect of number of surgeries with survivor's self-regulation on survivor's PTSD symptoms emerged. Figure 4 shows that the effect of self-regulation on PTSD symptoms remained from the acute phase until 18 months postburn in survivors who needed 1 or more surgeries (4b), but it diminished over time in survivors who did not need acute surgery (4a), with differences reaching significance from 12 months onward. A similar trend, though not significant, was found for the reverse effect of survivor's PTSD symptoms on survivor's self-regulation. In partners, the effect of PTSD symptoms on self-regulation was stronger if no surgeries were needed than if one or more surgeries were needed, up until 3 months postburn (Figure 5). For the other effects concerning self-regulation and expressed concern, no repeating significant interaction effects were found (see Appendix 3 for self-regulation and Appendix 4 for expressed concern in the Supplementary material).

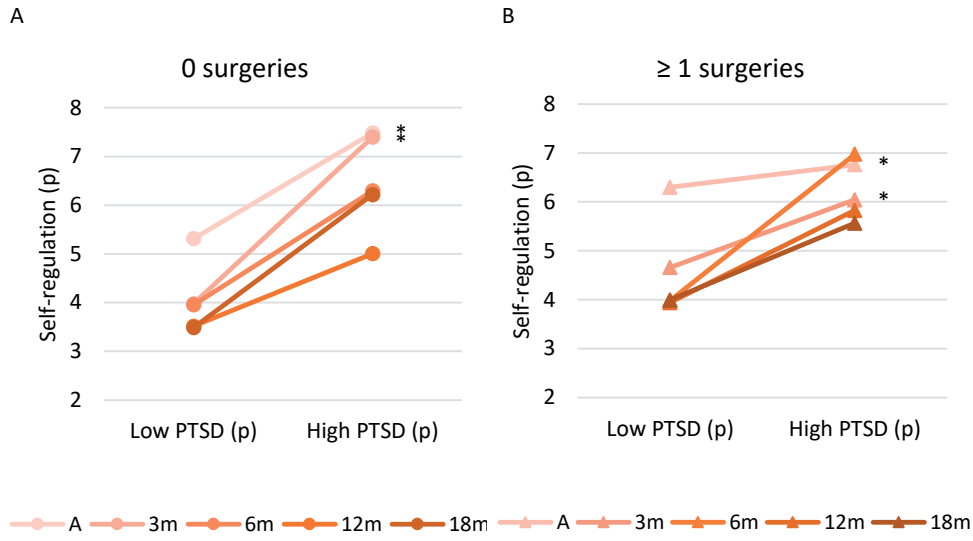

Figure 5

*Cross-sectional interaction effects of number of surgeries with PTSD of self-regulation of the partner at each of the five measurement times. Predicted values for partners of survivors without acute surgeries (A) and with at least 1 surgery (B) are shown. The 'low' and 'high' split for PTSD symptoms was defined by the average median of the five measurement points. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; s = survivor; p = partner; * p ≤ .01 for the interaction effect*

Discussion

This study examined the relationship between PTSD symptoms and the interpersonal processes of avoidance and approach in burn survivors and their partners from the acute phase until 18 months postburn. Levels of self-regulation (an avoidant interpersonal process), expressed concern (an approach interpersonal process) and PTSD symptoms of both survivors and partners were highest in the acute phase and decreased afterwards, specifically in partners. This study showed that only in partners, PTSD symptoms and self-regulation were intertwined in the subacute phase, and PTSD symptoms seemed to thrive self-regulation in the long term. In burn survivors, expressing concern was related to an increase in PTSD symptoms over time. Between couple members, we found that more concern expressed by the partner was related to a decrease in PTSD symptom levels in the survivor.

Results regarding 'self-regulation', which is an avoidance-oriented interpersonal process, demonstrated that in partners, PTSD symptoms and self-regulation reinforced each other in the first three months, after which PTSD symptoms continued to predict self-regulation, supporting the idea that avoidant self-

regulation and PTSD symptoms may form a maintaining cycle (Ehlers & Clark, 2000; Monson et al., 2010). That the effect from PTSD symptoms to later self-regulation lasted longer than the effect in the opposite direction is in line with the general literature (Campbell & Renshaw, 2018). Perhaps we only observed this effect in partners and not in survivors because the patient-supporter relationship after the burn event may make partners especially inclined to stay strong (Bäckström et al., 2018; Gullick et al., 2014). In survivors, additional exploratory analyses showed a probable moderation effect of burn severity in survivors. In more severely burned survivors, self-regulation was related to higher levels of PTSD symptoms throughout the study period, whereas in less severely burned survivors, this effect ceased after the first few months. Indeed, burn severity has been linked to PTSD-related avoidance processes, by showing that scars may form a constant reminder of the trauma and triggers avoidance-oriented processes (Macleod et al., 2016). Relations between avoidance and PTSD symptoms in both couple members are in line with previous research (Manne et al., 2021; Pielmaier & Maercker, 2011), supporting the idea that efforts to regulate the self may have deleterious consequences for one's wellbeing (Ehlers & Clark, 2000; Seligowski et al., 2015).

No interpersonal effects were found between one member's self-regulation and the other member's PTSD symptoms, in contrast to previous studies (Allen et al., 2021; Fredman et al., 2014; Pielmaier & Maercker, 2011), although some associations were demonstrated at the between-couple level. Differences in, for example, operationalization of interpersonal avoidance, sample (size) and statistical models make it difficult to interpret the cause of the difference in results with these studies. Notably, survivors' higher self-regulation in the acute phase predicted the partner dropping out during the study, suggesting that survivor's self-regulation impacts partners in at least some way, for example, it may cause the partner to think the burn event is no longer an issue, and study participation is no longer relevant.

With regard to the approach-oriented process 'expressed concern', findings showed that survivors' expressed concern predicted increased levels of PTSD symptoms over time, which contradicts the beneficial effects that were hypothesized, but have been found before (Siegel et al., 2021). This might be related to feelings of guilt of being a burden for the partner. Also, it may demonstrate emotional contagion, given that showing empathy for one's partner has been related to developing PTSD symptoms oneself (Gouin & Kiecolt-Glaser, 2012). In contrast, partners expressed concern predicted lower levels of survivors' PTSD symptoms over time, supporting the general literature that approach oriented

processes can mitigate PTSD symptoms (Brewin et al., 2000; Ozer et al., 2003; Pielmaier & Maercker, 2011; Su, 2018; Wang et al., 2021; Weinberg, 2013; Zalta et al., 2021) which is likely achieved through modification of posttraumatic negative appraisals (Robinaugh et al., 2011; Woodward et al., 2015). In sum, our results suggest that when a partner expresses empathic concerns this may enhance their role as supporter and have beneficial effects on the survivor's PTSD symptoms. Contrary, a survivor expressing empathic concerns about the impact of the burn event on the partner's well-being may contribute to the maintenance of their own PTSD symptoms.

Overall, this study indicated two different adverse intra-personal processes. In partners, self-regulation and PTSD symptoms are mutually exacerbating, whereas in survivors, expressed concern was related to higher levels of PTSD symptoms. Only for the survivor, a potential beneficial interpersonal effect was established, as partner's expressed concern was associated with lower subsequent PTSD symptoms in survivors. This is in line with a review in cancer populations, stating that patients were more affected by supportive communication than partners (Chen et al., 2021). Previous research with similar results in traumatic brain injury survivors and proxies (Pielmaier & Maercker, 2011) suggested that survivors often encounter a period of decreased social contacts due to their impairment, causing a stronger dependency on their partner for support, whereas partners can more easily turn to additional sources for support, making them less dependent on the survivor (see also Weinberg, 2013).

The strengths of this study included the use of dyadic longitudinal data, analysed to differentiate between within-couple effects and stable between-couple differences, providing unique insight into the dynamics of interpersonal processes and PTSD symptoms in burn survivors and partners. However, a number of limitations should be noted. First, the majority of the couples in the sample comprised of a male survivor with a female partner, which may have led to spurious survivor-partner differences that may actually reflect gender differences. Second, the limited number of couples in relation to the complex statistical model, prevented testing the model's assumption that effects were equal over time, and prevented the inclusion of gender and burn severity as moderators in the larger model. It may also have reduced the power to detect smaller effects. Third, no information was available on the quality of the couples' relationship, which may play a role in the effects between PTSD symptoms and interpersonal processes in couples (Lambert et al., 2015; LeBlanc et al., 2016). Fourth, the measures for self-regulation and expressed concern have not been validated, and need specific validation in the burn population. Also, these scales were self-reported

from the actor's point of view, while perceived partner support is more relevant for one's wellbeing (Fekete et al., 2007; Maercker & Horn, 2013; Reis & Shaver, 1988). Alternatively, the use of directly observed partner behaviours has been advocated (Maisel et al., 2008).

Future research in larger samples and with an alternative operationalization of interpersonal processes, such as accommodation, protective buffering, and actual or perceived social support, is needed to further shape our ideas about how PTSD symptoms and the regulation of behaviour, thoughts and feelings towards partners are related. Examining possible moderators, such as burn severity, and possible mediators, such as disclosure, may elicit specific conditions or mechanisms that strengthen or attenuate the relations.

This study has potential clinical implications. Health care providers in burn care are advised to assess the mental and emotional impact of the burn event on both survivors and partners in the acute phase as well as in the aftercare phase, given that the effects seem to persist. Specific attention may be needed for the survivor's concerns for their family and for their partner's use of self-regulation. Before discharge, a joint and open discussion about fears and worries may pave the way to more openness between partners. Partners may be encouraged to express their thoughts and feelings, for the sake of their own well-being. Special attention to the survivors' romantic relationship may continue during follow-up visits to support survivor and partner to continue their mutual openness about their feelings.

In conclusion, PTSD symptoms and interpersonal avoidance may mutually enforce each other, especially within partners of trauma survivors, who, although with altruistic intentions, may harm their own wellbeing. On the other hand, partner's expression of concern may enhance the survivor's processing of the traumatic event and mitigate PTSD symptoms.

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Appendix 1

Table A. Descriptive statistics of PTSD symptoms, self-regulation, and concern over time

	Survivors				Partners			
	n	*M*	*SD*	IES-R ≥ 33	*n*	*M*	*SD*	IES-R ≥ 33
PTSD								
Acute	116	18.56*	16.92	18.1%	118	25.47*	17.71	29.7%
3 months	105	14.06	15.80	14.3%	101	12.99	14.39	11.9%
6 months	101	11.18	15.09	10.9%	97	9.88	12.57	9.3%
12 months	89	10.89	13.61	9.0%	81	8.51	11.91	4.9%
18 months	88	7.25	10.95	5.7%	83	7.24	11.89	4.8%
Self-regulation								
Acute	116	5.75*	2.47		113	6.88*	2.85	
3 months	106	5.50	2.36		101	5.38	2.73	
6 months	97	5.12	2.54		97	5.09	2.69	
12 months	82	5.18	2.56		79	4.35	1.83	
18 months	85	4.87	2.48		82	4.24	1.97	
Expressed concern								
Acute	116	9.78*	2.97		93	11.01*	2.64	
3 months	93	9.26	3.36		101	9.47	3.04	
6 months	97	9.58	3.10		97	9.05	3.03	
12 months	78	9.28	3.20		80	8.58	3.15	
18 months	85	9.67*	3.09		83	8.13*	3.04	

Note. PTSD = Posttraumatic stress symptoms. *The means of survivors and partners differ significantly at this measurement time, with $p \leq .01$

Appendix 2

Since Model 4 (Table B) provided a significantly worse model fit than Model 3, we conducted post-hoc tests to investigate which cross-lagged paths differed significantly between survivors and partners.

Using Model 3 from table B, we used the Wald statistic to test whether each cross-lagged path of the RI-CLPM could be constrained between survivors and partners. Table C shows that especially the intra-personal path from expressed concern to later PTSD symptoms differed significantly between survivors and partners. Also, the intrapersonal path from PTSD symptoms to later self-regulation showed a trend towards significant differences between survivors and partners.

Table B. *Stepwise testing of equality constraints between survivors and partners in the time-invariant RI-CLPM*

Nr	Constraints between survivor & partner	χ^2	*df*	Scaling factor	*p*	RMSEA	CFI	TLI	$\Delta\chi^2_{SB}$ previous model (*p*)
	Self-regulation (*n* = 118)								
1	No constraints	247.0	152	1.17	<.001	.07	.91	.88	-
2	Autoregressive paths	244.3	154	1.18	<.001	.07	.91	.89	.86
3*	Model 2 + person-centered correlations	244.3	158	1.19	<.001	.07	.91	.90	.87
4	Model 3 + all cross-lagged paths	262.8	164	1.19	<.001	.07	.90	.89	.004
	Expressed concern (*n* = 117)								
1	No constraints	226.3	152	1.02	<.001	.07	.92	.91	-
2	Autoregressive paths	227.1	154	1.04	<.001	.06	.93	.91	.36
3*	Model 2 + person-centered correlations	229.9	158	1.04	<.001	.06	.93	.91	.55
4	Model 3 + all cross-lagged paths	250.9	164	1.03	<.001	.07	.91	.90	<.001

* Model 3 is the final model for which the results are reported in the article.

Table C. *Testing equality constraints between survivors and partners for each cross-lagged path of the RI-CLPM separately*

	Self-regulation (*n* = 118)			Expressed concern (*n* = 117)		
Constrained path	Wald	*df*	*p*	Wald	*df*	*p*
IP(s) → PTSD(s) & IP(p) → PTSD(p)	3.15	1	.08	7.43	1	.006
PTSD(p) → PTSD(s) & PTSD(s) → PTSD(p)	1.94	1	.16	1.02	1	.31
IP(p) → PTSD(s) & IP(s) → PTSD(p)	3.88	1	.05	3.28	1	.07
PTSD(s) → IP(s) & PTSD(p) → IP(p)	4.56	1	.03	2.79	1	.09
PTSD(p) → IP(s) & PTSD(s) → IP(p)	0.44	1	.51	1.12	1	.29
IP(p) → IP(s) & IP(s) → IP(p)	0.94	1	.33	0.28	1	.60

Note. s = survivor; p = partner; IP = interpersonal process

Appendix 3

The parameter estimates for the regression analyses concerning the within-person interaction effect of number of surgeries with self-regulation and PTSD symptoms are shown in Table D.

Table D. Regression analyses results for the interaction effects of surgeries on the intrapersonal relation between self-regulation and PTSD symptoms

	Survivors					Partners				
Effect	Est.	*SE*	95% CI		*p*	Est.	*SE*	95% CI		*p*
			LL	UL				LL	UL	
Effects on SR										
Acute										
Surg. (1+)	-0.25	0.45	-0.64	1.14	.58	-0.90	0.52	-1.93	0.14	.09
PTSD	0.05	0.02	0.01	0.08	.005	0.10	0.03	0.05	0.15	<.001
Surg. (1+) * PTSD	-0.00	0.03	-0.05	0.06	.90	-0.09	0.03	-0.15	-0.02	.006
3 months										
Surg. (1+)	0.02	0.41	-0.83	0.79	.96	-0.90	0.46	-1.82	0.01	.05
PTSD	0.07	0.02	0.04	0.10	<.001	0.21	0.03	0.15	0.27	<.001
Surg. (1+) * PTSD	-0.03	0.03	-0.02	0.08	.28	-0.15	0.03	-0.22	-0.08	<.001
6 months										
Surg. (1+)	0.04	0.46	-0.95	0.88	.94	0.36	0.41	-0.46	1.18	.38
PTSD	0.10	0.02	0.06	0.13	<.001	0.12	0.03	0.06	0.18	<.001
Surg. (1+) * PTSD	-0.02	0.04	-0.06	0.10	.67	0.03	0.03	-0.03	0.10	.32
12 months										
Surg. (1+)	-0.07	0.63	-1.19	1.33	.91	0.41	0.35	-0.29	1.10	.25
PTSD	0.12	0.02	0.08	0.16	<.001	0.08	0.02	0.03	0.13	.001
Surg. (1+) * PTSD	0.04	0.07	-0.18	0.09	.53	0.01	0.03	-0.05	0.07	.79
18 months										
Surg. (1+)	1.10	0.61	-2.31	0.11	.08	-0.34	0.46	-1.25	0.57	.46
PTSD	0.11	0.02	0.07	0.16	<.001	0.20	0.06	0.09	0.32	.001
Surg. (1+) * PTSD	0.19	0.09	-0.36	-0.01	.03	-0.13	0.06	-0.25	-0.01	.03
Effects on PTSD										
Acute										
Surg. (1+)	4.91	3.01	-10.88	1.05	.11	8.47	3.13	2.26	14.67	.008
SR	2.40	0.83	0.76	4.04	.004	2.51	0.77	0.98	4.03	.001
Surg. (1+) * SR	0.09	1.22	-2.50	2.32	.94	-1.73	1.10	-3.91	0.45	.12

Table D. Regression analyses results for the interaction effects of surgeries on the intrapersonal relation between self-regulation and PTSD symptoms (*continued)*

	Survivors					Partners				
Effect	Est.	*SE*	95% CI		*p*	Est.	*SE*	95% CI		*p*
			LL	UL				LL	UL	
3 months										
Surg. (1+)	5.02	2.61	-10.20	0.16	.06	8.16	2.34	3.51	12.81	.001
SR	2.98	0.70	1.59	4.38	<.001	3.11	0.61	1.89	4.32	<.001
Surg. (1+) * SR	-1.08	1.14	-1.19	3.34	.35	-0.97	0.86	-2.68	0.74	.26
6 months										
Surg. (1+)	5.73	2.46	-10.62	-0.84	.02	1.53	1.94	-2.32	5.38	.43
SR	3.46	0.56	2.35	4.57	<.001	2.75	0.63	1.50	4.00	<.001
Surg. (1+) * SR	1.00	1.10	-3.18	1.18	.36	0.56	0.77	-0.97	2.09	.47
12 months										
Surg. (1+)	9.23	2.18	-13.58	-4.88	<.001	1.68	2.28	-2.86	6.21	.46
SR	3.16	0.50	2.18	4.15	<.001	6.11	1.35	3.41	8.80	<.001
Surg. (1+) * SR	2.57	0.95	-4.45	-0.68	.008	-2.81	1.51	-5.81	0.19	.07
18 months										
Surg. (1+)	7.04	2.05	-11.12	-2.97	.001	6.23	2.25	1.76	10.71	.007
SR	2.53	0.47	1.60	3.46	<.001	1.64	0.96	-0.26	3.54	.09
Surg. (1+) * SR	2.95	0.95	-4.85	-1.05	.003	1.68	1.19	-0.69	4.05	.16

Reference category for Surgeries is 'No surgeries'. SR = self-regulation. Surg = Surgeries

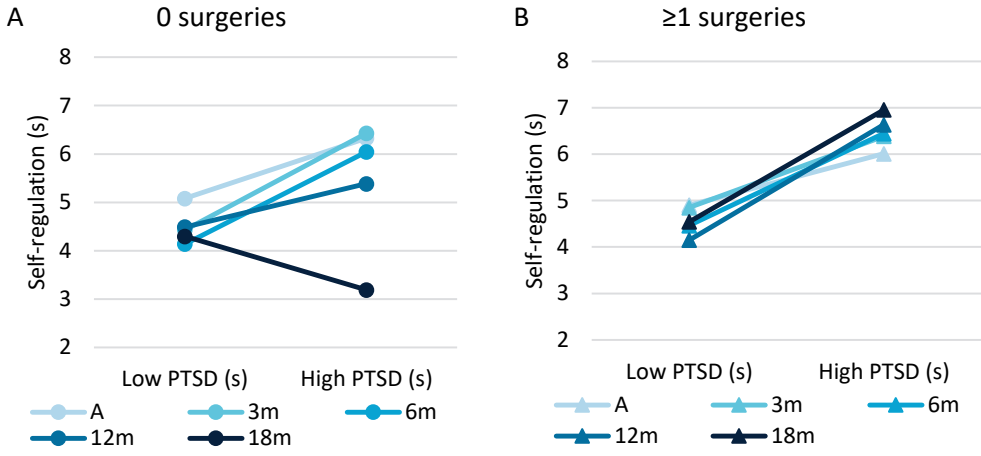

Figure A

Cross-sectional interaction effects of number of surgeries with PTSD on self-regulation of the survivor at each of the five measurement times. Predicted values for survivors without acute surgeries (A) and with at least 1 surgery (B) are shown. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; s = survivor;

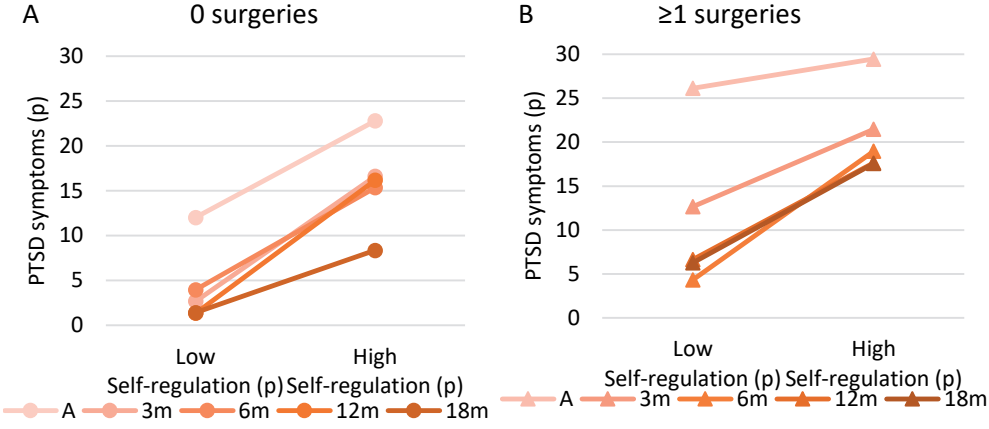

Figure B

Cross-sectional interaction effects of number of surgeries with self-regulation on PTSD symptoms of the partner at each of the five measurement times. Predicted values for partners of survivors without acute surgeries (A) and with at least 1 surgery (B) are shown. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; p = partner.

Graphical representations that were not reported in the main article of all within-person interaction effects between burn severity, self-regulation and PTSD symptoms are shown in Figure A for survivors and Figure B for partners. The 'low' and 'high' split for PTSD symptoms and for self-regulation were defined by their respective average median of the five measurement points. No significant differences emerged at any measurement time (*p*-values >.01).

Appendix 4

The parameter estimates for the regression analyses concerning the within-person interaction effect of number of surgeries with expressed concern and PTSD symptoms are shown in Table E.

Table E. *Regression analyses results for the interaction effects of surgeries on the relation between expressed concern and PTSD symptoms*

	Survivors					Partners				
Effect	Est.	*SE*	95% CI		*p*	Est.	*SE*	95% CI		*p*
			LL	UL				LL	UL	
Effects on EC										
Acute										
Surg. (1+)	4.94	3.21	-1.41	11.30	.13	-0.03	0.57	-1.16	1.10	.96
PTSD	0.11	0.73	-1.34	1.56	.88	0.02	0.03	-0.03	0.08	.38
Surg. (1+) * PTSD	0.36	1.08	-1.77	2.50	.74	0.03	0.03	-0.04	0.09	.46
3 months										
Surg. (1+)	7.70	3.33	1.07	14.32	.02	0.15	0.63	-1.11	1.41	.81
PTSD	-0.67	0.71	-2.08	0.74	.34	0.08	0.04	0.00	0.16	.04
Surg. (1+) * PTSD	1.78	0.99	-0.20	3.75	.08	-0.05	0.05	-0.15	0.04	.28
6 months										
Surg. (1+)	8.45	2.91	2.67	14.23	.005	0.47	0.58	-0.68	1.61	.42
PTSD	-0.44	0.66	-1.74	0.87	.51	0.12	0.04	0.04	0.19	.004
Surg. (1+) * PTSD	0.98	0.94	-0.89	2.84	.30	-0.03	0.05	-0.12	0.07	.55
12 months										
Surg. (1+)	11.09	2.68	5.75	16.44	<.001	0.78	0.70	-0.62	2.18	.27
PTSD	0.35	0.62	-0.88	1.59	.57	0.12	0.05	0.02	0.22	.02
Surg. (1+) * PTSD	0.65	0.84	-1.03	2.33	.44	-0.06	0.06	-0.18	0.07	.36
18 months										
Surg. (1+)	8.15	2.29	3.59	12.71	.001	-1.48	0.79	-3.04	0.09	.06
PTSD	0.13	0.48	-0.84	1.09	.80	0.36	0.10	0.17	0.55	<.001
Surg. (1+) * PTSD	-0.15	0.75	-1.64	1.34	.84	-0.34	0.10	-0.54	-0.14	.001
Effects on PTSD										
Acute										
Surg. (1+)	0.21	0.57	-0.93	1.35	.72	10.31	3.38	3.60	17.02	.003
EC	0.00	0.03	-0.05	0.05	.87	0.69	0.93	-1.15	2.54	.46

Table E. *Regression analyses results for the interaction effects of surgeries on the relation between expressed concern and PTSD symptoms (continued)*

	Survivors					Partners				
Effect	Est.	*SE*	95% CI		*p*	Est.	*SE*	95% CI		*p*
			LL	UL				LL	UL	
Surg. (1+) * EC	0.01	0.03	-0.06	0.08	.82	1.89	1.29	-0.66	4.45	.14
3 months										
Surg. (1+)	0.65	0.73	-0.79	2.10	.37	8.44	2.71	3.05	13.82	.002
EC	-0.04	0.04	-0.11	0.03	.28	1.10	0.66	-0.21	2.42	.10
Surg. (1+) * EC	0.08	0.05	-0.01	0.17	.09	-0.26	0.90	-2.05	1.53	.77
6 months										
Surg. (1+)	0.11	0.69	-1.26	1.48	.87	2.89	2.36	-1.79	7.58	.22
EC	-0.06	0.05	-0.17	0.05	.26	1.31	0.54	0.23	2.39	.02
Surg. (1+) * EC	0.08	0.06	-0.04	0.19	.20	0.73	0.78	-0.81	2.28	.35
12 months										
Surg. (1+)	-1.15	0.95	-3.03	0.74	.23	4.59	2.60	-0.59	9.78	.08
EC	0.12	0.10	-0.07	0.31	.23	1.18	0.59	0.00	2.36	.05
Surg. (1+) * EC	-0.07	0.10	-0.28	0.13	.47	0.01	0.82	-1.62	1.64	.99
18 months										
Surg. (1+)	-0.61	0.89	-2.39	1.16	.49	8.30	2.46	3.40	13.21	.001
EC	0.09	0.12	-0.16	0.33	.47	0.63	0.50	-0.37	1.62	.22
Surg. (1+) * EC	-0.09	0.13	-0.34	0.16	.48	0.03	0.85	-1.66	1.73	.97

Reference category for Surgeries is 'No surgeries'. EC = expressed concern. Surg = Surgeries

Graphical representations of all within-person interaction effects between burn severity, expressed concern and PTSD symptoms are shown in Figure C for survivors and Figure D for partners. The 'low' and 'high' split for PTSD symptoms and for expressed concern were defined by their respective average median of the five measurement points. No significant differences emerged at any measurement time (*p*-values >.01).

