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Trauma-Related Dissociation and the Dissociative Disorders:

Neglected Symptoms with Severe Public Health Consequences

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Abstract

Trauma-related dissociation is a major public health risk warranting the attention of the healthcare professions. Severe dissociative pathology or dissociative disorders (DDs) are more prevalent than some commonly assessed psychiatric disorders (e.g., Bipolar Disorder, Obsessive Compulsive Disorder, Schizophrenia), yet are often under-recognized and undertreated, despite being associated with significant disability and chronic medical issues, among many other severe and costly public health consequences. In fact, people living with DDs spend an average of 5 to 12.4 years actively engaged in treatment before receiving an accurate diagnosis. Detection and treatment of trauma-related dissociation and DDs leads to a myriad of positive outcomes including improved quality of life, treatment outcomes, reduction in health and social risks, decreased healthcare utilization and costs (25-64% reduction), and significant economic advantages for society. It is imperative that healthcare professionals are trained in recognizing, assessing, and treating dissociation in service of preventing the discussed public health consequences. This article provides a comprehensive review of the important public health implications resulting from often neglected or untreated trauma-related dissociation and DDs while offering a summary of assessment methods, treatments, and resources to empower individuals and healthcare professionals to effect change.

Introduction

Trauma is a widespread public health risk of grave proportions. It can be defined as a high impact stressor that overwhelms the individual's ability to cope and disrupts their relationship with self and others. There are many different types of traumas, including one-time events that involve actual or threatened serious injury or death, sexual violence, or chronic and repetitive experiences of abuse, neglect, marginalization, homelessness, and disrupted attachment relationships. The World Health Organization's (WHO) World Mental Health (WMH) Surveys found that 70% of individuals across the globe reported exposure to at least one traumatic event,1 indicating that trauma is ubiquitous and highly prevalent. Within the United States (U.S.), the vast majority (89.7%) of adults have experienced at least one traumatic event according to *Diagnostic and Statistical Manual of Mental Disorders-V-TR* (DSM-V-TR) criteria, suggesting that the prevalence of trauma exposure in the U.S. may be even higher than that of the global average.2 The largest studies to date investigating the prevalence and lasting effects of childhood trauma exposure in the U.S. revealed that about three out of every five U.S. adults experienced at least one traumatic event in childhood, and about one out of every four U.S. adults experienced three or more.3 The more trauma exposure in childhood, the greater the rates of chronic disease, suicide attempts, mental illness, substance misuse, disability, shortened life

expectancy, and healthcare utilization costs.3 A myriad of studies examining these effects indicate that trauma-related dissociation, a common yet widely unrecognized symptom of trauma, mediates this relationship among trauma exposure, post-traumatic stress disorder (PTSD), and many health and social risks.4,5 Dissociation is an often "hidden and neglected" public health issue warranting the attention of the healthcare professions (p.1).6

Etiology, Prevalence, and Clinical Features of Dissociation and Dissociative Disorders

Etiology of Dissociation and Dissociative Disorders

There is a robust correlation between dissociative symptoms and exposure to trauma, particularly early childhood trauma and disruptions in attachment and caregiving. Dissociation can be defined as disconnections between thoughts, feelings, behaviors, sensations, and other mental processes that would normally be connected. It is a human phenomenon, experienced by all to varying degrees on a continuum ranging from benign to problematic. On one end of the continuum are experiences of daydreaming, "highway hypnosis," or absorption and flow wherein the individual's mental energy is focused on a particular task while other thoughts or perceptions fade into the background. These dissociative experiences are often benign and under the individual's control.

