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Survey Reveals that Renaming Post-Traumatic Stress ‘Disorder’ to ‘Injury’ Would Reduce Stigma

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Abstract

Background

Self-stigmatization has an estimated prevalence of 41.2% among adults with post-traumatic stress disorder (PTSD). Since the name PTSD was introduced, arguments have been made that the term “disorder” may discourage patients from revealing their condition and seeking care. We hypothesize that renaming PTSD to post-traumatic stress injury (PTSI) would reduce the stigma associated with PTSD and improve patients’ likelihood of seeking medical help.

Methods

An anonymous online survey

Results

A total of 1025 subjects responded to the survey. The respondents were 50.2% female (49.4% had been diagnosed with PTSD) and 49.8% male (46.3% had been diagnosed with PTSD). Over two-thirds of the respondents agreed that a name change to PTSI would reduce the stigma associated with the term PTSD, and over half of respondents agreed that it would increase their hope in finding a solution and increase their likelihood of seeking medical help. The cohort diagnosed with PTSD was most likely to believe in the impact of name change.

Limitations

Surveys make it harder to communicate and capture an emotional response. There is a possibility of selection bias, as it was distributed to a limited population.

Conclusion

This study provides significant insight into the potential impact of renaming PTSD to PTSI. The biggest effect is likely to be reduction or elimination of stigma, followed by increase in hope of finding successful medical treatment for PTSD. Above changes are likely to improve access to care, and reduce suicidal ideation in a complex cohort.

Categories: Psychiatry, Public Health, Trauma
Keywords: stigma, ptsi, post-traumatic stress injury, ptsd, post-traumatic stress disorder

Introduction

Post-traumatic stress disorder (PTSD) is a mental health condition which may develop in individuals who experienced or witnessed a traumatic event. The symptoms have behavioral and psychological components, and typically affect mood, sleep and thoughts. The overall, international, lifetime prevalence of PTSD has been estimated by the World Health Organization World Mental Health Surveys at 3.9%, a number which goes up to 5.6% in the subgroup of those exposed to trauma in their lifetime [1]. Yet, PTSD prevalence averaged 10-20% among post-deployment US infantry personnel [2]. In women who had been victims of sexual assault a 46% lifetime prevalence of PTSD is reported [3]. Approximately 25-40% of PTSD patients are expected to remit within a year, although the mean duration of symptoms is upward of 13 years for those with combat-related PTSD [4,5]. PTSD is associated with serious disability, comorbidities and premature death. The economic costs of PTSD are ample, with work impairment estimated at 3.6 days per month per person with PTSD. One of the major barriers towards formal treatment among patients with PTSD is the fear of being stigmatized. In fact, self-stigmatization, which describes the internalization of negative social views and stereotypes, has an estimated prevalence of 41.2% among adults with PTSD [6].

Since the term PTSD has been formally introduced in 1980, arguments have been made that the term “disorder” may discourage patients from revealing their condition and seeking care [7-10]. Changing the name to post-traumatic stress injury (PTSI) has been debated since 2011, initially in response to the

increasing rates of suicide in the US Military. General Peter Chiarelli determined that service men and women hated the term “disorder”, and that it likely prevented them from seeking help. In 2012, Drs. Frank Ochberg and Jonathan Shay, two prominent scholars in trauma research, argued to the American Psychiatric Association that the “injury” model is more suitable to describing this condition, as it results from an injury to brain physiology. Since then, the proposed name change has received endorsements from veteran and civilian groups alike, and other traumatized populations such as journalists and women who survive rape, incest, and battering [7-10]. Despite these discussions taking place, there is yet no evidence-based consensus on the matter. We hypothesized that renaming PTSD to PTSI would reduce the stigma associated with PTSD, and improve patients’ hope in finding a solution.

Materials And Methods

Participants

This study has been exempted from Institutional Review Board (IRB) oversight by Advarra (Protocol number Pro00056144, 08/02/2021). An anonymous online survey was distributed by the Stella Center, between August 2021 and August 2022, to 3000 adult participants, of which 1500 were clinic patient and visitors of the Stella Center. Another 1500 participants interacted with an invitation to the survey made available to the greater public on the Stella Center’s website.