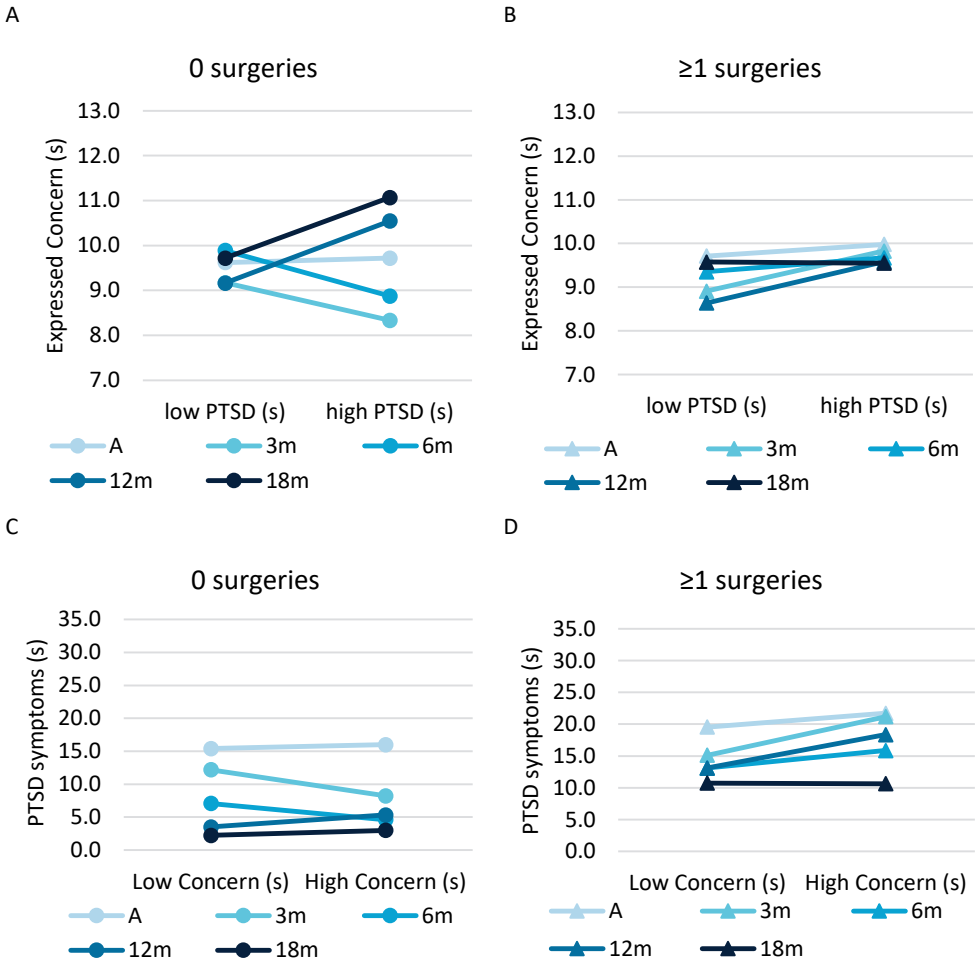

Figure C

Cross-sectional interaction effects of number of surgeries with expressed concern and PTSD symptoms of the survivor at each of the five measurement times. Predicted values for survivors without acute surgeries (A,C) and with at least 1 surgery (B,D) are shown. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; s = survivor;

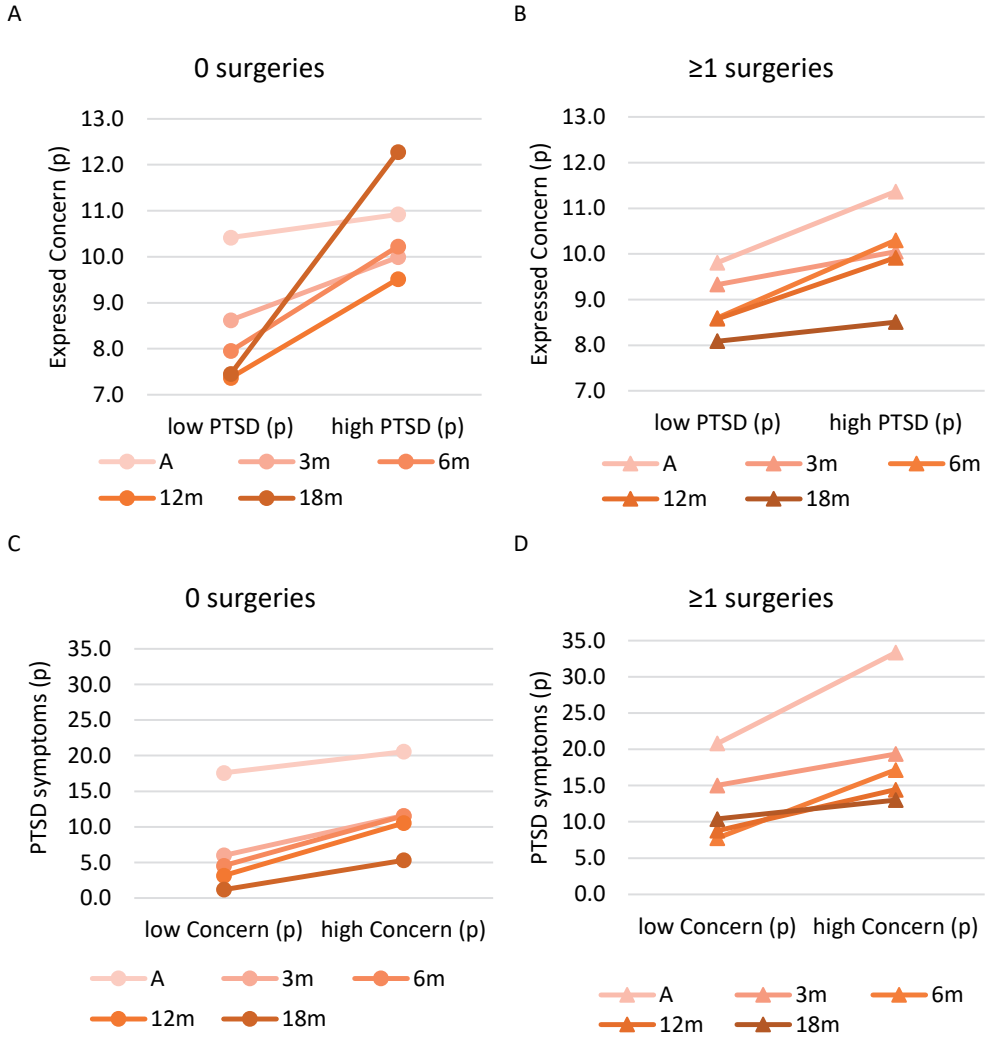

Figure D

Cross-sectional interaction effects of number of surgeries with expressed concern and PTSD symptoms of the partner at each of the five measurement times. Predicted values for partners of survivors without acute surgeries (A,C) and with at least 1 surgery (B,D) are shown. PTSD = Posttraumatic stress symptoms; A = Acute phase; m = months postburn; p = partner.

CHAPTER 4

4

Individual recovery of health-related quality of life during 18 months post-burn using a retrospective pre-burn measurement: an exploratory study

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Author contributions:
EB, RvdS, and NVL designed the study and analyzed and interpreted data. HH contributed to the data collection. EB drafted the initial article. RvdS, HH, IE, and NVL provided feedback on the manuscript. EB, NVL, RvdS, and IE reviewed and revised the article. All authors read and approved the final manuscript.

Abstract

Purpose: This study explored the individual trajectories of health-related quality of life (HRQL) compared to recalled preburn level of HRQL and investigated whether burn severity and post-traumatic stress disorder (PTSD) symptoms increase the risk of not returning to pre-burn level of HRQL.

Methods: Data were obtained from 309 adult patients with burns in a multicenter study. Patients completed the EQ-5D-3L questionnaire with a Cognition bolt-on shortly after hospital admission, which included a recalled pre-injury measure, and, again, at 3, 6, 12 and 18 months post-burn. Burn severity was indicated by the number of surgeries, and PTSD symptoms were assessed with the IES-R at three months post-burn. Pre- and post-injury HRQL were compared to norm populations.

Results: Recalled pre-injury HRQL was higher than population norms and HRQL at 18 months post-burn was comparable to population norms. Compared to the pre-injury level of functioning, four HRQL patterns of change over time were established: Stable, Recovery, Deterioration, and Growth. In each HRQL domain, a subset of patients did not return to their recalled preinjury levels, especially with regard to Pain, Anxiety/Depression, and Cognition. Patients with more severe burns or PTSD symptoms were less likely to return to pre-injury level of functioning within 18 months post-burn.

Conclusion: This study identified four patterns of individual change. Patients with more severe injuries and PTSD symptoms were more at risk of not returning to their recalled pre-injury HRQL. This study supports the face validity of using a recalled pre-burn HRQL score as a reference point to monitor HRQL after burns.

Background

Life after burn injury may encompass a range of difficulties, including physical symptoms such as pain and itch, psychological symptoms such as traumatic stress and anxiety and social difficulties such as stigmatization, all of which may affect health-related quality of life (HRQL) for years (Falder et al., 2009). HRQL is a widely used concept that encompasses a patient's perception of one's health condition on physical, psychological and social functioning (Testa & Simonson, 1996). Prior studies in burn populations have usually compared patients' HRQL with the general population (Oster et al., 2011; van Loey et al., 2012) to establish burn-related sequelae. However, improved technological possibilities, such as real-time processing of digitally completed patient-reported outcome measures, have created the means to systematically monitor a patient's therapeutic progress and make it possible to customize clinical approaches to specific needs (Black, 2013; Ryan et al., 2016). For the purpose of monitoring recovery from the patient's viewpoint, comparing patients' level of functioning with their pre-burn level is recommended (Polinder et al., 2010). Because prospectively collected information on pre-burn HRQL is usually not available in trauma populations, retrospective data collection is indicated (Van Beeck et al., 2007).

The extant literature on HRQL in burn patients has shown that, on average and compared to norm groups, most HRQL domains are affected shortly after a burn injury and recover over time, except domains such as anxiety, depression and pain (Spronk, Legemate, Oen, et al., 2018). The studies that have investigated recalled pre-burn HRQL, all using the SF-36 questionnaire, showed that, in general, HRQL decreased after the burn injury followed by a gradual increase over time (Fauerbach et al., 2005; Miller et al., 2013; Tahir et al., 2011; Wasiak, Lee, et al., 2014; Wasiak et al., 2016; Wasiak, Paul, et al., 2014). Two small studies investigating HRQL after wildfire, found reduced HRQL at 12 and 36 months compared to recalled pre-injury HRQL (Pfitzer et al., 2016; Wasiak et al., 2013). Of notice, the EQ-5D questionnaire has not been used to measure recalled pre-burn HRQL, few studies have included measures beyond 12 months post-burn (Miller et al., 2013), and individual recovery trajectories have not been described.

A number of predictors of HRQL after burn injuries have been established. Specifically, burn severity, as measured by length of hospital stay and number of surgeries, and psychological factors, such as post-traumatic stress disorder (PTSD) symptoms, are consistently associated with HRQL over time (Fauerbach et al., 2005; Palmu et al., 2015; Spronk, Legemate, Dokter, et al., 2018). PTSD is one of the most prevalent mental health problems after a burn injury: around

9% of patients are typically diagnosed with PTSD, about 15% show sub-threshold symptom levels 1 year post-injury, and up to 43% report substantial symptoms 1 year post-burn (Dyster-Aas et al., 2008; Ehde et al., 2000). The few studies that did assess recalled pre-burn HRQL have shown that, on average, more severely burned patients approach mean pre-burn HRQL level later or stayed at lower HRQL level than less severely burned patients (Fauerbach et al., 2005; Miller et al., 2013; Wasiak, Lee, et al., 2014; Wasiak, Paul, et al., 2014). As these studies focused on group level changes, it is not clear to what extent burn severity and PTSD symptoms are associated with individual trajectories, and specifically whether individuals return to their own (recalled) pre-burn level instead of returning to the group average or population norms.

The current longitudinal study had three aims: (1) to compare recalled pre-burn HRQL (assessed during hospitalization) and post-burn HRQL to population norms; (2) to explore individual patterns of change in HRQL domains assessed over a period of 18 months post-burn relative to recalled pre-burn level; and (3) to examine whether more severe burns and PTSD symptoms were associated with a higher risk of *not* returning to pre-burn HRQL at individual level.

Methods

Participants

The data ($N = 480$) from this study came from two larger projects: one focused on pain in three Dutch and two Belgian burn centers (Study 1 (Bosmans et al., 2015; Van Loey et al., 2018)) and one focused on the social impact in three Dutch and three Belgian burn centers (Study 2). Patients were recruited from April 2010 to December 2012 in Study 1 and from October 2013 to October 2015 in Study 2. Both cohorts were prospectively followed up for 18 months. Inclusion criteria for patients in both studies were: a hospital admission of >24 h following the burn event, aged 18 years or older and sufficient command of Dutch. Exclusion criteria were: psychiatric problems that interfere with questionnaire comprehension (e.g., psychosis, cognitive problems), and inhalation injury without external burns.

Procedure

Patients were invited to participate in the studies by a local researcher during their stay in the burn center. After they received oral and written information about the study, they provided written informed consent. Patients completed

T1 and the recalled pre-injury measure during hospitalization following the burn injury. They completed the follow-up assessments by mail at 3 (T2), 6 (T3), 12 (T4) and 18 (T5) months post-burn. The study was approved by institutional review boards in the Netherlands and Belgium (Study 1: NL27996.094.09, B670201112923; Study 2: NL44682.094.13, B670201420373).

Measures

Health*-related quality *of life. The EQ-5D-3L + Cognition is a self-report scale used to assess generic HRQL. It was completed during hospitalization, including the recalled pre-burn measure, and at 3, 6, 12, and 18 months after the burn injury. HRQL is assessed along six single-item health domains: Mobility, Self-care, Usual Activities, Pain, Anxiety/Depression and Cognition. The added Cognition domain measures to what extent the patient experiences problems with memory and concentration. For each domain, patients reported their health 'in the past week' or 'before the burn event' (for the recalled pre-burn measure). Answers were rated on a 3-point scale: 'no problems', 'moderate problems', or 'severe problems'. The first five domains were combined into the EQ-5D Summary Index based on a scoring algorithm. The Summary Index ranges from – 0.594 'worse than death' through 0 'death' to 1 'full health' (Dolan, 1997). In addition, the EQ-5D includes a Visual Analog Scale (VAS) that is scaled vertically and runs between 0 (worst imaginable health state) and 100 (best imaginable health state). The EQ-5D is short and easy to complete and it has good feasibility and reasonable criterion validity in the burn population (Öster et al., 2009). The addition of a Cognition domain slightly improved the psychometric performance of the EQ-5D in traumatic brain injury patients (Geraerds et al., 2019).

Post-traumatic stress disorder (PTSD) symptoms. PTSD symptoms during hospitalization, at 3 and 6 months post-burn were measured using the validated Dutch version of the Impact of Event Scale-Revised (IES-R; (van der Ploeg et al., 2004; Weiss & Marmar, 1997)). The IES-R is a self-report questionnaire that measures PTSD symptoms in the past week. The two studies in this research used different scoring systems of the Dutch IES-R. Study 1 used the original scoring of the 15-item version (Horowitz et al., 1979) with four answer categories 0 'never', 1 'rarely' 3 'sometimes' and 5 'often'. Answers on these 15 items were summed, with scores of 26 and higher indicating a possible diagnosis of PTSD based on symptoms, without taking into account the criterion of functional impairment or suffering due to symptoms. Study 2 used the 22-item scoring system that included also the hyperarousal subscale. Answers were given on a 5-point Likert scale and summed to obtain a total score ranging from 0 to 88, with scores of 33

and higher indicating a possible diagnosis of PTSD. The IES-R has high sensitivity as a screening tool for PTSD after burn injuries (Sveen et al., 2010).

Demographic data and injury severity. Age, gender, number of surgeries and total body surface area (TBSA) burned were recorded from the medical file. TBSA is the estimated percentage of the body covered with partial and full thickness burns. Number of surgeries was used as an indicator of burn severity. It indicates the number of skin graft procedures that was required to cover the wounds.

Statistical analysis

First, pre-burn and post-burn Summary and VAS mean scores in our sample were compared to population norms using t-tests. The normative data came from a national representative sample of the non-institutionalized adult population (Janssen & Szende, 2014). Effect sizes (Cohen's d) were calculated to quantify the differences between the sample and the population norms. The vast majority of the final sample came from the Netherlands (91.3%; the remainder came from Belgian burn centers), therefore the sample means were compared to Dutch population norms.

Second, for each of the six EQ-5D domains, the Summary Index and the VAS, patients were allocated to a pattern of change in HRQL relative to their recalled pre-burn HRQL. For the six domains, the post-burn item scores at all assessments were directly compared to the recalled pre-burn score to identify a decrease, increase or no change. For the EQ-Summary Index and EQ-VAS, the Minimally Important Difference (MID) was used as an indication of the minimum change that reflects a clinically relevant improvement or deterioration in HRQL. For the EQ-Summary Index, 'pre-burn level' was defined by a score as close as 0.074 to pre-burn state, based on the MID in patients with a wide range of medical conditions (Walters & Brazier, 2005). For the EQ-VAS, 'pre-burn level' was defined by a score as close as 8 to pre-burn state, based on the MID in several studies in specific (non-burn) patient populations (Hoehle et al., 2019; Pickard et al., 2007; Zanini et al., 2015). The MIDs were established using both anchor and distribution -based methods. Several patients were excluded in the concerning domain analyses because of a floor effect, as their health state could not be (measurably) negatively impacted after the burns. They had severe pre-burn problems in one or more domains ($n_{\text{Mobility}} = 2$ $n_{\text{Self-care}} = 3$, $n_{\text{Usual Activities}} = 7$ $n_{\text{Pain/Discomfort}} = 9$, $n_{\text{Anxiety/Depression}} = 2$, $n_{\text{Cognition}} = 1$), a pre-burn Summary Index ≤ 0 ($n = 5$) or a pre-burn VAS ≤ 10 ($n = 1$). Four patterns were defined: (1) Stable, including patients who did not show any post-burn decline in HRQL (beyond the MID) and who were at their pre-burn level of functioning at 18 months post-burn. (2) Growth, including patients who

did not show any post-burn decline in HRQL (beyond the MID) and who showed increased level of HRQL at 18 months post-burn relative to the pre-burn level; (3) Recovery, characterized by a post-burn decline in HRQL followed by recovery to pre-burn level or beyond at 18 months; and (4) Deterioration, characterized by a post-burn decline in HRQL and below pre-burn level functioning at 18 months. If HRQL at 18 months was unknown (n = 29 – 31; 9.4 – 10.0% of the sample), HRQL at 12 months was used as final outcome.

Third, to study who recovered to pre-burn HRQL and who did not, we selected the individuals attributed to the two patterns Recovery and Deterioration because they showed a decrease in HRQL after the injury, which suggests an effect of the burn injury. Logistic regression analyses were used to study whether burn severity and PTSD symptoms assessed at 3 months post-burn increased the risk to be assigned to the Deterioration pattern. The 3 months assessment was chosen, because symptoms should persist for at least 1 month to be diagnosed as PTSD and three months was the earliest available measurement after that point (2013). For the Summary Index and VAS, t-tests were conducted to test whether the mean pre-burn HRQL in the Recovery and Deterioration groups differed. Analyses were performed using IBM SPSS 24. Sample sizes may vary between analyses because of missing data in one of the health domains or PTSD symptoms.

Results

Sample and attrition

A total of 480 patients completed the first assessment (T1) and 258 (54%) completed EQ-5D assessments at all follow-up measurements (T2 – T5). A total of 169 patients were excluded from the statistical analyses due to missing recalled pre-burn EQ-5D measurements (n = 24) or missing EQ-5D measurements at both T4 and T5 (n = 145). The excluded patients did not differ from the final sample in terms of gender, χ^2 (1) = 0.40, p = .54, or PTSD symptoms, χ^2 (1) = 2.17, p = .16, but were significantly younger, M = 38.3 versus 44.8, t (478) = 4.44, p < .001, Cohen's d = 0.43, and had fewer surgeries, χ^2 (2) = 9.81, p = .007.

The final sample consisted of 311 patients. They had a mean age of 44.8 years (SD = 15.5), and most were male (n = 214, 68.8%). Mean total body surface area (TBSA) burned was 9.7% (SD = 10.0, range 0.40 – 75.0%). Median number of surgeries was 1 (range 0 – 14). For further analyses, this variable was recoded into

'no surgeries' (*n* = 132; 42.4%), 'one surgery' (*n* = 124; 39.9%) or 'more than one surgery' (*n* = 55; 17.7%). The number of patients scoring above the IES-R cut-off for a possible PTSD diagnosis at 3 months post-burn was 53 (18.0%). Seventeen patients did not complete the IES-R at 3 months.

HRQL over time and comparison to population norms

Table 1 shows that the mean recalled pre-burn Summary Index and VAS of the sample were somewhat higher than the general population norms (Janssen & Szende, 2014). During hospitalization, the Summary Index dropped to a mean of 0.44 (a reduction of 52.2% compared to pre-burn) and a VAS of 63.7 (a reduction of 25.7%). Over time, on average, HRQL recovered, and 18 months post-burn, the sample means for the Summary Index and VAS were comparable to those in the general population, but still somewhat lower than both the pre-burn Summary Index and VAS (Table 1).

Table 1. *Descriptives and Comparison of Pre- and Post-burn HRQL and General Population Norms*

Descriptives	Summary Index				VAS			
	N	*M*	*SD*		*N*	*M*	*SD*	
Population norm		.89				82.0		
Pre-burn	311	.92	.21		301	85.7	13.1	
In hospital	305	.44	.37		300	63.7	21.3	
18 months*	311	.87	.21		301	82.5	15.3	
Comparisons	*t*	*df*	*p*	*d*	*t*	*df*	*p*	*d*
Population norm vs Pre-burn	2.63	310	.009	0.14	4.87	300	<.001	0.28
Population norm vs 18 months*	-1.63	310	.11	0.10	0.59	300	.55	0.03
Pre-burn vs 18 months*	3.63	310	<.001	0.24	3.26	300	.001	0.22

HRQL = Health-related Quality of Life.
*If individuals' 18 months HRQL was missing, 12 months HRQL was used.

