

Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder

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Abstract

Recent studies have examined non-suicidal self-injury in community and clinical samples, but there is no published research on non-suicidal self-injury in individuals with autism spectrum disorder. This lack of research is surprising, since individuals with autism spectrum disorder have high rates of risk factors for non-suicidal self-injury, including depression and poor emotion regulation skills. Using an online survey, we examined non-suicidal self-injury methods, frequency, severity, functions, and initial motivations in adults with autism spectrum disorder ($n=42$). We also compared their non-suicidal self-injury characteristics to those of a gender-matched group of adults without autism spectrum disorder ($n=42$). Of the participants with autism spectrum disorder, 50% reported a history of non-suicidal self-injury. This proportion is higher than non-suicidal self-injury rates previously reported for college students, adult community samples, and adolescents with autism spectrum disorder, which suggests that adults with autism spectrum disorder have increased risk for engaging in non-suicidal self-injury. Women with autism spectrum disorder were significantly more likely to endorse non-suicidal self-injury, relative to men with autism spectrum disorder. A history of non-suicidal self-injury was not related to current depression or emotion dysregulation for the participants with autism spectrum disorder. Non-suicidal self-injury characteristics among the adults with autism spectrum disorder were similar to non-suicidal self-injury in adults without autism spectrum disorder. These preliminary findings highlight the need for increased awareness and further research about non-suicidal self-injury within autism spectrum disorder.

Keywords

adults, autism spectrum disorders, depression, emotion dysregulation, non-suicidal self-injury

Non-suicidal self-injury (NSSI) involves deliberate injury to body tissue that is inflicted without suicidal intent and for purposes that are not socially sanctioned (Nock and Favazza, 2009). NSSI is most prevalent during adolescence and young adulthood (Nock, 2010) and is present in both clinical and non-clinical populations (Klonsky, 2011; Rodham and Hawton, 2009). Lifetime prevalence of NSSI in the general population is estimated to fall between 5% and 17%, although published estimates are highly heterogeneous (Swannell et al., 2014). Recent studies have examined the characteristics and predictors of NSSI (e.g. Andover, 2014; Glenn and Klonsky, 2011; Nock, 2009), but there is no published research on NSSI in individuals with autism spectrum disorder (ASD). This is somewhat surprising given that many of the most salient predictors of NSSI, including depression and emotion dysregulation (e.g. Adrian et al., 2011; Wilcox et al., 2012), have been widely reported among people with ASD (e.g. Croen et al., 2015; Samson et al., 2014). The purpose of this study was to examine NSSI methods, frequency, severity, functions, and initial motivations in adults with ASD.

While methods of NSSI are diverse, the most commonly reported (in non-ASD samples) include cutting, carving, scratching, hitting, biting, burning, and skin picking (Klonsky, 2011; Nock and Prinstein, 2004). Research suggests that people often engage in NSSI for the purposes of regulating negative affect and reducing emotional distress (see Klonsky, 2007 for review). However, individuals who engage in NSSI tend to experience negative consequences such as anger, guilt, shame, and social isolation, along with physical harm (Favazza, 1998; Klonsky, 2009; Leibenluft et al., 1987). Furthermore, these individuals are at heightened risk for suicidal ideation and suicide attempts

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(Asarnow et al., 2011; Nock et al., 2006), highlighting the importance of identification and thorough understanding of this destructive behavior.

Although NSSI is a risk factor for suicidal behavior, NSSI and suicidal behavior are distinct concepts. By definition, both NSSI and suicide attempts involve intentional harm to oneself, but NSSI specifically excludes a core feature of suicidality, which is the intent to die. This article focuses exclusively on self-injurious behavior (SIB) that occurs in the absence of the intent to die.

There is a growing awareness and public health concern regarding NSSI given the high prevalence across populations and serious associated consequences. Historically, NSSI was included in the *Diagnostic and Statistical Manual (DSM)* only as a criterion of borderline personality disorder (American Psychiatric Association (APA), 2000). However, because NSSI behavior has been reported in non-clinical populations as well as across different psychiatric disorders (e.g. Andover, 2014; Glenn and Klonsky, 2013; Nock et al., 2006), NSSI disorder is included in the updated *Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013)* as a condition that requires further study.