On the other end of the continuum are trauma-related dissociative phenomena that, while adaptive in some ways, can become entrenched over time and impair overall functioning. In the face of overwhelming traumatic experience, dissociation can offer a psychic escape when there is no physical escape. For example, it is not uncommon for survivors of rape to report experiencing themselves as being outside of their body (i.e. depersonalization) during the assault. Individuals may also have thoughts and feelings that appear disconnected (e.g.: "Logically, I know that the trauma was not my fault, but I feel that it was my badness that caused it"). Over time, and particularly in the context of repeated trauma during childhood, the use of dissociation can become a rigid and automatic response to stress that disrupts "the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behavior" (p. 329).7 While in some ways adaptive for trauma survivors, severe trauma-related dissociative symptoms can interfere with almost all aspects of functioning and lead to a diagnosis of a DD.

Prevalence and Clinical Features of Dissociative Disorders

The DSM-V-TR identifies the following (DDs): depersonalization/derealization disorder, dissociative amnesia, dissociative identity disorder, unspecified dissociative disorder, and other specified dissociative disorder. Depersonalization/derealization disorder is characterized by persistent feelings of detachment from one's body or experiences (e.g.: feeling as though things are unreal or a dream). Dissociative amnesia is characterized by gaps in autobiographical memory beyond normal forgetting, that may range from one experience to several years. Dissociative identity disorder (DID), the most severe dissociative disorder, includes both persistent depersonalization/derealization and dissociative amnesia as well as the presence of distinct self-states with unique attributes or experiences. People with DID may experience disremembered behaviors; trance states; fugues; fluctuations in skills, habits, or knowledge; voice hearing; negative hallucinations; analgesia; unexplained somatoform symptoms; abrupt or

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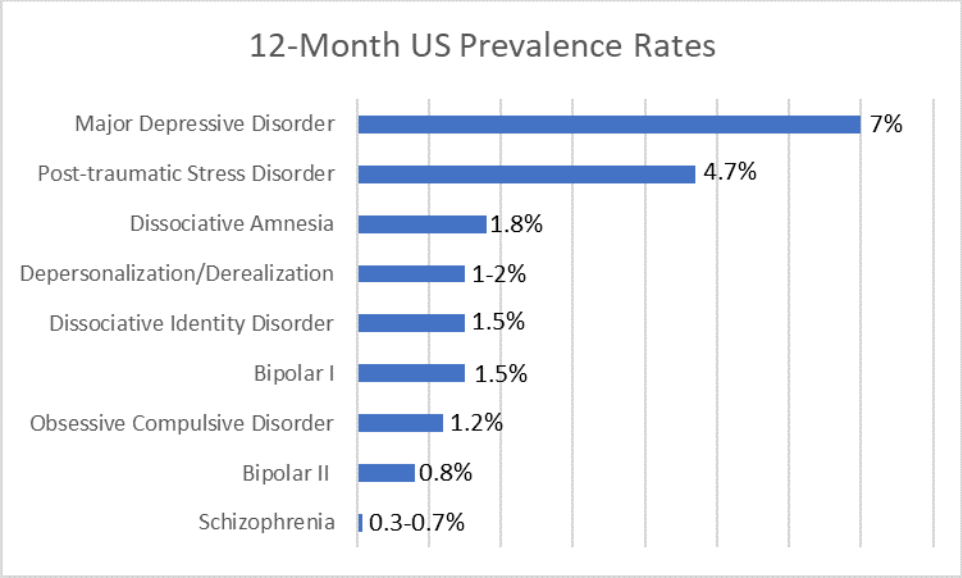
significant changes in mood; and intrusive thoughts, feelings, behaviors, or urges that do not feel like one's own (passive influence). Similar presentations that do not meet full criteria for DID may be captured by diagnoses of either unspecified DD or other-specified DD.

Many epidemiological studies have explored the prevalence of DDs. Lifetime prevalence of DDs ranges from approximately 9 to 18%.6 This wide prevalence range is attributable to differences in special populations or clinical/non-clinical settings and exceptionally limited clinician training in the assessment of dissociative symptoms that results in misdiagnosis. Across inpatient and outpatient clinical samples, the prevalence of DDs is up to 46%.8 Figure 1 summarizes the DSM-V-TR 12-month U.S. prevalence rates of the five DDs as compared to other common psychiatric disorders.7 Of note, because DDs are often the result of chronic and repetitive trauma beginning in early childhood, the vast majority of people with DDs also experience comorbid PTSD.