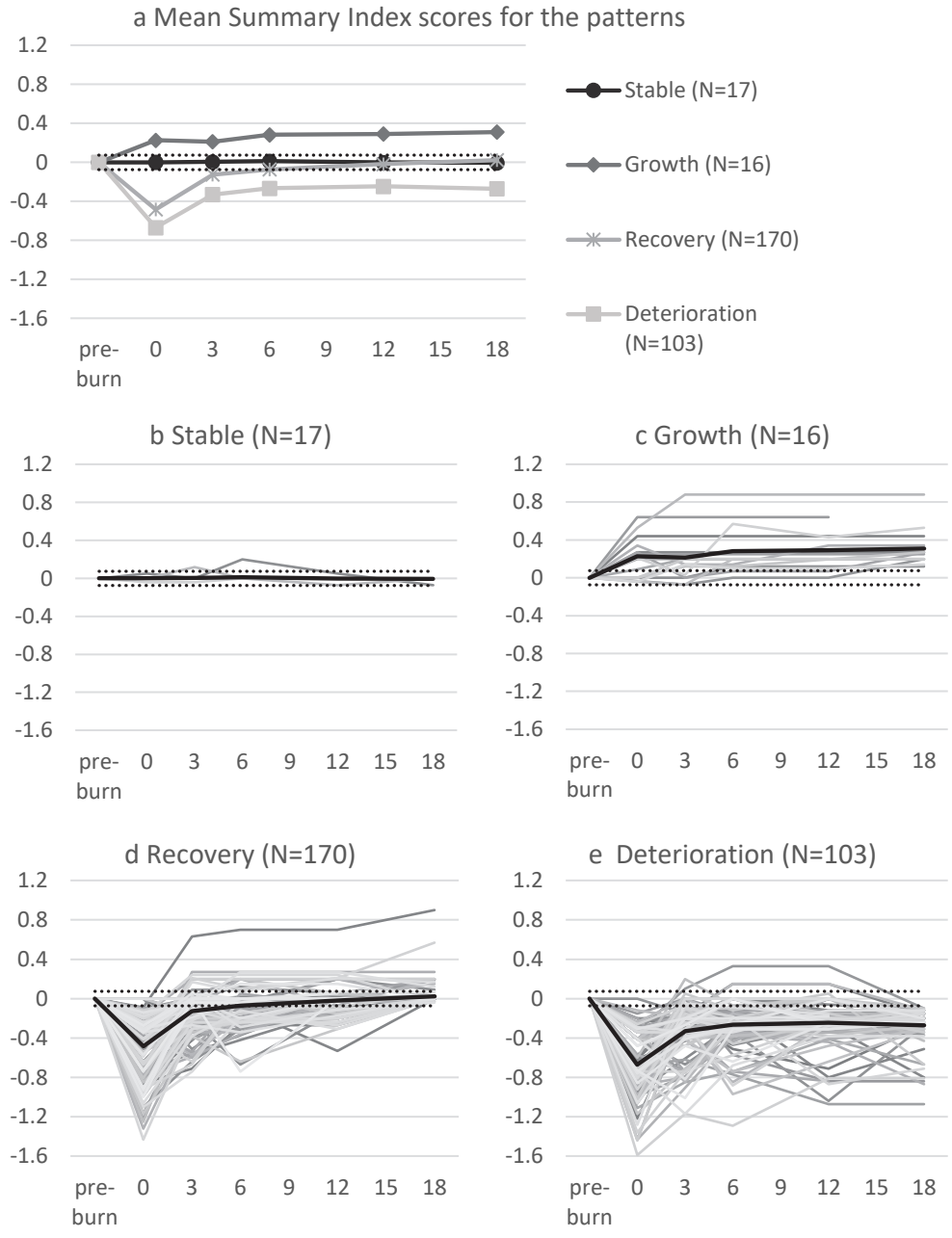

Figure 1. *Patterns of health-related quality of life change relative to pre-injury level of functioning during eighteen months post-burn for the EQ-5D Summary Index. Pattern means (Panel a) and individual trajectories over time per pattern (Panel b-e) are displayed. The black lines (Panel b-e) represent the pattern means; dotted lines represent the MID boundaries.*

Patterns of change

Four patterns of change in HRQL were observed in each domain and on the Summary Index and VAS: Stable, Growth, Recovery and Deterioration. Figure 1a shows the shape and frequency of each pattern over time on the Summary Index relative to pre-burn functioning. Figure 1b – e shows that individual trajectories in the four patterns varied widely. Table 2 presents the frequencies of the four patterns for each EQ-domain and for the Summary Index and VAS separately. For the Summary Index and VAS, the Recovery pattern was most common (55.6% and 48.5% respectively), followed by the Deterioration pattern (33.7% and 35.5% respectively). The Stable and Growth patterns were less common. In the physical domains *Mobility and Self-Care*, the Stable pattern and the Recovery pattern were most frequent, indicating that a substantial number of patients did not show problems in these areas after the injury, and for *Self-Care* only a few patients reported persisting problems (Deterioration). In the physical domains *Usual Activities and Pain/Discomfort*, the percentages of Stable patients were the lowest, indicating that most patients experienced (temporal) problems in these areas. The *Pain/Discomfort* domain was the most troublesome, as it included relatively many patients in the Deterioration pattern. In the *Anxiety/Depression and the Cognition domain,* most patients followed a Stable unaffected pattern. In each domain a subsample of patients showed persistent problems at 18 months post-burn (Deterioration pattern), especially regarding *Pain/Discomfort, Anxiety/Depression, Cognition and Usual Activities*.

Table 2. *Frequencies of HRQL patterns of change in each domain of the EQ-5D*

EQ-5D domain	Stable		Growth		Recovery		Deterioration		Total
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*
Summary	17	5.6	16	5.2	170	55.6	103	33.7	306
VAS	22	7.4	26	8.7	145	48.5	106	35.5	299
Mobility	139	45.0	9	2.9	136	44.0	25	8.1	309
Self-Care	107	34.7	6	1.9	187	60.7	8	2.6	308
Usual Activities	42	13.8	7	2.3	214	70.4	41	13.5	304
Pain/Discomfort	44	14.6	19	6.3	165	54.6	74	24.5	302
Anxiety/Depression	175	56.6	5	1.6	84	27.2	45	14.6	309
Cognition	163	52.6	10	3.2	89	28.7	48	15.5	310

HRQL = Health-related quality of life

Recovery status at 18 months in the Recovery and Deterioration pattern

Table 3 shows HRQL outcomes at 18 months compared to pre-injury level for all patients that showed a decrease in HRQL after the injury (i.e., the Recovery or Deterioration patterns). Regarding the Summary Index and VAS, the majority of patients returned to pre-injury level or higher level, but 37.7 and 42.2%, respectively, did not return to pre-burn level. Compared to the domains and Summary Index, the VAS showed the highest number of patients reporting growth beyond pre-injury level (16.7%). Of the individual domains, Self-Care showed the highest recovery rates, whereas in the other domains, 15.5% or more of the patients did not return to pre-injury level within 18 months.

Table 3. *Number of patients in a Deterioration or Recovery pattern with a health-related quality of life score at 18 months that is below, at, or above pre-burn level*

EQ-5D domain	Deterioration		Recovery				Total
	Below pre-burn level		At pre-burn level		Above pre-burn level		
	n	*%*	*n*	*%*	*n*	*%*	*n*
Summary	103	37.7	156	57.1	14	5.1	273
VAS	106	42.2	103	41.0	42	16.7	251
Mobility	25	15.5	134	83.2	2	1.2	161
Self-Care	8	4.1	186	95.4	1	0.5	195
Daily Activities	41	16.1	211	82.7	3	1.2	255
Pain/Discomfort	74	31.0	162	67.8	3	1.3	239
Anxiety/Depression	45	34.9	83	64.3	1	0.8	129
Cognition	48	35.0	88	64.2	1	0.7	137

Burn severity, PTSD symptoms and Recovery versus Deterioration

Figure 2 depicts the percentage of patients that returned to pre-burn HRQL as a function of number of surgeries and Figure 3 as a function of presence of PTSD symptoms for the Summary Index, VAS, and the individual domains. In most domains and the Summary Index, recovery percentages were highest in the group without surgeries at each time point and lowest in the group with multiple surgeries. Differences between surgery groups seemed small on the VAS. The largest differences in the individual domains between the three groups were observed for Usual Activities, Pain/Discomfort and Cognition. For Anxiety/Depression, the groups without surgery and with one surgery showed similar recovery percentages over time.

Regarding PTSD symptoms, in each domain, Summary Index and VAS, recovery percentages were lower in the group with substantial PTSD symptoms. The largest differences in the individual domains between the two groups were found for Pain/Discomfort, Anxiety/Depression and Cognition.

With logistic regression analyses, the probability of belonging to the Recovery group was regressed on burn severity and PTSD symptoms (see Table 4). For Self-care, the logistic regression was not useful, because of the high recovery rates (see Table 3). For the Summary Index and Usual Activities, the results showed that compared to patients without surgery, patients who needed multiple surgeries were significantly less likely to have recovered to pre-injury level at 18 months (Odds ratio of 3.70 and 3.85 respectively). For the Summary Index, VAS and the respective health domains, patients with substantial PTSD symptoms at 3 months post-burn were less likely to recover to pre-injury level at 18 months than patients without substantial PTSD symptoms (Odds ratios ranged between 2.70 and 5.56). The results for PTSD symptoms shortly after hospital admission and at 6 months post-burn were also explored. Associations were smaller at admission (Odds ratios ranged between 1.56 and 3.23, see Table 5 in the supplementary material) and stronger at 6 months post-burn (Odds ratios ranged between 3.23 and 6.67, see Table 6 in the supplementary material).

For the Summary Index, t-tests showed no significant differences on recalled pre-burn HRQL between the Recovery and Deterioration groups, t (255) = – 0.30, p = .76, d = 0.04. For the VAS, the Deterioration group (M = 90.6, SD = 9.1) scored significantly higher than the Recovery group (M = 84.2, SD = 12.7) on recalled HRQL, t (233.52) = – 4.47, p < .001, Cohen's d = 0.59.

Table 4. *Summary of logistic regression analyses with Recovery to pre-burn level of HRQL in each EQ-5D domain as dependent variables and number of surgeries and PTSD symptoms as independent variables*

	B	*SE*	*Wald*	*df*	*p*	*OR*	*95% CI OR*	*1/OR*
Summary Index $\chi^2(3) = 38.72$, $p < .001$, Nagelkerke $R^2 = 0.19$								
Surgery			10.92	2	.004			
1 surgery*	-0.35	0.31	1.22	1	.27	0.71	[0.38;1.31]	1.41
>1 surgeries*	-1.30	0.39	10.83	1	.001	0.27	[0.13;0.59]	3.70
PTSD symptoms *	-1.74	0.36	23.30	1	<.001	0.18	[0.09;0.36]	5.56
VAS $\chi^2(3) = 10.12$, $p = .02$, Nagelkerke $R^2 = 0.06$								
Surgery			0.54	2	.76			
1 surgery*	0.18	0.30	0.35	1	.55	1.19	[0.66;2.16]	0.84
>1 surgeries*	-0.06	0.37	0.02	1	.88	0.95	[0.46;1.95]	1.05
PTSD symptoms *	-1.03	0.34	9.30	1	.002	0.36	[0.18;0.69]	2.78
Mobility $\chi^2(3) = 9.29$, $p = .03$, Nagelkerke $R^2 = 0.11$								
Surgery			1.74	2	.42			
1 surgery*	-0.05	0.65	0.01	1	.94	0.95	[0.27;3.39]	1.05
>1 surgeries*	-0.71	0.68	1.06	1	.30	0.49	[0.13;1.89]	2.04
PTSD symptoms *	-1.36	0.50	7.53	1	.006	0.26	[0.10;0.68]	3.85
Usual Activities $\chi^2(3) = 16.06$, $p = .001$, Nagelkerke $R^2 = 0.11$								
Surgery			7.05	2	.03			
1 surgery*	-0.61	0.46	1.73	1	.19	0.54	[0.22;1.35]	1.85
>1 surgeries*	-1.33	0.50	6.93	1	.009	0.26	[0.10;0.71]	3.85
PTSD symptoms *	-1.08	0.40	7.30	1	.007	0.34	[0.15;0.74]	2.94
Pain/Discomfort $\chi^2(3) = 18.57$, $p < .001$, Nagelkerke $R^2 = 0.11$								
Surgery			4.63	2	.10			
1 surgery*	0.04	0.35	0.01	1	.90	1.04	[0.53;2.05]	0.96
>1 surgeries*	-0.77	0.41	3.53	1	.06	0.46	[0.21;1.03]	2.17
PTSD symptoms *	-1.35	0.36	13.97	1	<.001	0.26	[0.13;0.53]	3.85
Anxiety/Depression $\chi^2(3) = 10.70$, $p = .01$, Nagelkerke $R^2 = 0.12$								
Surgery			1.35	2	.51			
1 surgery*	0.18	0.46	0.15	1	.70	1.19	[0.49;2.91]	0.84
>1 surgeries*	-0.42	0.54	0.60	1	.44	0.66	[0.23;1.90]	1.52
PTSD symptoms *	-1.18	0.40	8.63	1	.003	0.31	[0.14;0.68]	3.23
Cognition $\chi^2(3) = 11.21$, $p = .01$, Nagelkerke $R^2 = 0.12$								
Surgery			3.57	2	.17			
1 surgery*	-0.09	0.46	0.04	1	.85	0.92	[0.37;2.27]	1.09
>1 surgeries*	-0.88	0.52	2.89	1	.09	0.42	[0.15;1.14]	2.38
PTSD symptoms *	-0.99	0.41	5.74	1	.02	0.37	[0.17;0.83]	2.70

HRQL=Health-related Quality of Life, PTSD = Post-traumatic Stress Disorder, OR = Odds Ratio. The logistic regression outcome variables are coded as 1 'Recovery' versus 0 'Deterioration'. Reference category for Surgery is 'no surgeries'. Reference category for PTSD symptoms is 'No substantial PTSD symptoms'.

Discussion

This is the first study that describes patterns of change in HRQL after burns using a recalled pre-injury score as the starting point to determine recovery and to investigate whether burn severity and PTSD symptoms increase the likelihood of *not* returning to pre-burn HRQL. Moreover, these findings support the face validity of using an in-hospital recalled pre-injury HRQL as an individual reference point to monitor the patient's return to pre-burn level of HRQL after a burn injury.

Comparisons between the burn sample and the general population norms showed that although population norms were reached after 18 months, the mean recalled pre-burn levels were not reached, which may reflect individual health loss. This is largely in concert with two pre-burn studies using the SF-36 to measure HRQL (Fauerbach et al., 2005; Wasiak, Lee, et al., 2014), but is now also found for the EQ-5D. Other research in burn populations also showed that the norm population's level is reached after 18 months (Spronk, Legemate, Oen, et al., 2018). However, because the recalled pre-burn level of functioning might not be regained, health loss in burn populations may be underestimated if population norms are used irrespective of pre-burn individualized measures. Our findings regarding the high pre-burn HRQL levels are in line with the broader literature, given that recalled pre-injury HRQL of patients with a variety of injuries produced systematically higher HRQL than population norms both in international research and within the Dutch population (de Graaf et al., 2019; Scholten et al., 2017). Consequently, these findings also suggest that the use of recalled pre-burn HRQL may further improve the accuracy of recovery estimation models (Spronk et al., 2020).

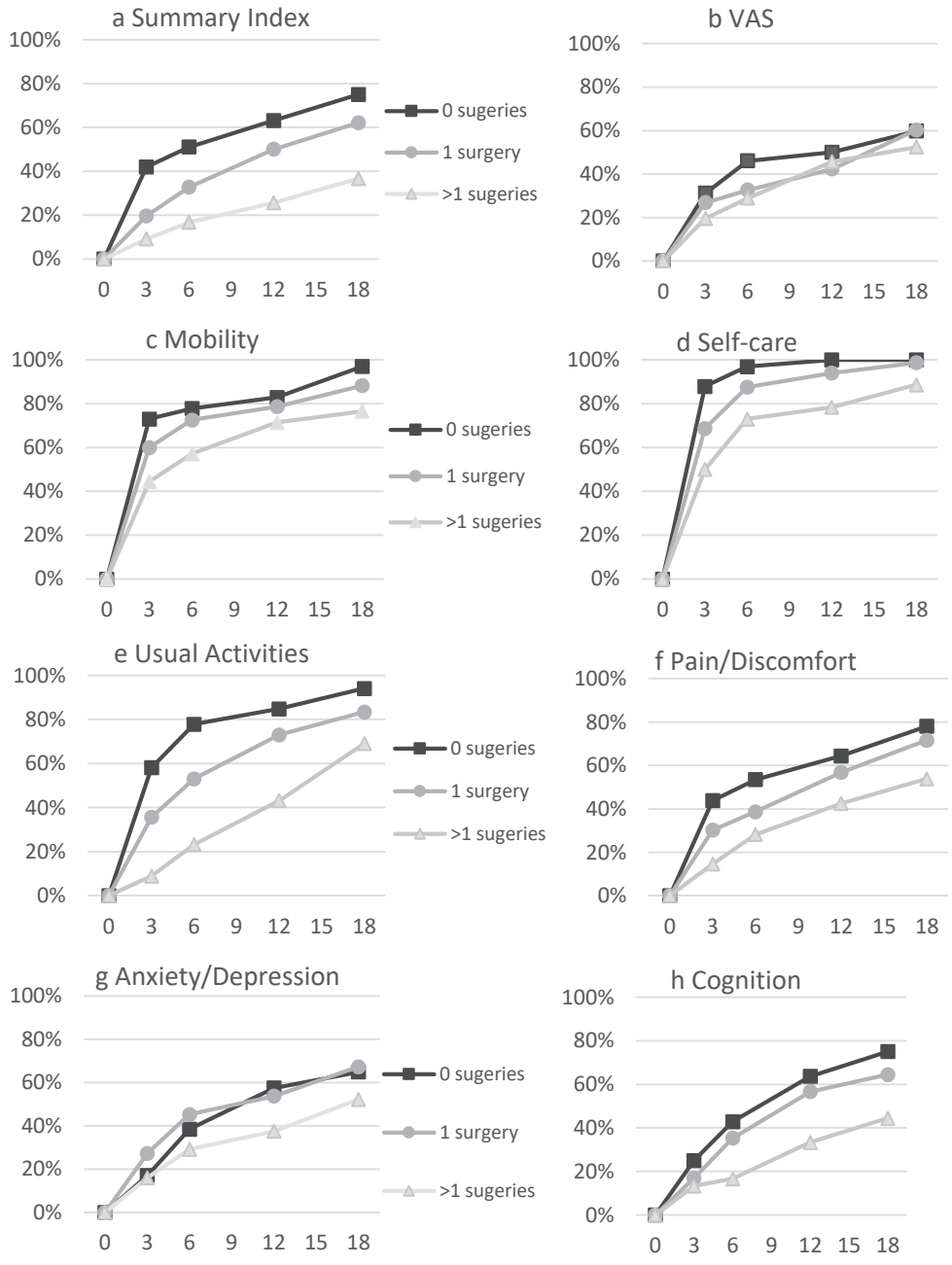

Figure 2. *Percentages of patients with three levels of burn severity returning to pre-injury health-related quality of life over time (months) on the Summary Index (Panel a), VAS (Panel b), and the six domains (panel c-h)*

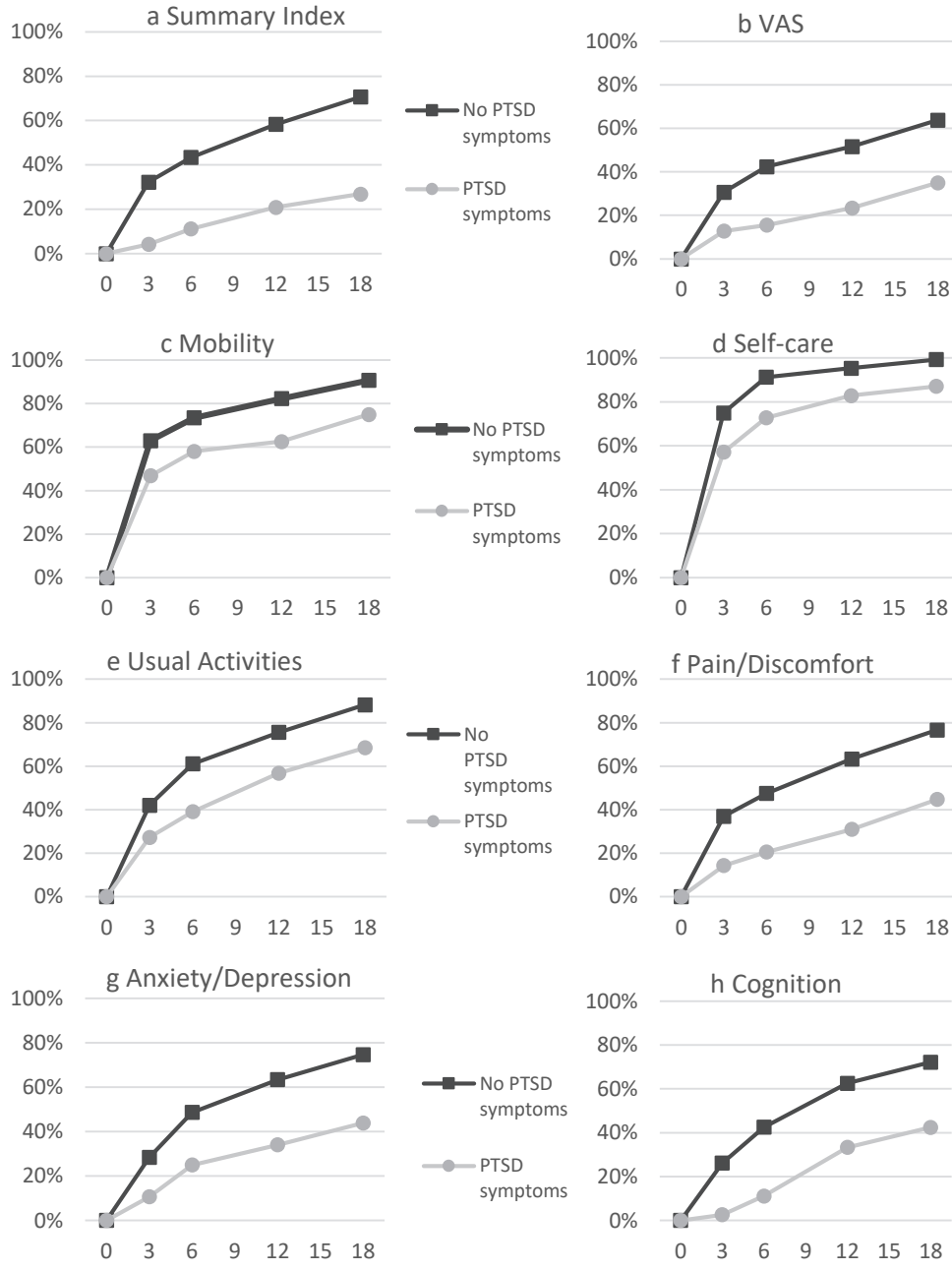

Figure 3. *Percentages of patients with and without substantial PTSD symptoms returning to pre-injury health-related quality of life over time (months) on the Summary Index (Panel a), VAS (Panel b), and the six domains (panel c-h)*

With reference to the recalled pre-burn baseline scores, four patterns of change in HRQL were defined. Among these patterns, Recovery was most prevalent, followed by the Stable and Deterioration patterns. The Growth pattern occurred only occasionally. For the Summary Index, VAS and most physical domains, the majority of the patients followed a Recovery pattern, whereas in the psychological domains (Anxiety/Depression and Cognition), most patients showed a Stable unaffected pattern. The predominance of the Recovery pattern is mirrored in previous studies using a pre-burn measure that showed a mean decrease in HRQL after the injury, followed by an increase (Fauerbach et al., 2005; Miller et al., 2013; Wasiak, Paul, et al., 2014). However, in each domain a subset of patients did not recover to pre-burn baseline levels, especially in the domains Pain/Discomfort, Anxiety/Depression and Cognition, which is in line with previous group level research (Spronk, Legemate, Oen, et al., 2018). Thus, findings extend the literature by showing the existence and extent of other patterns next to Recovery.

Comparing the Recovery and Deterioration pattern, more severely burned patients and patients with PTSD symptoms were less likely to fully recover within 18 months post-injury. These findings are in line with previous research that included a recalled pre-burn measure, that found a positive relationship between larger burn size and physical but not psychological impairment (Fauerbach et al., 2005) or found a relation between more severe burns and protracted recovery of HRQL in general (Miller et al., 2013; Wasiak, Lee, et al., 2014; Wasiak, Paul, et al., 2014). These findings support earlier studies at group level (Fauerbach et al., 2005; Palmu et al., 2015; Spronk, Legemate, Dokter, et al., 2018; van Loey et al., 2012) by showing that substantial PTSD symptoms were associated with a higher risk for both a long-term affected physical and mental HRQL, whereas more severe burn were associated with a higher risk for a reduced physical HRQL.

