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Treating self-injurious behaviors in autism spectrum disorder

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Abstract: Self-injurious behaviors (SIBs) are "a class of behaviors, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behavior." In the autistic population, SIBs are considered non-suicidal self-injurious behaviors, due to no apparent intent or willful self-harm. SIBs are highly prevalent in people with Autism Spectrum Disorder (ASD). There are few hypotheses for why people with ASD self-harm; one widely accepted method for assessing self-harm; and no real consensus for treatment. However, a comprehensive review of literature on SIBs make it evident the etiology of SIBs may lie in a specific deficit, similarly to how psychologists view SIBs in non-autistic persons; and that an effective treatment option exists, yet is not used on ASD patients. SIBs in the autistic population should be conceptualized the same way they are conceptualized in neurotypical individuals, and should be treated with the same goals currently used in Cognitive Behavioral Therapies even when the individual is nonverbal or minimally verbal.

Subjects: Self-Harm in Children and Adolescents; Autism & Aspergers in Children & Adolescents; Autism; Communication Disorders

Key words: autism; self-injurious behaviors; functional communication; treatment; dialectical behavior therapy

ABOUT THE AUTHOR

Alternative Teaching Strategy Center (ATSC) is a non-profit organization located in San Diego, California dedicated to providing services to families with children and adults with autism and other cognitive and learning disabilities. ATSC works directly with parents, insurance companies, school districts, and other State agencies, and provides one-on-one treatment services to children and adults from all over the world. ATSC is dedicated to researching treatments and interventions primarily in autism and related disorders with a primary focus on severe autism, due to a sparsely populated research base. The group's work includes topics related to the effective overall treatment options and methods, the use of technology in treatment, implementation of special education especially in public schools, socialization, and ethical practice, with a goal of improving the quality of life for the aforementioned populations.

PUBLIC INTEREST STATEMENT

Self-injurious behaviors (SIBs) are "a class of behaviors, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behavior." In the autistic population, SIBs are highly prevalent, and are considered non-suicidal self-injurious behaviors, due to no apparent intent or willful self-harm.

The aim of this paper is to review the literature on SIBs and to highlight the etiology of SIBs in Autism Spectrum Disorder (ASD) since it is similar to the way psychologists view SIBs in non-autistic persons. This is noteworthy as psychologists have successfully treated SIBs for many years, yet this treatment option and the theories behind it have never been applied to the understanding SIBs in persons with ASD. Furthermore, current approaches to SIBs in persons with ASD are actually counter-intuitive and can perpetuate abuse and learned helplessness. These researchers call upon professionals to use the same approaches used in the non-autistic population and to discontinue unscientific approaches to SIBS in this vulnerable population.

1. Self-injurious behaviors in autism compared to other populations

Self-injurious behaviors (SIB) are described as "a class of behaviours, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behaviour (Fee & Matson, 1992, p. 4)." When these behaviors occur in the autistic population they are considered what psychologists refer to as non-suicidal self-injurious behaviors, as there is no apparent intent or willful self-harm. These behaviors include but are not limited to biting, hair pulling, head-banging, and skin picking/scratching (Minshawi et al., 2014). Diagnostically, self-injurious behaviors are typically associated with Borderline Personality Disorder (BPD), but research has identified these behaviors to be highly prevalent in children with Autism Spectrum Disorder (ASD) as well (American Psychiatric Association [APA], 2013; Soke et al., 1971). In fact, research suggests 30% of children with Autism Spectrum Disorder in clinic-based studies engage in SIB. Additionally, SIBs are more common in children with ASD than in their typically developing peers (Minshawi et al., 2014; Soke et al., 1971). While ASD is diagnostically categorized as persistent deficits in social communication and interaction, as well as restricted or repetitive patterns of behaviors, interests or activities, but in addition to these core symptoms, ASD has also been strongly associated with sensory processing issues and self-injurious behaviors (Baghdadli, Pascal, Grisi, & Aussilloux, 2003; Duerden et al., 2012; Rattaz, Michelon, & Baghdadli, 2015; Richards, Oliver, Nelson, & Moss, 2012).

