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# **Clinical paper**

# Associations between posttraumatic stress symptoms and quality of life in cardiac arrest survivors and informal caregivers: A pilot survey study

# Alex Presciutti<sup>*a,b,\**</sup>, Mary M. Newman<sup>*c*</sup>, Jim Grigsby<sup>*a*</sup>, Ana-Maria Vranceanu<sup>*d*</sup>, Jonathan A. Shaffer<sup>*a*</sup>, Sarah M. Perman<sup>*b*</sup>

<sup>a</sup> University of Colorado Denver, Department of Psychology, United States

<sup>b</sup> University of Colorado School of Medicine, Department of Emergency Medicine, United States

<sup>c</sup> Sudden Cardiac Arrest Foundation, United States

<sup>d</sup> Harvard Medical School, Department of Psychology, United States

#### Abstract

Aim: To estimate the proportion of significant posttraumatic stress (PTS) in both cardiac survivors with good neurologic recovery and informal caregivers, and to pilot test the hypothesis that greater PTS are associated with worse quality of life (QoL) in both cardiac arrest survivors and informal caregivers of cardiac arrest survivors.

**Methods:** We distributed an online survey to survivor and caregiver members of the Sudden Cardiac Arrest Foundation. Participants provided demographic and cardiac arrest characteristics and completed the PTSD Checklist-5 (PCL-5), the Lawton Instrumental Activities of Daily Living scale, and the WHOQOL-BREF. We identified covariates through bivariate correlations or linear regressions as appropriate. Six multiple regression models (three each for survivors and caregivers) examined associations between PCL-5 scores with each QoL subscale, adjusted for covariates identified from the bivariate models.

**Results:** We included 169 survivors (mean months since arrest: 62.8, positive PTS screen: 24.9%) and 52 caregivers (mean months since arrest: 43.2, positive PTS screen: 34.6%). For survivors, the following showed significant bivariate associations with QoL: Lawton scores, daily memory problems, sex, months since arrest, age, and income; for caregivers, months since arrest, age, and income. In adjusted models, greater PCL-5 scores were associated with worse QoL ( $\beta$ : -0.35 to -0.53, p < .05).

**Conclusions:** Our pilot results suggest that PTS are prevalent years after the initial cardiac arrest and are associated with worse QoL in survivors and informal caregivers. Further study is needed to validate these findings in a larger, representative sample.

 $\textbf{Keywords:} \ \textbf{Posttraumatic stress, Quality of life, Informal caregiver, Survey}$ 

# Introduction

More people are surviving from cardiac arrest now than ever before, and greater attention is being directed to the quality of post-arrest survivorship.<sup>1</sup> Because of hypoxic brain injury suffered during the event, cardiac arrest survivors are faced with chronic neurological, functional, and psychological challenges<sup>1,2</sup> which may compromise the quality of their survivorship. Further, survivors' informal caregivers (i.e., family or friends who provide instrumental and emotional

\* Corresponding author at: Department of Psychology, Campus Box 173, PO Box 173364, Denver, CO 80217-3364, United States. E-mail address: Alexander.presciutti@ucdenver.edu (A. Presciutti).

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support)<sup>3</sup> may also struggle as they must juggle their own life responsibilities while also supporting their loved one's new multi-domain challenges.

Surviving a cardiac arrest can be an extremely traumatic event. Unsurprisingly, posttraumatic stress symptoms (PTS) are common in survivors (19–30.6%).<sup>4,5</sup> PTS are serious, debilitating psychological symptoms which are broadly categorized into domains of intrusive re-experiencing of the trauma, persistent avoidance of stimuli associated with the trauma, negative alterations in mood and cognition, and hyperarousal or reactivity.<sup>6</sup> Early, elevated PTS in cardiac arrest survivors have been associated with a 3-fold greater likelihood of experiencing major adverse cardiovascular events and mortality within 1-year post-discharge.<sup>7,8</sup> Further, PTS, not cognitive or functional impairment, have been associated with negative subjective recovery in cardiac arrest survivors.<sup>5</sup>