Although there has been recent attention to increased rates of suicidal ideation and attempts in adults with ASD (e.g. Cassidy et al., 2014; Croen et al., 2015), no published reports on NSSI in this population could be found. Individuals with ASD are often explicitly excluded in research on NSSI (e.g. Dickstein et al., 2015; Kim et al., 2015), owing, in part, to prior research suggesting that self-injury in this population may serve a different function and represent a distinct entity from NSSI, often referred to as SIB (e.g. Duerden et al., 2012; Minshawi, 2008). SIB, classified as any type of action directed toward the self that results in physical injury (Fee and Matson, 1992), has been shown to be highly prevalent among children with ASD (see Minshawi et al., 2014 for review). These behaviors (e.g. self-hitting, biting) are often rhythmic and repetitive and are therefore typically conceptualized as a form of restricted, repetitive behavior (RRB; e.g. South et al., 2005). In fact, many taxonomies or measures of repetitive behaviors in ASD name SIB as a category or subscale (e.g. Lam and Aman, 2007; Turner, 1999). Given the focus on self-injury as RRB in individuals with ASD, NSSI in the context of ASD may be overlooked by both researchers and clinicians.

However, empirical evidence suggests that NSSI and SIB/RRB are distinct. SIB within ASD tends to be more common among people with severe or profound intellectual disability, lower adaptive behavioral functioning, and deficits in receptive and/or expressive communication, whereas these characteristics are not known risk factors for NSSI in people without ASD (e.g. Lecavalier, 2006; McClintock et al., 2003). Adults with ASD also tend to display less SIB than children with ASD (Esbensen et al.,

2009), compared to the opposite pattern for NSSI in people without ASD (Jacobson and Gould, 2007). Furthermore, in an unpublished study with 30 adolescents with ASD and anxiety, no discernable differences in parent- or clinician-rated severity of repetitive behaviors could be identified between youth who engaged in NSSI (20% of sample, as reported during clinical interviews with the adolescent and parent) and those who did not (Maddox and White, 2013). Although these preliminary findings suggest that NSSI is distinct from RRB, additional research with larger samples is needed to better understand the characteristics and correlates of NSSI in adolescents and adults with ASD. Studying NSSI in people with ASD is critical in order to minimize the associated negative consequences, which might be difficult to assess and prevent without a thorough understanding of how NSSI presents specifically in this population.

The primary objective of this descriptive study was to examine NSSI methods, frequency, severity, functions, and initial motivations in adults with ASD. Based on previous research with adolescents with ASD (Maddox and White, 2013) and adults without ASD (e.g. Whitlock et al., 2006), it was expected that at least 20% of adults with ASD would endorse a history of NSSI. Our secondary aim was to compare NSSI characteristics across adults with ASD and history of NSSI and adults without ASD but with history of NSSI. In addition, we explored the degree to which depression symptoms and emotion regulation difficulties are associated with NSSI in adults with ASD, given the common co-occurrence of these problems with ASD (e.g. Croen et al., 2015; Samson et al., 2014), as well as the links between depression and emotion dysregulation with heightened risk of NSSI in non-ASD samples (e.g. Adrian et al., 2011; Wilcox et al., 2012) and increased SIB in youth with ASD (e.g. Mazefsky and White, 2014; Samson et al., 2014). Due to the lack of literature about NSSI characteristics and correlates in adults with ASD, no specific hypotheses were proposed for these analyses.

Methods

Procedures

This study involved a two-group, cross-sectional survey, with one survey for adults in the community with ASD and one survey for university students without ASD. A gender-matched subsample of participants who endorsed NSSI was drawn from our university-based survey in order to compare individuals with and without ASD on NSSI characteristics. Study procedures were approved by the institutional review board for human subject research. All study measures were completed as part of an anonymous online survey, which took approximately 45 min in entirety. The study was described as an anonymous online survey about self-care and self-harm behaviors. Adults with ASD were

recruited through the university's Center for Autism Research and its research registry database, the university's office for Services for Students with Disabilities, a university-affiliated Autism Clinic and its research registry database, adult ASD support groups, and research, outreach, and advocacy groups that work with adults with ASD. Their survey responses were collected during a 6-month period. In an effort to enroll a sufficient number of adults with ASD, a US\$10 electronic gift card was offered as incentive for participation.

Adults without ASD were recruited through an online study management site, departmental email distribution lists, and posted flyers at a large public university in the Southeastern United States. Data from these university students were collected during a 4-month period. As compensation for their time, participants earned extra credit in their psychology course (if applicable) or entry into a raffle for a chance to win one of four US\$20 cash prizes.

All participants accessed the survey through a secure web link. Participants indicated consent prior to beginning the survey by typing their email address at the bottom of a secure website that provided participants with information about the study, including risks and benefits. Participants were then directed to a separate, secure website where they completed all study measures so that responses were not linked to any identifying information. At the end of the online survey, participants were provided with a list of local counseling resources.