Of notice, this study showed that cognitive problems after burns persist beyond 18 months in about 35% of the patients, a health domain that has been scarcely studied in burn patients. A prior study reported cognitive problems in burn patients 2 years post-burn (Watson et al., 2018) and another study indicated that 16.6% of patients with minor burns and 33.3% of patients with severe burns experienced cognitive problems 5 – 7 years post-burn (Spronk et al., 2019). A positive association between PTSD symptoms and cognitive problems may be expected, because adults with PTSD show deficits in cognitive processes such as attention and executive functions (Flaks et al., 2014; Vasterling et al., 2002). Further research may disentangle possible bio psychological causes of cognitive problems after burns, for example related to the stress response (Kim & Diamond,

2002) or to sedation effects of mechanical ventilation (Fernandez-Gonzalo et al., 2018) or anesthesia during surgeries (Mason et al., 2010).

Regarding the recalled pre-burn measurement, it could be argued that the significantly higher pre-burn HRQL in our sample compared to population norms may reflect an idealization of pre-burn HRQL resulting in an upward bias (e.g. Scholten et al., 2017). This phenomenon has been called 'response shift' of internal standards, indicating a tendency to inflate the pre-injury assessment by implicit comparison with the poorer health state shortly after the injury (Schwartz et al., 2007). The results regarding pre-burn differences between the Deterioration and Recovery group suggests that the VAS, especially in the Deterioration group with more severely burned patients, may be more prone to an upward bias, whereas the Summary Index (and individual domains) may be more resistant to such an upward bias. However, the possible upward bias in retrospective pre-burn scores does not necessarily mean that the use of population norms is a better reference point to determine recovery, because previous trauma research showed that the upward bias of recall is smaller than the underrepresentation of population norms (Wilson et al., 2012). Moreover, burn patients in our sample may have had an actual better HRQL than the norm group from the general population, for example, because men and younger persons in the general population have a better HRQL and were somewhat overrepresented in our sample (de Graaf et al., 2019; König et al., 2009). Also, both the pre- and the 18 months post-burn situation were reported from the plausibly similar shifted post-injury standard of the patient, adding to the validity of the comparisons (Schwartz & Sprangers, 1999).

The study has some limitations that need to be taken into account. First, the MIDs for the EQ-5D Summary Index and VAS that were used as cut-off point for recovery to pre-injury level stem from other patient populations (Hoehle et al., 2019; Pickard et al., 2007; Walters & Brazier, 2005; Zanini et al., 2015). The strict MIDs partly explain lower frequencies of the Stable pattern on the Summary Index and VAS compared to the individual health domains. Larger MIDs may be more appropriate after burn injury, because of maturation of scars and psychological adjustment occurring during the first years post-burn. Second, we used a self-report questionnaire and not a diagnostic interview to assess PTSD symptoms (Engelhard, van den Hout, et al., 2007). The high sensitivity of the IES-R to detect PTSD has been indicated in prior research (Sveen et al., 2010), but specificity of screeners is typically lower (Engelhard, Arntz, et al., 2007). Third, dropout rates were substantial and may bias the found frequency of the different patterns. Also, the group sizes of Deteriorated patients in the three burn severity groups were small in some domains, which may underpower this study for detecting

(significant) differences in recovery percentages between the surgery groups in the logistic regression analysis.

The results may encourage clinicians to use a retrospective pre-burn EQ-5D plus Cognition measure as a reference point to monitor individual HRQL recovery over time. Also, the results indicate that patients with more severe burns and patients with elevated PTSD scores may not return to pre-burn level of functioning, and timely interventions for psychological problems may be beneficial for recovery (e.g. Birk et al., 2019; Fauerbach et al., 2020).

In conclusion, this study supports the face validity of using recalled in-hospital assessed pre-burn HRQL to monitor the patient's progress in HRQL. Different patterns of change in HRQL were found and patients with more severe burns and substantial PTSD symptoms were less likely to fully recover.

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Electronic Supplementary Material

This is supplementary material to the following article:

Individual recovery of health-related quality of life during 18 months post-burn using a retrospective pre-burn measurement: An exploratory study.
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Quality of Life Research

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Description
This Electronic Supplementary Material consists of two tables containing the logistic regression results for PTSD symptoms measured in hospital and at six months post-burn. The logistic regression results for PTSD symptoms at 3 months post-burn in reported in the main text.

Table A *Parameter estimates of the Logistic Regression Analyses for Recovery at 18 months in each domain with PTSD symptoms measured in-hospital*

	B	*SE*	Wald	*df*	*p*	*OR*	95% CI *OR*	1/*OR*
Summary Index $\chi^2(3) = 27.39$, $p < .001$, Nagelkerke $R^2 = 0.13$								
Surgery			15.46	2	<.001			
1 surgery	-0.46	0.30	2.45	1	.12	0.63	[0.35;1.12]	1.59
>1 surgeries	-1.52	0.39	15.45	1	<.001	0.22	[0.10;0.47]	4.55
PTSD in hospital	-1.04	0.30	12.32	1	<.001	0.35	[0.20;0.63]	2.86
VAS $\chi^2(3) = 6.58$, $p = .09$, Nagelkerke $R^2 = 0.04$								
Surgery			0.37	2	.83			
1 surgery	0.11	0.29	0.14	1	.71	1.11	[0.63;1.98]	0.90
>1 surgeries	-0.11	0.37	0.08	1	.77	0.90	[0.44;1.84]	1.11
PTSD in hospital	-0.74	0.30	6.29	1	.01	0.48	[0.27;0.85]	2.08
Mobility $\chi^2(3) = 5.77$, $p = .12$, Nagelkerke $R^2 = 0.06$								
Surgery			2.22	2	.33			
1 surgery	-0.19	0.59	0.11	1	.75	0.83	[0.26;2.61]	1.20
>1 surgeries	-0.85	0.64	1.77	1	.18	0.43	[0.12;1.50]	2.33
PTSD in hospital	-0.94	0.46	4.09	1	.04	0.39	[0.16;0.97]	2.56
Usual Activities $\chi^2(3) = 11.02$, $p = .01$, Nagelkerke $R^2 = 0.07$								
Surgery			8.65	2	.01			
1 surgery	-0.66	0.44	2.29	1	.13	0.52	[0.22;1.22]	1.92
>1 surgeries	-1.42	0.48	8.60	1	.003	0.24	[0.09;0.62]	4.17
PTSD in hospital	-0.61	0.38	2.60	1	.11	0.54	[0.26;1.14]	1.85
Pain/Discomfort $\chi^2(3) = 15.94$, $p = .001$, Nagelkerke $R^2 = 0.09$								
Surgery			6.31	2	.04			
1 surgery	-0.14	0.33	0.19	1	.67	0.87	[0.45;1.66]	1.15
>1 surgeries	-0.98	0.40	5.82	1	.02	0.38	[0.17;0.83]	2.63
PTSD in hospital	-1.06	0.32	10.77	1	.001	0.35	[0.18;0.65]	2.86
Anxiety/Depression $\chi^2(3) = 3.87$, $p = .28$, Nagelkerke $R^2 = 0.04$								
Surgery			2.93	2	.23			
1 surgery	0.22	0.43	0.27	1	.60	1.25	[0.54;2.90]	0.80
>1 surgeries	-0.63	0.52	1.45	1	.23	0.53	[0.19;1.48]	1.89
PTSD in hospital	-0.45	0.38	1.41	1	.24	0.64	[0.30;1.34]	1.56
Cognition $\chi^2(3) = 14.21$, $p = .003$, Nagelkerke $R^2 = 0.14$								
Surgery			6.40	2	.04			
1 surgery	-0.15	0.45	0.11	1	.75	0.87	[0.36;2.08]	1.15
>1 surgeries	-1.20	0.51	5.49	1	.02	0.30	[0.11;0.82]	3.33
PTSD in hospital	-1.16	0.39	8.66	1	.003	0.31	[0.15;0.68]	3.23

HRQL=Health-related Quality of Life, PTSD = Post-traumatic Stress Disorder, OR = Odds Ratio. The logistic regression outcome variables are coded as 1 'Recovery' versus 0 'Deterioration'. Reference category for Surgery is 'no surgeries'. Reference category for PTSD symptoms is 'No substantial PTSD symptoms'.

Table B *Parameter estimates of the Logistic Regression Analyses for Recovery at 18 months in each domain with PTSD symptoms measured at 6 months*

	B	*SE*	Wald	*df*	*p*	*OR*	95% CI *OR*	1/*OR*
Summary Index $\chi^2(3) = 42.19$, $p < .001$, Nagelkerke $R^2 = 0.21$								
Surgery			11.55	2	.003			
1 surgery	-0.42	0.32	1.78	1	.18	0.66	[0.35;1.22]	1.52
>1 surgeries	-1.34	0.40	11.52	1	<.001	0.26	[0.12;0.57]	3.85
PTSD at 6 months	-1.92	0.38	25.55	1	<.001	0.15	[0.07;0.31]	6.67
VAS $\chi^2(3) = 12.08$, $p = .007$, Nagelkerke $R^2 = 0.07$								
Surgery			0.35	2	.84			
1 surgery	0.12	0.30	0.15	1	.70	1.12	[0.62;2.02]	0.89
>1 surgeries	0.21	0.38	0.32	1	.57	1.24	[0.59;2.59]	0.81
PTSD at 6 months	-1.20	0.35	11.38	1	<.001	0.30	[0.15;0.61]	3.33
Mobility $\chi^2(3) = 7.82$, $p = .05$, Nagelkerke $R^2 = 0.09$								
Surgery			2.23	2	.33			
1 surgery	0.37	0.62	0.36	1	.55	1.45	[0.43;4.91]	0.69
>1 surgeries	-0.46	0.64	0.52	1	.47	0.63	[0.18;2.21]	1.59
PTSD at 6 months	-1.19	0.50	5.61	1	.02	0.30	[0.11;0.81]	3.33
Usual Activities $\chi^2(3) = 15.97$, $p = .001$, Nagelkerke $R^2 = 0.11$								
Surgery			7.08	2	.03			
1 surgery	-0.80	0.48	2.74	1	.10	0.45	[0.17;1.16]	2.22
>1 surgeries	-1.40	0.53	7.08	1	.008	0.25	[0.09;0.69]	4.00
PTSD at 6 months	-1.17	0.42	7.75	1	.005	0.31	[0.14;0.71]	3.23
Pain/Discomfort $\chi^2(3) = 24.11$, $p < .001$, Nagelkerke $R^2 = 0.14$								
Surgery			5.51	2	.06			
1 surgery	-0.10	0.35	0.09	1	.77	0.90	[0.45;1.79]	1.11
>1 surgeries	-0.92	0.41	4.89	1	.03	0.40	[0.18;0.90]	2.50
PTSD at 6 months	-1.60	0.38	17.91	1	<.001	0.20	[0.10;0.42]	5.00
Anxiety/Depression $\chi^2(3) = 11.19$, $p = .01$, Nagelkerke $R^2 = 0.12$								
Surgery			1.55	2	.46			
1 surgery	0.16	0.46	0.12	1	.73	1.17	[0.48;2.88]	0.85
>1 surgeries	-0.49	0.55	0.79	1	.37	0.61	[0.21;1.80]	1.64
PTSD at 6 months	-1.24	0.41	9.21	1	.002	0.29	[0.13;0.64]	3.45
Cognition $\chi^2(3) = 17.46$, $p < .001$, Nagelkerke $R^2 = 0.17$								
Surgery			3.65	2	.16			
1 surgery	-0.04	0.47	0.01	1	.93	0.96	[0.38;2.42]	1.04
>1 surgeries	-0.89	0.52	2.87	1	.09	0.41	[0.15;1.15]	2.44
PTSD at 6 months	-1.48	0.42	12.15	1	<.001	0.23	[0.10;0.52]	4.35

HRQL=Health-related Quality of Life, PTSD = Post-traumatic Stress Disorder, OR = Odds Ratio. The logistic regression outcome variables are coded as 1 'Recovery' versus 0 'Deterioration'. Reference category for Surgery is 'no surgeries'. Reference category for PTSD symptoms is 'No substantial PTSD symptoms'.

CHAPTER 5

5

Pre-Burn Health-Related Quality of Life: Patient and Partner Perspectives

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Abstract

A proxy-assessment of health-related quality of life (HRQL) may be an alternative for burn patients who are medically unable to self-report shortly after being admitted to the hospital. This study examined the patient–partner agreement on the recalled pre-injury HRQL of burn patients. In a multi-centre study of 117 patient–partner pairs, the recalled pre-burn HRQL was assessed with the EQ-5D-3L + Cognition during the acute phase following the burns. Agreement was evaluated with Kappa and ICC statistics. Burn severity and PTSD symptoms were assessed as potential predictors of disagreement. The results showed that pre-burn EQ-Index scores were similar to population norms, whereas the EQ Visual Analog Scale (EQ-VAS) scores of patients were significantly higher. Agreement varied across EQ-5D domains and, after adjusting for prevalence, was substantial to almost perfect. Average agreement on the EQ-Index and EQ-VAS was, respectively, substantial and moderate, but differences between partners were larger at lower levels of HRQL, and specifically in the pain/discomfort domain. Patient–partner differences could not be explained by the patient's age or gender, number of surgeries, partner's presence at the burn event, or post-traumatic stress disorder (PTSD) symptoms of either the patient or partner. In conclusion, patient–partner agreement is substantial and partner–proxy reports of pre-burn EQ-5D domains and EQ-Index scores may be used to complement or serve as a substitute for the patient's assessment. Given the moderate agreement on the EQ-VAS, it may be less suited for proxy assessment.

Background

A severe burn injury can vastly impact the patient's physical, psychological, and social well-being. Consequently, reduced levels of health-related quality of life (HRQL; Testa & Simonson, 1996) are common within the first year post-burn (Spronk et al., 2018). A growing number of studies have assessed pre-burn HRQL (Abouzeid et al., 2022; Sibbett et al., 2020), which may serve as a reliable benchmark for patient recovery of HRQL and may aid prognosis and treatment choices (Hofhuis et al., 2008). Since sustaining burns is an unexpected event, pre-burn functioning is preferably assessed retrospectively and within the first weeks after the injury (Polinder et al., 2010; Van Beeck et al., 2007). Compared to a prospective assessment, a retrospective assessment carries the risk of recall bias, but prevents bias related to scale recalibration or response shift (Blome & Augustin, 2015). To estimate pre-burn health status more accurately, partner–proxy assessment may complement the patient's self-reporting, since partners are well aware of the patient's pre-burn functioning. Alternatively, the partner's proxy assessment may serve as a substitute for the patient's assessment if medical status prevents timely self-report by the patient. In that case, data collection by proxy may avoid systematic non-participation and reduce missing data (Van Beeck et al., 2007; von Essen, 2004).

In general, proxies of critically ill patients tend to report lower levels of HRQL than patients, both prospectively (McPhail et al., 2008; Tol et al., 2021) and retrospectively (Geense et al., 2020; Scales et al., 2006). Furthermore, patients usually report pre-injury HRQL levels that are higher than population norms (Scholten et al., 2017). Proxy agreement of (pre-injury) HRQL has not been studied in the adult burn population, but studies in intensive care unit (ICU) patients have shown varying levels of pre-injury agreement, ranging from slight-to-moderate (Dinglas et al., 2013; Gifford et al., 2010; Scales et al., 2006) to moderate-to-high agreement (e.g. Capuzzo et al., 2000; Hofhuis et al., 2003).

For clinical decision making, reliance on proxy judgements in the absence of self-report may have significant implications for the evaluation of the success of care and treatment. To better understand the origin of proxy–patient disagreement and to estimate whether the partner is a reliable proxy, it is important to study factors that may predict disagreement (von Essen, 2004; Weinfurt et al., 2002). First, the level of HRQL impairment may impact agreement, in either a linear or u-shaped relation (von Essen, 2004). Some empirical research shows lower levels of agreement in relation to more impaired functioning (Hwang et al., 2017; von Essen, 2004; Weinfurt et al., 2002), while another study showed larger discrep-

ancies for patients with moderately impaired health rather than for those with either good or poor health (Sneeuw et al., 1999). Second, it is important to study the relation between burn severity and patient–partner disagreement to establish the accuracy of proxy reports for more severely burned patients. Indeed, proxy–patient agreement may be most relevant for patients who are medically unable to self-report their HRQL (von Essen, 2004). Third, agreement may partly depend on the concreteness of the domains under consideration. That is, proxies may have most difficulty in assessing the more subjective domains (e.g., anxiety and depression) compared to more objective physical aspects (e.g., mobility and self-care (Hofhuis et al., 2003; Hwang et al., 2017)). Fourth, increased levels of post-traumatic stress disorder (PTSD) symptoms may be related to patient–partner differences. Increased levels of PTSD symptoms have been reported in both patients with burns (Giannoni-Pastor et al., 2016) and their partners (Boersma-van Dam, van de Schoot, Geenen, et al., 2021; Bond et al., 2017), and memory disturbances, which are part of the PTSD diagnostic criteria (American Psychiatric Association, 2013), have been related to its symptoms (Samuelson, 2011). Empirical evidence shows that increased PTSD symptom levels were related to changes in recalled pre-injury HRQL over a period of 12 months (Haagsma et al., 2019), exemplifying the possible effect of PTSD symptoms on the recollection of pre-injury HRQL.

The aim of the current study was twofold. First, to compare recalled pre-burn HRQL from patients and their proxies (partners) to population norms and second, to evaluate patient–partner agreement on the recall of a patient's pre-burn HRQL and study factors related to discrepancies. In line with relevant factors reported in the literature, the effect of HRQL impairment, burn severity, and PTSD symptoms on patient–partner differences was studied.

Materials and Methods

Inclusion and Procedure

The data in this study were collected as part of a larger project concerning the social impact of burns. All consecutively admitted patients and their partners were invited to participate by a local researcher during the patient's stay in one of the three Dutch or three Belgian burn centres. Recruitment took place between October 2013 and October 2015. The patients' pre-burn HRQL data were also part of previous work that described patients' recovery to pre-burn HRQL (Boersma-van Dam, van de Schoot, Hofland, et al., 2021). In the current

study, a subsample of patients with a participating partner was studied. The larger project was approved by the ethics boards in The Netherlands and Belgium (NL44682.094.13 and B670201420373). Inclusion criteria for patients were a hospital stay of > 24 h following the burn event, age ≥ 18 years and proficiency in Dutch. The latter two criteria also applied to the partners. Exclusion criteria were psychiatric problems that interfere with the comprehension of questionnaires (e.g., psychosis, cognitive problems), and inhalation injury without external burns. After receiving oral and written study information, the participants provided informed written consent.

Measures

Recalled Pre-Burn Health-Related Quality of Life. The EQ-5D-3L + cognition (Brooks, 1996) is a self-report scale used to assess generic HRQL and was administered in the acute phase following the burn injury ($M_{patients}$ = 22 days post-burn, *SD* = 23; $M_{partners}$ = 24 days post-burn, *SD* = 24). The HRQL was assessed along five single-item health domains: mobility, self-care, usual activities, pain and anxiety/depression as well as the added cognition domain, which measured the extent to which the patient experienced problems with memory and concentration. For each domain, patients and partners independently recalled the patient's health before the burn event from their own perspective. Answers were rated on a 3-point scale: "no problems", "moderate problems", or "severe problems". The first five domains were combined into the EQ-5D Index (EQ-Index) using calculations based on the European Visual Analog Scale (VAS) value set (Greiner et al., 2003). The resulting EQ-Index ranges from 0 "death" to 1 "full health". In addition, the EQ-5D includes an EQ-VAS that is scaled vertically and runs from 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-5D, which is short and easy to complete, is often used after burns (Synodinou et al., 2022) and has good feasibility and reasonable criterion validity in the burn population (Öster et al., 2009). The addition of a cognition domain slightly improved the psychometric performance of the EQ-5D in traumatic brain injury patients (Geraerds et al., 2019).

Posttraumatic Stress Disorder Symptoms. The Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997)) was used to assess patient and partner PTSD symptoms in the acute phase following the burn event. The IES-R is a 22-item self-reporting questionnaire that measures three PTSD symptom clusters –– intrusion, avoidance and hyper-arousal –– over the previous week. Answers were given on a 5-point Likert scale and summed to obtain a total score, and sumscores ≥ 33 indicated a possible diagnosis of PTSD (Creamer et al., 2003). If at least 19 of the 22 items were completed, the sum scores were calculated based on the

mean of the completed items. The IES-R was validated in Dutch trauma populations and showed good psychometric properties (Olde et al., 2006). Reliability of the IES-R in the current study was excellent, with a Cronbach's alpha of 0.95 for patients and 0.93 for partners.

Burn Characteristics. The total body surface area (TBSA) burned, number of surgeries and need for mechanical ventilation were recorded from the medical file. The TBSA is the estimated percentage of the body covered with partial and full thickness burns. The number of surgeries indicates the number of skin graft procedures that was required to cover the wounds, and it is used as an indicator of burn severity. Presence at the burn event was self-reported by the partner.

Statistical Analysis

First, the pre-burn EQ-Index and EQ-VAS scores of patients and their partners were compared to gender-and-age adjusted population norms from a national representative sample of the non-institutionalized adult population of their country: Belgium or The Netherlands (Janssen & Szende, 2014). One-sample Student's t-tests were used to test the differences for significance.

Second, agreement between patients and partners on the six domains of the EQ-5D was assessed using Cohen's Kappa with 95% confidence intervals. Linear weights were applied to account for the ordinal structure in the data (Cicchetti & Allison, 1971), and a prevalence-adjusted weighted kappa (Sim & Wright, 2005) was reported. A prevalence effect may be present if the majority of the sample reported the same response option, (e.g., "no problems") on a given EQ-5D domain, causing large absolute differences among the counts in the cells of agreement (i.e., the cells on the diagonal of a cross-table). These differences increase the proportion of agreement expected by chance, thereby reducing the kappa, even with a large proportion of absolute agreement. To obtain a prevalence-adjusted kappa (PAK) the cells of agreement were replaced by their combined average before calculating the weighted kappa (Sim & Wright, 2005). For the EQ-Index and EQ-VAS, agreement was assessed by the intraclass correlation coefficient (ICC) using a two-way random effects model for absolute agreement (Koo & Li, 2016). Differences in the EQ-Index and EQ-VAS were also compared to the minimally important difference (MID), which indicates the minimum change that reflects a clinically relevant change in the HRQL. For the EQ-Index, a MID of 0.074 was used, based on a study in patients with a wide range of medical conditions (Walters & Brazier, 2005). For the EQ-VAS, an MID of 8 was chosen, based on several studies in specific (non-burn) patient populations (Hoehle et al., 2019; Pickard et al., 2007; Zanini et al., 2015). The MIDs were established using both an-

chor- and distribution-based methods. For the kappa and ICC coefficients, 0.00 to 0.20 was considered slight, 0.21 to 0.40 fair, 0.41 to 0.60 moderate, 0.61 to 0.80 substantial, and 0.81 to 1.00 almost perfect agreement (Landis & Koch, 1977).

Third, differences between patients and partners regarding EQ-Index and EQ-VAS scores were further tested using paired Student's t-tests. Bland–Altman plots were generated to visually inspect the difference between patients and partners in relation to the combined mean of the patient and partner responses (Bland & Altman, 1986). The mean difference and limits of agreement (95% confidence interval) were also calculated. Furthermore, the effects of gender, age, burn severity, partner's presence at the burn event, and PTSD symptoms on patient–partner differences on the EQ-Index and the EQ-VAS were examined in multiple regression analyses. A p-value < 0.05 was considered significant. Analyses were performed using IBM SPSS 24 (IBM Corp., Armonk, NY, USA).

Results

Descriptive Analyses

The final sample consisted of 117 pairs of patients with burns and their partners. Of the 266 originally participating patients, 71 reported no partner and 8 did not say. Of the remaining 187 patients with a partner, 117 (62.6%) couples completed the pre-burn HRQL measure and were included in the study. Comparing the 117 included couples to the 70 couples with incomplete data and to the 79 patients without a partner, no statistically significant differences ($p > 0.05$) were observed with respect to patient's gender, patient's reported pre-burn and post-burn HRQL, TBSA burned, and number of surgeries. However, the 79 patients without a partner were significantly younger ($M = 39.2$, $SD = 16.9$) than the included patients ($M = 45.8$, $SD = 15.1$, $p = 0.012$) and the patients with incomplete couple data ($M = 45.7$, $SD = 14.5$, $p = 0.035$).