Psychologists observe SIBs in children and adults in the typical population and have conceptualized SIBs as a result of difficulty regulating extreme negative emotions, and physical and/or psychological pain (Skegg, 2005). Meaning, many of these individuals do not have the skills to regulate or communicate and therefore it is their only way to cope. This is also why SIBs are typically associated with hopelessness and low self-esteem. In the field of psychology, SIBs are often conceptualized as a" cry for help", meaning that the person needs and may be trying to obtain help, but is unable to do so in an adaptive manner. SIBs can be viewed as a nonverbal means to cry for help when the language and coping skills are not available, and/or the pain is unbearable. In persons without ASD, the communication deficit is not referring to speech ability but is referring to effective communication and interpersonal effectiveness. That is, one can have full verbal abilities but is unable to express themselves in an adaptive and effective manner, or they do not have a supportive environment to do so. For example, some individuals who engage in SIBs may theoretically be able to communicate effectively but they are oppressed by their environment and so they are not free to do so. The results are that the individual cannot openly ask for help and resorts to SIBs-a silent cry for help.

This conceptualization of SIBs and the variables that contribute to SIBs is not breaking news. In fact, a "cry for help" has even been implemented in various standardized assessments such as the Minnesota Multiphasic Personality Inventory (MMPI) (Hathaway & McKinley, 1943). The MMPI and other assessments help psychologists readily identify such psychological distress and personality characteristics in order to inform treatment. Once psychologists are aware of any SIBs they act immediately to help identify pain, ameliorate the pain, and improve the client's coping and communication skills. Dialectical Behavior Therapy (DBT) is the most widely used, evidence-based treatment for SIBs. Dialectical Behavior Therapy is a modified form of Cognitive Behavior Therapy (CBT), which emphasizes the interconnectedness of one's physiology, thoughts, emotions and behavior. Dialectical Behavior Therapy (DBT) uses this foundation and focuses on interpersonal effectiveness, distress tolerance/reality acceptance, emotion regulation, and mindfulness (Linehan, 1993). Trained psychologists incorporate clinical judgment, empathy and rapport as they implement interventions to improve communication, increase frustration tolerance, and improve emotion regulation in individuals who self-injure.

The hallmark of DBT is to help the individual with SIBs learn skills to communicate, regulate their emotions, and to develop frustration tolerance. DBT and other similar Cognitive Behavioral Therapies have worked wonders for individuals who suffer and engage in SIBs. However, this conceptualization of SIBs in general, has not been applied to children with ASD.

While it may be surprising to some, the reasons why someone with ASD may engage in SIBs are the same reasons why an individual without ASD may engage in SIBs mentioned above (i.e. pain, inability to communicate). Research from various fields indicates that communication and/or "adaptive skills" can be triggers for, and very often directly correlate with SIBs in people with ASD (Baghdadli et al., 2003; Chiang, 2008; Matson, Boisjoli, & Mahan, 2009; Murphy et al., 2005; Richards et al., 2012; Weiss, 2003). Researchers have consistently found that self-injurious behaviors in individuals with ASD are highly associated with lower levels of adaptive and/or expressive language skills (Baghdadli et al., 2003; Chiang, 2008; Matson et al., 2009; Murphy et al., 2005; Richards et al., 2012; Weiss, 2003). Interestingly, there is a strong association between challenging behaviors and learning disabilities, but the children with ASD who manifest SIBs are typically those with no expressive language at all (Moss et al., 2000). Children with ASD who are nonverbal or have lower levels of expressive language have higher incidence of SIB (Baghdadli et al., 2003; Chiang, 2008; Foxx & Livesay, 1984; Moss et al., 2000; Rattaz et al., 2015; Talkington et al., 1971). Research has been fairly transparent that a high proportion of children with ASD with severe impairments use challenging behavior as a form of expression, and even if the behavior is ignored, the child will still engage in SIB in order to try to communicate (Chiang, 2008). As previously mentioned, this is consistent with what many psychologists understand to be a skills deficit and/or cry for help. Research has continued to find a high prevalence of challenging behavior in children with ASD who have limited spoken language, and a decrease in these behaviors when teaching functional communication, again supporting the relationship between expressive language skills and challenging or self-injurious behaviors (e.g. Baghdadli et al., 2003; Chiang, 2008; Murphy et al., 2005; Saloviita, 2000). Some therapists and researchers have begun to realize that challenging behaviors are a reflection of deficits that can be ameliorated by teaching communicative skills, or what is sometimes called functional communicative training (Carr & Durand, 1985; Durand, 1990; Murphy et al., 2005). However, it appears that despite the consistency in research indicating poor expressive language or communication skills are significantly correlated with SIB, the application of this research is lacking (Matson et al., 2009; Rattaz et al., 2015; Shodell & Reiter, 1968; Talkington et al., 1971).