Figure 1: United States 12-Month Prevalence Rates of Dissociative Disorders Compared to Other Common Psychiatric Disorders



Prevalence and Clinical Features of PTSD Dissociative Subtype

In 2013, the American Psychiatric Association added a dissociative subtype to the PTSD diagnosis that is characterized by persistent symptoms of depersonalization and derealization. The 12-month U.S. prevalence for PTSD generally is 4.7%.7 In the WHO's World Mental Health Surveys of 16 countries, 14.4% of individuals with PTSD met criteria for this dissociative subtype.9

Neurobiology of Dissociation

Neuroimaging studies demonstrate fascinating structural and functional brain alterations among individuals with DDs that are similar and yet distinct from PTSD. These findings are enhancing understandings of the unique presentations and treatment needs of these individuals. Lotfinia, Soorgi, Mertens, and Daniels offers a thorough review of the research in this area, including structural MRI, resting fMRI, and task-related fMRI studies by diagnostic group (PTSD,

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Borderline Personality Disorder, Depersonalization/Derealization Disorder, and DID).10 Researchers have attempted to replicate the brain activation patterns using professional actors of varying levels of fantasy-proneness who are trained to feign dissociative symptoms, but the actors were unsuccessful in duplicating these unique patterns.11

Public Health Implications of Untreated DDs

Implications of Misdiagnosis or Lack of Access to Non-Specialty Treatment

Trauma-related dissociation and DDs not only significantly impact the individual's experience, but they also play a central role in the pathway from trauma exposure to adverse and costly public health outcomes. Figure 2 provides a summary of these outcomes. Unfortunately, few clinicians have training on how to assess for and identify DDs, and their lack of training exacerbates skepticism and diagnostic errors.12 As a result, people living with DDs, particularly DID, spend an average of 5 to 12.4 years actively engaged in treatment with six or more clinicians before receiving a correct diagnosis, all the while experiencing worsening symptoms and increasing functional impairment throughout that time.8,13,14 Even after finding a clinician, patients with DID often have a difficult time sustaining treatment due to poor responses from their provider (i.e., skepticism, being disrespected by their clinician, or assumptions that treatment is no longer necessary).12,13,15 For many, accurate diagnosis and specialty treatment can be a matter of life or death. These widespread barriers in access to appropriate assessment, diagnosis, and treatment for DDs lead to adverse outcomes with significant public health implications.

Figure 2: Public Health Issues Associated with Dissociative Disorders

Disability and Impaired Functioning

The often-significant delays in diagnosis and limited access to specialty DD treatment lead to increased symptom severity, decreased quality of life, and disability.16,17 In one sample, 60% of people with DDs described themselves as disabled, with difficulty functioning across multiple domains.13 Without access to appropriate treatment, people with DDs may struggle with activities of daily living (e.g., self-care), engagement in medical care, and occupational

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functioning.18 In relationships, they may also experience understandable fears of being harmed and may have patterns of withdrawal due to trauma-related shame.19 Additionally, those with comorbid dissociation and substance use disorders demonstrate higher severity of substance dependence than those without dissociation. Dissociation is generally correlated with increased symptom severity across diagnoses and higher psychiatric relapse rates that can be disabling in the absence of accurate diagnosis and treatment.