The patients had a mean age of 45.8 years ($SD = 15.1$); for partners this was 44.4 years ($SD = 14.4$). Most pairs consisted of a male patient and a female partner ($n = 90$, 76.9%); the remainder were female patients with a male partner ($n = 27$, 23.1%). The patient's mean total body surface area (TBSA) burned was 10.4% ($SD = 11.1$, range 1.0 – 75.0). The median number of surgeries was 1 (range 0 – 14). For further analyses, this variable was categorised as: "no surgeries" ($n = 53$; 45.3%), "one surgery" ($n = 39$; 33.3%) or "more than one surgery" ($n = 25$; 21.4%). Forty-four partners (40%) were present at the burn event. The number

of patients with clinically relevant levels of PTSD symptoms was 21 (18.1%); for partners, this was 34 (29.1%). One patient did not complete the IES-R.

Recalled Pre-Burn HRQL Compared to Population Norms

Table 1 describes the average pre-burn EQ-Index and EQ-VAS, reported by both patients and their partners. Compared to age, gender and country specific population norms (Janssen & Szende, 2014), the EQ-Index from both patients and partners did not deviate significantly from the adjusted norm. Patients' EQ-VAS was on average 4 points higher than the adjusted population norms, which was a significant difference but within the bounds of the MID. Partners' EQ-VAS did not differ significantly from the population norms.

Table 1. *Descriptive and one-sample t-test results for the comparison of pre-burn EQ-Index and EQ-VAS of patients and partners (proxy) with population norms.*

Description	*N*	*M*	*SD*	Population Norm [1]	*t*	*df*	*p*
EQ-Index							
Patients	117	0.93	0.17	0.90	1.73	116	.087
Partners	117	0.88	0.19	0.90	−1.12	116	.26
EQ-VAS							
Patients	113	85.79	12.98	81.56	3.56	112	.001
Partners	110	83.05	16.01	81.55	0.98	109	.33

[1] Age- and gender- adjusted population norms (Janssen & Szende, 2014)

Agreement

Table 2 shows that most patients and partners reported no problems in a specific EQ-5D domain. Exact agreement was around 90% for most domains except for pain (71.8%). Agreement based on the weighted kappa, ranged from slight to substantial for the six EQ-5D domains. After adjustment for prevalence, the weighted kappa (PAK_w) was considerably higher and indicated substantial-to-almost-perfect agreement for the six domains. Agreement according to the PAK_w was the lowest for pain/discomfort and highest for mobility. Exact agreement for the EQ-Index was acceptable, but exact agreement for the EQ-VAS was low even if defined within the borders of the MID. The single-rater ICC for the EQ-Index and EQ-VAS was, respectively, moderate and fair, and the average inter-rater ICC was substantial and moderate.

Table 2. *Agreement between patients and partners on pre-burn EQ domains, EQ-Index and EQ-VAS.*

Patient Response [1]	Partner Response [1]			Exact Agreement	K_w	95% CI K_w	PAK_w	95% CI PAK_w
	No	Some	Extreme					
Mobility								
No	102	5	0	93%	.64	.39–.88	.92	.87–.98
Some	3	6	0					
Extreme	0	0	1					
Self-care								
No	107	7	0	92%	.28	-.17–.73	.91	.86–.97
Some	2	0	0					
Extreme	0	0	1					
Usual Activities								
No	101	7	2	89%	.36	.07–.64	.85	.77–.93
Some	3	2	0					
Extreme	0	1	1					
Pain/Discomfort								
No	75	22	1	72%	.32	.15–.49	.66	.56–.77
Some	6	8	0					
Extreme	0	4	1					
Anxiety/Depression								
No	102	7	1	90%	.34	.08–.60	.87	.80–.94
Some	3	3	1					
Extreme	0	0	0					
Cognition								
No	102	7	0	89%	.18	-.11–.46	.78	.66–.89
Some	6	2	0					
Extreme	0	0	0					

	Agreement ≤ MID	Exact Agreement	ICC single-rater	95% CI	ICC average rater	95% CI
EQ-Index	64%	62%	.45	.29–.58	.62	.45–.73
EQ-VAS (*n* = 107)	43%	22%	.39	.22–.54	.56	.36–.70

[1] The exact wording of the response options of the EQ-5D varied over the domains, but for reasons of clarity and uniformity, responses have been labelled "no (problems)", "some (problems)", and "extreme (problems)"; PAK = prevalence-adjusted kappa; CI = confidence interval; MID = minimally important difference; ICC = intraclass correlation coefficient.

Predictors of Differences on the EQ-Index and the EQ-VAS

Patients reported significantly higher pre-burn EQ-Index scores than their partners, (t (116) = 2.93, p = 0.009), but the mean paired difference of 0.05 (see Table 1) lies within the MID. The mean paired difference on the EQ-VAS was 3.0 and was not significant (t (106) = 1.89, p = 0.062). To examine the relation between patient–partner differences and possible explaining factors, differences on the EQ-Index and EQ-VAS were regressed on the couple's mean score, patient's age and gender, number of surgeries, partner's presence at the burn event, and PTSD symptoms of both patients and partners. The regression models were not significant for either the EQ-Index, (F (8, 100) = 0.83, p = 0.58, R^2 = 0.25) or the EQ-VAS, (F (8, 90) = 1.50, p = 0.17, R^2 = 0.34), indicating that the predictors did not significantly add to the prediction of systematic differences. *Absolute* differences between patients and partners were significantly correlated to couple's mean scores for both the EQ-Index (r = -.61, p < 0.001) and EQ-VAS (r = -.53, p < 0.001), indicating that differences between patients and partners tended to be larger at lower EQ-Index and EQ-VAS scores. The Bland–Altman plots of actual differences between patients and partners in Figure 1 illustrate this relationship. The plots also show that on both the EQ-Index and the EQ-VAS, extreme differences were reported that fell outside the confidence intervals.

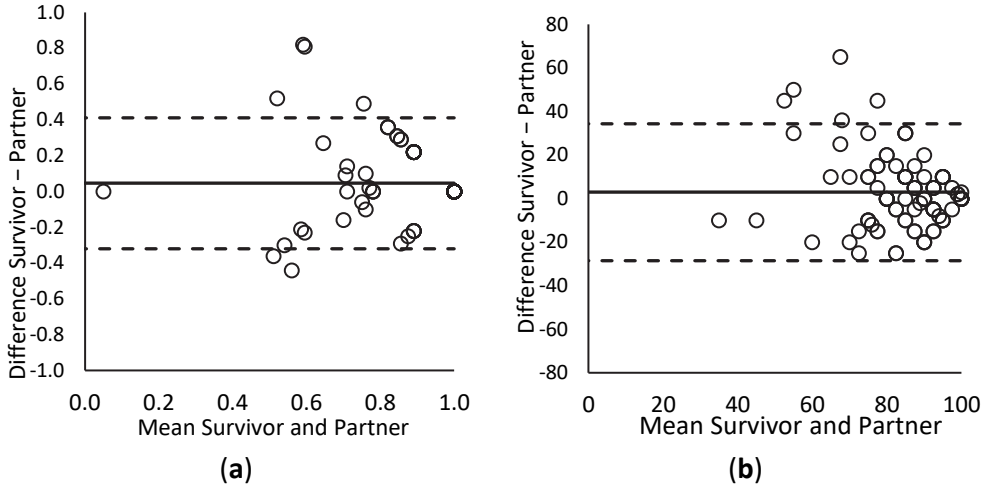

Figure 1. *Bland–Altman plots of differences between patient and partner ratings against the mean of both ratings for* **(a)** *the EQ-Index and* **(b)** *the EQ-VAS. The horizontal lines represent the mean difference and limits of agreement (95% Confidence Interval around the mean difference).*

Discussion

This study examined patient–partner agreement on the retrospectively recalled pre-burn HRQL. EQ-Index scores from both patients and partners were comparable to population norms, whereas the patients' EQ-VAS scores were higher. Agreement varied across the six EQ-5D domains, but after adjustment for prevalence, it was substantial to almost perfect. The average inter-rater agreement on the EQ-Index and EQ-VAS was, respectively, substantial and moderate. On average, patients reported a higher pre-burn EQ-Index compared to partners. Differences were larger at lower HRQL levels, but could not be explained by demographic or burn-related factors or by the PTSD symptoms of patients and partners.

Compared to age- and gender- adjusted population norms, the EQ-Index scores from both perspectives were comparable to the norm scores, but patients' EQ-VAS scores exceeded the norms, whereas the partners' did not. However, post hoc analyses excluding three extremely low-scoring partners (with high-scoring patients), showed that, on average partners may also exceed population norms. This was in line with studies that reported a pre-injury HRQL above population norms (de Graaf et al., 2019; Fauerbach et al., 2005; Scholten et al., 2017). Deviation from the norms on the EQ-VAS, but not the EQ-Index, may be related to a more subjective interpretation of the EQ-VAS compared to the more objectively rated EQ domains (Blome & Augustin, 2015), which makes the EQ-VAS more prone to recall bias and response shift. Recall bias may cause inflated pre-burn EQ-VAS scores, because of the idealization of the pre-burn situation (Scholten et al., 2017). Alternatively, and especially in patients themselves, the experience of the burn event may cause a response shift — an change in the internal standards of what constitutes "good" health (Haagsma et al., 2020; Schwartz & Sprangers, 1999) — resulting in a more highly recalled EQ-VAS than in the (mostly uninjured) norm population, and possibly making comparisons to the norm populations less valid.

The EQ-Index outperformed the EQ-VAS on both the single-rater and the average inter-rater agreement. Single-rater agreement on the EQ-Index and EQ-VAS was, respectively, moderate and fair, and the average inter-rater agreement was substantial and moderate. However, the ICC estimates may have been compromised by three extremely low scoring partners. Indeed, post hoc analyses, excluding these cases, showed that all ICC estimates increased by about 0.10. Agreement according to the unadjusted weighted kappa was only fair in most individual domains. These results fit within the wide range of agreement levels reported

in the ICU literature (e.g. Capuzzo et al., 2000; Dinglas et al., 2013; Gifford et al., 2010; Hofhuis et al., 2003; Scales et al., 2006)), and are the first assessment of proxy agreement in the adult burn population. However, the current study showed that the kappa for pre-burn HRQL is highly affected by prevalence (Sim & Wright, 2005) since the vast majority of patients and partners reported no problems in any EQ-5D domain. Adjustment for prevalence revealed almost perfect agreement between patients and partners on mobility, self-care, usual activities, and anxiety/depression, and substantial agreement for pain/discomfort and cognition. Agreement was the lowest on the pain/discomfort domain, which is not surprising, given that pain is a subjective experience that cannot directly be observed by others (Wideman et al., 2019). Besides, the experience of severe burn-related pain may have especially recalibrated the patient's interpretation of pain (Blome & Augustin, 2015; Schwartz & Sprangers, 1999), while the partner's interpretation may not have changed that much, resulting in disagreement on pre-burn levels of pain. The results partly support previous findings, showing that proxies have more difficulty in assessing subjective domains compared to more the objective physical aspects of HRQL (Hofhuis et al., 2003; Hwang et al., 2017) although (prevalence adjusted) agreement on anxiety/depression was high in the current study.

The analyses of patient–partner differences showed that patients reported higher levels of pre-burn HRQL than partners, in line with the ICU literature (Geense et al., 2020; Scales et al., 2006). However, post hoc inspection of the data revealed that these differences were partly driven by a few partners who reported an extremely low pre-burn HRQL. These partners may have erroneously reported on the post-burn HRQL of the patient. Nevertheless, the Bland–Altman plots showed that differences between the two informants were larger at lower levels of HRQL. Although this supports the idea of a linear relationship between agreement and functioning, we cannot exclude the existence of a u-shaped relationship due to the lack of data in the lower HRQL spectrum (von Essen, 2004). Furthermore, it should be noted that the relationship between absolute differences and a couple's mean HRQL scores may also be the consequence of a ceiling effect because the majority of couples reported a perfect pre-burn health state (i.e., the maximum of 1 on the EQ-Index), preventing variability at the higher end of the spectrum. Differences on the EQ-Index and EQ-VAS were not related to burn severity, indicating that proxy reports were similarly accurate for severely and less severely burned patients. Furthermore, differences were also not explained by the PTSD symptoms of patients or partners, indicating that the symptoms did not disturb agreement in any direction. Further research should investigate patient–partner agreement and differences with respect to

the post-burn HRQL because it may well be that these factors do relate to post-burn differences.

Some limitations of this study should be noted. First, the sample was mostly restricted to patients with good pre-burn health, limiting generalizability to those who have low levels, especially since the results showed that differences between patients and partners increased at lower levels of a pre-burn HRQL. Second, the results cannot be generalized over other close relatives because the sample was limited to partners. Future research could compare multiple proxy perspectives (e.g., adult children, parents and siblings) to evaluate the eligibility of each of these proxies. Third, the partners were only asked to estimate a patient's pre-burn health status, which precludes conclusions about agreement on post-burn HRQL. An assessment of both the pre-burn and post-burn HRQL by the partners could also have reduced the possibility of their erroneously evaluating the current HRQL instead of the pre-burn HRQL, which could explain some of the extreme differences between patients and partners in the current study. Fourth, about half of the patients and partners completed the pre-burn assessment after the recommended two weeks post-injury (Van Beeck et al., 2007), which may have increased the possibility of recall bias. Although we cannot rule out recall bias on the EQ-5D Index, the average recalled pre-burn scores of both patients and partners did not differ from prospectively assessed population norms, which is a preliminary indication that no substantial recall bias (or response shift) occurred for the EQ-Index. Recall bias and response shift more likely have occurred on the EQ-VAS because of the subjective nature of this scale. Future research could investigate the effects of recall bias and response shift on the retrospective assessment of pre-burn functioning.

In conclusion, this study demonstrated that patient–partner agreement on the pre-burn HRQL is substantial. These results are a first indication that partner reports of pre-burn EQ domains may be reliably used to complement or, if needed, substitute for the patient's assessment for research purposes. For monitoring the patient's recovery in clinical practice, partner assessment may also substitute for the patient's assessment if the patient is medically not able to self-report. However, the pain/discomfort domain may be more difficult to assess for partners, so it should be interpreted with caution. Furthermore, the EQ-VAS may be less suited for proxy reporting because of its subjective interpretation and lower level of agreement. Further research on proxy agreement is needed to evaluate the use of a proxy in the post-burn context and to evaluate the eligibility of other close relatives as proxies.

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CHAPTER 6

Bio-Psychological Predictors of Acute and Protracted Fatigue After Burns: A Longitudinal Study

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EBvD, IE, RvdS, and NVL designed the study. EBvD, RvdS, and NVL analyzed the data. EBvD drafted the initial article. RvdS, IE, and NVL provided feedback on the manuscript. All authors reviewed and revised the article and read and approved the final manuscript.

Abstract

Objective: Fatigue after burns is often attributed to the hyperinflammatory and hypermetabolic response, while it may be best understood from a bio-psychological perspective, also involving the neuro-endocrine system. This longitudinal multi-center study examined the course of fatigue up to 18 months postburn. The contribution of bio-psychological factors, including burn severity, pain, and acute PTSD symptoms, to the course and persistence of fatigue was studied in a multifactorial model.

Methods: Participants were 247 adult burn survivors. Fatigue symptoms were assessed with the Multidimensional Fatigue Inventory during the acute phase and subsequently at 3, 6, 12, and 18 months postburn, and were compared to population norms. Age, gender, burn severity, acute PTSD symptoms and pain were assessed as potential predictors of fatigue over time in a latent growth model.

Results: At 18 months postburn, 46% of the burn survivors reported fatigue, including 18% with severe fatigue. In the acute phase, higher levels of fatigue were related to multiple surgeries, presence of pain, and higher levels of acute PTSD symptoms. Fatigue gradually decreased over time with minor individual differences in rate of decrease. At 18 months, pain and acute PTSD symptoms remained significant predictors of fatigue levels.

Conclusions: Protracted fatigue after burns was found in almost one out of five burn survivors and was associated with both pain and acute PTSD symptoms. Early detection of PTSD symptoms and early psychological interventions aimed at reducing PTSD symptoms and pain may be warranted to reduce later fatigue symptoms.

Background

Burn survivors often report fatigue symptoms in the aftermath of burn injuries (Dahl et al., 2012; Holavanahalli et al., 2016; Kool et al., 2017). This feeling of persistent tiredness, weakness or exhaustion can manifest mentally and physically, is not relieved by rest, and may interfere with general activities, mood, and work-related ability (Dittner et al., 2004; Gabbe et al., 2016). Fatigue is prevalent upon hospital discharge with rates between 66 and 75% (Esfahlan et al., 2010; Simko et al., 2018), including 37% with moderate to severe fatigue (Gabbe et al., 2016). Fatigue levels tend to normalize after the 1st year postburn (Corry et al., 2010; Edwards et al., 2007; Gabbe et al., 2016; Simko et al., 2018), although levels may not return to retrospective preburn levels (Simko et al., 2018). Generally, higher levels of fatigue were found in women compared to men and in older compared to younger burn survivors (Edgar et al., 2013; Edwards et al., 2007; Gabbe et al., 2016; Simko et al., 2018; Toh et al., 2015). However, particularly long-term fatigue after burns is still poorly understood.

Fatigue may involve multiple interacting physiological and psychosocial factors (Geenen & Dures, 2019). Its exact pathophysiology is unknown, but there is consensus that the immune system and neurological system play a key role. Pro-inflammatory cytokines disturb the neuronal environment and signal the brain to set illness-related behavioral priorities, such as fatigue, that contribute to survival and repair (Dantzer et al., 2014). Burns typically trigger a local and systemic inflammatory response, characterized by an excessive production of pro-inflammatory cytokines (Jeschke et al., 2011; Mulder et al., 2020), which intensifies with increasing burn size (Barber et al., 2008). The inflammatory response gradually decreases with time, although prolonged elevated levels have been reported (Mulder et al., 2020). In the post-acute phase, the pathophysiological stress response (Herndon & Tompkins, 2004; Jeschke et al., 2011; Porter et al., 2016) may explain the reported relation between burn severity and fatigue (Edgar et al., 2013; Gabbe et al., 2016; Simko et al., 2018), but it may fall short in explaining chronic fatigue.

In the critical illness literature, it is proposed that the endocrine system may also be involved in fatigue through dysregulation of several endocrine axes (Stanculescu et al., 2021; Weekers & Van den Berghe, 2004). The hypothalamic-pituitary adrenal axis (HPA-axis) may be of particular relevance. This fundamental physical stress response system regulates hormonal levels such as corticotropin-releasing factor (CRF) and corticosteroid levels including cortisol, in response to physical and mental challenges (Gupta et al., 2007). Over time, initially high

levels of CRF gradually normalize through a feedback loop, in which elevated cortisol levels trigger HPA-axis suppression. However, prolonged suppression may occur in the aftermath of critical illness and is also observed in persons with chronic fatigue. Hence, prolonged HPA-axis suppression is presumably related to protracted fatigue (Stanculescu et al., 2021).

Besides the extensive wounds that challenge the stress system, triggers of the HPA-axis may include severe pain related to daily repetitive wound care procedures and the potentially traumatic nature of the burn event. A review showed that about 2 to 30% of burn survivors develop acute stress disorder and up to 40% may develop posttraumatic stress disorder (PTSD; American Psychiatric Association, 2013) after 3 to 6 months (Giannoni-Pastor et al., 2016). Studies have shown that both pain and PTSD symptoms are related to higher levels of fatigue after burns (Corry et al., 2010; Esfahlan et al., 2010), and both decrease with time, but are entangled (Ravn et al., 2018; Van Loey, Klein-Konig, et al., 2018). In the acute phase, PTSD symptoms and pain have been related to biological markers of stress, such as cortisol (Brown et al., 2014), and to the neuropeptide oxytocin, that is associated with HPA-axis regulation (Van Loey, Hofland, et al., 2018; Yoon & Kim, 2019). Also, PTSD has been associated with immune activation, in which pro-inflammatory cytokines can act as mediators of the stress response (Yehuda et al., 2015). So far, only one longitudinal burn study has investigated pain and PTSD symptoms in relation to fatigue after burns and found a temporal effect of PTSD symptoms, but not of pain (Corry et al., 2010). In sum, pain and PTSD symptoms may exert an influence on the neuro-endocrine and immune systems involved in (chronic) fatigue.

The aim of the current longitudinal multi-center study was to test the predictive value of burn severity, pain, and acute PTSD symptoms for acute and chronic (at 18 months) fatigue symptoms, and its course over time. Based on the literature, it was expected that older age, female gender, burn severity, and higher levels of pain and acute PTSD symptoms would be related to higher initial levels of fatigue, and that particularly pain and acute PTSD symptoms would be related to protracted fatigue levels.

Methods

Inclusion

The data from this study were part of a larger longitudinal project in three Dutch and three Belgian burn centers. Previous work focused on quality of life in burn survivors (Boersma-van Dam et al., 2021). Patients were recruited between October 2013 and October 2015 and were followed for 18 months. Inclusion criteria were: hospital stay of >24 h following the burn event, age of 18 years or older, and proficiency in Dutch. Exclusion criteria were: psychiatric problems that may interfere with the comprehension or completion of questionnaires (e.g., psychosis, cognitive problems).

Procedure

Patients were invited to participate in the study by a local researcher during their stay in the burn center. After they received oral and written information about the study and agreed to participate, they provided written informed consent. Patients completed the first assessment in the acute phase and follow-ups at 3, 6, 12, and 18 months postburn by postal mail. The study was approved by ethics boards in the Netherlands and Belgium (NL44682.094.13 and B670201420373).

Sample and Missing Data

Of the 266 burn survivors enrolled in the larger study, 247 were included in the analyses. They were admitted to the burn center in Groningen (n = 42), Beverwijk (n = 49), Rotterdam (n = 97), Antwerp (n = 16), Ghent (n = 17), or Brussels (n = 26). These 247 burn survivors completed at least one General Fatigue measure *and* completed all predictor measures at the first assessment. Thirteen burn survivors did not complete any of the General Fatigue measures and six missed information on at least one predictor. The 247 burn survivors did not differ significantly (ps > .05) from the excluded 19 burn survivors in terms of age, gender, TBSA, and number of surgeries.

The number of burn survivors that completed General Fatigue measurements in the acute phase (denoted as T1), and at 3 (T2), 6 (T3), 12 (T4), and 18 (T5) months postburn was 246 (99.6%), 212 (85.8%), 198 (80.2%), 165 (66.8%) and 156 (63.2%), respectively. A total of 141 (57.1%) burn survivors completed all five measurements. Burn survivors with partially missing fatigue data (n = 106) did not differ significantly (p > .05) from burn survivors with complete data (n = 141) in terms of gender, TBSA, number of surgeries, duration of mechanical ventilation, acute PTSD symptoms, and General Fatigue at T1. However, those

with partially missing fatigue data were significantly younger than those with complete data (M = 41.4, SD = 15.5 vs. M = 46.0, SD = 15.2), t (245) = -2.3, p = .022, and reported significantly less pain (20.8% reported no pain vs 7.8% in those with complete data), χ^2 (2) = 10.1, p = .007.

Measures

Fatigue. The Multidimensional Fatigue Inventory (MFI-20; Smets et al., 1995) is a self-report questionnaire with five dimensions, i.e., General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation and Mental Fatigue. It was assessed at all five measurement points. The 5-point Likert scale items were summed for each dimension, with higher scores indicating higher levels of fatigue. General Fatigue results were reported and analyzed, as recommended in the manual and in line with common definitions of fatigue. Results regarding the other dimensions are included in the Supplementary Material. The MFI-20 was tested and validated in several Dutch patient groups (Smets et al., 1995). Reliability of General Fatigue in the current study was good, with Cronbach's alpha ranging from .87 to .90 over time.

Pain. The pain item of the EQ-5D-3L (Rabin & de Charro, 2001) self-report scale was used to assess overall pain in the acute phase. Patients rated whether they experienced no pain or discomfort", "moderate pain or discomfort", or "extreme pain or discomfort". The EQ-5D has good feasibility and reasonable criterion validity in the burn population (Öster et al., 2009).

Post-traumatic Stress Disorder Symptoms. The Impact of Event Scale-Revised (IES-R; van der Ploeg et al., 2004; Weiss & Marmar, 1997) is a 22-item self-report questionnaire that was used to asses symptoms of intrusions, avoidance, and hyper-arousal in the acute phase (T1). Answers were given on a 5-point Likert scale and summed to obtain a total score ranging from 0 to 88. This questionnaire cannot be used to diagnose PTSD, but a score of 33 or higher may reflect a possible diagnosis of PTSD. If at least 20 of the 22 items were completed, sum scores were calculated based on the mean of the completed items. The IES-R has been validated in Dutch trauma populations and showed good psychometric properties (Olde et al., 2006).

Demographics and Burn Characteristics. Age, gender, number of surgeries and total body surface area (TBSA) burned were recorded from the patient's medical file. Number of surgeries indicates the number of skin graft procedures that was required to cover the wounds and is considered an indicator of burn severity.

TBSA is the estimated percentage of the body covered with partial and full thickness burns.

