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# Development of a Conceptual Disease Model of the Patient Experience of Post-Traumatic Stress Disorder

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## Introduction

- Post-traumatic stress disorder (PTSD) is a psychiatric disorder characterized by symptoms impairing mood, cognition, somatic experience, and behavior that can result from experiencing or witnessing a traumatic event, such as exposure to actual or threatened death, serious injury, or sexual violence[1]
- The course of PTSD varies[1] and may last months or years, with triggers that can bring back memories of the trauma accompanied by intense emotional and physical reactions
- Previous research has quantitatively reported the symptom burden of PTSD and its impact on quality of life and daily functioning using patient-reported outcome measures[2-4]
- Since symptoms of PTSD are heterogeneous and the course of the condition varies among patients, it is important to collect data directly from individuals who have PTSD; however, patient-centered, qualitative research on PTSD is limited

## Objectives

- To qualitatively identify important and relevant symptoms and impacts of PTSD based on results from a targeted literature review, interviews with expert clinicians, and interviews with adults diagnosed with PTSD
- To develop a comprehensive conceptual disease model for PTSD informed by the converging evidence from this research

## Methods

- A targeted literature review (supplemented by gray literature) was conducted to identify published articles describing patients' experiences with PTSD and to develop a preliminary conceptual disease model of the symptoms and impacts of this condition
  - The search was limited to English-language articles published from 2017 to 2022 and involving adults ≥18 years of age
  - Symptoms were defined as internal experiences of PTSD best reported through patient expression of feelings
  - Impacts were defined as effects of symptoms on patients' day-to-day lives and functioning (eg, difficulties with work, relationships, and activities of daily living)
- Expert clinician interviews (N=5) were conducted to explore the signs, symptoms, and impacts of PTSD and its treatment that are important, from a clinical perspective, for evaluating patients with PTSD, and to obtain clinician feedback on the preliminary draft of a conceptual disease model
- Adult participants (N=20) each completed a 60-minute, web-based concept elicitation interview describing their experience with PTSD
  - Key inclusion criteria: 18–70 years of age at time of screening, outpatient with a primary diagnosis of *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5)-defined PTSD, and United States resident
  - Key exclusion criteria: suicidal behavior occurring within the past 2 years; major depressive episodes occurring within the past 6 months; history or presence of a medical condition, psychiatric disorder (other than PTSD), cognitive, hearing, or speech problem; and inadequate command of the English language that could affect their ability to complete the study
- A semi-structured interview guide was used that included open-ended and probing questions informed by the targeted conceptual literature review and expert clinician interviews
- Participants rated symptom severity and bothersomeness using numerical rating scales (0=not at all to 10=extremely) and were asked to describe their top 3 worst symptoms and top 3 worst impacts
- Interview transcripts were coded using ATLAS.ti (version 22)[5] and were guided by a prespecified coding framework, informed by the preliminary conceptual disease model, discussion guide, and research objectives
  - Coders were trained and monitored by study scientists

**References: 1.** Bryant RA. *World Psychiatry.* 2019;18(3):259-269. **2.** Sancassiani F, et al. *Clin Pract Epidemiol Ment Health.* 2019;15:38-43. **3.** Danielsson FB, et al. *Scand J Trauma Resusc Emerg Med.* 2018;26(1):44. **4.** Miller CR, et al. *Trauma Care.* 2024;4(1):87-97. **5.** Friese S. User's Manual for ATLAS.ti 71.0. 2013. https://atlasti.com/manuals-and-documents.