Even research in other fields outside of traditional approaches to psychology have attempted to study possible neurochemical implications that could help explain these behaviors, in order to inform treatment.

The hypotheses developed from a neurochemical perspective have been generally unremarkable but are included here for comprehensiveness. Research has generally found inconsistent associations or links between any major neurochemical issues as well as inconsistent effectiveness of treatments for SIBs. However, some of the common hypotheses indicate the role of natural opiates or endorphins, as well as a deficit in specific neurotransmitters. Dopamine and serotonin have been linked to SIBs in Autism Spectrum Disorder based on animal studies (Goldstein, 1989) as well as the use of dopamine and serotonin antagonists such as Haloperidol and Risperidone (Weiss, 2003). Researchers suggest that perhaps a deficiency in serotonin may be the culprit of increased rates of self-aggression (Cohen, Ihrig, Lott, & Kerrick, 1998; Vanden Borre et al., 1993). However, there is no empirical evidence to support the idea that the serotonin system alone underlies self-injury (Rothenberger, 1993b). The opiate or "addiction hypothesis" suggests that the release of opiates after the pain produced by SIB is reinforcing in it of itself. This and similar hypotheses suggest that someone who self-injures can become addictive to the opiates or endorphins released and will subsequently engage in self-injury even more (Rothenberger, 1993a, 1993b; Sandman, 1990; Sandman & Hetrick, 1995). Opiates are addictive for everyone, and so by the same logic one could argue that those with BPD also engage in SIB because they are addicted to the release of opiates after the pain produced by SIBs. However, empirical evidence and general support for these hypotheses do not exist in order to apply this research to SIBs in any population (including the autistic population) with any reliability (Rothenberger, 1993a, 1993b). Additionally, while most research in this area has focused on whether or not physiology or neurochemical processes can be considered the etiology for SIB, other studies have viewed SIB as merely a symptom and the physiological component as a part of a maladaptive coping strategy (Groschwitz & Plener, 2012; Kartzinel, 2018). These studies have indicated that the

physiological responses resulting in pain from non-suicidal self-injury can be an attempt to heal psychological pain or other pain, especially for individuals with an insufficient stress response. This hypothesis is more consistent with the way most psychologists conceptualize self-injurious behaviors, particularly those psychologists who use evidence-based treatment such as Cognitive Behavioral Therapy or Dialectical Behavior Therapy (DBT) (Linehan, 1993).

Since neurochemical or physiological hypotheses consist of a very small portion of research regarding SIB and has not produced any consistent results, many paraprofessionals are still searching for answers evidently without the knowledge of two things: firstly, that psychologists already know how to appropriately treat SIB, and secondly, that research indicates SIBs in ASD has the same or similar etiology (e.g. pain and/or communication deficits) as SIBs in the non-autistic population, indicating that existing treatment methods are likely adequate. Why is it when individuals with ASD engage in SIB, the research, knowledge, and expertise regarding SIB and its treatment are ignored? When neurotypical individuals engage in SIB, they are approached with empathy, competency and the application of research and evidence-based practices (e.g., DBT, CBT), while an equivalent autistic individual engaging in SIB goes without any of these. This may be in part because the majority of children with ASD who engage in SIBs have minimal expressive language, so traditional talk therapies and interventions are not appropriate. While the treatment may have to be adjusted, the question still stands as to why the general conceptualization of SIBs is ignored? It is likely due to a disconnect between those who are experts in human psychology and those who deliver services to the ASD, as well as the current approach to SIBs in the ASD population.