Informal caregivers of cardiac arrest survivors also commonly experience PTS (30–40%),<sup>9,10</sup> as they witness traumatic aspects of their loved one's arrest, resuscitation, hospitalization, and recovery.<sup>9</sup> <sup>-12</sup> Further, they support their loved ones without a clear direction for post-arrest follow-up care.<sup>13</sup> Importantly, informal caregivers have reported a lack of mental health resources to cope with their loved one's arrest, as well as a lack of preparedness for caregiving after their loved one's hospital discharge.<sup>1,13</sup>

Quality of Life (QoL) is a patient-centered construct defined by the World Health Organization as an individual's perceived position in life in the context of their culture and value systems, and in relation to their goals, expectations, standards, and concerns.<sup>14</sup> QoL can be further specified in terms of physical, psychological, and social domains. In cardiac arrest survivors, greater PTS have been shown to be associated with worse health-related and physical QoL.<sup>15,16</sup> In neurocritical care populations, PTS have been shown to be interdependent in patients and their informal caregivers<sup>17</sup> and have been associated with worse physical, psychological, and social QoL.<sup>18</sup> Importantly, given the apparent absence of post-arrest followup support,<sup>1,13</sup> cardiac arrest survivors and informal caregivers may be uniquely burdened compared to other medical populations that have specialized, multidisciplinary follow-up centers (such as in myocardial infarction and stroke). To date, there is a paucity of studies examining PTS and specific QoL domains (i.e., physical, psychological, social) in both cardiac arrest survivors and informal caregivers, particularly in American samples. Understanding associations between PTS and specific QoL domains is important for organizing post-cardiac arrest care efforts.

In this pilot survey study, we first estimated the proportion of clinically significant PTS in both cardiac arrest survivors with good neurological recovery and informal caregivers. Next, based on findings in cardiac arrest and neurocritical care populations, we hypothesized that greater PTS would be more strongly associated with worse physical, psychological, and social QoL in both cardiac arrest survivors and informal caregivers.

# Method

This study is part of a larger open online survey study distributed between October and November 2019 to a convenience sample of cardiac arrest survivors and informal caregivers of cardiac arrest survivors who were registered as members of the Sudden Cardiac Arrest Foundation (SCAF). SCAF membership is free, opt-in, and open to all cardiac arrest survivors and informal caregivers to cardiac arrest survivors. The SCAF is a non-profit online organization based in Pittsburgh, United States, whose mission is to serve as an information clearinghouse and social marketing force to raise awareness about the prevention and treatment of sudden cardiac arrest. It offers an online social network, the SCA Network, for survivors, family members and other advocates. SCAF regularly participates in research projects that contribute to its mission. People find out about SCAF through its website, https://www. sca-aware.org, bi-monthly newsletters, social media channels, and outreach at national conferences.

Survivors and caregivers completed the surveys independently, and thus, we did not collect paired, dyadic data. We sent survey invitations via email to a total of 1288 SCAF members and 2 email reminders for members that had not completed the survey after the initial invitation; a total of 221 members (169 survivors and 52 caregivers) provided sufficient data for inclusion in this analysis (17% survey completion rate). The surveys were developed and conducted through REDCap, a secure data capture software. The usability and technical functionality of the survey was tested by the study authors prior to fielding the questionnaire.

In terms of survey administration, the surveys were voluntary, and we offered no incentives. We did not randomize survey items or use adaptive questioning. All surveys were marked as complete or incomplete automatically by the REDCap server. Participants were able to review and change their answers up until submitting their responses. Cookies were not used to identify unique users, instead we queried survey respondents to provide the first three letters of their first and last names as well as their email address to create a unique identification number. In cases of duplicate entries, we kept the most complete entry for analysis. For this study, we used only survey entries that contained complete data for the primary outcome measures in the present analyses.

This study was approved by the local Institutional Review Board; participants were informed of the approximate length of the survey, where data was stored, who the investigators were, the purpose of the study, and consented to participation prior to beginning the survey.

#### Measures

#### Survivor characteristics

Survey items varied slightly for survivors and informal caregivers. For survivors, the survey probed for demographic variables such as age at arrest, sex, income (later categorized as low: <\$50,000, medium: \$50,000-\$99,999, and high: >\$99,999) and race, as well as arrest characteristics such as months since initial cardiac arrest, comorbidities at the time of the arrest (which were then used to calculate the Charlson Comorbidity Index),<sup>19</sup> provision of cooling therapy, and arrest location.