Participants

To be eligible for the study, participants had to be aged 18 years or older. Participants in the ASD group also had to have a formal ASD diagnosis (i.e. diagnosis received from an evaluation with a written report) and indicate their age at the time of diagnosis. Survey respondents who endorsed practicing or attempting suicide as their primary reason for self-injury were excluded from analyses, given this study's focus on NSSI. A total of 53 participants began the online survey for adults with ASD. Five participants reported that they had not received a formal diagnosis of ASD and were therefore directed to a disqualification page. One participant indicated that practicing or attempting suicide was the primary reason behind NSSI, and four participants did not complete the study measures. We excluded one participant for invalid data based on answering at least one reading validity item incorrectly (e.g. when presented with the item, "For this item, please choose 3," a response option other than 3 was provided). Therefore, the final sample included 42 adults with ASD.

A total of 1252 students completed the university-based survey, with 257 (20.53%) endorsing NSSI. In light of our aim to compare characteristics associated with NSSI across adults with and without ASD, a list of comparison group survey respondents endorsing NSSI, matched to

each of the participants with ASD and NSSI on gender, was generated. A random number generator was then used to select two comparison group participants for each participant with ASD and NSSI, which resulted in a total of 42 comparison group participants (41 undergraduate students and 1 graduate student). Demographic information for all participants is provided in Table 1.

Measures

Non-Suicidal Self-Injury Assessment Tool. The Non-Suicidal Self-Injury Assessment Tool (NSSI-AT) was developed as a web-based tool for measuring NSSI in non-clinical populations for research purposes (Whitlock et al., 2014). The tool comprises modules to assess various aspects of NSSI, such as method, severity, recency, frequency, and wound location. It also includes a series of questions about NSSI functions, or reasons why respondents intentionally hurt themselves, which are rated from 1 ("strongly disagree") to 4 ("strongly agree"). These functions comprise five factors: Affective Imbalance-Low Pressure (i.e. regulation of depression or dissociated emotions), Affective Imbalance-High Pressure (i.e. regulation of agitation or high-energy affective states), Social Communication and Expression (i.e. related to social reasons), Self-Retribution and Deterrence (i.e. self-punishment or an alternative to more severe behaviors), and Sensation Seeking (i.e. related to sensory pleasure or excitement). Using college student samples (from eight different public and private universities), the NSSI-AT has been shown to have adequate psychometric properties; scores were moderately correlated with measures of related problem behaviors, test-retest stability for any NSSI behavior reported was 0.74, and test-retest stability for NSSI functions was 0.79 (Whitlock et al., 2014). Modules A (self-injury forms) through G (severity) of the NSSI-AT were included in this study. Participants from both groups completed this measure. Derived internal consistency estimates (alpha) were acceptable for four of the five function factors (Affective Imbalance-Low Pressure=0.763 for full sample, 0.707 for ASD group, and 0.826 for control group; Affective Imbalance-High Pressure=0.806 for full sample, 0.752 for ASD group, and 0.847 for control group; Social Communication and Expression=0.446 for full sample, 0.305 for ASD group, and 0.524 for control group; Self-Retribution and Deterrence=0.749 for full sample, 0.804 for ASD group, and 0.709 for control group; Sensation Seeking=0.764 for full sample, 0.727 for ASD group, and 0.785 for control group).

Severity Measure for Depression-Adult. This Depression measure is one measure comprising a battery developed by the American Psychiatric Association (APA, 2013) to promote consistency in clinical research. It was modeled after the Patient Health Questionnaire-9 (PHQ-9; Spitzer

Table 1. Demographic information.

	ASD w/NSSI (n=21), mean (SD); range	ASD only (n=21), mean (SD); range	Control (n=42), mean (SD); range
Age (in years) ^{***}	25.29 (7.77); 18–47 n (% of group)	29.19 (10.87); 18–56 n (% of group)	19.90 (1.43); 18–24 n (% of group)
Gender			
Men*	8 (38.10)	16 (76.19)	16 (38.10)
Race			
Asian/Asian-American	0 (0.00)	1 (4.76)	5 (11.90)
Black/African-American	1 (4.76)	1 (4.76)	1 (2.38)
Caucasian	19 (90.48)	17 (80.95)	34 (80.95)
Hispanic/Latino(a)	0 (0.00)	0 (0.00)	2 (4.76)
Bi-/multi-racial	1 (4.76)	1 (4.76)	0 (0.00)
Age of first formal ASD diagnosis (years)			
Before 12	7 (33.33)	8 (38.10)	N/A
Between 12 and 14	2 (9.52)	0 (0.00)	N/A
Between 15 and 18	2 (9.52)	2 (9.52)	N/A
After 18	10 (47.62)	11 (52.38)	N/A
Highest level of education			
High school degree	7 (33.33)	5 (23.81)	–
Some college	6 (28.57)	6 (28.57)	–
College degree	4 (19.05)	8 (38.10)	–
Master's degree	4 (19.05)	1 (4.76)	–
Doctoral degree	0 (0.00)	1 (4.76)	–
Employment status			
Unemployed	13 (61.90)	9 (42.86)	25 (59.52)
Employed	8 (38.10)	12 (57.14)	17 (40.48)
Residential status			
On-campus residence ^{**}	1 (4.76)	2 (9.52)	18 (42.86)
Non-university housing [*]	5 (23.81)	8 (38.10)	23 (54.76)
Parent's/guardian's house ^{***}	15 (71.43)	11 (52.38)	0 (0.00)
Fraternity/sorority house	0 (0.00)	0 (0.00)	1 (2.38)