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## Results

### Table 1. Participant Demographics and Health Information

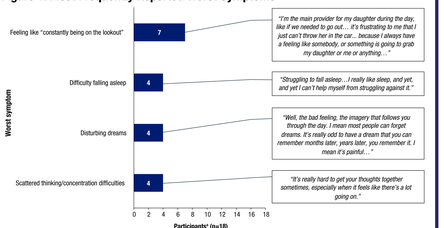
| Characteristic | Participants With Post-Traumatic Stress Disorder N=20 |
|---|---|
| **Age** | |
| Mean (SD) | 41.8 (16.4) |
| Range, min–max | 20.0–66.0 |
| Missing,[a] n (%) | 2 (10.0) |
| **Gender (identity receive care for), n (%)** | |
| Male | 4 (20.0) |
| Female | 15 (75.0) |
| Missing[a] | 1 (5.0) |
| **Ethnicity, n (%)** | |
| Hispanic or Latino | 0 (0.0) |
| Not Hispanic or Latino | 18 (90.0) |
| Prefer not to say | 1 (5.0) |
| Missing[a] | 1 (5.0) |
| **Race,[b] n (%)** | |
| American Indian or Alaska Native | 0 (0.0) |
| Asian or Asian American | 1 (5.0) |
| Black or African American | 2 (10.0) |
| Native Hawaiian or other Pacific Islander | 0 (0.0) |
| White | 16 (80.0) |
| Other[c] | 1 (5.0) |
| Missing[a] | 1 (5.0) |
| **Employment status,[b] n (%)** | |
| Employed, full time | 6 (30.0) |
| Employed, part time | 2 (10.0) |
| Self-employed, full time | 2 (10.0) |
| Self-employed, part time | 0 (0.0) |
| Homemaker/stay-at-home parent | 1 (5.0) |
| Student | 0 (0.0) |
| Unemployed | 3 (15.0) |
| Retired | 4 (20.0) |
| Unable to work due to disability | 1 (5.0) |
| Unable to work due to current COVID-19 situation | 0 (0.0) |
| Missing[a] | 1 (5.0) |
| **Education level, n (%)** | |
| Less than high school/technical school or equivalent | 1 (5.0) |
| High school/technical school or equivalent | 7 (35.0) |
| College (including junior college)/university degree (BA, BSc) | 6 (30.0) |
| Post-graduate degree (MA, PhD, MD) | 2 (10.0) |
| Other[c] | 3 (15.0) |
| Missing[a] | 1 (5.0) |
| **Have ever served on active duty in the US military,[b] n (%)** | |
| No, never served in the military | 14 (70.0) |
| No, training for Reserves or National Guard only | 0 (0.0) |
| Yes, now on active duty | 0 (0.0) |
| Yes, on active duty during the last 12 months, but not now | 0 (0.0) |
| Yes, on active duty in the past, but not during the last 12 months | 1 (5.0) |
| Missing[a] | 5 (25.0) |

| Characteristic | Participants With Post-Traumatic Stress Disorder N=20 |
|---|---|
| **Age at diagnosis of PTSD, years** | |
| Mean (SD) | 38.3 (12.7) |
| Range, min–max | 18.0–60.0 |
| Missing,[a] n (%) | 8 (40.0) |
| **PHQ-9 score** | |
| Overall mean score (SD) | 12.6 (6.4) |
| Range, min–max | 2.0–23.0 |
| Missing,[a] n (%) | 1 (5.0) |
| **PHQ-9: Categorical score, n (%)** | |
| Minimal (0–4) | 2 (10.0) |
| Mild (5–9) | 4 (20.0) |
| Moderate (10–14) | 4 (20.0) |
| Moderately severe (15–19) | 6 (30.0) |
| Severe (20–27) | 3 (15.0) |
| Missing[a] | 1 (5.0) |
| **Years since diagnosis of PTSD** | |
| Mean (SD) | 3.6 (5.5) |
| Range, min–max | 0.4–25.3 |
| **Currently receiving pharmacologic treatment for PTSD symptoms, n (%)** | |
| No | 5 (25.0) |
| Yes | 15 (75.0) |
| **If currently receiving pharmacologic treatment for PTSD, type of treatment,[b] n (%)** | N=15 |
| Alprazolam | 2 (13.3) |
| Amitriptyline | 1 (6.7) |
| Brexpiprazole | 1 (6.7) |
| Bupropion | 4 (26.7) |
| Buspirone | 2 (13.3) |
| Citalopram | 1 (6.7) |
| Clonazepam | 1 (6.7) |
| Divalproex | 2 (13.3) |
| Duloxetine | 1 (6.7) |
| Fluoxetine | 1 (6.7) |
| Prazosin | 1 (6.7) |
| Trazadone | 1 (6.7) |
| Venlafaxine | 3 (20.0) |
| **Other mental health conditions,[b] n (%)** | |
| Anxiety | 10 (50.0) |
| Attention deficit hyperactivity disorder (ADHD) | 2 (10.0) |
| Anxiety and major depressive disorder | 1 (5.0) |
| Depression | 1 (5.0) |
| Depression and attention deficit hyperactivity disorder | 1 (5.0) |
| Major depressive disorder | 1 (5.0) |
| Major depressive disorder and insomnia | 1 (5.0) |

[a]Missing response/participant did not provide an answer to the question. [b]Not mutually exclusive. [c]No free-text response for "other" were reported. [d]Other education includes: some college (n=1).
ADHD, attention deficit hyperactivity disorder; BA, Bachelor of Arts; BSc, Bachelor of Science; MA, Master of Arts; max, maximum; MD, Doctor of Medicine; min, minimum; PhD, Doctor of Philosophy; PHQ-9, Patient Health Questionnaire-9; PTSD, post-traumatic stress disorder; SD, standard deviation.