We assessed functional independence via the Lawton Instrumental Activities of Daily Living scale.<sup>20</sup> The Lawton is an 8-point scale measuring functional dependence; higher scores indicate higher independence. Because the majority of respondents were fully independent (Lawton score 8 = 83.4%) we dichotomized survivors as being either functionally independent (Lawton score 8) or functionally dependent (Lawton score <8). Additionally, survivors reported if they had daily memory problems.

Finally, we collected zip code data which we used to characterize the geographic make-up of participants.

#### Informal caregiver characteristics

Informal caregivers reported the same demographic variables as survivors did, as well as relationship to survivor. For the income variable, we later dichotomized responses at a cut-off of \$99,999 because the majority of responses below \$99,999 were greater than \$50,000. Arrest characteristics included months since initial cardiac arrest of the survivor and arrest location. Informal caregivers reported if the survivors still had daily memory problems. Finally, we collected zip code data to characterize the geographic make-up of caregivers.

#### Posttraumatic stress symptoms

We measured PTS through the Posttraumatic Stress Disorder Checklist-5 (PCL-5),<sup>21</sup> a 20-item measure that queries for severity of all 20 symptoms of *Diagnostic and Statistical Manual for Mental Disorders*-5<sup>6</sup> posttraumatic stress disorder, as experienced in the past month. Items are rated on a scale of 0–4, with higher scores indicating greater PTS severity. A total symptom severity score is yielded by summing individual items. In this study, survivors were prompted to consider each symptom item in response to the cardiac arrest event and subsequent recovery. Informal caregivers were prompted to consider each item in response to the survivor's cardiac arrest event and subsequent recovery.

The PCL-5 authors suggest a cut-off of 31 as being indicative of clinically significant PTS. Importantly, scores >31 are indicative of a probable PTS screen, though elevated PTS scores on a diagnostic screener in the absence of a clinical interview are not sufficient in diagnosing full posttraumatic stress disorder (PTSD). Nevertheless, participants with elevated PTS scores could still benefit from psychotherapeutic intervention regardless of whether they meet full criteria for PTSD.

#### Quality of life

We measured three domains of QoL (i.e., physical, psychological, and social QoL) through the WHOQOL-BREF.<sup>22</sup>The physical QoL subscale measures perceived independence in activities of daily living, utilization of medical treatments, pain, mobility, sleep quality, fatigue, and work capacity. The psychological QoL subscale assesses experience of

#### Table 1 - Demographic and participant characteristics included in this analysis.

Demographics	Survivors	Caregivers	Scale range
Age at arrest, mean $\pm$ SD <sup>a</sup>	50.8 ± 11.5	48.7 ± 13.7	
Gender—female, % (n)	49.7 (84)	86.5 (45)	
Race, % (n)			
-White	95.9 (162)	88.5 (46)	
-Non-white	4.1 (7)	11.5 (6)	
Spousal caregiver, % (n)		82.7 (43)	
Income, % (n)			
-Low (<\$50,000)	17.8 (30)	3.8 (2)	
-Medium (\$50,000-\$99,999)	25.4 (43)	36.5 (19)	
-High (>\$99,999)	53.8 (91)	57.7 (30)	
Participant characteristics			
Pre-arrest Charlson Comorbidity Index, median (IQR <sup>b</sup> )	1 (0–2)		
Out-of-hospital arrest, % (n)	84.6 (143)	92.3 (48)	
Therapeutic hypothermia, % (n)	40.8 (69)		
Months since arrest, mean $\pm$ SD, (IQR)	$62.8 \pm 52.5 \; (26{-}91)$	43.2 ± 36.4 (17–55)	
Self-reported presence of daily memory problems % (n)	47.3 (80)	34.6 (18)	
Lawton IADLs $^{\circ}$ , mean $\pm$ SD	$7.7\pm0.8$		0-8
Functional dependence, % (n)	16.6 (28)		
PCL-5 <sup>d</sup> mean, $\pm$ SD	$22.1\pm18$	$23.3\pm18.7$	0-80
Positive PCL-5 screen, % (n)	24.9 (42)	34.6 (18)	
Geographic region, % (n)			
United States East	17.8 (30)	9.6 (5)	
United States South	34.3 (58)	21.2 (11)	
United States Midwest	20.1 (34)	28.8 (15)	
United States West	20.7 (35)	34.6 (18)	
Non-United States	7.1 (12)	5.8 (3)	
WHOQOL-BREF Subscales <sup>e</sup>			
Physical QoL mean, $\pm$ SD	$15.2\pm3.1$	$16.1\pm2.3$	4–20
Psychological QoL mean, ±SD	$14.4\pm3.3$	$14.7\pm3$	4–20
Social QoL mean, ±SD	$13.9\pm3.7$	$14.1\pm3.5$	4–20