Statistical Analysis

Descriptive analyses were conducted in IBM SPSS v24. Continuous predictors were correlated with General Fatigue at each time point. Categorical predictors were related to General Fatigue at each time point using ANOVA's and (post hoc) *t*-tests. To correct for multiple testing in the (post hoc) *t*-tests, the Benjamini-Hochberg multiple testing procedure was followed (Raykov et al., 2013). That is, we calculated a corrected alpha value (*l*). The *p*-values of the (post hoc) *t*-test should then be smaller than *l* instead of the default alpha of .05. The formula for obtaining *l* is provided in the footnote of Table 2. To determine the prevalence of fatigue, scores were compared to the age and gender adjusted mean, 75th percentile (moderate fatigue) and 90th percentile (severe fatigue) of a national representative sample of the non-institutionalized adult population of Germany (Schwarz et al., 2003). T-tests were used to test the mean difference of the General Fatigue scores at each time point and the adjusted norm score for significance against 0.

Longitudinal trajectories of General Fatigue were estimated using Latent Growth Modeling (LGM) in Mplus 8.5 (Muthén & Muthén, 1998-2017). Full Information Maximum Likelihood (FIML) was used to handle missing data in the model. By including the observed variables related to the probability of missingness in the model, FIML leads to unbiased parameter estimates (Enders, 2010; Hox, 2010). To account for the non-normality of some of the variables, Robust Maximum Likelihood (MLR) was used. Model fit of nested models was compared using adjusted chi-square difference tests (Satorra & Bentler, 2001).

Three consecutive growth models were estimated. First, a linear growth model was constructed with the slope growth factors representing the timing of the measurements since the burn event. Second, the addition of a quadratic term was evaluated, to determine the best fitting shape of the curve. Third, predictors were added to the best fitting growth model, i.e., gender, age, number of surgeries, pain, and acute PTSD symptoms were regressed on the intercept (starting point at T1) and the slope. Age and acute PTSD symptoms were grand-mean centered to aid interpretation of the intercept and slope estimates. Also, to investigate the relevance of the predictors for protracted symptoms of fatigue, we reran the final growth model, but changed the specifications such that the intercept became the endpoint at 18 months postburn.

Model fit was evaluated with the comparative fit index (CFI), the Tucker-Lewis Index (TLI), and the root mean square error of approximation (RMSEA). Models with a TLI and CFI > 0.90 and RMSEA < 0.08 indicate an acceptable fit, and models with TLI and CFI values > 0.95 and RMSEA values < 0.05 indicate a good fit to the data (Kline, 2011).

Results

Descriptive Analyses

The sample of 247 burn survivors included predominantly men (*n* = 176, 71.3%), and had a mean age of 44.0 years (*SD* = 15.5, range: 18–82). Mean TBSA was 9.2% (*SD* = 11.1, range: 1 – 75). Median number of surgeries was 1 (range 0 – 14). For further analyses, this variable was recoded into "no surgeries" (*n* = 118; 47.8%), "one surgery" (*n* = 87; 35.2%) or "more than one surgery" (*n* = 42; 17.0%). Twenty-nine (11.7%) burn survivors had received mechanical ventilation with a mean duration of 9 days (*SD* = 10.5, *Mdn* = 4, range 1–39). In the acute phase, 33 (13.4%) burn survivors reported no pain, 169 (68.4%) moderate pain, and 45 (18.2%) severe pain or discomfort. Forty-four (17.8%) burn survivors showed acute PTSD symptoms within the clinical range.

Table 1. *Number and Percentage of Burn Survivors Reporting Fatigue, Moderate-Severe Fatigue and Severe General Fatigue at Each Measurement*

	Fatigue > mean[1]		Moderate-Severe Fatigue > 75th percentile[1]		Severe Fatigue >90th percentile[1]	
Measurement	*n*	%	*n*	%	*n*	%
Acute Phase	185	75.2	155	63.0	108	43.9
3 Months	141	66.5	112	52.8	83	39.2
6 Months	119	60.1	88	44.4	54	27.3
12 Months	86	52.1	58	35.2	33	20.0
18 Months	72	46.2	48	30.8	28	17.9

Note. [1] Individual scores were compared to respectively the mean, 75th percentile, and 90th percentile of gender and age adjusted population norms (Schwarz et al., 2003).

Table 1 shows the prevalence of General Fatigue at three severity levels compared to population norms (Schwarz et al., 2003). In the acute phase, 75.2% of the burn survivors reported fatigue (> mean of the general population), includ-

ing 43.9% reporting severe fatigue (> 90th percentile of the general population). Over time, these percentages decreased to, respectively, 46.2 and 17.9% at 18 months postburn. At 18 months, moderate to severe and severe fatigue prevalence rates were about 6% and 8% higher than in the general population (25 and 10%, respectively). A comparison between all fatigue dimensions and population norms can be found in the **Supplementary Material** (Supplementary Figure 1 and Supplementary Tables 1**,** 2). Figure 1 shows the mean General Fatigue score over time. Fatigue was highest during the acute phase and showed a significant decrease within 18 months ($p < .001$). Nevertheless, General Fatigue scores were significantly higher than general population norms from the acute phase up to 12 months postburn.

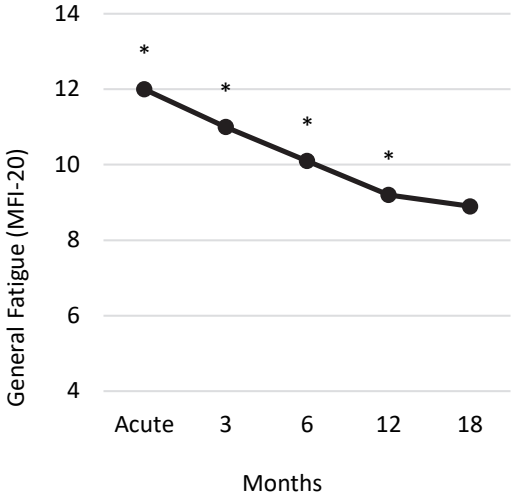

Figure 1. *Observed course of the mean General Fatigue measured with the Multidimensional Fatigue Inventory (MFI-20) during 18 months postburn. Asterisks indicate significant differences from population norms (Schwarz et al., 2003), with ps ≤ .01*

Table 2 presents bivariate associations between the predictors and General Fatigue scores over time. Pearson correlations between age and General Fatigue were not statistically significant, whereas correlations between acute PTSD symptoms and General Fatigue all were. Women showed significantly higher levels of General Fatigue in the acute phase and at 3 months (Cohen's *d*s = 0.5) and a higher level of acute PTSD symptoms ($d = 0.7$) compared to men. Those with severe pain showed significantly higher levels of fatigue over time than those with no pain (d ranged from 1.0 – 1.6) and reported significantly more acute PTSD symptoms than those with no pain ($d = 1.1$) and moderate pain ($d = 0.7$). Also, women reported relatively more severe pain than men, χ^2 (2) = 6.9, p

= .031. At 3 and 6 months postburn, General Fatigue was significantly higher in those with multiple surgeries than those with no surgeries (d = 0.7 and d = 0.6, respectively). Finally, having received mechanical ventilation was significantly related to higher levels of fatigue in the acute phase, t (244) = -2.2, p = .030, and at 6 months postburn, t (196) = -2.4, p = .017, to higher levels of acute PTSD symptoms, t (245) = -2.0, p = .044, and to multiple surgeries, x^2 (2) = 22.8, p < .001.

Table 2. *Descriptives and Bivariate Pearson Correlation Matrix of Study Variables and General Fatigue.*

	1	2	3	4	5	6	7
1 Age							
2 PTSD symptoms	-.08						
3 General Fatigue T1	-.05	.39**					
4 General Fatigue T2	-.02	.39**	.52**				
5 General Fatigue T3	-.10	.43**	.48**	.69**			
6 General Fatigue T4	-.03	.41**	.47**	.60**	.64**		
7 General Fatigue T5	-.00	.41**	.44**	.58**	.67**	.65**	
N	247	247	246	212	198	165	156
Mean	44.0	18.0	12.0	11.0	10.1	9.2	8.9
Gender[1]							
Male (n = 176)	44.2	14.8[a]	11.3[a]	10.3[a]	9.6	8.6	8.2
Female (n = 71)	43.5	25.8[b]	13.6[b]	12.7[b]	11.2	10.6	10.4
Surgeries[1]							
0 surgeries (n = 118)	41.9	17.3	11.7	9.9[a]	9.3[a]	8.5	8.0
1 surgery (n = 87)	45.0	17.3	12.0	11.4[a,b]	10.1[a,b]	9.5	9.4
>1 surgeries (n = 42)	47.9	21.3	12.7	13.2[b]	12.0[b]	10.3	10.0
Pain[1]							
None (n = 33)	43.1	10.3[a]	9.0[a]	8.4[a]	7.7[a]	6.4[a]	6.6[a]
Moderate (n = 169)	45.0	16.4[a]	11.7[b]	10.8[a]	10.0[a,b]	9.0[a]	8.6[a,b]
Severe (n = 45)	40.9	29.5[b]	15.2[c]	13.3[b]	12.0[b]	11.6[b]	11.1[b]
SD	15.5	16.7	4.7	5.0	4.7	4.7	4.5
Median	43	12	12	11	10	9	8

** $p \leq .010$

[1] Sample size at T1;

[abc] Groups with non-identical superscripts differ significantly with $p < l$; l = (0.05 / (31 * (1/1 + 1/2 + 1/3 + […] + 1/31))) * c where c = 1, 2, 3, […], 31 for the ranked p-values to obtain a new alpha value for each new t-test. Post-hoc t-tests for surgeries and pain were only performed if the ANOVA yielded significant results.

PTSD = Post-traumatic Stress Disorder; T1 = Acute, T2 = 3 months, T3 = 6 months, T4 = 12 months, T5 = 18 months postburn;

Latent Growth Modeling

A linear growth model approximated the thresholds for acceptable fit to the General Fatigue data, χ^2 (10) = 29.41, p = .001; RMSEA = .089; CFI/TLI = .933. The quadratic model that was tested produced an impossible high negative correlation (r < -1.0) between the linear and quadratic slope, indicating that this model was not reliable. Therefore, predictors were added to the linear growth model. The results are shown in Table 3. Addition of the predictor variables resulted in a model with an acceptable model fit, $\chi^2(31)$ = 56.45, p = .004; RMSEA = .058; CFI = .942; TLI = .916. This model accounted for 38% of the variance in fatigue in the acute phase, and 3% of the variance around the decline in fatigue over time. With regard to the intercept, burn survivors with multiple surgeries, higher levels of pain or acute PTSD symptoms, reported higher levels of fatigue, compared to burn survivors who did not need surgeries, or who reported lower levels of pain or acute PTSD symptoms, respectively. No significant associations were found between the predictors and the slope. When the variance around the slope in the model without predictors was constrained to zero, this resulted in a non-significant difference in model fit compared to the original model, $\Delta\chi^2_{SB}(2)$ = 1.26, p = .12, indicating little variability in change of fatigue scores over time between burn survivors.

To investigate the relevance of the predictors for long-term symptoms of fatigue, we reran the model such that the endpoint at 18 months postburn was predicted instead of the intercept (acute phase). This adjusted model accounted for 31% of the variance in fatigue at 18 months postburn. Table 3 shows that burn survivors with extreme levels of acute pain and those with higher acute PTSD symptoms, reported higher levels of fatigue at 18 months postburn compared to those who reported no acute pain or lower acute PTSD symptoms, respectively. See also Supplementary Table 3 for the linear growth modeling results of Mental Fatigue.

Table 3. *Linear Growth over Time: Predictors of General Fatigue (N = 247)*

	Intercept Acute Phase			Slope			Endpoint 18 months		
	Est.	SE	*p*	Est.	SE	*p*	Est.	SE	*p*
Correlation with Slope	-.19	0.17	.27				.56	0.12	<.001
Intercept	13.62	0.79	<.001	-1.39	0.54	.01	6.39	0.80	<.001
Gender[1]	0.78	0.57	.17	0.08	0.43	.85	0.92	0.70	.19
Age	-0.01	0.02	.61	0.01	0.01	.28	0.02	0.02	.40
Surgeries									
1 vs 0	0.47	0.53	.37	-0.09	0.40	.83	0.31	0.66	.64
>1 vs 0	1.46	0.72	.043	-0.36	0.58	.54	0.82	0.94	.39
>1 vs 1	0.99	0.75	.19	-0.27	0.58	.64	0.51	1.00	.61
Pain									
No vs Moderate	1.87	0.72	.009	-0.27	0.55	.63	1.39	0.84	.10
No vs Severe	3.26	0.89	<.001	-0.36	0.77	.64	2.62	1.22	.032
Moderate vs Severe	1.39	0.62	.024	-0.09	0.57	.87	1.22	0.94	.20
Acute PTSD symptoms	0.09	0.02	<.001	0.01	0.01	.61	0.10	0.02	<.001

PTSD = Post-traumatic Stress Disorder;
[1] male is the reference category.

Discussion

This longitudinal study examined the prevalence, course and possible predictors of fatigue in burn survivors. The estimated prevalence of (severe) fatigue was high in the acute phase, and decreased considerably over time. Initial higher levels of fatigue were predicted by multiple surgeries, extreme pain and higher levels of acute PTSD symptoms. Higher levels of fatigue at 18 months were predicted by extreme pain and higher levels of acute PTSD symptoms. None of the predictors were associated with the rate of decline in fatigue over time.

The estimated prevalence of fatigue of around 75% (44% severe) in the acute phase, and 46% (18% severe) at 18 months are consistent with previous studies in burn survivors (Gabbe et al., 2016; Simko et al., 2018). At 18 months postburn, the average fatigue level was similar to that of the general population and 6 months fatigue prevalence rates were comparable to chronic critally ill patients (Wintermann et al., 2018). Still, almost one in five burn survivors continued to report severe fatigue at 18 months postburn. Previous research showed that, as a group, burn survivors did not return to retrospectively assessed preburn levels of fatigue and quality of life (Boersma-van Dam et al., 2021; Simko et al., 2018)

and that population norms may be unrepresentative of pre-trauma health (Wilson et al., 2012). Together, these findings emphasize the need to look beyond mean population levels to accurately describe health and recovery after burns over time and call for research aimed to establish adequate cutt-offs for early screening of moderate and severe fatigue in burn survivors.

As hypothesized, fatigue was related to both biological and psychological factors. Burn severity was a robust predictor of fatigue in the acute phase, in line with previous longitudinal studies (Edgar et al., 2013; Gabbe et al., 2016; Simko et al., 2018; Toh et al., 2015), but not of protracted fatigue. This finding subscribes previous research showing a relation between TBSA and fatigue up to 12 months postburn, but not beyond (Simko et al., 2018). The initial effect of burn severity on fatigue may be explained by the hyper-metabolic and hyper-inflammatory responses in severe burns that attenuate after the sub-acute phase, but also by other factors associated with burn severity, i.e., burn survivors with multiple surgeries were more likely to have received mechanical ventilation, which in turn was related to higher acute PTSD symptom levels. Both mechanical ventilation and PTSD symptoms are characteristics of post-intensive care syndrom (PICS) that also encompasses fatigue (Lee et al., 2020; Stanculescu et al., 2021). More (biological) research to disentangle the influence of these factors may be indicated to move the field forward.

Overall pain and acute PTSD symptoms were significantly related to fatigue over time. The relationship between pain and fatigue is well established in patient populations with a chronic disease, such as rheumatoid arthritis, and cancer (Ma et al., 2020; Madsen et al., 2016), but hardly studied in the burn population. Pain resulting from burns may continue along with scar formation (Bijlard et al., 2017), and hence may remain associated with fatigue over time. Although pain and acute PTSD symptoms were related, both factors were unique predictors of fatigue in the multivariate model, indicating that each has a unique relationship with fatigue. In contrast, Corry et al. (2010) did not find a unique effect of pain after controlling for PTSD symptoms, preburn health and functioning, indicating that the effect of PTSD symptoms may be more robust than that of pain. A burgeoning body of evidence points to the connection between pain and PTSD (Fishbain et al., 2017; Ravn et al., 2018) and their association with fatigue over time (Astill Wright et al., 2020). These relations may point to the role of dysregulated endocrine axes, as proposed by Stanculescu et al. (2021), and prolonged activation of the immune system, as both pain and PTSD symptoms become chronic in a subgroup of patients (Yehuda et al., 2015). Future research could investigate whether a lasting relation between pain and PTSD symptoms

with fatigue can be explained by prolonged suppression of the HPA-system and crosstalk with other bio-active components.

Finally, our results partly supported the general finding that women reported higher levels of fatigue than men (Engberg et al., 2017; van't Leven et al., 2010), although the bivariate relation between fatigue and female gender disappeared in the longitudinal prediction model that included also pain and acute PTSD symptoms. Indeed, prevalence rates of PTSD and pain levels are generally higher in women, (Bartley & Fillingim, 2013; Brewin et al., 2000), therefore future research may investigate whether pain and PTSD symptoms partly explain gender differences in fatigue.

Of notice, the decrease in fatigue over time was similar for all burn survivors and none of the predictors interfered with the amount of decrease in fatigue, indicating there was no difference in the course of fatigue for burn survivors with surgeries, more pain or higher acute PTSD symptom levels compared to their counterparts. This finding suggests that early interventions to reduce the initial psychological impact of burns may have the potency to reduce lasting effects on fatigue levels.

Strengths of the present study include the bio-psychological perspective, the longitudinal design, and the investigation of short- and long-term effects. However, some limitations should be noted. First, the sample size was relatively small and the drop-out rate was considerable, which may have affected statistical power, especially to find significant effects on the slope. Second, no information was available on preburn fatigue, nor on possible treatments for PTSD symptoms or fatigue that took place during the study period. Third, fatigue may be influenced by many other factors, such as sleep quality, depression, long-term impairment, physical fitness, and weight, which were not included in this study. Fourth, PTSD symptoms were not studied beyond the acute phase, although symptoms may be related to fatigue over time. Finally, acute PTSD symptoms were assessed with a valid and reliable self-report questionnaire, but questionnaires are known to overestimate PTSD rates compared to a clinical interview (Engelhard et al., 2007).

This study yields some potential clinical implications. First, it calls for monitoring fatigue, especially in more severely burned patients, those with high pain scores and acute PTSD symptoms. Psychological interventions, such as cognitive behavioral therapy and graded exercise therapy are generally effective in decreasing chronic fatigue (Yancey & Thomas, 2012). The mutual relations between pain,

PTSD symptoms and fatigue emphasize the need to address all these factors in an early stage to improve burn survivors' health. In the acute phase, burn survivors may benefit from additional non-pharmacological pain treatment (Abdi & Zhou, 2002; de Jong et al., 2007) and early treatment focused at acute PTSD symptoms (Birk et al., 2019; Fauerbach et al., 2020). More research is needed on the effects of early interventions on fatigue, functioning and mental health after burns.

In conclusion, fatigue rates after burns are considerable and decrease slowly over time. Protracted fatigue may occur, especially in those with higher levels of pain and PTSD symptoms. More attention for fatigue after burns is needed, and psychological interventions may be used to ameliorate fatigue.

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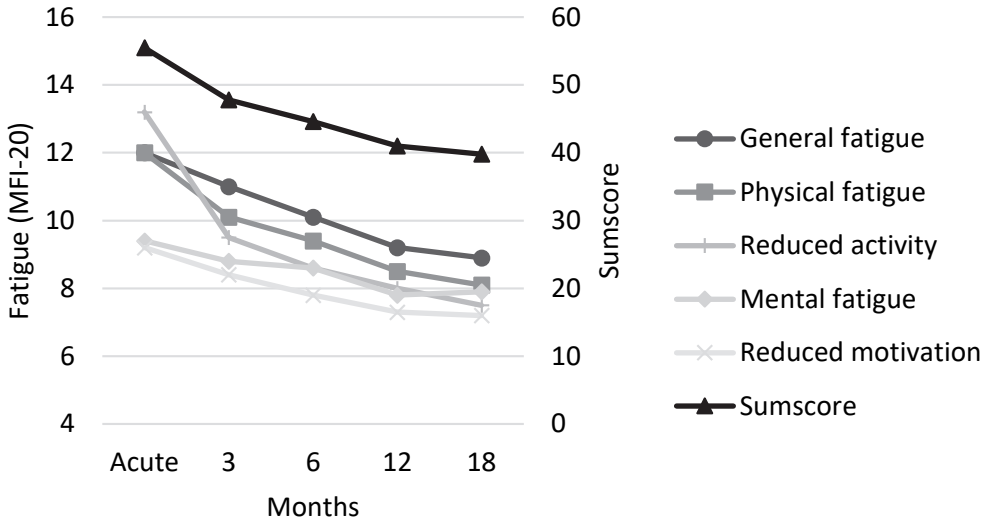
Supplementary Material

A comparison of all five MFI-20 dimensions



SUPPLEMENTARY FIGURE 1 | *Observed course of mean fatigue levels for each dimension of the Multidimensional Fatigue Inventory (MFI-20) during 18 months post-burn.*

Supplementary Figure 1 shows the means for the five fatigue dimensions of the MFI-20 (Smets et al., 1995) over time. For each dimension, fatigue levels were highest during the acute phase and showed a significant decrease within the study period ($p < .001$ for each dimension). Supplementary Table 1 shows the means for the five fatigue dimensions of the MFI-20 over time. Comparisons between dimensions at each measurement occasion showed that General Fatigue was significantly higher than the other dimensions over time, except for Reduced Activity in the acute phase. Compared to the general population norms (Schwarz et al., 2003), the mean scores for General, Physical and Mental Fatigue were significantly higher from the acute phase up to 6 months post-burn; for Reduced Motivation and Reduced Activities this was true up to 3 months post-burn (see Supplementary Table 1). As of 12 months post-burn, none of the mean differences between the sample and the general population norm were statistically significant for any of the dimensions.

SUPPLEMENTARY TABLE 1 | *Descriptive statistics and comparisons of the MFI-20 subscale scores at each time point.*

	General Fatigue	Physical Fatigue	Reduced Activity	Reduced Motivation	Mental Fatigue	Sum Score
Acute Phase						
N	246	245	240	242	243	232
Mean	12.0[a*]	12.0[a*]	13.2[*]	9.2[b*]	9.4[b*]	55.5
Median	12.0	12.0	13.5	8.0	9.0	55.0
SD	4.7	4.9	4.2	4.2	4.5	17.9
Skewness	0.04	-0.05	-0.4	0.6	0.5	0.1
3 Months						
N	212	213	212	214	211	206
Mean	11.0[*]	10.1[*]	9.5[a*]	8.4[b*]	8.8[ab*]	47.8
Median	11.0	10.0	9.0	8.0	8.0	45.0
SD	5.0	4.9	4.5	4.0	4.6	20.0
Skewness	0.1	0.3	0.5	0.8	0.6	0.3
6 Months						
N	198	196	196	197	196	191
Mean	10.1[*]	9.4[a*]	8.6[b]	7.8	8.6[ab*]	44.6
Median	10.0	8.0	8.0	7.0	8.0	43.0
SD	4.7	4.6	4.2	3.8	4.6	18.6
Skewness	0.4	0.6	0.9	1.2	0.8	0.7
12 Months						
N	165	169	168	170	170	162
Mean	9.2	8.5[a]	8.0[a]	7.3[b]	7.8[ab]	41.0
Median	9.0	8.0	7.0	6.0	6.0	38.0
SD	4.7	4.3	4.0	3.6	4.4	18.0
Skewness	0.6	0.7	1.1	1.4	1.1	0.9
18 Months						
N	156	159	159	159	159	153
Mean	8.9	8.1[a]	7.5[bc]	7.2[c]	7.9[ab]	39.8
Median	8.0	7.0	7.0	6.0	6.0	37.0
SD	4.5	4.2	3.7	3.7	4.4	18.2
Skewness	0.7	1.0	1.1	1.3	0.9	1.0

Note.

[abc] At each measurement occasion, subscale means with identical superscripts do not differ significantly, with $p \leq l$; l = (0.05/(50*(1/1+1/2+1/3+1/4+ …+1/50)))*c where c = 1,…,50 for the ranked p-values to obtain a new alpha value for each new test. See the Benjamini-Hochberg procedure (Raykov et al., 2013).

[*] Subscale mean differs significantly from the general population norm (Schwarz et al., 2003), with $p < q$; q = (0.05/(25*(1/1+1/2+1/3+1/4+ … +1/25)))*c where c = 1,…,25 for the ranked p-values to obtain a new alpha value for each new test.

Supplementary Table 2 shows the prevalence of fatigue and severity for each dimension compared to population norms.

SUPPLEMENTARY TABLE 2 | Number and percentage of burn survivors reporting fatigue, moderate-severe fatigue and severe fatigue at each measurement occasion.

