

Trauma Informed Care and Disability: The Complexity of Pervasive Experiences

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Commentary

Trauma Informed Care (TIC) is a structured organizational and treatment framework which involves recognizing, understanding and responding to the effects of all kinds of trauma. It emphasizes the physical, psychological and emotional wellbeing of survivors to rebuild a sense of control and empowerment [1]. The total life experiences of patients impact their beliefs, coping mechanisms, reactions and health. TIC does not segment singular experiences of a patient, but recognizes that each experience accumulates over a lifespan, leaving the patient with a set of complex challenges.

The first question to investigate is "What is trauma?" Trauma is defined by The American Psychiatric Association (APA) as "direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate" [2]. The response to trauma is defined by DSM IV-TR as "emotions of intense fear, horror and helplessness" [2]. Pervasive trauma has a devastating effect on survivors, their families and their communities. Individuals that have experienced pervasive trauma are faced with mood disorders, stress, physical disabilities and chronic health problems. The families are exposed to secondary effects of trauma as well. The community becomes impacted when maladaptive behaviors have consequences that place an additional toll on limited resources. The nation accrues billions of dollars in expenses as patients lose their ability to cope or work and subsequently need government assistance to survive [3].

TIC has grown since the first study on Adverse Childhood Experiences (ACEs) was started. It is ongoing study which includes 17,000 patients and is collaboration between the Center of Disease Control and Keiser Permanente [4]. The initial results were so profound that it prompted further studies and use of ACEs scores globally. TIC has been implemented in, but is not limited to the following areas: school settings, justice systems, behavioral health, homelessness service settings and acute care [5,6]. Attention to ACEs in correlation with disability in later life has recently been recognized by the American Academy of Physical Medicine and Rehabilitation [7]. The AAPM&R supports a gradient relationship between childhood trauma, adult health and disability.

To understand the broad spectrum of trauma, we must first review the prevalence of child abuse. The CDC reports that state and local agencies receive more than 3 million referrals of child maltreatment every year [8]. The Children's Data Network reports that, out of more than 500,000 children who are born in California every year, approximately 25,000 babies are reported for maltreatment during the first year of life. By age five the count increases to more than 80,000 [9]. The World Health Organization (WHO) reports that

approximately 20% of women and 5 to 10% of men report sexual abuse as a child. Reported physical abuse as a child is 23% [10]. Child maltreatment is not confined to specific demographics or socioeconomic factors. It is widespread, with known repercussions. It is estimated that there are 34,000 homicide deaths in children under fifteen years of age [10]. The ACE study recognized that household dysfunction, abuse and physical or emotional neglect occur in almost 64% of the population [11]. There is a close association between medical illnesses and ACEs. A multitude of studies demonstrate that the increase in number of ACEs correlates with the increase risks of morbid obesity, diabetes, gastrointestinal problems, neurological diseases, gynecological problems, autoimmune disease, COPD, depression, ischemic heart disease, liver disease, sexually transmitted diseases or suicide [12,13]. For children surviving to adulthood, the challenges can be immeasurable. ACEs interrupt the development of the limbic system and cause a neural dysregulation within the survivor. Other related brain areas are the corpus callosum, cortex, right temporal gyrus, and cerebellar vermis [14]. These areas are involved in emotional reactions, memory, processing social cues, development of language, proficiency in math, thinking, judgment, executive function, vision, mental health and movement. The stress response from ACEs has psychological, social, and neurological consequences [13]. The psychological impacts include fear, mood disorders, decreased trust, low self-esteem, and an increased risk of unhealthy relationships [15]. Children who have experienced trauma may have difficulty socializing or establishing appropriate healthy relationships with other people [16]. ACEs lead to relationship issues, promiscuity, early pregnancy, poor dietary choices, smoking, alcohol, drug abuse, work absenteeism, aggressive tendencies, high risk behaviors and further trauma [17]. Primary and acute care settings are disconnected from behavioral health, therefore making it difficult for referrals or cross coverage to take place. This disconnection, along with decreased awareness, social taboos and cultural limitations are factors that prevent healthcare providers from identifying the relationship between ACEs and adult health [10].

The growing disability population renders the need to explore multiple factors affecting a trauma survivor, essentially focusing on the premorbid psychosocial aspects. In a rehabilitation setting, TIC mainly focuses on the strong relationship between patients and their ACEs. Patients incur many social problems in addition to their complex medical issues and disabilities. These issues can be attributed to biological changes or secondary to adoption of health-risk behaviors that originated from emotional and cognitive impairment from adverse childhood events [3,10]. Understanding the complexity of pervasive experiences can provide necessary information to rehabilitation clinicians to help identify and address potential barriers in the functional recovery of patients with disabilities. Organizations that recognize the importance of functional outcomes build frameworks that support and educate a clinician's understanding of

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complexity of pervasive trauma. Rehabilitation approaches are utilized to increase quality of life within the community. Integration of TIC in rehabilitation programs can promote a higher level of knowledge that complements the basis of rehabilitation. It addresses, educates and essentially protects patients from continuing maladaptive behaviors. Consequently, TIC promotes improved choices, corrects unhealthy belief systems, embeds coping strategies to improve functioning and enhances community health.