Poorer Physical Health and Chronic Medical Issues

Dissociation and trauma are both linked to poor physical health outcomes through multidirectional pathways that connect the three.8,18 Broadly, trauma and dissociation impact the responsivity of catecholamine system, HPA axis, and immune system. The effect on these systems increases risk of diabetes, cardiovascular issues, and inflammation, while also decreasing the individual's threshold for pain.18,20 Individuals who experience trauma-related dissociation are likely to experience somatic symptoms.21 Studies have shown that individuals who have higher rates of various types of chronic pain are also likely to report dissociation.22 Adults and children who experience psychogenic non-epileptic seizures (PNES) also have higher rates of dissociation.23 Unaddressed trauma-related dissociation or DDs can also negatively impact treatment and medication adherence or pharmacological response.18,24

Engagement with Social Services

Individuals with DDs have higher rates of social service utilization due to the additional impairments and needs associated with medical illness, disability, and other consequences of dissociation.25 The health and social risks and impairments associated with untreated DDs may compound and produce a domino effect wherein individuals with DDs experience a progressive decline in functioning, resulting in increased engagement in costly social services. Thus, in addition to increased healthcare costs, DDs may also be associated with increased *non-healthcare* costs. This may include direct non-healthcare costs, such as those connected to special education, disability programs or pension, child welfare programs, judicial involvement, transportation expenses, and resources to combat housing instability, as well as indirect nonhealthcare costs, including those associated with fatality, lack of productivity, and lost wages for individuals with DDs or their loved ones who may be servings as their caregivers.25

Increased Likelihood of Revictimization

Dissociative symptoms are also strongly linked to higher rates of revictimization, including sexual assault and intimate partner violence.26 Several researchers have investigated the pathway through which dissociation predicts revictimization. Although dissociation is adaptive and protective in the face of inescapable trauma, persistent use of dissociation often interferes with the individual's ability to process cues of danger and discern threatening from non-threatening information by keeping this information outside of awareness.27 By hindering the process by which one would detect a safety risk, dissociation may prevent individuals from employing self-protective behaviors (e.g., such as fleeing from an unsafe situation) and ultimately lead to greater risk of further victimization among individuals with DDs.

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Increased Suicidal Ideation and Self-Injurious Behaviors

There is robust evidence linking DDs, self-injurious behaviors (SIBs), suicidal ideation (SI), and history of multiple suicide attempts. Higher levels of dissociation are associated with greater severity of SI (e.g., increased frequency, having a suicide plan) and increased likelihood of suicide attempts. In fact, over 70% of outpatients diagnosed with DID have attempted suicide at least once and people often require multiple hospitalizations.7 DDs are an independent risk factor for multiple suicide attempts, even when controlling for other variables such as age, gender, personality disorders, PTSD, or substance abuse.28 The presence of a DD is a greater predictor of suicide risk than SI, depression, or PTSD.29

Similarly, dissociation also strongly predicts engagement in SIBs and is an independent risk factor for them, even when controlling for variables such as age, gender, education, sexual abuse, physical abuse, personality disorders, substance use, and PTSD.4,28 The vast majority of DD patients (92.31%) report only partial awareness of precipitants to their SIBs.15 SIBs may be precipitated by trauma triggers, emotion dysregulation, stress, psychiatric or physical health problems, dissociative experiences, or limited or less helpful coping skills. They may serve the function of stopping uncomfortable dissociation (i.e., grounding) or inducing dissociation to numb or regulate emotions, but they often have significant negative consequences including scarring, hospitalization, and strong feelings of shame.

Increased Hospitalization and Healthcare Costs

People with DDs are higher utilizers of healthcare and social services than other diagnostic groups. In a study of children in the child welfare system, dissociation was the key predictor of rapid need for psychiatric hospitalization.30 Approximately 48% of adults with DDs report experiencing hospitalizations, with 68% noting <5 hospitalizations.13 Şar et al. noted a prevalence of DDs in emergency psychiatric admissions to be 34.9% in one sample.6 Macy compared acute care utilization rates among Massachusetts Medicaid patients diagnosed with DID, PTSD, major depressive disorder (MDD), panic disorder, and bipolar disorder.31 Patients with DID demonstrated the highest utilization rates of any diagnostic group and the most expensive hospitalizations at $2,300 per patient, compared to $300 or less for other diagnostic groups. In another sample that compared healthcare spending among patients with DDs, MDD, psychosis, or bipolar disorders, those with DDs demonstrated higher indices of healthcare spending, suicide, self-injury, emergency consultations, and psychotropic drug use.32