- The mean (SD) age was 41.8 (16.4) years; 15 participants (75.0%) identified as female
- Of the 19 participants who completed the Patient Health Questionnaire-9, 13 (68.4%) reported depression with moderate or greater severity

### Figure 1. Most Frequently Reported Worst Symptoms




[a]Not all participants reported worst symptoms.

- The symptoms most frequently reported among the worst were feeling like constantly "being on the lookout," difficulty falling asleep, disturbing dreams, and scattered thinking/concentration difficulties
- Other symptoms reported among the worst by ≥3 participants included anxiety, distressing memories, and fear/terror

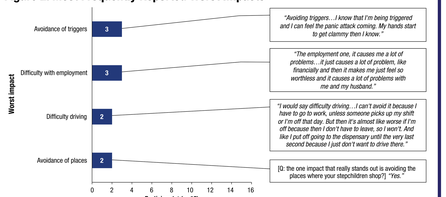
### Table 2. Frequency, Severity, and Bothersomeness of Symptoms Reported by ≥30% of Participants[a]

| Symptoms | Participants With PTSD, N=20 n (%) | Severity Rating Mean (SD) | Bothersomeness Rating Mean (SD) |
|---|---|---|---|
| **Energy-related symptoms** | | | |
| Fatigue | 18 (90.0) | 8.3 (2.2) | 7.8 (3.0) |
| **Pain and discomfort** | | | |
| Chronic pain | 11 (55.0) | 8.5 (1.6) | 8.9 (1.9) |
| **Anxiety/fear/paranoia** | | | |
| Desire to feel control over environment | 19 (95.0) | 8.4 (2.3) | 6.3 (3.6) |
| Feeling like constantly "being on the lookout" | 16 (80.0) | 8.8 (1.9) | 8.4 (2.6) |
| Physical reactions to trauma-related cues | 16 (80.0) | 7.4 (2.5) | 7.5 (2.5) |
| Increased sense that danger is present | 15 (75.0) | 8.4 (2.5) | 7.8 (3.2) |
| Jumpy at loud noises | 13 (65.0) | 7.1 (2.0) | 7.1 (2.3) |
| Exaggerated startle response | 12 (60.0) | 7.3 (3.2) | 6.7 (2.7) |
| Fear of falling asleep | 7 (35.0) | 5.7 (2.6) | 5.0 (3.2) |
| **Memory/cognition** | | | |
| Distressing memories | 19 (95.0) | 7.7 (2.2) | 8.0 (2.2) |
| Difficulty with memory | 18 (90.0) | 8.2 (1.5) | 7.7 (3.0) |
| Scattered thinking | 18 (90.0) | 7.3 (1.9) | 7.0 (3.1) |
| Scattered concentration[b] | 15 (75.0) | 7.9 (1.6) | 7.4 (2.2) |
| **Emotional difficulties** | | | |
| Flashbacks | 17 (85.0) | 7.8 (2.0) | 7.7 (2.7) |
| **Sleep symptoms** | | | |
| Disturbing dreams | 19 (95.0) | 7.7 (2.6) | 7.2 (2.9) |
| Insomnia, restlessness at night[b] | 17 (85.0) | 7.9 (2.1) | 7.9 (2.2) |
| Struggle to fall asleep | 17 (85.0) | 7.7 (2.5) | 6.7 (3.4) |

[a]Other symptoms reported with low frequency but high severity and bothersomeness included fear, feeling weak, and seizures. [b]Question on severity rating was not asked for 1 participant; question on bothersomeness rating was not asked for 2 participants.
PTSD, post-traumatic stress disorder; SD, standard deviation.

- Feeling like constantly "being on the lookout" was reported by 16 participants (80.0%), and this symptom was given the highest mean severity rating (8.8 out of 10), as well as a high mean bothersomeness rating (8.4 out of 10)
- Other symptoms that were frequently reported (≥80%) and rated as highly bothersome (≥7) included fatigue; physical reactions to trauma-related cues; distressing memories; difficulty with memory; scattered thinking; flashbacks; disturbing dreams; struggle to fall asleep; and insomnia, restlessness at night

### Figure 2. Most Frequently Reported Worst Impacts




[a]Not all participants reported worst impacts.