<sup>a</sup> Standard Deviation.

<sup>b</sup> Interquartile Range.

<sup>c</sup> Lawton Instrumental Activities of Daily Living (scale range 0-8). Lower scores = more functional dependence.

<sup>d</sup> Posttraumatic Stress Disorder Checklist -5 (scale range 0-80). Higher scores = more severe posttraumatic stress symptoms. 31 is the recommended cut-off for a probable posttraumatic stress disorder screen.

<sup>e</sup> World Health Organization Quality of Life Scale – Brief (subscale ranges 4–20). Lower scores = lower QoL.

positive and negative emotions, cognitive function, self-esteem, meaning making, and body image. The social QoL subscale measures quality and availability of social support and satisfaction with sex life. Individual items are rated on a 5-point scale, with higher scores indicating greater QoL. From these ratings, we calculated domain scores according to published scoring recommendations (range 4-20).<sup>23</sup>

#### Statistical analysis

We followed an identical but separate analytic plan for survivors and informal caregivers. First, we calculated measures of central tendency to describe participant characteristics, PCL-5 scores, and QoL subscales. Second, we calculated Cronbach's alpha for each QoL subscale to measure reliability. Next, for continuous variables, we ran bivariate correlations between each QoL subscale and participant characteristics, and for categorical variables we ran bivariate linear regression models. Participant characteristics that were significantly associated with any of the QoL subscales (p < 0.10; two-tailed) were then included in subsequent multivariable regression models as covariates. We utilized an alpha of < 0.10 because it allows for greater inclusion of covariates that in turn could have synergistic confounding effects when included together in a multivariable model. Additionally, more traditional alpha levels, such as < 0.05, can fail to identify important covariates.<sup>24</sup>

We then ran six multiple linear regression models (three for patients and three for caregivers) to examine associations between PCL-5 scores (continuous scores) with each QoL domain (continuous scores), adjusted for significant covariates as indicated by the bivariate correlations and regressions. We examined standardized Beta-values ( $\beta$ ) to identify the strength of associations between PCL-5 scores and covariates with each QoL domain. The closer the  $\beta$  value is to 1 or -1 the stronger the association; weak associations correspond to  $\beta$  values < 0.4, moderate associations correspond to  $\beta$  values > 0.7 (absolute values). The direction of the association is identified by whether the  $\beta$  is negative or positive. We used Bonferroni correction for multiple tests to limit the risk of committing a Type I error.

#### **Results**

#### Participant characteristics

#### Survivors

A total of 179 cardiac arrest survivors initiated the survey; 169 survivors (mean months since arrest: 62.8) provided sufficient data for inclusion in this analysis. A total of 42 (24.9%) of survivors screened positively for clinically significant PTS. Full descriptive statistics for survivors are presented in Table 1.

#### Caregivers

A total of 53 informal caregivers initiated the survey; 52 informal caregivers (mean months since arrest: 43.2, 82.7% spousal caregivers) provided sufficient data for inclusion in this analysis. A total of 18 (34.6%) of caregivers screened positively for clinically significant PTS. Full descriptive statistics for caregivers are presented in Table 1.

## Reliability of quality of life subscales

#### Survivors

All QoL subscales demonstrated acceptable to good reliability. The Cronbach's alpha of each QoL subscale in survivors were as follows: physical QoL: 0.85 (good reliability), psychological QoL: 0.88 (good reliability), social QoL: 0.76 (acceptable reliability).