Langeland et al. conducted a systematic review of studies concerning the economic burden of DDs, which summarized the significant direct healthcare costs for psychiatric or medical emergency care, hospitalizations, community care, and medications.25 They found that appropriate diagnosis and access to specialty treatment for DDs significantly reduces costs (e.g., by 25% to 64%) by decreasing treatment length (e.g.: from 10 to 4 years), emergency care services, and hospitalizations. Myrick et al. demonstrated similar findings with significant reductions in both inpatient and outpatient costs when people with DDs were able to access treatment.33 Accurate diagnosis and treatment not only greatly reduces healthcare costs, but also offers life-altering, and potentially life-saving, implications for people with DDs.

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Assessment and Treatment

Assessment

Assessing and diagnosing DDs can be a challenging feat, as symptoms are often trauma-related and shrouded in shame. Moreover, healthcare professionals rarely receive any training on DDs and instead rely on film and media portrayals that are often inaccurate, fantasized, and dramatic, leading them to miss the far more common subtle presentations. Validated clinical interviews and measures can be helpful in accurately identifying and differentiating DDs from other psychiatric disorders or from feigning or malingering. Specifically, there are two semi-structured clinical interviews that can yield DD diagnoses and an Office Mental Status Exam for Dissociation for adults34 or children and adolescents.30 Numerous self-report measures exist for dissociation, including one measure that has been researched in over 1,000 studies: the Dissociative Experiences Scale-II (DES-II).35 An adolescent version of this also exists, as well as Child Dissociative Checklist.36 Many clinicians assessing adults also use multiscale dissociation measures, performance-based tests, or non-dissociation specific broadband measures or malingering measures, for which normative data exists to differentiate true from simulated DID. Brand and Loewenstein offer a brief summary of the Loewenstein mental status exam for dissociation and useful screening or assessment measures.34

Treatment

While some people have expressed concern that treating dissociation or DDs will exacerbate symptoms, research demonstrates the opposite: those patients who are able to access specialty treatment experience significant symptom reduction,37,38 decreased rates of self-harm and hospitalization,33,38 decreased rates of revictimization, decreased substance use,38 reduced inpatient and outpatient costs over time, reduced treatment length,25 and improved social, emotional, and occupational functioning.33,37,38 Without specialty treatment that targets dissociation, dissociative symptoms not only persist, but worsen.15 This is also true for dissociative children and adolescents, as untreated dissociation puts the aging child at risk for the development of more severe impairments in functioning over time due to worsening symptoms.30 Identifying and addressing trauma-related dissociation or DDs in childhood and adolescence, closer to the onset of symptoms, improves treatment outcomes and can prevent a lifetime of hardship and disability as well as the broader public health consequences discussed above. In short, specialty treatment for adults or children with DDs exists and works (see Figure 3).

Figure 3: Summary of Treatment Outcomes from Specialty Treatment for Dissociative Disorders

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Outcome of treatments targeting dissociation	↓ symptoms of dissociation, PTSD, depression, anxiety
	↓ self-injurious behaviors and suicide
	↓ hospitalization, length of treatment, and treatment-related costs
	↓ medication use
	↓ pain and psychogenic nonepileptic seizures
	↓ rates of revictimization
	↑ emotion regulation
	↑ social, occupational, and school functioning
	↑ overall functioning

Randomized controlled trials (RCTs) supporting many evidenced-based trauma treatment models, such as Prolonged Exposure (PE) and Cognitive Processing Therapy (CPT), have unfortunately often excluded individuals with DDs. However, an RCT is currently being conducted to examine treatment outcomes of a manualized treatment for complex trauma and DDs. The Treatment of Patients with Dissociative Disorders (TOPDD) Studies are currently the largest body of research concerning the most effective interventions for DDs. The TOPDD Studies are comprised of naturalistic studies with DD experts and patients, efficacy studies of a web-based educational program for DD patients and their treatment providers, and expert surveys about DD treatment interventions.