Measures

The survey was administered on Qualtrics. After consenting to participate anonymously in the survey, demographic data on the participants was collected by asking the following questions:

– What is your sex? [Male/Female]

– How old are you? [text box]

– Which of these statements best describes you? [Active military duty/ Military veteran/ Other (please describe)]

– Have you ever been diagnosed with PTSD? [Yes/No]

Next, the participants were asked four questions regarding whether using the term “PTSI” rather than “PTSD” would reduce stigma and improve subjects’ hope and likelihood of seeking treatment. This section of the survey constituted of the following statements:

– The name Post-Traumatic Stress Injury (PTSI) would reduce the stigma associated with the term PTSD.

– The name Post-Traumatic Stress Injury (PTSI) would increase my hope in finding a solution for my symptoms.

– The name Post-Traumatic Stress Injury (PTSI) would increase my likelihood of seeking medical help.

– The name Post-Traumatic Stress Injury (PTSI) would increase my likelihood of seeking interventional treatments such as Transcranial Magnetic Stimulation (TMS) or Stellate Ganglion Block (SGB).

The subjects’ strength of agreement to the statements was assessed using a five-point Likert scale (Strongly disagree/ Somewhat disagree/ Neither agree nor disagree/ Somewhat agree/ Strongly agree).

Data analysis

Data analysis was performed using SPSS (IBM). Two-tailed t-tests were used to statistically analyze demographic variables of the subjects. Two-sided Pearson Chi-Square tests were performed to statistically analyze survey responses by sex or PTSD diagnosis. A p-value of $p<0.05$ was considered statistically significant.

Results

Of the 3000 survey invitations distributed, a total of 1353 responses were received. 1025 of these survey responses were complete, with answers to every question, and were used in this analysis. These respondents were 50.2% female (average age of 37.5 ±13.3) and 49.8% male (average age 46.2 ±12.6) ($p < 0.001$). 11.9% of female respondents had a military status (5.1% were active military and 6.8% were veterans), and 62.7% of male respondents had a military status (13.9% were active military and 48.8% were veterans) ($p<0.001$). Furthermore, 49.4% of the female subjects had been diagnosed with PTSD, along with 46.3% of the male subjects.

Approximately 69% of survey respondents agreed with the statement “The name PTSI would reduce the stigma associated with the term PTSD." (Figure *1A*) The respondents who had been diagnosed with PTSD reported the highest rates of strong agreement (40%). Only 15% of respondents were ambivalent on the topic.

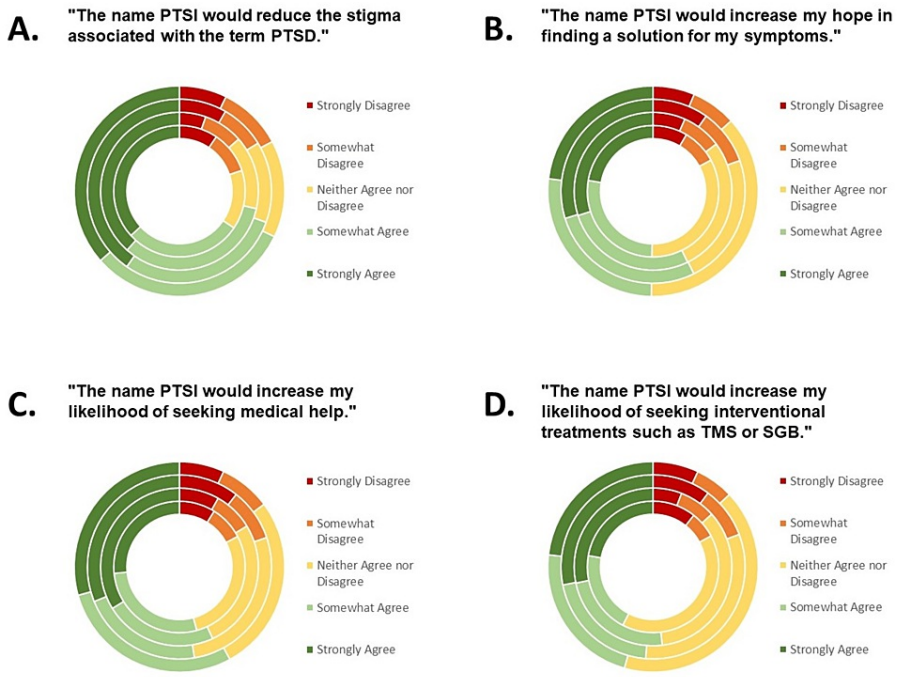

FIGURE 1: Strength of agreement of survey respondents with statements regarding renaming PTSD to PTSI.