About 15% of the world's population has some form of disability. Between 110 million and 190 million adults have significant functional limitations [10]. The rate of disability in the United States is rising. 2010 statistics show that the rate of disability in the United States is 18.7% [18]. In 2011, an estimated 8.1% (or about one in 12) of civilian, non-institutionalized men and women aged 18 to 64 in the United States reported a work limitation [19]. 70% of disabled adults rely on family and friends for assistance with daily activities [20]. The American Academy of Pediatrics states that, over the past five decades, the prevalence of childhood disability has increased dramatically, with notable increases in the prevalence of mental health and neurodevelopmental disorders [21]. Mental health disorders account for 20% of the total burden of disease worldwide, while depression is the highest contributor to non-fatal burden of disease and disability for both high and low/middle income countries [22]. People with disabilities are at greater risk of developing mental health problems than the general population [22]. More than two-thirds (69.8%) of people with mental disorders in the United States have a disability, out of which, less than 20% receive a disability program [23]. Studies investigating the effects of socio-economic factors on the mental health of people with disabilities suggest that the presence of one stressor makes the individual more vulnerable to the effects of other stressors [22]. People tend to use personal and social resources when coping with negative life events or circumstances [22]. Those who live in worse socio-economic situations lack material resources to cope with adverse life events. Disability becomes a potential stressor in such situations. Financial stressors and poor social support may deplete an individual's resources so that they are unable to effectively cope with disability. This change in health, stress response and lack of healthy coping skills creates a downward spiral that indirectly leads to complex health problems [12].

To date, relatively little attention has been given to the subject of ACEs among persons with disabilities. Two recent studies have begun to explore the association between ACEs and disability in adulthood [7,24]. A recently published study examined the effects of high level ACE on health and risk behavior showed alarming results [25]. The study found that an estimated one-in-four adults in the state of North Carolina with a disability and high ACE exposure reported being forced to be involved in sex with an adult before the age of 18. The additional significant finding was that the smoking prevalence (38.2%) and the relative risks were significantly higher for those with a disability compared to those without a disability. Additionally, it also revealed that the measures of perceived poor health were at least 2.4 times higher for those with a disability as compared to those without it.

ACEs are often accumulative. The accumulation of trauma increases the likelihood of disability. Patients are admitted into the inpatient rehabilitation setting due to debilitating function and complex medical problems. Their impairments are often linked with poor social and financial support, impaired coping mechanisms, decreased safety awareness, mood problems and personality disorders. Inpatient rehab clinicians need to ask "What has happened to this person?" instead of "What's wrong with this person?" This would encourage the clinicians to consider factors beyond dysfunction of an organ or organ system. Multiple factors need to be considered when devising a rehabilitation plan for each patient including functional comorbidities, medical impairments, participation level. environmental factors, personal traits and psycho-social aspects. This framework provides a better understanding of how to manage the impact of ACEs on functional improvements [8]. The AAPM&R recommends that physician, researcher and policymaker awareness is essential in assisting those affected by childhood adversity for better functional lives [8].

Assessing, planning and implementing TIC are the first steps to prevent and address trauma. All service areas from schools, colleges, justice systems, behavioral health, primary care, acute healthcare and long term healthcare have equal opportunities to address trauma. The ACE study has been examined and utilized by multiple programs, states and countries. The WHO has also included the Adverse Childhood Experiences International Questionnaire (ACE-IQ) in violence and injury prevention program [26]. Rehabilitation facilities interested in practicing TIC would first need to evaluate their structure, framework, processes and practice prior to training their staff. Training would need to include the definition of traumatic stress, its effects on the body and brain, the relationship between mental health, substance use, homelessness, education in child development, and education regarding the relationship between childhood trauma and adult re-victimization. The knowledge of different cultural practices, beliefs and rituals is extremely important. Staff would need to be aware of how culture impacts understanding and responses to trauma. Because ACEs may predispose survivors to high risk behaviors and violent tendencies, all rehabilitation team members need to recognize challenging behaviors of trauma survivors on staff and learn strategies to de-escalate threatening situation before they become a crisis. The organization would need to develop protocols, safety plans, assessment tools, crisis prevention and staff education on maintaining professional boundaries. Staff support and self-care should be emphasized and routinely evaluated. The physical environment should be safe and supportive. Healthcare systems may face an economic burden if ACEs are not recognized at onset. The long term effects of ACEs may involve billions of dollars in funds and resources. A patient with a history of abuse has an increased frequency of symptoms, primary care visits, prescription needs, acute hospital stays and community health needs [6].

In an interesting study carried out in women suffering from spouse abuse, an integrated model of trauma group therapy combining dancemovement therapy and somatic experiencing was carried out [27]. There were five body-mind healing indicators found as part of the healing process: vitality and aliveness; body-mind integration; selfregulation and relaxation; empowerment; and self-boundaries. A very high level of change was observed in most of the women on all the indicators. The same principles can be applied to disability population as it focuses on resiliency, resources and the body's natural innate capacity to heal. This contributes to coping with trauma even if it was accumulated for many years.

In conclusion, TIC has yet to be made a standard for education and practice, but many organizations are altering their framework and initiating process changes. A similar yet more integrative model system needs to be implemented in rehabilitation settings. Rehabilitation clinicians are in a unique position to identify and address the effects of ACEs on complex functional limitations. The core focus of this approach is to minimize disability, facilitate neurological recovery and maximize functional independence within the community. These practices can improve overall patient and community health and reduce the cost of health care. Strategies are needed to help improve the physical and mental well-being of persons with disability who have been exposed to childhood abuse and trauma. Future studies are needed to determine the directionality of childhood abuse and disability onset.

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