ASD w/NSSI: participants with ASD who endorsed a history of NSSI; ASD only: participants with ASD who did not report a history of NSSI; ASD: autism spectrum disorder; NSSI: non-suicidal self-injury; SD: standard deviation.

Both ASD groups are significantly different from the control group on age, on-campus residence status, and parent's/guardian's house status. The ASD-only group significantly differs from the ASD + NSSI and control groups on gender. The ASD + NSSI group significantly differs from the control group on non-university housing status. One participant with ASD chose not to provide information about race/ethnicity. Survey response options for age of first formal ASD diagnosis correspond approximately to elementary school or earlier (before age 12 years), middle school (between age 12 and 14 years), high school (between age 15 and 18 years), and post high school (after age 18 years). Of the participants with ASD, 9 (21.43%) were currently college students and 3 (7.14%) were graduate students at the time of the study. Participants in the control group did not explicitly report on highest level of education obtained; however, 41 (97.62%) of these participants were currently college students and 1 (2.38%) was a graduate student at the time of the study. Employment was defined as working for income, either part-time or full-time. Of the 20 participants with ASD not currently employed, 50% endorsed receiving disability benefits.

Significant between-group differences are indicated: * $p < 0.05$; ** $p < 0.01$; and *** $p < 0.001$.

et al., 1999) and is in the public domain. The scale's nine items are rated on a 4-point scale, from "not at all" to "nearly every day." Total scores range from 0 to 27, with higher scores indicating greater severity of depressive symptoms. All participants completed this measure. In the present sample, internal consistency was high ($\alpha = 0.889$ for full sample, 0.906 for ASD group, and 0.834 for control group).

Difficulties in Emotion Regulation Scale. A 36-item scale that measures a person's typical emotion dysregulation, the Difficulties in Emotion Regulation Scale (DERS) has been

used in college samples, clinical samples, and in treatment outcome research (Gratz and Roemer, 2004). The measure yields six domain scores (nonacceptance of negative emotion, inability to engage in goal-directed behavior, difficulty controlling impulsive behavior, limited access to appropriate regulatory strategies, lack of emotional awareness, and lack of emotional clarity) and a total score. Each item is scored from 1 ("almost never") to 5 ("almost always"), with higher scores reflecting more dysregulation or more impairment. Only participants in the ASD group completed the DERS, with the total score used in this study. Consistent with previous research (Gratz and

Roemer, 2004), derived internal consistency for this sample was high ($\alpha=0.953$).

Data analyses

Data were analyzed with IBM SPSS Statistics Version 21. All variables were assessed for normality and outliers. Descriptive statistics were computed for all demographic variables to characterize the sample. To examine NSSI characteristics in adults with ASD, we calculated descriptive statistics for the NSSI-AT questions. For the NSSI-AT functions, the Likert ratings were used to calculate total scale scores. In replication of the NSSI-AT developers' method (Whitlock et al., 2014), scores of 1 ("strongly disagree") and 2 ("somewhat disagree") were collapsed to indicate denial of a certain function, while scores of 4 ("strongly agree") and 3 ("somewhat agree") were collapsed to indicate endorsement of a certain function. This was done for both groups, in order to compare adults with and without ASD on key NSSI characteristics. For continuous variables, independent samples *t*-tests were conducted. For categorical variables, Pearson's chi-square tests were used when expected cell counts were five or greater, and Fisher's exact tests were used when expected cell counts were less than five. Alpha was set conservatively for between-group analyses, at 0.01, to protect against Type I error with multiple comparisons. We also explored the degree to which depression symptoms and emotion regulation difficulties are associated with NSSI in adults with ASD by computing point-biserial correlations between a history of NSSI (0=no, 1=yes) and total scores on the Depression measure and DERS. Finally, within the subset of adults with ASD who endorsed a history of NSSI, we calculated bivariate correlations between total scores on the NSSI-AT functions' scales, Depression measure, and DERS.