	Fatigue (> Mean)		Moderate-Severe Fatigue (> 75th percentile)		Severe Fatigue (> 90th percentile)	
	n	%	*n*	%	*n*	%
General Fatigue						
Acute	185	75.2	155	63.0	108	43.9
3 months	141	66.5	112	52.8	83	39.2
6 months	119	60.1	88	44.4	54	27.3
12 months	86	52.1	58	35.2	33	20.0
18 months	72	46.2	48	30.8	28	17.9
Physical Fatigue						
Acute	185	75.5	156	63.7	108	44.1
3 months	133	62.4	97	45.5	63	29.6
6 months	111	56.6	83	42.3	39	19.9
12 months	80	47.3	57	33.7	26	15.4
18 months	67	42.1	48	30.2	23	14.5
Reduced Activity						
Acute	209	87.1	185	77.1	135	56.3
3 months	121	57.1	88	41.5	52	24.5
6 months	88	44.9	57	29.1	32	16.3
12 months	70	41.7	43	25.6	20	11.9
18 months	59	37.1	32	20.1	12	7.5
Reduced Motivation						
Acute	136	56.2	89	36.8	58	24.0
3 months	106	49.5	63	29.4	47	22.0
6 months	87	44.2	47	23.9	26	13.2
12 months	63	37.1	26	15.3	16	9.4
18 months	59	37.1	27	17.0	16	10.1
Mental Fatigue						
Acute	147	60.5	111	45.7	72	29.6
3 months	108	51.2	87	41.2	62	29.4
6 months	99	50.5	72	36.7	53	27.0
12 months	69	40.6	53	31.2	31	18.2
18 months	71	44.7	50	31.4	31	19.5

Note. Number and percentages of burn survivors scoring above the mean, 75th and 90th percentile of the gender and age adjusted population norms (Schwarz et al., 2003)

In the acute phase, 75.2% of the burn survivors experienced General Fatigue, and 43.9% experienced severe General Fatigue compared to the general popula-

tion. Over time, these percentages decreased to respectively 46.2% and 17.9% at 18 months post-burn. In the acute phase, the highest prevalence was found for Reduced Activity. At 18 months, General Fatigue and Mental Fatigue had the highest prevalence. For the dimensions General, Physical, and Mental Fatigue, 18 month moderate to severe fatigue prevalence rates were about 6% higher than in the general population (25%), and prevalence rates of severe fatigue were respectively 5%, 8% and 10% higher than in the general population (10%).

Latent growth modeling

SUPPLEMENTARY TABLE 3 | Linear Growth over Time: Predictors of Mental Fatigue.

	Intercept Acute Phase			Slope			Endpoint 18 months		
	Estimate	*SE*	*p*	Estimate	*SE*	*p*	Estimate	*SE*	*p*
Correlation with Slope	-0.18	0.12	.13				-0.77	0.05	<.001
Intercept	7.93	0.64	<.001	-0.90	0.49	.068	6.31	0.75	<.001
Gender	0.31	0.53	.56	-0.32	0.42	.44	-0.27	0.71	.70
Age	-0.02	0.01	.093	0.02	0.01	.20	0.00	0.02	.89
Surgeries									
1 vs 0	0.53	0.48	.27	0.32	0.39	.42	1.10	0.66	.098
>1 vs 0	0.85	0.63	.17	-0.14	0.52	.79	0.60	0.87	.49
>1 vs 1	0.32	0.67	.63	-0.46	0.54	.40	-0.50	0.90	.58
Pain									
Moderate vs No	0.78	0.66	.24	-0.05	0.47	.91	0.69	0.74	.35
Severe vs No	0.52	0.86	.54	1.58	0.79	.046	3.37	1.27	.008
Severe vs Moderate	0.26	0.62	.68	1.63	0.67	.014	2.68	1.10	.014
Acute PTSD symptoms	0.12	0.02	<.001	-0.02	0.01	.15	0.09	0.02	<.001

PTSD = Post-traumatic Stress Disorder

The linear growth model that was reported in this article was also fitted to the other MFI-20 dimensions, but this resulted in bad model fit (and problems with negative residuals) for Physical Fatigue, Reduced Activity and Reduced Motivation. For Mental Fatigue, a linear growth model showed an acceptable fit to the data, χ^2 (10) = 21.73, p = .017; RMSEA = .069; CFI/TLI = .960. Next, predictors were added to the linear growth model, resulting in a model with an acceptable model fit, χ^2 (31) = 59.80, p = .001; RMSEA = .061; CFI = .942; TLI = .916. The results are shown in Supplementary Table 3. This model accounted for 44% of the variance in Mental Fatigue in the acute phase, and 11% of the variance of the decline in fatigue over time. With regard to the intercept, burn survivors with higher levels of acute PTSD symptoms reported higher levels of fatigue. With regard to the slope, burn survivors who reported extreme pain or discomfort in the acute phase showed a significantly less steep decline in Mental Fatigue over time than those with no or moderate pain or discomfort.

To investigate the relevance of the predictors for long-term symptoms of Mental Fatigue, we reran the model to predict the endpoint at 18 months post-burn instead of the intercept (acute phase). This adjusted model accounted for 25% of the variance in Mental Fatigue at 18 months post-burn. Supplementary Table 3 showed that burn survivors with extreme levels of acute pain/discomfort and those with higher acute PTSD symptoms, reported higher levels of Mental Fatigue at 18 months post-burn compared to those who reported no or moderate acute pain or lower acute PTSD symptoms respectively.

Notes

- The MFI-20 operationalized 'Mental Fatigue' as concentration problems.
- Note that in the main article, the General Fatigue score differs significantly from the population norms at 12 months post-burn. This result differs from what is reported here, due the different number of t-tests that is performed (25 vs 5), and hence a different correction factor for the p-values, leading to a different conclusion.

References Supplemental Material

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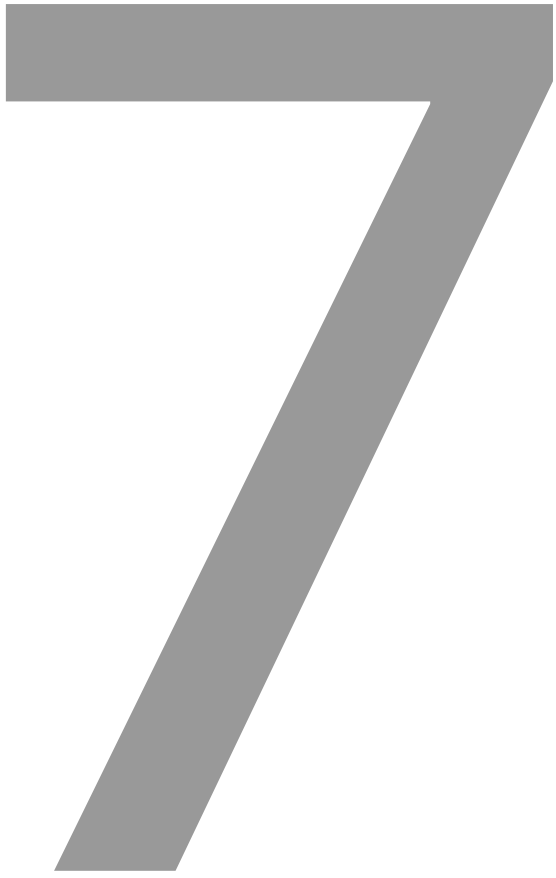
CHAPTER 7



Summary of the main findings and general discussion

The aim of this thesis was to increase our understanding of the traumatic impact of burn injuries on burn survivors' quality of life and psychological symptoms in their partners. In the first part, we focused on the development and course of PTSD symptoms in partners of burn survivors and investigated how both couple members' interpersonal behavior affected their PTSD symptoms over time. In the second part, we focused on the impact of PTSD symptoms on health-related quality of life (HRQL) and fatigue. We also explored the existence of different patterns of recovery to the pre-burn level of HRQL, and we compared patient and partner perspectives on pre-burn HRQL. In this chapter, the main findings of the dissertation are summarized and discussed. Further, implications of the findings for improvement and consolidation of psychosocial care after burns, and suggestions for future research are provided.

Summary of the main findings

In **Chapter 2**, we showed that about 30% of the partners showed clinically relevant levels of PTSD symptoms in the acute phase, which is a substantial rate but it decreased to 4% at 18 months postburn. Partners showed a remarkably sharp decline in PTSD symptoms in the first three months postburn. While short-term symptoms were related to perceived life threat, anger, guilt, and rumination, long-term persistence of symptoms was related to burn severity and high levels of acute PTSD symptoms.

In **Chapter 3**, individual and interpersonal processes related to PTSD symptoms of couples were uncovered. With regard to survivors, it was found that showing concern towards the partner was related to the survivor's higher levels of subsequent PTSD symptoms, but concern expressed by the partner was related to lower levels of PTSD symptoms in survivors. In partners, avoidant self-regulation and PTSD symptoms reinforced each other over time.

In **Chapter 4**, four HRQL patterns of change over time were established: stable, recovery, deterioration, and growth. A subset of patients did not return to their recalled pre-injury level in a specific domain, especially with regard to pain/discomfort, anxiety/depression, and cognition, which was related to higher burn severity and higher levels of PTSD symptoms at 3 months postburn.

Chapter 5 showed that survivor-partner agreement on survivor's preburn HRQL varied across the specific domains from substantial to almost perfect. The average agreement on the total score and the visual analogue scale (VAS) were substantial and moderate, respectively. Survivor-partner differences were larger

at lower levels of HRQL and were specifically present in the pain/discomfort domain.

In **Chapter 6**, we showed that 44% of the burn survivors experienced severe fatigue in the acute phase, and 18% showed persistent fatigue at 18 months postburn. In the acute phase, higher levels of fatigue were related to higher burn severity, pain, and acute PTSD symptoms, of which the latter two predicted persistent levels of fatigue at 18 months postburn.

The traumatic impact of burns in a couple perspective

This dissertation shows that besides physical recovery and scar formation, psychosocial recovery is important after burns. Long-term psychosocial consequences can be experienced by both the survivor and the partner, and interpersonal processes should be taken into account in the assessment, prevention, and support of the families' recovery. While most burn survivors and family members show resilience in their adaptation to life after a burn injury, identification and follow-up for those at risk of psychosocial problems remains a key priority to improve psychosocial burn care.

Impact on partners

While a growing stack of research has elucidated the course and predictors of PTSD symptoms in burn survivors (Giannoni-Pastor et al., 2016; Hobbs, 2015), the current dissertation is among the first to uncover the traumatic impact of burns on partners. Almost one in three partners showed elevated levels of PTSD during the acute phase of the burns, which was more than in burn survivors themselves (one in five; **Chapters 2 and 3**), but lower than previously reported in mothers of burned children (one in two; Bakker et al., 2013; Egberts et al., 2017). Although these figures in part reflect the general notion that women show higher levels of PTSD than men (Brewin et al., 2000), – most partners were female –, they stress without prejudice the impact a burn can have on other family members.

In comparison to other medical populations (e.g. stroke, heart attack, ICU), burns are the medical condition with the highest PTSD prevalence over time (Cyr et al., 2021), and a somewhat higher symptom severity. With regard to symptom severity at three months post-injury, IES-R scores of the partners in our sample (*Mdn* = 7.5, *IQR* = 2 – 17) were higher than in relatives of Dutch critically ill patients (*Mdn* = 6, *IQR* = 2 – 16.3) who had been admitted to the ICU (de Ridder et al., 2021). Similarly, the IES-R symptom severity of our burn survivors at 6 months

post-injury (*M* = 12.8, *SD* = 15.6) was higher compared to both mildly (*M* = 8.4, *SD* = 13.0) and severely (*M* = 9.3, *SD* = 12.2) injured Dutch Emergency Department survivors (Asscheman et al., 2023).

Our study also gives valuable insights into factors related to partners' PTSD symptoms at different stages of the postburn recovery period. In the acute phase, psychological factors such as perceived life threat, emotions, and coping were strongly connected to acute PTSD symptoms, and seem to prevail over burn-related factors, in line with the general findings for survivors (Giannoni-Pastor et al., 2016). Directly following the acute phase, when (perceived) life threat has abated in virtually all cases, partners' PTSD symptoms steeply decreased. In the months that followed, burn severity played an increasing role in explaining persistent symptomatology in a subgroup of partners, even when controlling for the acute traumatic response. This long-term effect provides preliminary support for the hypothesis that has been posed in the literature, that scars may act as a reminder of the burn event (Macleod et al., 2016; Shepherd, 2015), and thereby maintain PTSD symptoms. In both survivors and partners, we observed that the correlation between the need for surgeries in the acute phase, – which is a rough proxy of permanent scarring, – and PTSD symptoms increased in strength over time (**Chapter 3**). To further investigate the 'scars-as-reminder hypothesis', we aim to conduct a systematic review and meta-analysis to evaluate the support for this hypothesis in the wider burn literature.

The dynamic interplay between couple members

While previous research has mostly elucidated the traumatic impact of burns at the individual level of the survivor, the current dissertation comprises cutting-edge insights into the interactional processes that take place at the second level of the social-interpersonal model of PTSD (Maercker & Hecker, 2016), specifically at the couple level. We showed that the survivor and the partner may both face their own pitfalls in dealing with the effects of the traumatic event on the couple level (**Chapter 3**). Survivors who are particularly preoccupied with the well-being of their partner may deprive themselves of processing their own traumatic experiences. From the perspective of the supporting partner, we saw that partners who avoid showing their feelings and concerns regarding the burn event to the survivor,– although well intended to protect the survivor, – may end up in a vicious cycle in which PTSD symptoms and avoidant interpersonal behavior reinforce each other (Monson et al., 2010). Fortunately, interpersonal processes may also aid the recovery from PTSD symptoms, and partners who express concern about the mental well-being of the survivor may contribute to the recovery of the survivor's traumatic experience. These insights form a valuable starting

point for how couples can be guided to deal with the traumatic experience in a way that is fruitful for the recovery of the survivor as well as the partner.

Scarred by burn trauma

The second part of this dissertation highlights that PTSD symptoms may have a profound and long-term impact on other areas of well-being, such as HRQL and fatigue. Our study on these concepts demonstrated that early traumatic stress symptoms in the acute phase and at 3 months postburn are indicators of risk for long-term impairments in HRQL (**Chapter 4**) and persistent fatigue (**Chapter 6**). In each domain of the HRQL, – physical and mental –, those with clinically high levels of PTSD symptoms at 3 months postburn were 3 to 6 times less likely to recover to preburn HRQL in the 18 months following the burn. Also, PTSD symptoms were in all but one of the outcome domains a stronger predictor of recovery than burn severity. These results stress the persistent and profound impact PTSD symptoms can have on a broad range of health-related long-term outcomes.

Unraveling the mechanisms behind fatigue after burns

With regard to fatigue, our study showed that fatigue is prevalent during the acute phase of the burns, and gradually declines in the months that follow. Still, almost 1 in 5 burn survivors remained with severe fatigue symptoms at 18 months postburn, which is about twice as much compared to population norms (Schwarz et al., 2003). Although preburn causes for fatigue cannot be excluded and preburn levels of fatigue were not (prospectively) measured, the results suggest at least some relation with burns exists, stressing the need for a deeper understanding of the mechanisms behind fatigue. Although our research did not unravel the specific mechanisms behind persistent fatigue, we did find that burn severity was a predictor of acute fatigue levels, but not of persistent fatigue. In contrast, pain and PTSD symptoms, measured as early as the acute phase, did predict fatigue both in the short-term and as long as 18 months postburn. These findings may support the suggestion that dysregulation of the endocrine axes and the immune system both play an important role in maintaining fatigue in the long term (Stanculescu et al., 2021). Further research is needed to find biological and psychological mechanisms that are suitable for (early) intervention, to prevent persistent problems with fatigue.

Beyond resilience

The positive message that is present throughout this dissertation is the remarkable resilience that most survivors and partners show in response to the burn event and its consequences. The majority of the couples did not show clinically high levels of PTSD symptoms in the acute phase, and those who did mostly recovered within 12 to 18 months postburn. Similarly, our findings regarding fatigue and HRQL showed that most survivors recover to healthy levels of functioning within the study period. And, we saw that the two most prevalent pathways of HRQL after burns are characterized by resilience, comprising either a stable level of HRQL throughout the study period or a pattern of impairment and recovery. These findings are in line with the general literature showing that most burn survivors recover both physically and mentally, return to work, and have satisfying lives (Mason et al., 2012; Parvizi et al., 2023; Stoddard et al., 2014) and is congruent with the wider trauma literature showing that resilience is the most common response to potentially traumatic events (Galatzer-Levy et al., 2018).

By looking beyond population-level patterns of recovery and resilience, we also identified a group of survivors that grew beyond their pre-burn HRQL, suggesting that some burn survivors may experience post-traumatic growth. A literature review showed that growth is a process of increased understanding of the self, the world, and others, which may result in an improved quality of life and the use of more effective coping strategies (Martin et al., 2017). However, perceived post-traumatic growth can also predict more PTSD symptoms later on (Engelhard et al., 2015), and the precise nature of these relations is not yet understood.

Moreover, this dissertation stresses that looking beyond the group-level resilience pattern is needed to identify survivors who do show a persistent struggle with their (mental) recovery, in terms of PTSD, fatigue, or HRQL. For example, we identified a subgroup that did not fully recover to the pre-burn level of HQRL, especially with regard to the mental HRQL domains, in line with the literature (Spronk, Legemate, Oen, et al., 2018). These findings stress that problems with mental recovery should be an issue of main concern in the (long-term) aftercare for burns.

Implications for the psychosocial care of burn survivors and their families

Early screening

The most important implication of this dissertation is the need for early screening of mental health problems in burn survivors and their families. Early screening

is the first step to timely identify those with substantial mental health problems and at risk for chronic problems like PTSD and to target prevention and early intervention efforts. Currently, the Dutch guidelines for burn care recommend referral to a certified psychologist in case a medical professional suspects a burn patient or close family member may meet the criteria of depression, PTSD, ASD, or sleeping disorder (Nederlandse Verening voor Heelkunde, 2017). This guideline stands in poor contrast to other countries and European guidelines, which require routine psychological screening for all burn survivors and adequate follow-up (American Burn Association, 2019; British Burn Association, 2018; European Burns Association, 2017).

Early screening questionnaires (Oaie et al., 2018; Shepherd et al., 2017; Stockly et al., 2022) should be developed for the Dutch burn care practice, assessing symptoms of acute stress as well as other common mental health issues after burns, such as depression and anxiety. Besides, the assessment of risk factors for persistent symptomatology is essential, including perceived life threat, pain, history of psychiatry, coping, and personality (Giannoni-Pastor et al., 2016; Hobbs, 2015).

Successful implementation of routine early screening can be challenging because of time constraints, a lack of appropriate screening tools, a shortage of mental health care providers to support the process, and insufficient knowledge of appropriate follow-up (Padalko et al., 2023; Smith et al., 2021). Therefore, in the next section, we describe a framework that integrates mental health care into all aspects of burn care. This process starts with the embedding of mental health care professionals into multi-disciplinary burn care teams, with the ultimate goal of improving mental health care and general recovery of burn survivors and their family members, while at the same time creating a supportive work environment for health care staff.

Trauma-informed care during hospitalization

Ideally, early screening is part of an integrated psychosocial care approach that recognizes the potential trauma of the survivors. Trauma-informed care (TIC) is such an approach that addresses the relationship between healthcare users and healthcare providers in such a way that it recognizes the impact of trauma and the history of the survivor on their needs, experiences, and recovery while minimizing the risk for re-traumatization (Harris & Fallot, 2001; Sweeney et al., 2018). Central to TIC are supportive relationships that serve to nurture safety and collaboration, and promote social support and self-efficacy. Figure 1 shows

the application of TIC to the burns settings, proposed by Cleary and colleagues (2020).

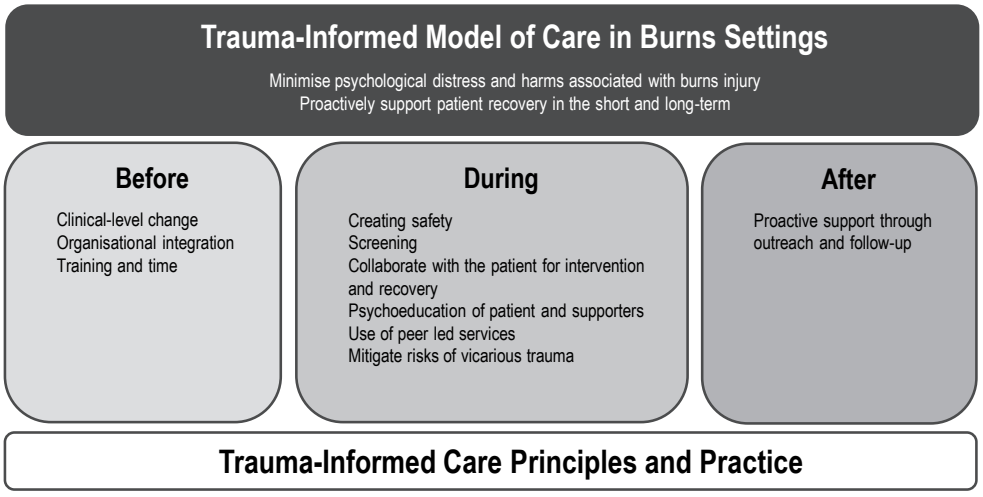


Figure 1. *Trauma-informed care principles in the burns setting.*

Note. From "Before, during and after: Trauma-informed care in burns settings", by M. Cleary et al., 2020, *Burns*, 46, p. 1173 (doi: 10.1016/j.burns.2019.12.003). Copyright 2019 by Elsevier Ltd and ISBI.

Implementing TIC requires education and training at all levels of the organization to ensure at least a basic understanding of how trauma can impact people's recovery (Cleary, West, et al., 2020; Huo et al., 2023). Those directly working with survivors and family members need further education and training to be well equipped in using the principles of TIC, i.e. to ensure a safe environment for the survivor, to implement early psychosocial screening, to engage in supportive collaboration with the survivor and its family, to be able to provide psychoeducation and offer participation in a peer-support network, to effectively collaborate with other (mental) health services for referral, and to recognize and deal with the psychological impact on staff members themselves (see Figure 1). Mental health professionals may guide this implementation process and create a supportive work environment of ongoing training, case discussions, supervision, and mutual support between colleagues, which also mitigates risks for vicarious traumatization and burnout among the staff (Moloney et al., 2018).

To do justice to the impact of burns on partners *and* other family members, the principles of TIC may best come into their own combined with a family-centered approach. Family Centered Care includes family members actively in the decision making and care processes, and addresses the (psychological) impact of hospital

admission and discharge on the family (Davidson et al., 2017; Kokorelias et al., 2019). The personal needs of family members can be addressed by creating a family support zone where family members can rest or take care of their own needs.

Within a family-centered TIC approach, the results of the early screening can be used to ensure adequate psychosocial support and referral to specialized clinical psychologists. While all survivors and families may benefit from basic psychoeducation about psychosocial responses to a traumatic event and adequate coping strategies, those with high levels of acute stress may benefit from more intensive support. Couples may be made aware of possible negative or positive effects of their interpersonal behavior and mutual communication on recovery. Uninjured partners may be especially encouraged to show concern and interest in the survivor's mental well-being and to avoid hiding their own feelings and getting trapped in a cycle of avoidance and PTSD symptoms. Besides, the coping capacity of the uninjured partner and their ability to provide care and social support should be assessed to guide them in their role of supporter both during hospitalization and after the transition to home.

Intervention and treatment

For survivors and families who suffer from debilitating mental health problems, such as ASD or PTSD, appropriate intervention should be offered. A recent systematic review identified five clinical trials testing interventions aimed at reducing PTSD symptoms in adult burn survivors (Paggiaro et al., 2022). Among these, Cognitive-behavioral therapy (CBT) provided the most promising results in reducing PTSD symptoms after burns, in line with systematic reviews on PTSD after medical events and with the larger PTSD literature (Birk et al., 2019; Haerizadeh et al., 2020; Lewis et al., 2020). CBT uses a variety of strategies and techniques, such as psychoeducation, cognitive restructuring, and exposure to traumatic memories and related situations, in order to modify inadequate behavior such as avoidance, to revert dysfunctional thoughts, and to improve emotional self-regulation. Eye movement desensitization and reprocessing (EMDR) therapy has also proven to be effective in the treatment of PTSD following a medical event (Haerizadeh et al., 2020; Lewis et al., 2020). It has not been specifically investigated in the burn population, though one case study provides preliminary support for its usefulness as a treatment for PTSD (McCann, 1992).

