



Women on the Autism Spectrum and Self-Injury

A Low Arousal Framework to Support Coping

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Abstract

Self-injury (SI) is a relatively common mental health concern. Despite the high prevalence of SI in the autistic community, this particular form of distressed behaviour appears to be widely misunderstood by services, especially if presented by women. In this article, the author aims to describe the Studio 3 approach to assessment of and intervention in SI, drawing from the professional experience of supporting women on the spectrum and the application of the Low Arousal Approach.

Introduction

Self-injury (SI) is a form of behaviour of concern presented by people who have difficulties coping with distress (Taylor et al., 2018). The behaviour is sometimes characterised as an intentional attempt to cause harm to oneself to reduce emotional distress and dysregulation (Klonsky, Victor & Saffer, 2014). SI may take many forms, often as non-suicidal self-injury, such as cutting, scratching, burning, hitting and headbanging. An individual may engage in several forms of SI.

Studies show that the prevalence of self-injury in the autistic community is high, and that it is a relatively common mental health concern (Maddox, Trubanova & White, 2017; Moseley et al., 2019; Licence et al., 2020), with some studies reporting up to 50% of autistic adults having a history of SI (Maddox, Trubanova & White, 2017). SI displayed by the autistic population may be repetitive and stereotypic in nature (Licence et al., 2020). A person displaying SI may not be in control or even aware of engaging in such behaviour.

Literature highlights several factors associated with an increased risk for self-injury, such as differences in communication (Chiang, 2008) and intellectual disability (Richards et al., 2012). Additionally, co-morbid mental health difficulties, such as depression and anxiety, have been found to increase the risk of SI (Cassidy et al., 2014).

Some studies have found that a later diagnosis of autism can be associated with suicidal ideation (Cassidy et al., 2014), although to date relatively little is understood about these mechanisms. Gender may also be linked to a higher incidence

of SI. Maddox and colleagues (2017) found higher rates of SI for women. While other studies have not replicated these results (Licence et al., 2019; Moseley et al., 2019), in our clinical experience at Studio 3, we have noted an increased number of referrals regarding women who present with SI. Many of these individuals have received a late diagnosis or are undergoing a diagnostic assessment for autism via Studio 3. We have observed a pattern of autistic women with significant difficulties frequently attracting multiple diagnoses.

This may be due to the fact that women tend to be diagnosed significantly later than males (Benevides et al., 2020). Oftentimes, other diagnostic labels are explored to explain the difficulties these women experience. Late and inaccurate diagnoses may delay access to autism-informed support and services. Consequently, autistic women are at higher risk of poorer mental health, trauma, and distress. There is an emerging understanding amongst practitioners that women tend to be labelled not with autism as a primary diagnosis, but other conditions such as emotionally unstable personality disorder (EUPD) and ADHD. In addition, particular behaviours may overshadow and mask autistic features. Most notably, there are consistent studies which show a strong association between eating disorders and undiagnosed autism.

Despite self-injury being a significant difficulty, autistic individuals report that services struggle to support these individuals (Camm-Crosbie et al., 2019). SI in autism is an under-researched and poorly understood area of need (Cassidy & Rodgers, 2017). Furthermore, it has been highlighted that the experiences of autistic women need closer attention (Taylor & DaWalt, 2020). In this article, the author discusses their experiences of assessing and supporting autistic women who self-injure. The information presented reflects the author's views based on their professional experience and practical application of the Low Arousal Approach (McDonnell, 2010).

Assessment

Like any other distressed behaviour, self-injury is multifaceted in nature (Duffy, 2009). Consequently, a comprehensive assessment is needed to establish the functions and maintenance factors of the behaviour. Traditional functional

assessments of SI and other behaviours of concern tend to focus on reinforcement theories. These assume SI is maintained by gaining a reward or removing an unpleasant stimulus based on exhibited behaviour (Iwata et al., 1994). However, it is commonly agreed that whilst one reinforcer may be implicated in the onset of SI, maintenance of SI may be influenced by different and multiple factors.

Analysing antecedents, behaviours, and consequences tends to help gain an understanding of triggers and reinforcements influencing occurrences of SI. However, in the author's opinion, these assessments provide a superficial understanding of incidences of SI. As Low Arousal Practitioners, we tend to look 'beyond the behaviour' and focus on examining the relationship between occurrences of SI, heightened stress, and coping abilities (McDonnell et al., 2015). Stress and trauma are associated with self-injury. Understanding these mechanisms is essential to developing empathic and appropriate responses.

Stress

Stress is a natural response which informs us of the dangers in the environment and regulates alertness levels throughout the day. Stress is ever-present, and most people have developed a way of managing it. According to the transactional model of stress and coping (Lazarus & Folkman, 1984), difficulties coping with stress present when the stressor exceeds personal resources. This could be influenced by the interactions between an individual and their environment (Lazarus & Folkman, 1984, p. 19):

“Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing.”