#### Informal caregivers

The Cronbach's alpha values of each subscale in informal caregivers were as follows: physical QoL: 0.73 (acceptable reliability), psychological QoL: 0.86 (good reliability), social QoL: 0.79 (acceptable reliability).

#### Covariate selection

#### Survivors

For survivors, significant correlations with worse QoL in at least one subscale included: male sex, younger age at arrest, low income (<\$50,000), fewer months since arrest, functional dependence, and self-reported presence of daily memory problems (r: 0.17–0.18;  $\beta$ : 0.14–0.52 (absolute values), p < 0.1).

#### Informal caregivers

For informal caregivers, significant correlations with worse QoL in at least one subscale included: younger age at arrest, fewer months since arrest, and low-medium income (<99,999) (r: 0.25–0.33;  $\beta$ : 0.26–0.37 (absolute values), p < 0.1)

# Associations between total posttraumatic stress symptoms with quality of life subscales

Full details on multiple regression models are presented in Tables 2 and 3 for survivors and informal caregivers respectively.

Table 2 - Associations between total posttraumatic stress symptoms and quality of life subscales in survi
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Variable	Physical QoL β [95% Cl] (p-value)	Psychological QoL $\beta$ [95% CI] (p-value)	Social QoL β [95% Cl] (p-value)		
Posttraumatic stress symptoms	-0.35 [-0.49, -0.2] (<0.001)*	-0.53 [-0.66, -0.4] (<0.001)*	-0.37 [-0.53, -0.2] (<0.001)*		
Functional dependence	-0.27 [-0.4, -0.16] (<0.001)*	-0.08 [-0.19, 0.03] (0.18)	0.01 [-0.14, 0.15] (0.95)		
Daily memory problems	-0.22 [-0.37, -0.09] (0.001)*	<b>−0.25 [−0.38, −0.12] (&lt;0.001)*</b>	-0.15 [-0.31, 0.01] (0.07)		
Male sex	0.11 [-0.01, 0.23] (0.08)	0.09 [-0.02, 0.2] (0.14)	-0.03 [-0.17, 0.12] (0.71)		
Months since arrest	0.04 [-0.08, 0.17] (0.45)	0.06 [-0.05, 0.18] (0.31)	0.02 [-0.13, 0.17] (0.8)		
Age at arrest	-0.06 [-0.18, 0.06] (0.32)	0.06 [-0.06, 0.17] (0.34)	0.02 [-0.12, 0.16] (0.8)		
Income <\$50,000	-0.11 [-0.23, 0.01] (0.08)	0.06 [-0.06, 0.17] (0.33)	-0.14 [-0.28, 0.01] (0.06)		
Total R <sup>2</sup>	0.49	0.56	0.27		
* Bold indicates significant after Bonferroni correction for multiple tests ( $n < 0.007$ )					

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Variable	Physical QoL B [95% Cl] (p-value)	Psychological QoL B [95% CI] (p-value)	Social QoL β [95% Cl] (p-value)		
Posttraumatic stress symptoms	-0.33 [-0.59, -0.05] (0.02)	-0.51 [-0.77, -0.26] (<0.001)*	-0.35 [-0.65, -0.08] (0.01)*		
Age at arrest	-0.26 [-0.5, 0.01] (0.06)	0.06 [-0.18, 0.3] (0.61)	0.11 [-0.16, 0.38] (0.4)		
Months since arrest	-0.03 [-0.29, 0.23] (0.81)	0.13 [-0.11, 0.37] (0.3)	0.27 [0.01, 0.53] (0.04)		
Income <\$99,999	-0.21 [-0.47, 0.06] (0.13)	-0.2 [-0.45, 0.05] (0.11)	-0.15 [-0.43, 0.12] (0.26)		
Total R <sup>2</sup>	0.25	0.41	0.3		
* Bold indicates significant after Bonferroni correction for multiple tests ( $p$ <0.013).					