Furthermore, Acceptance and Commitment Therapy (ACT) may be a promising therapy for burn survivors who struggle with their appearance. ACT takes a contextual-functional approach aimed at creating psychological flexibility by

teaching mindfulness and acceptance of oneself on the one hand, and by using behavioral change to commit to living in alignment with personal life values on the other hand (Hayes et al., 2006). This therapy seems promising for both trauma populations (McLean & Follette, 2016) and those with visible differences (Zucchelli et al., 2022). The first studies on ACT in the burn population showed that psychological flexibility was related to lower levels of appearance anxiety, and demonstrated a reduction in appearance anxiety and an increase in living a valued and meaningful life in three case studies (Shepherd et al., 2019; Shepherd et al., 2020).

Trauma-informed care and monitoring during after-care

Proactive delivery of TIC should continue after the in-patient period, with a long-term perspective, since a substantial group of burn survivors struggles with psychological symptoms beyond 2 years postburn (Oster & Sveen, 2014; Schneider et al., 2012; Su & Liang, 2022). Coordination, integration, and accessibility of physical, mental, and social health after-care services is essential to smoothen pathways for trauma recovery. Accessibility could be safeguarded by sending proactive reminders for upcoming appointments and by engaging peer support networks and services that can address survivors' emotional or practical barriers to engagement in after-care services (Cleary, Kornhaber, et al., 2020).

Since 2018, the Dutch burn centers started the Outcome Registry the Netherlands (BORN) to uniformly measure, register, and monitor long-term patient-reported outcome measures of burn survivors at multiple time points post discharge, and with yearly long-term follow-up. (Stoop et al., 2020). The survivor's results are summarized on a dashboard for use by the healthcare provider during aftercare visits. Based on the survivor's outcomes, specific information available in the online platform may be suggested to educate the survivor, to improve self-management, and to assist shared decision making with regard to scar treatment.

While this initiative provides valuable data for research and aids the monitoring of the participating burn survivors' recovery, not all burn survivors complete these measures, for example, because of lower (health) literacy or because they find the (repeated) completion too burdensome. To effectively address the needs of *all* survivors and family members during after-care visits, – again – a *systematic* short screening prior to each aftercare visit is needed to identify (psychological) difficulties that need attention (Carmean et al., 2019; Potter et al., 2023). A recent Dutch study (Hofland et al., 2022) demonstrated the clinical utility of a short screener that identifies possible areas of concern for the burn survivor that can even be completed while waiting for the appointment. Further research

and development has resulted in a burn-specific after-care screener (Van Loey, 2024), guided by previous work in this area (Gibson et al., 2019; Kool et al., 2017).

Methodological considerations and future research

The studies that formed this dissertation were based on the longitudinal multicenter study about the social impact of burns, comprising measures of PTSD symptoms, interpersonal processes, fatigue, and HRQL in the acute phase after the burns, and at 3, 6, 12, and 18 months postburn. For both PTSD symptoms and HRQL, we saw major group-level changes in the first six months and stabilization between 12-18 months postburn, in line with the larger literature (Spronk, Legemate, Oen, et al., 2018), suggesting that a follow-up period of 1.5 -2 years is a sufficient time period to capture the significant changes in wellbeing and recovery after burns. Our studies also stress the importance of conducting longitudinal studies to gain insight into the relative importance of risk factors at different stages of recovery. For example, we observed an increasing correlation between surgeries (as an indicator of scars) and PTSD symptoms over time, which spurred the initiation of a systematic review and meta-analysis to investigate the 'scars as reminder'-hypothesis. Such subtle changes in the relevance of predictors over time stress the need for more detailed future research, explicitly addressing the relative importance of risk factors at different time points postburn.

Chapter 4 was a first exploration of patterns of change in HRQL from preburn to 18 months postburn and the definition of the patterns may need further adjustment and validation in other burn samples. For example, the rather narrow definition of the growth pattern did not allow for a 'dip' in HRQL postburn, which reduced the number of survivors that comprised this pattern. This definition may not hold in the light of posttraumatic growth theory, which states that growth arises as a result of struggling with trauma, a process that takes time and may develop in response to PTSD symptoms (Calhoun et al., 2010; Tedeschi & Calhoun, 2004). Consequently, it may be more accurate to reallocate some survivors that eventually grew beyond pre-burn HRQL from the recovery pattern to the growth pattern. Besides, it is questionable whether the EQ-5D-3L is suited to identify a growth pattern, because of a ceiling effect. The majority of our sample reported perfect preburn HRQL, which made it impossible to capture recovery beyond the preburn level. Using a newer version of the EQ-5D-5L (Feng et al., 2021) may (partly) solve this problem since it has five answer options instead of three. Further, future studies may use the knowledge obtained from this study to conduct latent growth curve analyses to more precisely cluster survivors in the different HRQL trajectories.

Furthermore, the accurate measurement of 'recovery' and preburn HRQL could form the subject of an entire dissertation. In **Chapter 5**, we drew attention to the idea of response shift (Howard & Dailey, 1979), indicating that a burn injury and its consequences may cause a change in internal standards of what constitutes 'good health'. This change can be relevant for the subjective experience of the survivor and is not merely a measurement-distorting mechanism. In fact, it has been argued that, in the long-term, being able to adapt one's health standards to life after a (severe) burn, may be an expression of an individual's ability to come to terms with their changed life (Öster, 2010). In this light, response shift may be an expression of resilience. Internal standards of good HRQL may change not only from preburn to postburn but may evolve during a longer postburn period (Haagsma et al., 2019). Such a perspective on recovery requires a different measurement method than applied in our study, including multiple simultaneous measures of current and retrospective HRQL (e.g. Haagsma et al., 2020). With this approach, comparisons between current and pre-burn HRQL are (re)calibrated on the same internal standard at each measurement time. Future research may thus focus on comparing various ways to measure recovery after burns and dealing with response shift and recall bias (Ortega-Gómez et al., 2022).

Similarly, the complementary pre-burn HRQL proxy rating by the uninjured partner in **Chapter 5** was only measured in the acute phase. In the underaged population, it is more common to include both child and parent perspectives for HRQL at all measurement times (e.g. Pan et al., 2015; for a review see Spronk, Legemate, Polinder, et al., 2018), and this practice may also be useful in the case of retrospective measurements of adult HRQL.

Future research

In addition to the input for future research that arose from methodological considerations, a number of goals for future research have risen from this dissertation. First, the development of Dutch population norms for the Multiple Fatigue Inventory (MFI) is warranted. Currently, only German population norms (Schwarz et al., 2003) are available, so for a good comparison of fatigue in the burn population and the general population, Dutch norms should be developed.

Second, future research with regard to PTSD may especially focus on the screening and monitoring of PTSD symptoms after burns. Specifically, the development of a short psychosocial screener is necessary to achieve a successful implementation and acceptance of routine screening of all burn survivors and family members. While instruments such as the IES-R and the BDI are already validated in Dutch trauma populations, these lists are quite extensive, which may impede the

acceptability of the instrument by (impaired) survivors and health care providers. Similarly, the after-care screener that has been developed (Van Loey, 2024) needs validation.

With regard to TIC, implementation studies are needed to investigate how such a framework can best be adapted to the Dutch situation. Since the British burn care standards already included most of the TIC principles, expert elicitation including British TIC experts (by experience) may be a fruitful starting point. Recently, a project proposal has been submitted which aims to develop both a PTSD screening instrument for the acute postburn phase, and a personalized trauma-informed care program, in which individual trauma-related care goals are identified and addressed (Van Loey, 2022).

Finally, with regard to treatment of PTSD, studies on the effectiveness of EMDR and ACT are needed to move the field forward and increase the evidence of the applicability of these intervention for the (Dutch) burn population.

General conclusion

A burn injury may leave survivors not only with scars on their body, but also with long-term consequences for their quality of life and for their own and their partner's mental wellbeing. Both the physical and the psychosocial consequences need attention during inpatient and outpatient burn care. This dissertation presented the result of a longitudinal observational study of the traumatic impact of burn injuries on survivors and their partner up to 18 months postburn.

Elevated levels of traumatic stress were common in the acute phase after the burns, but most survivors and partners recovered in the long-term. Nevertheless, a subgroup of partners and survivors showed persistent long-term posttraumatic stress symptoms, that need clinical attention. In survivors, the experience of acute traumatic stress has long-lasting impact on functioning with regard to both HRQL and fatigue, which stresses the importance of early screening and appropriate psycho-education and prevention to intervene in this process early on.

The adoption of a couple perspective yielded valuable insights in the dynamic interplay between survivors and supporting partners, and showed that partners who express more concern towards the mental wellbeing of the survivor, may help to ameliorate lasting traumatic impact on the survivor. Health care providers may try to be aware of avoidant self-regulation in partners, and stimulate

partners to disclose their thoughts and feelings to ameliorate the traumatic consequences for them as well.

Psychosocial care of burn survivors and their family may be further improved by implementing a TIC approach, resulting in basic knowledge of trauma throughout the organization, and development of appropriate screening, prevention, and intervention programs. As a result, burn care becomes trauma-sensitive, psychology becomes 'everyone's business', and psychological support can be optimally tailored to the needs of the survivor and the family members.

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Samenvatting
Summary in Dutch

Introductie

Een brandwondenongeval laat vaak niet alleen lichamelijk, maar ook mentaal sporen na en kan impact hebben op de partner en de andere gezinsleden. Dit proefschrift richt zich op de psychische gevolgen voor mensen met brandwonden (in het vervolg 'survivors' genoemd) en hun partner, en op de daarmee verbonden gevolgen voor de kwaliteit van leven van de survivor. In dit hoofdstuk volgt een samenvatting van de resultaten uit de studies in dit proefschrift, gevolgd door een discussie van de bevindingen en implicaties voor onderzoek en praktijk.

Samenvatting van de resultaten

De empirische hoofdstukken in dit proefschrift beschrijven de resultaten van een prospectieve studie naar de sociale impact van brandwonden op survivors en hun partner. De studie is uitgevoerd in zes brandwondencentra in Nederland en België. Ze kent vijf meetmomenten gedurende de eerste 18 maanden na het oplopen van brandwonden. De studie beslaat een groep van ruim 240 volwassenen met brandwonden en ongeveer 120 partners. Verschillende aspecten van het psychische, sociale en algemene welzijn zijn onderzocht door middel van vragenlijsten. Binnen deze aspecten richt dit proefschrift zich met name op posttraumatische stresssymptomen, kwaliteit van leven en vermoeidheid.

In **Hoofdstuk 2** richtten we ons specifiek op de posttraumatische stressklachten bij de partner als gevolg van de brandwonden van de survivor. In de acute fase na het ongeval rapporteerde bijna 1 op de 3 partners traumatische stressklachten in de klinische bandbreedte. Bij partners die de situatie als levensbedreigend hadden ervaren, werden hogere niveaus van acute traumatische stress gevonden, die bovendien gepaard gingen met sterkere gevoelens van boosheid en schuld en meer rumineren. In de onderzochte groep partners was er een sterke afname in posttraumatische stress zichtbaar in de eerste 3 maanden. Vanaf 3 maanden nam posttraumatische stress minder af bij partners van mensen met ernstigere brandwonden. Na 18 maanden had nog 4% van de partners klachten in de klinische bandbreedte en waren ernstige brandwonden en een hogere mate van acute traumatische stress voorspellers van langdurige posttraumatische stressklachten.

Een brandwondenongeval kan ook impact hebben op de relatie tussen de partner en de survivor. In **Hoofdstuk 3** bestudeerden we daarom twee verschillende interactiepatronen binnen de partnerrelatie, namelijk zelfregulatie en betrokkenheid, in relatie tot de individuele posttraumatische stressreacties. Naarmate de survivor meer betrokkenheid toonde bij het welbevinden van de

partner, ervoer de survivor vervolgens relatief meer posttraumatische stress. Echter, wanneer de partner meer betrokkenheid toonde bij het welbevinden van de survivor, ervoer de survivor vervolgens minder posttraumatische stress. Bij partners was een vicieuze cirkel te zien, waarbij een hoge mate van zelfregulatie (bijv. jezelf groot houden) en meer posttraumatische stress elkaar in stand hielden. Exploratieve moderatie-analyses suggereren dat bij survivors met ernstige brandwonden deze vicieuze cirkel ook lijkt te spelen.

Het tweede deel van dit proefschrift richt zich met name op het herstel van de kwaliteit van leven na een brandwondenongeval. In **Hoofdstuk 4** verkenden we verschillende patronen van het herstel van de kwaliteit van leven na het oplopen van brandwonden. Voor dit doel combineerden we de informatie uit de 'sociale impact'- studie met eerdere gegevens uit een vergelijkbare populatie. Op groepsniveau zagen we een abrupte daling in de kwaliteit van leven na het brandwondenongeval, die in de loop van de tijd weer herstelde naar het niveau van vóór het ongeval. Onze verkennende analyses onderscheidden vier relevante patronen die de ontwikkeling van de kwaliteit van leven ten opzichte van de (retrospectieve) situatie vóór het ongeval beschrijven: Stabiliteit, Herstel, Onvolledig herstel en Groei. In elk van de zes domeinen van kwaliteit van leven identificeerden we een subgroep van mensen die niet herstelden naar hun niveau van vóór het ongeval. Deze 'Onvolledig herstel'-groep was het grootste in de domeinen Pijn, Angst/Depressie en Cognitie. De aanwezigheid van ernstigere brandwonden en meer posttraumatische stress verhoogden de kans op onvolledig herstel.

In **Hoofdstuk 5** zoomden we verder in op het retrospectief meten van kwaliteit van leven vóór het ongeval als ijkpunt voor herstel en evalueerden we het gebruik van de EQ-6D voor proxyrapportage door de partner. De mate van overeenstemming op de EQ-6D tussen de survivor en de partner verschilde per domein, maar was, na een prevalentiecorrectie, goed te noemen, en varieerde van 'substantieel' tot 'bijna perfect'. Overeenstemming was relatief lager in het Pijn-domein en bij een lagere kwaliteit van leven. De overeenstemming op de visueel analoge thermometer was matig. Geen van de getoetste factoren vormden een verklaring voor verschillen in rapportage tussen partners en survivors.

Tenslotte richtten we ons in **Hoofdstuk 6** op de mate van vermoeidheid die mensen met brandwonden sinds het ongeval hadden ervaren. De acute fase na het ongeval gaat doorgaans gepaard met de meeste vermoeidheid, waarbij 44% van de survivors ernstige vermoeidheid ervoer. De gemiddelde vermoeidheid nam vervolgens in de loop van de tijd gestaag af. Desalniettemin had 18% van de

survivors 18 maanden later nog last van ernstige vermoeidheid. In de acute fase speelde naast pijn en posttraumatische stress, ook de ernst van de brandwonden een rol bij het verklaren van vermoeidheid, maar na 18 maanden waren alleen pijn en acute posttraumatische stress gerelateerd aan vermoeidheid.

Discussie

Dit proefschrift laat zien dat in de nasleep van een brandwondenongeval naast fysiek herstel en littekenzorg, ook psychosociaal herstel aandacht verdient. In de discussie gaan we in op vier onderwerpen, namelijk de impact op partners en de partnerrelatie, de doorwerking van PTSS op andere aspecten van het welzijn, implicaties voor psychosociale zorg, en methodologische overwegingen voor toekomstig onderzoek.

Allereerst de impact van brandwonden op partners en de partnerrelatie. Dit proefschrift laat zien dat naast survivors ook partners kampen met (acute) traumatische stress en dat aanhoudende posttraumatische stressklachten zich met name manifesteren wanneer sprake is geweest van ernstige brandwonden. Dit patroon, waarbij de ernst van de brandwonden op lánge termijn een rol speelt bij het in stand blijven van posttraumatische stressklachten, is zowel bij survivors als partners waarneembaar. Aangezien ernstige brandwonden en met name diepe brandwonden gepaard gaan met permanente littekenvorming, ondersteunen deze bevindingen de hypothese dat littekens kunnen werken als een reminder aan het brandwondenongeval en de nasleep daarvan, en zo posttraumatische stress mede in stand kunnen houden. Daarnaast ontdekten we dat interpersoonlijke processen een rol spelen bij het in stand blijven van posttraumatische stress bij survivors en partners. Zo zagen we dat wanneer de survivor zich teveel richt op het welzijn van de partner, dit het eigen herstel in de weg staat. Ook kan er een vicieuze cirkel ontstaan bij partners, waarbij een partner die zich groot probeert te houden om de survivor te beschermen, de eigen posttraumatische stressklachten in stand houdt. De partner kan echter ook bijdragen aan het herstel van posttraumatische stress bij de survivor door betrokkenheid te tonen bij diens (mentale) welzijn. Deze bevindingen vormen een praktisch uitgangspunt voor het aanscherpen van de psychosociale begeleiding van koppels na een brandwondenongeval.

Ten tweede geeft dit proefschrift inzicht in de doorwerking van posttraumatische stress op andere aspecten van het welzijn, zoals kwaliteit van leven en vermoeidheid. Vroege posttraumatische stressreacties zijn een belangrijke

voorspeller van blijvende vermindering van kwaliteit van leven en langdurige vermoeidheid. Vermoeidheid is een veelvoorkomende klacht na brandwonden, maar de oorzaken voor aanhoudende vermoeidheid zijn tot nog toe voornamelijk toegeschreven aan ontregeling van het immuunsysteem. De sterke samenhang tussen vermoeidheid, pijn en posttraumatische stress suggereert echter dat ook de endocriene assen een belangrijke rol spelen. Toekomstig onderzoek in die richting is dan ook van belang om vermoeidheid na brandwonden verder te ontrafelen en beter te kunnen behandelen.

Ten derde vormt dit proefschrift een aanzet voor het verbeteren van de psychosociale zorg na brandwonden. De meeste mensen herstellen na een brandwondenongeval uiteindelijk zowel fysiek als mentaal volledig. Desalniettemin vormen de veelvoorkomende acute stressklachten en de voorspellende waarde hiervan voor aanhoudende psychische klachten, een duidelijk signaal dat vroege screening op mentale klachten kan helpen bij het opsporen, voorkomen en behandelen ervan. In de discussie pleiten we voor het implementeren van *Trauma Informed Care* (TIC) binnen de brandwondenzorg, waarbij op alle niveaus van de zorgorganisatie rekening wordt gehouden met de impact van trauma en de persoonlijke voorgeschiedenis, de behoeften, en het herstelproces van een persoon, om verergering van klachten zoveel mogelijk te voorkomen. Deze manier van zorgverlening vereist opleiding en training op alle niveaus in de organisatie, zodat iedereen er ten minste een basaal begrip heeft van hoe trauma het herstel nadelig kan beïnvloeden en hier rekening mee kan houden. Een dergelijke benadering kan niet zonder een gezinsgerichte aanpak, waarbij ook de impact op en de draagkracht van familie wordt gemonitord en hun behoeften meegewogen worden. Voor personen die intensieve traumazorg nodig hebben, vormen cognitieve gedragstherapie en Eye Movement Desensitization and Reprocessing (EMDR) bewezen effectieve behandelingen. Daarnaast kan Acceptatie en Commitment therapie (ACT) nuttig zijn voor mensen die worstelen met de veranderingen in het uiterlijk. De bevindingen in dit proefschrift benadrukken ook het belang van doorlopende TIC en psychosociale hulp in de nazorg, aangezien psychische problemen een van de opvallendste langetermijnklachten zijn bij mensen met brandwonden. Door van monitoring en screening een vast onderdeel van de nazorg te maken, kunnen diegenen die extra hulp nodig hebben opgespoord en ondersteund worden.

Ten vierde vormt dit proefschrift een basis voor het verder aanscherpen van de kwantitatieve methoden van psychosociaal onderzoek in dit veld. Het benadrukt het belang van longitudinale studies om inzicht te verkrijgen in vroege klachten, het verloop van klachten en het vinden van verklaringen voor aanhoudende

klachten. De resultaten van hoofdstuk 4 vormen een belangrijk startpunt voor het verder onderzoeken van verschillende patronen van herstel van kwaliteit van leven, en het verder aanscherpen van de definities en indeling van deze patronen. De retrospectieve meting van kwaliteit van leven vóór het ongeval vormt hierbij een ijkpunt. Aangezien een brandwondenongeval en de nasleep daarvan kunnen zorgen voor voortdurende veranderingen in iemands denken over wat een 'goede kwaliteit van leven' behelst, vormt een retrospectieve meting in de acute fase slechts een momentopname in dit proces. Door herhaaldelijk retrospectieve metingen te doen, wordt preciezer inzicht verkregen in het subjectieve herstel in de loop van de tijd. Een herhaaldelijke proxymeting bij de partner kan hierbij een aanvullend perspectief geven. Verder onderzoek kan zich ook richten op het ontwikkelen, valideren en implementeren van screeningsinstrumenten voor de verschillende fases van de brandwondenzorg. Effectiviteitsstudies met betrekking tot EMDR en ACT zijn nodig om de effectiviteit binnen de brandwondenpopulatie te bevestigen. Ten slotte zijn ontwikkelings- en implementatiestudies nodig om TIC te kunnen afstemmen op de Nederlandse brandwondenzorg.

Conclusie

Een brandwondenongeval laat niet alleen littekens achter op het lichaam van de survivor, maar heeft langdurige gevolgen voor de kwaliteit van leven en het mentale welzijn, ook van de partner. Aandacht voor psychosociale gevolgen verdient dan ook een volwaardige plek in het (na)zorgtraject naast de zorg voor het fysieke herstel. Dit proefschrift presenteert de resultaten van een longitudinale observationele studie naar de traumatische impact van brandwondenongevallen op survivors en hun partner tot 18 maanden na het ongeval.

Traumatische stressklachten zijn een veelvoorkomende reactie in de acute fase na het ongeval en de meeste survivors en partners herstellen in de maanden die volgen. Desalniettemin vertoont een subgroep aanhoudende posttraumatische stresssymptomen op de lange termijn, waarbij klinische begeleiding wenselijk of noodzakelijk is. Vroege traumatische stress kan een langdurige negatieve uitwerking hebben op de kwaliteit van leven en vermoeidheid van mensen met brandwonden. Het is daarom ook belangrijk dat vroege screening en passende psycho-educatie en preventie worden ingezet om vroegtijdig in dit proces in te kunnen grijpen.

Het bestuderen van trauma in koppelperspectief levert waardevolle inzichten op in de wisselwerking tussen survivors en hun partner, en laat zien dat partners

die meer betrokkenheid tonen bij het mentale welzijn van de survivor kunnen bijdragen aan het verminderen van diens traumatische stress. Zorgprofessionals kunnen door alert te zijn op vermijdende zelfregulatie door partners, de dreigende vicieuze cirkel proberen te doorbreken. Zij kunnen partners stimuleren om hun gedachten en gevoelens te delen en zo de traumatische gevolgen voor die partners zelf te verminderen.

Psychosociale zorg voor survivors en hun gezin kan verder verbeterd worden door het implementeren van TIC- principes, resulterend in een basiskennis van trauma in alle lagen van de zorgorganisatie, en ontwikkeling van geschikte screening, preventie en interventieprogramma's. Op deze manier wordt brandwondenzorg trauma-sensitief en wordt mentaal welzijn een zaak van algemeen belang, waardoor zowel psychosociale als fysieke zorg optimaal afgestemd worden op de behoeften van de survivor en diens gezin.

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A

About the author

Curriculum vitae

Elise was born in Gorinchem on a stormy day in 1990 (the 26th of February). She obtained her secondary school degree (gymnasium) from the Lyceum Oudehoven in Gorinchem. In 2008, she enrolled at Utrecht University to study Pedagogical Sciences. After obtaining her bachelor's degree in 2011, she enrolled in the master 'Clinical Child, Family and Education Studies' (Orthopedagogiek). During her clinical internship, she discovered that it was not clinical practice, but research and statistics that constituted her primary interest. In 2012, she switched to the two-year research master's program 'Development and Socialization in Childhood and Adolescence', and obtained her master's degree in 2014. After her studies, Elise explored different roles involving scientific research, starting as a research assistant at the University Medical Center Groningen, where she was involved in a study that investigated the use of a patient-reported outcome measure to capture patients feelings and cognitions during a trajectory of genetic counseling and heredity of serious conditions. In the meantime, she also worked as a research assistant at the University of Utrecht, where she conducted a literature search on the role of motivation in the math achievement of primary school students. In 2017, she changed jobs and started at GGz Centraal to support the coordination of scientific research in the organization, and was involved in organizing skills labs, PR work, and providing (statistical) advice to researchers. To further develop her skills in data analysis, in 2018, she obtained a position as a junior researcher at Nivel, where she was involved in analyzing and reporting data from the primary care database and on seasonal influenza in the Netherlands. In 2019, she found a PhD project that matched her interests in the interplay of physical and mental health, at the Association of Dutch Burn Centers and Utrecht University, under the supervision of Dr. Nancy Van Loey, prof. Iris Engelhard, and prof. Rens van de Schoot. The results of this research on the psychological consequences of burns for adult burn survivors and their partners, are presented in this dissertation and were presented by Elise at various national and international congresses and meetings. Elise was also involved in thesis supervision of master students at Utrecht University.

Research output

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