Research has shown that autistic people generally have higher stress levels than neurotypical people. Autistic people often show elevated levels of the stress hormone cortisol in their nervous system, which is associated with higher levels of stress (Nason, 2014; Lopata et al., 2008). Additionally, when we consider the different experiences of autistic women, for example 'masking' (Hull, Petrides & Mandy 2020), we can better understand the stressful nature of the world around them. Social,

sensory, interoceptive, and communication differences can make any environment overwhelming and stressful.

When social and environmental demands exceed an individual's ability to cope, their stress can sometimes manifest itself in distressed behaviours which can be challenging for supporters. In these instances, behaviours of concern can be viewed as 'maladaptive coping strategies.' From the perspective of the diathesis-stress model, we can understand how lived experiences as an autistic individual and stressors in the environment can intersect with pre-existing vulnerabilities (Broerman, 2020).

Stress is, therefore, an essential factor to consider. We should closely observe any signs which suggest that an individual's coping ability is impacted. SI, as previously mentioned, is a coping strategy, and although 'maladaptive' may be the only effective strategy the person has to regulate their distress. Consequently, an assessment should thoroughly examine potential stressors the person may experience, including:

- Environmental factors - Is the environment meeting the person's needs; for example, from a sensory and information-processing perspective?
- Personal factors - Are the needs of this person being met? Consider their emotional, social, psychological, and physical well-being.
- Interpersonal and systemic factors - Are the support systems around the person managing or experiencing stress and dysregulation themselves? This is incredibly important, as SIB tends to be emotionally challenging to witness.

Trauma

Trauma is another significant factor to consider when assessing self-injury. Research involving the autistic community has shown higher rates of PTSD symptoms than the neurotypical population (Rumball, Happé & Grey, 2020; Rumball et al., 2021; Haruvi-Lamdan et al., 2020). These figures are not surprising considering the stressful nature of navigating the 'neurotypical world' and other vulnerabilities associated with autism (Rumball, Happé & Grey, 2020; Kerns et al., 2022). The autistic population is

at higher risk of experiencing traumatic life events such as bullying and physical, emotional, and sexual abuse (Reuben, Stanzione & Singleton, 2021).

We also meet women who may have been ‘traumatised by the system’ through a lack of autism-informed support. Such approaches may include frequent use of restrictive practices; for example, restraint and seclusion. Some of the individuals we support have difficulties coping and engaging with the services offered, partially due to a misunderstanding of their needs and how their autism manifests. Inevitably, this contributes to re-traumatising these women.

Self-injury may be an attempt to manage trauma and cope with trauma triggers, thus it is essential to consider individuals’ history and any traumatic events they may have experienced. This may help to create an understanding of SI, particularly if the behaviour is present or intensifies around specific triggering events. Consider:

- Has the person experienced any traumatic experiences in early childhood (see Adverse Childhood Experiences (ACE’s) (Felliti et al., 1998)?
- Has the person been subject to physical, emotional or sexual abuse?
- Have restrictive practices such as restraint, segregation, or seclusion been used to manage the person’s behaviour?
- Are there any environmental factors that may trigger trauma? Consider sensory stimuli such as smells, noises, or sight of staff congregating in one area (may trigger memories of physical restraint/abuse).
- Is the person grieving and struggling with bereavement or another form of loss?

Body Sensation/Interoception

It is not uncommon for people who self-harm to report that they often feel ‘numb.’ This is particularly true of individuals who routinely cut. Understanding our own body sensations, from our heart rate to sensations of pain, is critical to answering why some people use self-injury to block out or create bodily sensations. The ability to be aware of our own body sensations is known as interoception (Mahler, 2016 a). Interoception is a sense responsible for signalling internal needs such as hunger, thirst and

emotions, including stress (Craig, 2002). The ability to interpret internal cues has significant implications for homeostatic processes and emotional regulation (Craig, 2015). Interoception is considered the first step to recognising an arising need. Thus, interoception has received increased attention in recent research on emotional regulation, trauma, and developmental disabilities. Studio 3 practitioners routinely work with individuals who confuse emotional and physical pain. It is interesting to note that the emotional and physical pain pathways in the brain do appear to be intertwined and interlinked.

Given the sensory differences experienced by the autistic community, interoceptive awareness may vary considerably. For many individuals, this system can be either hyper or hyposensitive (Mahler, 2016a). In practice, this means that one may not feel the urge to act on a need, or may feel these cues at an intensified level. An insight into how one experiences and makes sense of their 'internal world' may significantly shape our understanding of self-injury's manifestation and stress regulation, for instance:

- Is the person able to recognise signs of building stress and emotions?
- Is the person able to communicate this and look for support?
- Is the person easily overwhelmed by their sensory experiences?
- Can they recognise building stressors and know what to do when overwhelmed?