2. The current unscientific approach of assessing self-injurious behaviors

Despite the current research and knowledge regarding self-injurious behaviors and a well-established evidence-based treatment, many professionals and paraprofessionals neglect best practices and attempt to differentiate SIB in the autistic population, as if it was an entirely different symptom or psychosis. Currently, the most popular "go-to" assessment for SIBs in the autistic population is a Functional Behavioral Assessment or Analysis (FBA). An FBA is intended to develop and then test various hypotheses in order to eventually determine the "function" of a behavior, in this case self-injurious behaviors (Maurice, Green, & Luce, 1996). A Functional Behavior Assessment or Analysis is a method that is widely used in Applied Behavioral Analysis (ABA) therapy and is typically conducted by a Board Certified Behavioral Analyst (BCBA), in order to assume the function of a behavior. Applied Behavioral Analysis utilizes one very small subset of psychology called behavioral psychology or behaviorism as the premise for its treatment practices. The behaviorist movement began predominantly with John B. Watson and B.F. Skinner in the early 1900s. Behaviorists believe that all behavior is simply a reflex or reaction to our outside environment. These early behavioral psychologists insisted that what cannot be observed cannot be scientifically studied and measured, especially intangibles such as sensations, emotions, and thoughts (Myers & DeWall, 2017). The importance of thoughts, emotions, and internal processes became evident with the rise of cognitive psychology, which became more widely acknowledged in the mid-1900s. As a result, the principles of behaviorism that are implemented through ABA therapy do not take into account internal processes. Consequently, the FBA was designed to determine the function or cause of external behaviors by identifying external triggers or stimuli. ABA uses an FBA to try to determine the function of the behavior by using what is called "ABC"-antecedents, behavior, and consequences (Martin & Pear, 2011). An antecedent is stimuli that exists right before a behavior, and the consequence is what occurs after a behavior. For example, a child sees his friend (antecedent), the child runs to his friend and falls down (behavior), the child begins to cry (consequence). In this scenario, you can clearly determine one external function for why the child is crying-he is physically hurt. Now consider an actual case from clinical practice when a nonverbal child was asked to match photos of his family members. Every time he was shown a photo of his father (antecedent), he would throw the iPad (behavior) and thus he did not have to match the photo of his father (consequence). However, the real reason for the behavior was his parents were getting divorced and the father

had just moved out of the house. Continuing with the chain of behaviors, the child avoids the task (antecedent), the behaviorist uses reward or punishment to make the child do the task again (behavior), and then the child throws the iPad again and becomes psychologically distressed (consequence). The cycle continues and as a result, the therapist continues to invalidate the child and exacerbate the child's emotional and psychological distress relating to his parents' separation. Now recall the first example, the child who falls as he runs to his friend may also be crying due to embarssment or shame, but this would not be an external, measureable factor and it no longer fits within the realm of behaviorism. Behaviorists might realize that the observable behavior is an expression of an internal process, but the understanding and treatment of the behavior is now beyond the scope of a behaviorist.

ABA therapists use an FBA to look at both the antecedent and the consequence of SIBs in order to hypothesize the function of SIBs. It is unclear why one would assume such an assessment/analysis would also be appropriate to assess the thoughts, feelings, and other internal processes that often determine the function of self-injurious behaviors (especially since we know this is the case for SIBs in the non-autistic population). Instead of approaching these SIBs and understanding them the way we understand SIBs in other populations, we have misapplied an FBA in an attempt to measure SIBs despite the fact that it cannot measure such a construct. This makes the assessment unscientific and methodologically flawed. Consequently, the misapplied FBA has sometimes obtained the same information and observation as the previously mentioned research (communication difficulties correlated with SIB), but the conclusions for the functions of SIB reached are varied, inconsistent, and without any scientific basis. Therefore, any treatment recommendations that are derived from an FBA should be considered unreliable since the assessment method in it of itself is unscientific, as it attempts to measure an unobservable construct, which is outside of the sphere of behaviorism and should only be performed by someone trained in psychology.