Results

In the ASD sample, 21 participants (50%) reported engaging in NSSI behavior. Although the participants with ASD who endorsed a history of NSSI did not differ in age from those who denied a history of NSSI ($t(40)=1.34, p=0.188, d=0.33$), the two groups did differ significantly in gender, $\chi^2(1)=6.22, p=0.013, \phi=0.38$. Of the 18 women with ASD, 13 (72.2%) reported NSSI, compared to only 8 of the 24 men with ASD (33.3%). Participants who received their initial ASD diagnosis after age 18 ($n=21$) did not differ from participants with a childhood ASD diagnosis ($n=21$) on history of NSSI, $\chi^2(1)=0.10, p=0.758, \phi=0.05$. In addition, these two groups did not differ in their Depression measure ($t(40)=1.41, p=0.167, d=0.43$) or DERS ($t(40)=1.04, p=0.306, d=0.32$) scores.

Descriptive data on participants' responses on the NSSI-AT are presented in Table 2. Pearson's chi-square

tests and Fisher's exact tests revealed no statistically significant differences between the ASD and non-ASD groups on any of the NSSI-AT items, with the exception of one NSSI functions item (described below). The mean age of initiating NSSI behaviors for adults with ASD was 12.70 years (standard deviation (*SD*)=5.51 years), which did not differ from that of adults without ASD ($M=13.19, SD=4.57, t(61)=0.37, p=0.713, d=0.10$).

In terms of NSSI functions, there were no significant between-group differences ($ps=0.291-0.938$) on the Affective Imbalance-Low Pressure ($d=0.02$), Affective Imbalance-High Pressure ($d=0.23$), Self-Retribution and Deterrence ($d=0.27$), or Sensation Seeking ($d=0.07$) scales. Although a moderate effect size ($d=0.46$) was found for the between-group difference on the Social Communication and Expression scale, this difference was not statistically significant, $t(61)=1.78, p=0.08$. Examination of this scale reveals that at least twice the rate of participants with ASD engaged in NSSI to either shock or hurt someone (23.8%) or because their friends hurt themselves (9.5%), compared to participants without ASD (7.1% and 4.8%, respectively). A significant between-group difference, at the item-level, was found for the NSSI function of *to avoid committing suicide* (Fisher's exact $p=0.009$). This function was endorsed by 42.9% of the adults with ASD, and just 11.9% of adults without ASD.

Within the ASD group, point-biserial correlations revealed that a history of NSSI was not significantly related to current depression ($r=-0.013, p=0.936$) or emotion dysregulation ($r=0.054, p=0.734$). Indeed, the mean Depression measure and DERS scores were almost identical between the adults with ASD who endorsed NSSI (Depression: $M=9.38, SD=7.87$; DERS: $M=103.67, SD=28.70$) and those who did not endorse NSSI (Depression: $M=9.57, SD=7.41$; DERS: $M=100.62, SD=29.10$). Within the subset of individuals with ASD who endorsed a history of NSSI, more difficulty with emotion regulation was significantly related to Sensation Seeking functions of NSSI ($r=0.512, p=0.018$), as shown in Table 3. Positive relationships between depression and emotion dysregulation with Affective Imbalance-Low Pressure functions also approached significance ($r=0.420, p=0.058$ and $r=0.418, p=0.059$, respectively).

Discussion

This descriptive study is one of the first investigations of NSSI in adults with ASD. Using an innovative web-based measure (Whitlock et al., 2014), we collected information about a wide range of NSSI characteristics, including methods, frequency, severity, functions, and initial motivations, from a non-treatment-seeking sample. Consistent with our hypothesis that at least 20% of adults with ASD would endorse a history of NSSI, 50% of the current participants reported engaging in at least one episode of NSSI.

Table 2. NSSI-AT descriptive information for adults with ASD and a history of NSSI ($n=21$) and controls with a history of NSSI ($n=42$).