The Comprehensive Assessment of Interoceptive Awareness by Mahler (2016b) is a helpful tool for assessing interoceptive needs.

Case Study - Assessment

Julia¹ is in her mid-thirties. She was diagnosed as autistic at the age of 25. Since she experienced a significant bereavement, she has been hospitalised multiple times due to self-injury (cutting) and suicidal thoughts. During her time at hospital, she was assessed for a personality disorder and referred for Dialectical Behaviour Therapy (DBT). Upon discharge, she was referred to a community mental health team and had weekly meetings with a care coordinator. Julia was also provided with emergency

¹ Name and personal details have been changed to protect confidentiality

helplines for support in times of crisis. Despite these supports, Julia frequently engaged in SI and was readmitted several times.

During an assessment by Studio 3, it became apparent that Julia's support needs associated with autism were not fully understood by her supporters. Julia struggled to communicate her needs and found it incredibly difficult to recognise her emotions and feelings. She reported that cutting gave her a "sense of relief" during a crisis. The individuals supporting her could not understand the complex reasons underlying her self-harm. Why would someone harm themselves?

From the above example, we can understand that self-injury provided Julia with a regulatory function during an emotional crisis. It offered her a 'numbing sensation' which helped her escape the emotional turmoil. It was clear that sometimes self-injury would be triggered by a traumatic thought or 'flashback.' At other times, she struggled to regulate the overwhelming sensations from her body, such as an elevated heart rate, which felt painful to her. It was also evident that unmet needs contributed to high arousal states. Julia was not always able to make sense of her internal body signals. Consequently, she did not respond to these cues until she was 'melting down.' Her 'default' coping method was to engage in SI. The trauma from losing a loved one increased her vulnerability, especially around triggers associated with grief and loss.

Intervention

Understanding the complexity of her self-injury was a core part of the problem. Now that we understand self-injury in terms of complexity, it is fair to acknowledge that complex situations require complex solutions (McDonnell, 2019). Intervention is often a process that requires time and manipulation of the environment (including accommodations and changes in responses from others) rather than simply teaching new strategies to replace old behaviours. This change requires a two-fold approach (McDonnell, 2010):

1. Short-term crisis management
2. Long-term behavioural change

Short-Term Crisis Management

Short-term management refers to strategies in response to a crisis (reactive strategies). However, what can a supporter realistically do when a person is self-injuring? As discussed, SI is a coping strategy; therefore, removing or stopping the only strategy a person can access to self-regulate is like removing a life jacket from a drowning person. Unless SI poses a real danger to the person (i.e., risk of severe injury or death is imminent), we should not intervene more than gently guiding the person to ride out their storm (Pitonyak, 2008).

SI is particularly distressing for supporters to witness and, consequently, may attract chaotic responses. Management strategies guided by high emotions and control-seeking are most often unsuccessful. We cannot expect a person experiencing severe dysregulation to hold space for our emotions as supporters. Likewise, we would not attempt to teach a person to swim while they are drowning. Attempting to lecture the individual and use reasoning is also highly ineffective when applied 'in the heat of a moment' (McDonnell, 2019). The person engaging in SI is most often beyond the point of being able to access rational thinking.

So, what can we do when we witness self-injury? The first step is to remain, or at least present as, calm. By appearing calm, supporters can start the co-regulation process, holding space for the person having a meltdown. By doing so, we can slowly begin to reduce their stress levels by making gentle accommodations to the environment. The Low Arousal Approach (McDonnell et al., 1998) recognises the following strategies for crisis management:

- Removing any spectators
- Removing known triggers
- Reduction of unnecessary communication, including demands and requests
- Avoiding arousing behavioural cues such as shouting, confrontational stances, unexpected physical touch and direct eye contact
- Planned escape - Allowing the person to escape the overwhelming environment in a safe and pre-planned manner

- Tactical withdrawal from the person if our presence is adding to the person's distress

Once the storm is over, it is expected that everyone involved will be emotionally (and physically) exhausted. By this point, safety is likely regained, and the recovery phase can begin. As much time as is needed for recovery must be allowed. Making demands too quickly may trigger escalation. While the person engaged in SI may be regulated and calm now, carers and supporters may not be. It is helpful for supporters to access emotional support themselves. It is our standard practice to schedule regular debriefing sessions with parents and supporters for support with the emotional aftermath following incidents of SI.