## Table 3 - Associations between total posttraumatic stress symptoms and quality of life subscales in caregivers.

## Survivors

For survivors, in adjusted models, greater PCL-5 scores ( $\beta$ : -0.35, p < 0.001), functional dependence ( $\beta$ : -0.27, p < 0.001), and presence of daily memory problems ( $\beta$ : -0.22, p = 0.001) were associated with worse physical QoL; greater PCL-5 scores ( $\beta$ : -0.53, p < 0.001) and presence of daily memory problems ( $\beta$ : -0.25, p < 0.001) were associated with worse psychological QoL; greater PCL-5 scores ( $\beta$ : -0.37, p < 0.001) were associated with worse psychological QoL; greater PCL-5 scores ( $\beta$ : -0.37, p < 0.001) were associated with worse social QoL.

After correcting for multiple tests at p < 0.007, all associations remained statistically significant.

#### Informal caregivers

For informal caregivers, in adjusted models, greater PCL-5 scores were associated with worse physical QoL ( $\beta$ : -0.33, p = 0.02) and worse psychological QoL ( $\beta$ : -0.51, p < 0.001); greater PCL-5 scores ( $\beta$ : -0.35, p = 0.01) and less months since arrest ( $\beta$ : 0.27, p = 0.04) were associated with worse social QoL.

After correcting for multiple tests at p < 0.013, PCL-5 scores were no longer significantly associated with physical QoL and months since arrest were no longer significantly associated with social QoL.

## Discussion

In this pilot survey study, clinically significant PTS were present in 1 in 4 cardiac arrest survivors and in 1 in 3 informal caregivers. In survivors, greater PTS were associated with worse physical, psychological, and social QoL even after adjusting for functional dependence and self-reported presence of daily memory problems. In informal caregivers, greater PTS were also associated with worse psychological and social QoL. Importantly, given that the mean time since arrest in this study was over 5 years in survivors and 3.5 years in caregivers, it is likely that PTS may endure beyond the initial post-arrest recovery period.

By using a comprehensive assessment of QoL, we were able to identify specific associations between PTS and QoL. PTS showed weak-moderate associations with physical, psychological, and social QoL in survivors, and weak-moderate associations with psychological and social QoL in informal caregivers. These findings are important when considering that PTS are conceptualized as psychological phenomena. Indeed, these symptoms can have marked implications with physical functioning vis a vis hyperarousal, impaired sleep, and avoidance. Further, PTS may disrupt socialization through symptoms of emotional numbing, detachment from others, diminished interest, and avoidance. As such, while mainly psychological phenomena, PTS are related to disruptions in multiple aspects of daily life. These multiple disruptions in daily life should be considered when organizing post-cardiac arrest care.

A growing literature base points to the problematic impact of PTS in cardiac arrest populations. In survivors, greater PTS at hospital discharge have been associated with worse 1-year clinical outcome,<sup>7,8</sup> negative subjective recovery at hospital discharge,<sup>5</sup> and worse health-related and physical QoL.<sup>15,16</sup> Our findings contribute to this literature, indicating that greater PTS are associated with worse QoL in both survivors and caregivers in multiple specific QoL domains. Based on these collective findings, in-hospital PTS screening of cardiac arrest survivors and their informal caregivers should be explored.

Our findings complement previous work in neurocritical care patient-caregiver dyads, such that greater PTS during hospitalization have been associated with worse 3-month QoL.<sup>18</sup> More so, PTS have been found to be interdependent between dyad members, such that survivors' PTS predicts caregivers' PTS and vice versa.<sup>17</sup> In response to this interdependence, an in-hospital, dyadic-based psychological intervention has been developed to prevent early, problematic PTS.<sup>25</sup> Cardiac arrest survivors experience a similar course to neurocritical care patients in terms of acquired brain injury and lengthy intensive care unit stays. Based on these similarities, a future direction could be to examine the feasibility and acceptability of an in-hospital dyadic-based intervention in cardiac arrest survivors and their informal caregivers.