3. Attempts made to explain and differentiate self-injurious behaviors in autism

Most hypotheses and research surrounding SIB in the Autism population have been derived from Applied Behavioral Analysis (ABA), specifically through the application of a Functional Behavioral Analysis (FBA), previously described. Although the FBA was invented to assess external behaviors and stimuli, it has been inappropriately applied to address SIB to develop hypotheses as to the internal, invisible processes within a child in order to determine why they are engaging in SIB. As a result, various behavioral hypotheses and treatment recommendations have arisen from these FBA, despite the inappropriate use of this assessment tool and its inherent methodological flaws. These hypotheses have ignored the evidently common trigger for SIB across a multitude of studies perhaps due to the division of professional fields, confirmation bias, and a lack of cross-disciplinary education. Some common hypotheses derived from the application of an FBA suggest the function of SIB is likely social attention, access to tangible rewards, to escape or avoid certain activities or situations, or due to internal self-stimulation (Minshawi et al., 2014). For an understanding of why the FBA is inappropriate, let us examine the conclusion that SIB is used for task avoidance. Consider a student who hits his own head when the therapist gives him a difficult task to perform. One assumption would be that the student did not want to do the task so the SIB is an expression of task avoidance. Another assumption could be that the presentation of the difficult task triggered a stress response and/or a pain response. In this case, the SIB is an expression of pain relief. Yet another assumption could be the student had a headache and by presenting a task to be performed, the therapist was not acknowledging the pain, and so the SIB is an expression of frustration and helplessness. At this point, it should be apparent that each of these assumptions are just assumptions and cannot be validated without sophisticated equipment (e.g. an FMRI) or expertise in human psychology, and therefore are not scientifically reliable and cannot form the basis for any treatment protocol. Moreover, an FBA attempting to identify internal processes and motivations for SIB is contradictory to Behaviorism, and produces only assumptions that cannot be considered scientifically reliable.

Since an FBA cannot adequately assess the child's intentions or motives, researchers have manipulated various settings and responses to SIB in order to better pinpoint the etiology for SIB. Some of the responses to a child who is engaging in SIB as in the prior example are punishment-based such as misting the child in the face with water or taking away desired objects. Other responses include withholding attention from the child, ignoring the child, or removing the child from the situation (Carr, 1977; Minshawi et al., 2014; Weiss, 2003). It is unclear why one would think these responses are appropriate for someone who is engaging in SIB since these responses do not follow any evidenced-based treatment or theoretical orientation. A psychologist or therapist would not respond to any client this way after discovering their client has been or is engaging in SIB.

4. Do no harm

Many paraprofessionals and professionals continue to use Functional Behavioral Analysis (FBA) repeatedly, often completely ineffectively, with the same child, perhaps with the hopes of eventually identifying the function of SIB as something external or some kind of behavior that can be modified. This kind of confirmation bias may be partly to blame for why a focus toward functional communication has not been widely established. Instead, children who engage in self-injurious behaviors are ignored, forced to engage in an activity they cannot complete or do not understand, are punished with dog-training techniques such as electrical shock or water misting, are forced to wear helmets, forced into restraints, are left in padded rooms, etc. (Carr, 1977; Minshawi et al., 2014; Weiss, 2003). In addition to the fact that these responses to SIB are abusive and contraindicated in almost every theoretical orientation and evidence-based practice, these responses have also been identified within Marsha Linehan's Biosocial Theory as the causes of Borderline Personality Disorder (1993). The invalidating and ignoring of a child, as well as punishing to control behavior, and not taking seriously the child's needs are all common and even recommended responses to SIB in the autistic population, despite these responses being linked to the development of Borderline Personality Disorder.