Long-Term Behavioural Change

Changing established behaviours is a long-term process. We must remember that SI has a longstanding function for the person engaging in it. When we consider the individual's stress, trauma, sensory profile and other support needs, we can begin to develop plans to address those needs. The first goal of behavioural change needs to focus on creating space and opportunities for learning. It has been the author's experience that to achieve behaviour change, supporters need to reflect on why a person behaves in the way they do. Seeing an individual as stressed and traumatised - going beyond their behaviours (Delahooke, 2019) - is an essential component. Studio 3 practitioners often have to create a sense of empathy and understanding around why a person would self-harm. Most positively, focusing on arousal regulation, stress reduction and trauma-informed approaches help supporters rethink their goals and the influence of their own behaviour.

The Low Arousal Approach does not just focus on crisis management. At the heart of the philosophy lies proactive support in anticipating and preventing distress. Often, support plans may focus on supporting individuals with specific difficulties, such as minimising triggers leading to processing overloads and subsequent meltdowns, for example:

- Reducing aversive sensory experiences

- Adapted communication e.g., using visual supports and non-verbal signals
- Reduction of unpredictability and increased structure

Whilst the supports discussed above are essential, we also believe in applying a strengths-based approach to overall psychological well-being. Refocusing people's understanding of autism without referring to 'deficits' is essential. Studio 3 practitioners try to avoid talking about sensory triggers in their work. It is more important to talk about positive sensory experiences that may help an individual reduce their stress. We like to use the term 'sensory strengths', which can inform a personalised relaxation programme. When we consider the profiles of the autistic women referred to us, more often than not, these individuals have few opportunities to experience positive emotions, meaningful engagement, relationships, meaning and achievement within their support system. These elements refer to the PERMA(H) model of well-being (Seligman, 2018). Focusing on subjective psychological well-being can support an individual's resilience and happiness, and also reduce stress. Physical health is also significant. Diet, sleep and exercise all have an impact on how we feel. Cardiac exercise specifically has been shown to reduce the stress hormone cortisol.

All these factors can inform the development of a Stress and Wellbeing Plan. This plan not only focuses on reducing behaviours of concern, such as SI, but aims to promote overall well-being. Implementing such a plan is essential to support emotional regulation, which inevitably will impact engagement with supports aiming to teach new coping strategies.

Based on the established function, we can explore safer alternatives to self-injury with the individual we support. It is often helpful when this intervention involves psychoeducation around stress to support the person in understanding their current coping methods. This can provide a framework for working with the person on their goals. We must be mindful, however, of adaptations of materials, communication, and providing logical structure. Psychoeducation must be 'autism-friendly' in order to succeed. Replacement behaviours worth considering may include the following:

- 'Symbolic' cutting e.g., with a pen

- Holding an ice cube close to the skin
- Pulling and releasing an elastic band on the wrist
- Sensory strategies offering deep pressure stimulation

Working towards alternative coping strategies is often the final goal. However, we must question whether the individual we support can apply these strategies in practice. A period of prompting and modelling is often required as the individual may not be able to recognise their internal stress cues, signalling dysregulation. The *Interoceptive Curriculum* (Mahler, 2018) is a helpful resource for strategies aiming at developing interoceptive awareness.

Case Study – Intervention

Maria² has a long history of engaging in self-injury as a response to the overwhelming world around her. Since she transferred to an autism-informed service, her self-injury has decreased. Staff worked closely with her and the Studio 3 Clinical Team to understand her autism, trauma, and stress needs. The staff team has consistently applied the Low Arousal Approach when supporting her.

Maria occasionally experiences heightened stress due to situations largely outside the staff's control. However, the staff team feels confident in managing these incidents, and they have significantly reduced in duration, intensity and frequency. Consequently, Maria has expressed that she wants to develop new coping strategies as she feels safe with her staff team.

The power of co-regulation is well illustrated in the above case study. Maria's stress levels have become more manageable following an autism-informed and Low Arousal approach to her support. These two elements alongside the positive relationships between the staff team and Maria have resulted in Maria's wish to develop new coping methods.

Conclusion

² Name and personal details have been changed to protect confidentiality.

As practitioners, we should always seek to understand a person's presentation in the context of their history and present needs. Often, behavioural assessments overlook these factors, which may lead to superficial solutions and ineffective interventions. It is, therefore, essential that self-injury is assessed holistically and beyond the use of incident data.

Many other factors may need to be considered when assessing and intervening with SI. However, this article focuses on the common themes observed when supporting autistic women. These women may attract a label of 'high functioning' or multiple mental health diagnoses if their autism needs are not recognised. The factors discussed in this article are not exhaustive when assessing and intervening in SI, and the individual's unique profile must shape the process.

For more information about supporting an individual who self-injures, see our recent publications:

<https://www.studio3.org/post/practitioner-article-best-practice-in-the-assessment-of-self-injurious-behaviour>

<https://www.studio3.org/self-harm>

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