Our PTS and QoL data can be compared to prior studies using the same measures in American college students,<sup>26</sup> neurocritical care patients and caregivers, <sup>18</sup> and members of the global and American population who participated in the WHOQOL-BREF field trial.<sup>22</sup> In one PCL-5 development study of 278 American college students, which utilized a cut-off of 31,26 16% of participants reported clinically significant PTS, which is lower than that observed in cardiac arrest survivors (24.9%) and informal caregivers (34.6%) in this study. In terms of QoL, cardiac arrest survivors and informal caregivers in this study reported slightly worse QoL than a cohort of neurocritical care patients (n = 70) and informal caregivers (n = 64) at 3-month followup.<sup>18</sup> When compared to a global sample of well and sick respondents as part of the WHOQOL-BREF field trial (n = 11,830),<sup>22</sup> both cardiac arrest survivors and caregivers reported worse QoL on average on all three subscales. Curiously, however, when compared to a sample of United States well and sick respondents who were part of the WHOQOL-BREF field trial (n = 159), the cardiac arrest survivors and caregivers in this study reported slightly better QoL on average. As our pilot results are preliminary, these apparent differences and similarities in QoL could be further parsed out in future research.

Notably, the manifestation of PTS is likely different in cardiac arrest survivors compared to informal caregivers. Survivors are typically amnesic of the events before and after their arrest; as such, their index trauma is likely not one index event per se but rather a gradual realization of persistent debilitations and a lengthy recovery. This is consistent with the Enduring Somatic Threat model<sup>27,28</sup> which posits that survivors of life-threatening medical events experience persistent, internal somatic reminders of their event, which can perpetuate a posttraumatic stress response. Caregivers, instead, may experience both a discrete index trauma (e.g., witnessing the arrest and/or resuscitation) and continual exposures of their loved one's newfound debilitations. Future study should examine the differences in contributing factors for PTS in cardiac arrest survivors and informal caregivers.

#### Limitations

Our pilot survey study has important limitations that warrant consideration. First, we assessed PTS and QoL cross-sectionally, and thus we cannot exclude the possibility of a bi-directional relationship such that poor QoL could lead to worse PTS. Theoretically, however, trauma typically precedes worse QoL. Second, we recognize the importance of survivor-caregiver interdependence; although we did not collect dyadic data, we suggest future study to collect and analyze paired cardiac arrest survivor-caregiver data. Additionally, although we utilized the WHOQOL-BREF to capture specific QoL domains, future studies should consider utilizing QoL measures recommended in the Core Outcome Set for Cardiac Arrest (COSCA)<sup>29</sup> for greater congruence with ongoing efforts in measuring QoL post-arrest. Third, our convenience sample of survivors was prone to selection bias given that a majority had full independence and that they had enough functioning to independently complete an online survey. As such, given the "opt-in" nature of the SCAF, it is possible that our participants were highly motivated to receive post-arrest support, which may had introduced a bias in terms of PTS and QoL responses. Fourth, our survivor pool was not representative of those with more severe neurological deficits. More so, we did not collect important medical data such as etiology, initial arrest rhythm, and other post-resuscitation interventions, which limits our ability to fully conceptualize or survivor sample clinically. Similarly, while we queried survivors on provision of cooling therapy, this question is prone to recall bias and responses should be interpreted as such. Finally, the study sample was not racially diverse, and featured little representation of financially disadvantaged individuals (17% and 3.8% had low income <\$50,000 in survivors and caregivers respectively). Despite these limitations, the contents of this survey provide a potential framework for future assessments in more diverse participant populations.

# Conclusion

PTS is common in cardiac arrest survivors and informal caregivers and may persist years after the initial cardiac arrest event. Our pilot results suggest that greater PTS are associated with worse QoL in both cardiac arrest survivors and informal caregivers of cardiac arrest survivors. Should our preliminary findings be validated in larger, representative samples, early, in-hospital screening could be considered to identify those at risk for developing chronic PTS.

# **Author statement**

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other publication

#### Contributions

Alex Presciutti, MA, MSCS - conception and design of study, acquisition of data, analysis and interpretation of data, drafting of manuscript, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

Mary Newman, MS - conception and design of study, acquisition of data, drafting of manuscript, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

Jim Grigsby, PhD - conception and design of study, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

Ana-Maria Vranceanu, PhD - conception and design of study, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

Jonathan Shaffer, PhD, MS - conception and design of study, analysis and interpretation of data, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

Sarah Perman, MD, MSCE - conception and design of study, acquisition of data, analysis and interpretation of data, drafting of manuscript, revising the manuscript critically for important intellectual content, approval of the version of the manuscript to be published.

# **Conflicts of interest**

All authors report no conflicts of interest.

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