	% Yes (n)	
	ASD	Control
NSSI forms		
Severely scratched or pinched with fingernails or other objects to the point that bleeding occurs or marks remain on the skin	71.4 (15)	59.5 (25)
Cut wrists, arms, legs, torso, or other areas of the body	33.3 (7)	38.1 (16)
Ripped or torn skin	33.3 (7)	14.3 (6)
Bitten yourself to the point that bleeding occurs or marks remain on the skin	33.3 (7)	21.4 (9)
Banged or punched objects to the point of bruising or bleeding	28.6 (6)	31.0 (13)
Punched or banged yourself to the point of bruising or bleeding	23.8 (5)	19.0 (8)
Intentionally prevented wounds from healing	23.8 (5)	7.1 (3)
Pulled out hair, eyelashes, or eyebrows (with the intention of hurting yourself)	23.8 (5)	11.9 (5)
Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin (not including tattooing, body piercing, or needles used for medication use)	19.0 (4)	2.4 (1)
Carved words or symbols into the skin	9.5 (2)	7.1 (3)
Burned wrists, hands, arms, legs, torso, or other areas of the body	4.8 (1)	7.1 (3)
Engaged in fighting or other aggressive activities with the intention of getting hurt	4.8 (1)	2.4 (1)
Tried to break your own bones	0 (0)	2.4 (1)
Functions (I hurt myself ...)		
Affective Imbalance-Low Pressure scale	Scale $M=2.20$ $SD=0.73$	Scale $M=2.18$ $SD=0.92$
... to cope with uncomfortable feelings (e.g. depression or anxiety)	61.9 (13)	61.9 (26)
... to change my emotional pain into something physical	61.9 (13)	50.0 (21)
... to feel something	38.1 (8)	45.2 (19)
... to get control over myself or my life	28.6 (6)	28.6 (12)
Affective Imbalance-High Pressure scale	Scale $M=2.64$ $SD=0.98$	Scale $M=2.43$ $SD=0.88$
... to relieve stress or pressure	71.4 (15)	54.8 (23)
... to deal with frustration	61.9 (13)	59.5 (25)
... to deal with anger	61.9 (13)	59.5 (25)
Social Communication and Expression scale	Scale $M=1.65$ $SD=0.64$	Scale $M=1.38$ $SD=0.53$
... in hopes that someone would notice that something is wrong or that so others will pay attention to me	33.3 (7)	31.0 (13)
... to shock or hurt someone	23.8 (5)	7.1 (3)
... because my friends hurt themselves	9.5 (2)	4.8 (2)
Self-Retribution and Deterrence scale	Scale $M=1.90$ $SD=0.88$	Scale $M=1.68$ $SD=0.72$
... as a self-punishment or to atone for sins	42.9 (9)	33.3 (14)
... to avoid committing suicide	42.9 (9)	11.9 (5)
... because of my self-hatred	38.1 (8)	35.7 (15)
... so I do not hurt myself in other ways	19.0 (4)	19.0 (8)
Sensation Seeking scale	Scale $M=1.71$ $SD=0.69$	Scale $M=1.66$ $SD=0.74$
... because I get the urge and cannot stop it	52.4 (11)	35.7 (15)
... because it feels good	28.6 (6)	23.8 (10)
... to get a rush or surge of energy	28.6 (6)	19.0 (8)
... because I like the way it looks	4.8 (1)	16.7 (7)
Initial motivations		
I was upset and decided to try it	38.1 (8)	42.9 (18)
I was angry with myself	38.1 (8)	45.2 (19)
I was angry at someone else	19.0 (4)	23.8 (10)
I cannot remember	19.0 (4)	11.9 (5)

(continued)

Table 2. (Continued)