Responses are illustrated by group from inner to outer circles: males, females, subjects with a PTSD diagnosis, and subjects without a PTSD diagnosis. Respondents answered on a Likert scale to assess the strength of agreement with the following statements. A. “The name Post-Traumatic Stress Injury (PTSI) would reduce the stigma associated with the term PTSD.” B. “The name Post-Traumatic Stress Injury (PTSI) would increase my hope in finding a solution for my symptoms.” C. “The name Post-Traumatic Stress Injury (PTSI) would increase my likelihood of seeking medical help.” D. “The name Post-Traumatic Stress Injury (PTSI) would increase my likelihood of seeking interventional treatments such as Transcranial Magnetic Stimulation (TMS) or Stellate Ganglion Block (SGB).”

When asked whether: "The name PTSI would increase my hope in finding a solution for my symptoms", 53% of subjects agreed. (Figure *1B*) Respondents who had been diagnosed with PTSD reported the highest rates of agreement (57%) that renaming PTSD would increase their hope. PTSD diagnosis may be connected to feelings regarding hope, as more of the responders with PTSD diagnosis strongly agreed (30% vs 23%), and more of the responders without PTSD diagnosis neither agreed not disagreed (37% vs 23%) ($p<0.001$).

Next, subjects were asked whether "The name PTSI would increase my likelihood of seeking medical help." (Figure *1C*) Once again, more than half of respondents agreed with the statement (55%). When asked more specifically whether "The name PTSI would increase my likelihood of seeking interventional treatments such as transcranial magnetic stimulation (TMS) or stellate ganglion block (SGB)", the rates of agreement reached 47%, counting 49% of responders with a PTSD diagnosis. (Figure *1D*)

Discussion

This is the first study of its kind, demonstrating that renaming post-traumatic stress disorder (PTSD) to post-traumatic stress injury (PTSI) is likely to have a significant impact, by reducing the stigma associated with PTSD, improving patients’ hope in finding a treatment, and increasing the patient population seeking medical help. The results of this survey are striking with over two-thirds of the 1025 respondents agreeing that a name change to PTSI would reduce the stigma associated with the term PTSD, and only 15% of respondents feeling undecided on the topic. With nearly half of the surveyed population having a PTSD diagnosis, it is evident that the stigma associated with the term “disorder” is recognized by those with and without a diagnosis alike. The respondents with a PTSD diagnosis were most likely to strongly agree that the name change would decrease stigma and increase their hope in finding a solution. PTSD is known to be associated with hopelessness, as well as suicidal ideation in response to feelings of guilt [11,12]. Seeing as our results suggest that a name change may result in decreased stigma, we further hypothesize that it may

also reduce the rates of suicidal ideation among patients with PTSD. Indeed, suicide prevention may be achieved by reducing both perceived stigma and self-stigma [7,13].

Self-stigmatization occurs when an individual agrees with a public stereotype of people with mental illness, and applies it to themselves [14]. Among people with PTSD, self-stigma has an estimated prevalence of 41.2% [6]. In the same cohort were found a 68.5% prevalence of alienation, 12.4% prevalence of stereotype endorsement, 53.6% prevalence of discrimination experience, 60.3% prevalence of social withdrawal, and 28.9% prevalence of stigma resistance. No association was found between self-stigma and gender, age, sexual trauma or military trauma. However, self-stigma was associated with lower income and higher levels of anxiety, depression and traumatic stress symptoms.

High levels of self-stigma are typically associated with low self-esteem and quality of life, and may interfere with rehabilitation goals [15]. A study found that treatment-seeking veterans with combat-related PTSD believe that they are stigmatized by the public, most commonly with stereotypes such as “dangerous” or “violent” [15]. This group of veterans were also found to believe that the public would hold them responsible for causing their own illness, because they volunteered for military duty. In fact, military stigma, specifically, has been defined “a set of beliefs based on a service member’s military and prior civilian enculturation that seeking mental health treatment would be discrediting or embarrassing, cause harm to military career prospects, or cause peers or superiors to have decreased confidence in the service member’s ability to perform assigned duties” [16].