In fact, research indicates co-morbidities and commonalities in symptoms of BPD and ASD such as interpersonal instability, SIBs, social impairments, irregular facial emotion recognition, and a dysfunctional pattern of empathic capacity (Dell'Osso et al., 2018; Fertuck et al., 2009; Harari, Shamay-Tsoory, Ravid, & Levkovitz, 2010). Fertuck and colleagues found "Mental state discrimination based on the eye region of the face is enhanced in BPD. An enhanced sensitivity to the mental states of others may be a basis for social impairments in BPD." (Fertuck et al., 2009, p. 1) This research is not dissimilar to what we know about the autistic brain. In Autism research, the "hyperarousal model" is a much supported model which states that gaze avoidance is an adaptive (appropriate) response because the face and eyes are strongly aversive to those with ASD (Corden, Chilvers, & Skuse, 2008; Dalton et al., 2005; Richer & Coss, 1976; Senju & Johnson, 2009). Research also indicates a general hyperactivity in various areas of the autistic brain resulting in overstimulation which can explain a number of symptoms, in addition to just aversive responses to eye-gaze (Dichter, Felder, & Bodfish, 2009; Markram & Markram, 2010; Martineau, Andersson, Barthélémy, Cottier, & Destrieux, 2010).

Another study exploring co-morbidities found 15% of female patients with a verified diagnosis with BPD also met full criteria for ASD (Rydén, Rydén, & Hetta, 2008). In addition, these patients had more frequent suicide attempts and more negative self-image. When looking at Asperger's, Autism and a control group, researchers found the Asperger's and Autism groups were significantly elevated on the Borderline Personality Disorder scale when compared to the control group (Thede & Coolidge, 2007). Research even suggests that BPD and ASD might "be variant presentations of empathic imbalance the diagnostic outcome influenced by the severity of the imbalance and the presence or absence of childhood maltreatment" (Smith, 2013, p.1). Yet, ABA therapists and other paraprofessionals with evidently no training in human psychology or child development are engaging the kind of maltreatment identified in BPD research. This current response to SIBs in the Autism population is incompatible with any formal education or knowledge regarding current research and appropriate ways to address SIB. A therapist is duty bound to Do No Harm, and yet by these very actions we are causing more harm and may even be affecting the child's propensity for the development of BPD.

5. Communication is key

Regardless of the inappropriate nature of the current attempt at "treating" or understanding SIBs in ASD, many patterns and existing research have been blatantly ignored. For example, researchers have found that interspersing simple demands amongst more difficult demands instead of forcing a child to sit and engage in a very difficult task, lowers physical aggression (Horner, Day, Sprague, O'Brien, & Heathfield, 1991). This would appear to be common sense, as forcing anyone to engage in something they are unable to do would naturally create stress, anxiety, and frustration; the difference being that most people or children can verbally express their dissatisfaction and can ask for a break, or have the autonomy to take a break when needed. Similarly, the most prominent pattern found is that SIB significantly decreases when the child is taught how to communicate. Cox and Schopler (1993) used an iceberg metaphor describing SIB as the tip of the iceberg, on the surface and easily visible; but underlying are various deficits, especially communicative deficits. A review of the research previously mentioned suggests Cox and Schopler's metaphor may have been spot on, yet it has been systematically ignored. One study in particular even states "As mentioned, teaching communicative behaviors that result in access to tangibles or escape from aversive situations can replace the functional properties of the SIB, stripping the problematic behaviors of their adaptive qualities" (Weiss, 2003, p. 137). Yet in clinical settings, expressive communication is still not viewed as an etiology or hypothesis for SIB in the ASD population.

6. Conclusion

Although DBT cannot be used with many children with ASD who exhibit SIB, we can nevertheless learn from the DBT approach and apply similar strategies for children with ASD. The first step is to treat them with empathy and acknowledge their cry for help. Since one of the major causes of SIB is physical pain, and some children with ASD cannot communicate that pain, we need to be diligent in the recognition and treatment of that pain. The hallmark of DBT is to help the individual with SIB learn to communicate, regulate their emotions, and to develop frustration tolerance. For children with ASD we need to focus on teaching them functional communication, and slowly build their tolerance for frustration and teach them to regulate their emotions. To do anything else would violate the Hippocratic Oath.

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