	% Yes (n)	
	ASD	Control
I wanted someone to notice me and/or my injuries	14.3 (3)	21.4 (9)
I wanted to shock or hurt someone	14.3 (3)	7.1 (3)
It felt good	9.5 (2)	21.4 (9)
I saw it in a movie/on TV or read about it in a book and decided to try it	9.5 (2)	14.3 (6)
It seemed to work for other people I know	4.8 (1)	2.4 (1)
A friend suggested that I try it	4.8 (1)	0 (0)
I felt bored	4.8 (1)	0 (0)
I was drunk or high	0 (0)	9.5 (4)
It seemed to work for celebrities I have heard of	0 (0)	2.4 (1)
Frequency		
Only once	4.8 (1)	19.0 (8)
2–3 times	23.8 (5)	14.3 (6)
4–5 times	9.5 (2)	26.2 (11)
6–10 times	19.0 (4)	4.8 (2)
11–20 times	4.8 (1)	7.1 (3)
21–50 times	14.3 (3)	9.5 (4)
More than 50 times	23.8 (5)	19.0 (8)
Recency		
Less than 1 week ago	9.5 (2)	14.3 (6)
Between 1 week and 1 month ago	9.5 (2)	7.1 (3)
Between 1 and 3 months ago	14.3 (3)	16.7 (7)
Between 3 and 6 months ago	0 (0)	0 (0)
Between 6 months and 1 year ago	33.3 (7)	16.7 (7)
Between 1 and 2 years ago	4.8 (1)	11.9 (5)
More than 2 years ago	28.6 (6)	33.3 (14)
Wound locations		
Arms	57.1 (12)	40.5 (17)
Hands	47.6 (10)	42.9 (18)
Thighs	42.9 (9)	35.7 (15)
Fingers	38.1 (8)	23.8 (10)
Face	38.1 (8)	11.9 (5)
Wrists	33.3 (7)	35.7 (15)
Stomach or chest	33.3 (7)	14.3 (6)
Head	28.6 (6)	14.3 (6)
Calves or ankles	19.0 (4)	4.8 (2)
Shoulders or neck	19.0 (4)	0 (0)
Lips or tongue	14.3 (3)	11.9 (5)
Legs	9.5 (2)	9.5 (4)
Back	9.5 (2)	0 (0)
Genitals or rectum	9.5 (2)	2.4 (1)
Feet	4.8 (1)	4.8 (2)
Buttocks	4.8 (1)	0 (0)
Severity		
Ever hurt self more severely than expected	42.9 (9)	21.4 (9)
Ever hurt self so badly should have been seen by medical professional	23.8 (5)	7.1 (3)
Ever sought medical treatment for any physical NSSI injuries	19.0 (4)	7.1 (3)

ASD: autism spectrum disorder; NSSI: non-suicidal self-injury; SD: standard deviation; NSSI-AT: Non-Suicidal Self-Injury Assessment Tool.

Only one significant between-group difference was found for the NSSI-AT items: the function of *to avoid committing suicide* (Fisher's exact $p=0.009$).

This proportion is higher than NSSI rates previously reported for college students (e.g. 17%; Whitlock et al., 2006), adult community samples (e.g. 23%; Andover,

2014), and adolescents with ASD (20%; Maddox and White, 2013), which suggests that adults with ASD have increased risk for engaging in NSSI during their lifetimes.

Table 3. Bivariate correlations for adults with ASD and NSSI ($n = 21$).

	DERS	Dep.	Affect low	Affect hi	Soc-comm	Self-deter
Dep.	0.722***					
Affect low	0.418*	0.420*				
Affect hi	0.084	0.058	0.617***			
Soc-comm	0.095	0.081	0.304	0.138		
Self-deter	0.205	0.322	0.853***	0.454**	0.318	
Sensation-seek	0.512**	0.366	0.525**	0.175	0.198	0.386*

ASD: autism spectrum disorder; DERS: Difficulties in Emotion Regulation Scale; Dep.: Severity Measure for Depression-Adult; Affect low: Affective Imbalance-Low Pressure functions' scale of NSSI-AT; Affect hi: Affective Imbalance-High Pressure functions' scale of NSSI-AT; Soc-comm: Social Communication and Expression functions' scale of NSSI-AT; Self-deter: Self-Retribution and Deterrence functions' scale of NSSI-AT; Sensation-seek: Sensation Seeking functions' scale of NSSI-AT; NSSI-AT: Non-Suicidal Self-Injury Assessment Tool.

* $p < 0.10$; ** $p < 0.05$; and *** $p < 0.01$.

Epidemiological research with larger samples is needed to precisely determine the prevalence of NSSI among adults with ASD.

NSSI, with respect to age of onset, form, and function, among the adults with ASD was similar to NSSI in adults without ASD, and the patterns reported in our sample are consistent with other studies using the NSSI-AT (e.g. Whitlock et al., 2014). This study's preliminary findings suggest that NSSI is (1) similar to NSSI as it is conceptualized in the non-ASD literature, (2) a common problem among adults with ASD, and (3) overlooked in the extant research, and likely overshadowed or misconstrued (e.g. as SIB, or core ASD symptoms) in clinical practice. Our results underscore the need for increased awareness about NSSI within ASD.

In our sample with ASD, women were more likely than men to endorse a history of NSSI. Almost 75% of the women with ASD reported a history of NSSI, compared to only 33% of the men with ASD. Many non-ASD studies have found NSSI to be more common in females, although this gender difference has not been consistently found (e.g. Jacobson and Gould, 2007; Klonsky, 2011; Whitlock et al., 2011). In addition, recent studies have revealed that almost twice as many women with ASD have attempted suicide (2.72%), compared to men with ASD (1.45%; Croen et al., 2015), and women with ASD are more likely than men on the spectrum to commit suicide (Hirvikoski et al., 2016). The greater proportion of women endorsing NSSI in our sample further supports the distinction between NSSI and SIB/RRB, given previous research showing no gender differences in SIB, specifically (e.g. Baghdadli et al., 2003; Solomon et al., 2012), and evidence that males with ASD show more RRB symptoms than females with ASD (e.g. Hartley and Sikora, 2009; Mandy et al., 2012). In the context of a growing body of research about the female phenotype of ASD (e.g. Mandy et al., 2012; Solomon et al., 2012), it is possible that the gender difference in NSSI prevalence is associated with unique challenges that females with ASD face as they transition into adulthood (Halladay et al., 2015).