Stigma has been repeatedly highlighted as the key barrier to help-seeking behaviors [17]. Studies on mental health disorders have shown that self-stigmatization may decrease treatment seeking, and undermine adherence to treatment recommendations [15]. In fact, a majority of veterans choose to cope without treatment, relying on their own resilience and, in some cases, on substance use. As a result of refraining from seeking mental health services due to stigma, patients with PTSD may endure extreme and life-threatening consequences such as depression, substance abuse, and suicide [18,19].

Until 2013, there was little evidence suggesting the superiority of either pharmacotherapy or psychotherapy [20]. There is now strong evidence backing non-pharmacological approaches such as manualized trauma-focused psychotherapy and cognitive processing therapy. As for pharmacological approaches, there is strong evidence for the use of fluoxetine, paroxetine, sertraline, and venlafaxine. Stigma remains a major barrier to treatment-seeking behaviors.

When it comes to discussing possible medical treatments, our study found that 55% of respondents agreed the name change would increase their likelihood of seeking medical help, and 47% agreed that the name change would increase their likelihood of seeking interventional treatments in particular. Indeed, randomized clinical trials have shown safety and efficacy of interventional treatments such as transcranial magnetic stimulation (TMS) and stellate ganglion block (SGB) in treating PTSD symptoms [21-23]. Although the quality of evidence remains low, a need for large, well-designed clinical trials is clear.

The use of an anonymous survey certainly has advantages in the ease of collecting data from a large number of respondents. Nonetheless, some limitations are also attributed to this study type, as surveys make it harder to communicate and capture an emotional response. On this note, the positive phrasing of the statements to be assessed using a Likert scale may have been leading to the participants. Additionally, there is a possibility of selection bias, as our survey was distributed to a limited population, and some demographic characteristics were significantly different between groups. Due to the brevity of the survey, little demographic data was collected from the participants, such as socioeconomic status, education level, race and co-morbidities. Our sampled population may not reflect the general population.

Conclusions

This study provides some significant insight and evidence into a potential reversal of the stigma associated with PTSD as a “disorder”. These results indicate that renaming the condition to post-traumatic stress injury (PTSI) would decrease the stigma associated with this condition. Increasing the hope of medical treatment and improving the care for this patient population may lead to higher patient acceptance of current and new treatments such as SGB and TMS, hopefully decreasing misery due to PTSD and the occurrence of suicidal behavior in this complex cohort.

Additional Information

Disclosures

Human subjects: Consent was obtained or waived by all participants in this study. Advarra IRB issued approval Project Pro00056144. Using the Department of Health and Human Services regulations found at 45 CFR 46.104(d)(2), the IRB determined that your research project is exempt from IRB oversight. All study related documents will be removed from our active files and archived. Please be advised that as Advarra IRB is not overseeing the conduct of the study, specific IRB details such as the IRB company name and contact information should be removed from the consent form and all study materials, and study materials should

not state that the study is "approved" by an IRB. Study materials may include a general statement that the study was reviewed by an IRB, such as, "This study has been reviewed by an institutional review board (IRB), which is a committee that has reviewed this research study to help ensure that your rights and welfare as a research participant are protected and that the research study is carried out in an ethical manner". Note: You will still be able to access this study via the Advarra CIRBI Platform under the "Archived" tab on your Dashboard for three years. After three years, the study will be removed from the system in accordance with IRB regulations. The IRB granted this exemption with an understanding of the following: 1. The research project will only be conducted as submitted and presented to the IRB, without additional change in design or scope. 2. Should the nature of the research project change, or any aspect of the study change such that the nature of the study no longer meets the criteria found in 45 CFR 46.104(d)(2), you will resubmit revised materials for IRB review. 3. It is the responsibility of each investigator to ensure that the project meets the ethical standards of the institution. Specifically, the selection of subject is equitable, there are adequate provisions to maintain the confidentiality of any identifiable data collected, and when there are interactions with research subjects, they will be informed that the activity involves research, a description of the procedures, participation is voluntary, and the contact information for the researcher. The IRB will evaluate the new information and make a determination at that time regarding the research project's status. This project is not subject to requirements for continuing review. If you have any questions or concerns, please use the Contact IRB activity on the Advarra CIRBITM Platform. Thank you for selecting Advarra IRB to review your research project. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** All authors have declared that no financial support was received from any organization for the submitted work. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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