Research and expert consensus suggest that the primary treatment for DDs is psychotherapy, with psychiatric medication as a potential helpful adjunctive treatment. Evidence-based guidelines exist to help clinicians facilitate effective specialty treatment for both children/adolescents and adults by the International Society for the Study of Trauma and Dissociation (ISSTD).39,40 Psychotherapy is typically conducted one to three times weekly over the course of several years for adults *(M*=6 years for DID).40 Children and adolescents may experience results more quickly. Treatments are often psychodynamic, but may integrate other modalities such as Cognitive Behavioral Therapy (CBT), Dialectical Behavior Therapy (DBT), hypnosis, Internal Family Systems (IFS), Eye-Movement Desensitization and Reprocessing (EMDR), and sensorimotor psychotherapy.40 All effective psychotherapy treatments for DDs utilize the tri-phasic trauma therapy approach as outlined by ISSTD (2011)40 and Brand et al.,38 including a prolonged period of focus on building a strong therapeutic alliance, establishing safety, stabilization, and symptom reduction (Phase I), followed by trauma processing and mourning (Phase II), and then integration and rehabilitation (Phase III).

Conclusion

Dissociation is a human phenomenon experienced by all. Trauma survivors experience higher rates of dissociation and may utilize it as an escape when there is no physical escape from trauma. When dissociative symptoms become a pattern or entrenched, they can negatively impact many domains of functioning in a person's life and warrant a DD diagnosis. DDs are far more prevalent than most clinicians recognize. In fact, they are more prevalent than numerous

psychiatric disorders commonly encountered in clinical settings. Across inpatient and outpatient clinical samples, the prevalence of DDs is up to 46%.8 Despite their prevalence, clinicians typically receive no training on the assessment or treatment of DDs. As a result, people living DDs are often not believed, misunderstood, misdiagnosed, and undertreated for 5 to 12.4 years. When unable to access adequate diagnosis or treatment, the individual and public health implications are undeniable, with individuals experiencing increased functional impairment across domains, disability, health issues, risk of revictimization, self-injurious behaviors, suicidal ideation, frequent hospitalizations, and utilization of health and social services. To prevent these outcomes, it is imperative that clinicians are trained to assess, recognize, and treat dissociative symptom patterns that have historically been overlooked or disbelieved.

Validated screening instruments, that are available to the public at no cost, as well as formal assessment measures and clinical interviews are very helpful in early and accurate identification of DDs. Effective, evidence-based treatments for DDs also exist and can produce life-altering results, even after one year of treatment (e.g., significant reduction in SIBs, SI, hospitalizations, reduced treatment length). By training healthcare professionals on trauma-informed care as well as how to screen, assess, and treat trauma-related dissociation and DDs, we can not only substantially decrease economic and social burdens, but also spare these marginalized individuals further pain, suffering, and debilitation.

Resources

Treatment of Patients with Dissociative Disorders: topddstudy.com

International Society for the Study of Trauma and Dissociation: isst-d.org

International Society for Traumatic Stress Studies: istss.org

National Alliance on Mental Illness—Dissociative Disorders: nami.org/Learn-More/Mental-Health-Conditions/Dissociative-Disorders

Trauma Disorders Program at Sheppard Pratt: sheppardpratt.org/care-finder/the-trauma-disorders-program

Harvard McLean Dissociative Disorders and Trauma Inpatient Program: https://www.mcleanhospital.org/treatment/trauma-inpatient

An Infinite Mind®: aninfinitemind.com

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