The lack of a relationship between NSSI and depression symptoms or emotion regulation difficulties in the ASD group is inconsistent with the general NSSI literature (Gratz and Roemer, 2008; Wilcox et al., 2012). Although this finding could relate to ASD-specific pathways to NSSI, it is more likely explained by the reporting timeframes of our variables. *Current* depression symptoms and emotion regulation difficulties were assessed, whereas participants reported any *history* of NSSI. Although we were interested in examining the history of NSSI in adults with ASD, the limited number of participants reporting recent NSSI complicates the interpretation of associations with current depression symptoms and emotion regulation difficulties. Only 33% of the adults with ASD endorsing NSSI reported engaging in NSSI in the past 3 months. Another 33% of the participants reported no NSSI in the past year, and 28.6% were at least 2 years free of NSSI. Perhaps these individuals were more depressed or more emotionally dysregulated during their previous episodes of NSSI, but those differences are not apparent currently. Unfortunately, our sample size is too small to only examine the participants who engaged in NSSI within the past 3 months ($n = 7$).

Limitations

It is important to note that our small sample size likely limited our ability to find statistically significant differences between the ASD and control groups. For example, a moderate effect size was found for the between-group difference on the Social Communication and Expression functions' scale, with more participants with ASD endorsing these functions compared to participants without ASD. Of the five factors related to NSSI functions, the Social Communication and Expression scale is the only one that includes social reasons (e.g. to shock or hurt someone; because their friends hurt themselves). It is possible that adults with ASD, given their core social impairment, endorse these socially related functions more often. However, it is also important to note that the Social Communication and Expression scale showed low internal

consistency in this sample, and future research is needed to examine the NSSI-AT factor structure and overall validity in people with ASD. Of note, the Social Communication and Expression scale had the lowest internal consistency estimate ($\alpha=0.38$) of the five NSSI-AT functions' scales in Whitlock et al.'s (2014) development and initial validation article. Since the NSSI-AT was developed to measure NSSI in non-clinical populations, it may lack items that capture possibly unique features and clinical correlates of NSSI specific to ASD. Methodologically, although use of an online, anonymous survey likely enhanced participation, it prohibited us from confirming ASD diagnosis clinically. It is also important to consider the representativeness of the ASD group, given that 50% of these participants reported that their first formal ASD diagnosis occurred after age 18 years, almost 50% reported part- or full-time employment, and almost 30% were current university students at the time of the study. Based on this information, along with the fact that all participants were computer literate and able to complete the online survey, it is clear that our ASD sample represents a high-functioning group of individuals, which likely limits the generalizability of our findings. Furthermore, this study was cross-sectional in design, limiting our ability to make inferences about directionality. It is possible that the description of the study in recruitment materials (i.e. an anonymous online survey about self-care and self-harm behaviors) led to people with a history of NSSI being more motivated to participate. Finally, we were unable to match participants with and without ASD on age because the control group mostly comprised college students, whereas the ASD group had no upper age limit.

Future directions

Larger scale studies are needed to further investigate the prevalence and characteristics of NSSI in adults with ASD, and longitudinal studies with well-characterized samples will be important to examine the potential pathways to NSSI and the associated consequences. Such research should include in-laboratory measures of NSSI, validated for use in samples with ASD, in order to further disentangle NSSI from RRB and explore whether people with ASD display unique features and clinical correlates of NSSI. Clinical research is also needed to understand how to effectively prevent and treat NSSI in people with ASD. Although our results suggest that NSSI in the context of ASD is similar to NSSI in the general population, consideration of core social difficulties may need to be considered in the context of treatment or prevention.

Conclusion

In conclusion, this study represents a preliminary investigation of the experience of NSSI among adults with ASD.

NSSI is a serious problem that elevates risk for suicide attempts (Asarnow et al., 2011; Nock et al., 2006). Although NSSI may affect as many as one in two adults with ASD, it is poorly understood and under-appreciated clinically. Further research is needed to replicate and extend these findings, in order to inform clinicians working with this population.

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