- The impacts most frequently identified among the worst were avoidance of triggers, difficulty with employment, avoidance of places, and difficulty with driving

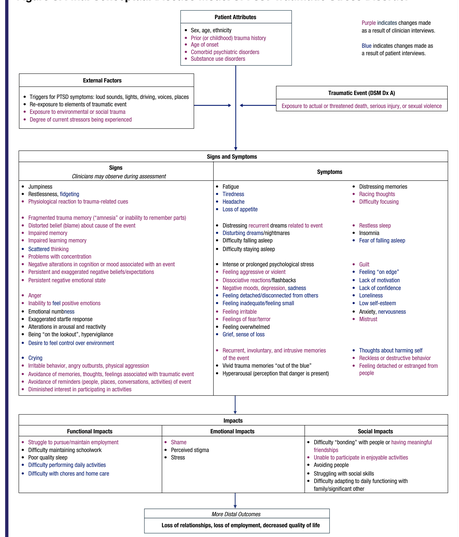
### Table 3. Impacts Reported With ≥30% Frequency[a]

| Impacts | Participants With PTSD, N=20 n (%) |
|---|---|
| **Impacts on behavioral health** | |
| Difficulty with motivation | 16 (80.0) |
| Reckless or self-destructive behavior | 8 (40.0) |
| Feeling aggressive or violent | 6 (30.0) |
| Increased drug and alcohol use | 9 (45.0) |
| **Changes in daily performance and lifestyle** | |
| Avoidance of people, places, or activities | 19 (95.0) |
| Avoidance of triggers (general) | 18 (90.0) |
| Difficulty carrying out typical everyday tasks and activities | 14 (70.0) |
| Struggle to find and maintain employment | 8 (40.0) |
| Difficulty with day-to-day functioning in family life | 6 (30.0) |
| Difficulty driving | 6 (30.0) |
| **Impacts on relationships and social functioning** | |
| Generally preferring to not be around people | 15 (75.0) |
| Socially isolated, struggles with social skills | 12 (60.0) |
| **Additional impacts** | |
| Difficulty with cognition (memory, attention, focus) | 17 (85.0) |
| Sense that traumatic event is recurring | 10 (50.0) |
| Periods of amnesia (inability to remember things associated with traumatic event) | 8 (40.0) |

[a]Sleep difficulties were also reported, in addition to impacts such as avoidance of alcohol, compartmentalizing, embarrassment due to symptoms, and frustration due to symptoms; <30% of participants reported concepts in these subdomains.
PTSD, post-traumatic stress disorder.

- Most participants reported impacts across subdomains, including behavioral health, changes in daily performance and lifestyle, and relationships and social functioning
- Avoidance of people, places, or activities; general avoidance of triggers; difficulty with cognition; and difficulty with motivation were each reported as impacts by ≥80% of participants

### Figure 3. Final Conceptual Disease Model of Post-Traumatic Stress Disorder




*DSM, Diagnostic and Statistical Manual of Mental Disorders*; Dx, diagnosis; PTSD, post-traumatic stress disorder.

- Qualitative participant interviews with individuals with PTSD were used to inform and refine a conceptual disease model for PTSD that had been preliminarily developed with reference to published literature and interviews with clinicians
- Signs and symptoms added as a result of these interviews included crying, sadness, feeling detached, feeling inadequate, grief/sense of loss, nervousness, and having a desire to feel control over one's environment
  - Notably, many of the signs and symptoms that were included in the conceptual model as a result of this qualitative work are not listed as part of the diagnostic criteria in the DSM-5

## Conclusions

- Converging evidence from the literature review, clinician interviews, and patient interviews revealed that the PTSD patient experience extends beyond emotional difficulties, including energy, pain, memory, cognition, and sleep symptoms, as well as impacts on behavioral health, usual daily activities, relationships and social functioning, and cognition
- Because the inclusion criteria aimed to identify individuals who were sufficiently stable for safe participation in interviews and without confounding comorbidities, the participant population may be slightly different than the population seen in real-world clinical practice
- This new conceptual disease model of PTSD provides a framework to describe the relationship between aspects of PTSD, health perceptions, and overall quality of life, and may inform the understanding and management of the disease

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