Exploring the pattern between self-injurious behaviours and epilepsy in an autistic learner

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ABSTRACT: A study comparing the autism phenotype in children with and without epilepsy reported that children with co-occurring epilepsy displayed significantly higher autism indicators and behaviours that challenge, including self-injury (Viscidi et al., 2013). We report the case of a 16-year-old autistic learner and co-occurring epilepsy who regularly engages in various self-injurious behaviours (SIBs) which include hand and knuckle biting, knuckle hitting, head hitting, mouth hitting and head banging. There is a concern that the learner's engagement in SIBs may have a relationship with the presence of seizures as periods of SIBs are frequently incidentally observed to be followed by seizures. Therefore, this study aims to investigate the possibility of a pattern between the presence of SIBs and seizures in this learner. Our findings show that while higher counts of SIBs are observed in the presence of seizures, no clear patterns were identified as many of the seizures occurred in the absence of SIBs. This study acknowledges that SIBs are multifunctional for this learner (i.e., not only to communicate developing seizures) and recommended several improvements if the study were to be replicated.

Introduction

Self-injury is a debilitating behaviour often engaged by a proportion of individuals diagnosed as autistic and can have a devastating impact on their physical health, developmental outcomes, and quality of life. This may also affect the wellbeing of parents and caregivers (Ludlow et al., 2011) as it is understandably distressing to see individuals harm themselves and not know the reasons why and how to stop it. In autism, SIBs are classified as "stereotyped SIBs" as opposed to "impulsive SIBs" which are habitual and generally observed in severe psychiatric illnesses and typically developing adolescents and adults. SIBs in autism can be highly repetitive behaviours (dozens of instances per minute) and can be episodic (occurs under highly specific stimulus contexts or in bursts after a long period without behaviours that challenge) (Yates, 2004). The learner in this case study is a 16-year-old female diagnosed as autistic, with epilepsy and learning difficulties who often engages in various forms of SIBs. The learner experienced focal, tonic-clonic and convulsive seizures. The most dominant form of SIBs for this learner is hand and knuckle biting but may also manifest in other forms which may inflict physical injuries. The learner primarily communicates in gestures (e.g., head shakes of yes/no and choosing from 2 options of 3D items). The learner is attending a school which utilises the principles of behavioural analysis in which she receives 1:1 support.

There is a concern that her engagement in SIBs may have a relationship with her seizures. Some people with epilepsy reported being able to predict a developing seizure well in advance (a few hours to days). This ability to predict is also known as 'prodrome symptoms'. Prodromes may include changes in mood, trouble sleeping, light-headedness and anxiety. Additionally, people with epilepsy also experience auras (contrary to prodromes, auras immediately precede a developing seizure) and these may manifest as vision problems, dizziness, "pins and needles" in parts of the body, headaches, and intense fear (Spencer, 2015; Tuchman & Barker, 2017; Booth, 2021). However, due to this learner's limited communication abilities, we suspect that SIBs tendencies may have the function of communicating signs of a developing seizure.

The generalisability of these results is subject to certain limitations. For example, the learner sometimes uses SIBs to communicate frustrations over communication barriers. In one instance, she started biting her hands because she was struggling to communicate, she was hungry. However, it is also constantly observed that episodes of SIBs are usually followed by seizures, hence the need to identify if there is a pattern between the two. Another withstanding issue is the compounding characterisation of behaviours that challenge (including SIBs) and epilepsy is that none of them are static in nature and continue to evolve over the lifespan of the individual (Casanova & Casanova, 2016). The results may be applicable to the individual now but may not be useful in her later life. Additionally, due to the severity of her epilepsy, she was routinely absent from school (64% attendance in Autumn 2022 term) and therefore, we do not have information on the presence of SIBs and seizures on those days (in which we can assume that seizures and possibly SIBs are potentially higher on those days due to illness). When the learner did come to school, she slept regularly and for extended periods which often resulted in seizure activity being more likely. Therefore, the current data we have may not accurately reflect the full presentation of SIBs and seizures in this learner.

A functional behavioural assessment (FBA) on the possibility of a relationship between the presence of SIBs and seizures was conducted for 3 months during the Autumn term 2022. This case study aims to investigate the relationship between the presence of SIBs and seizures in this autistic learner. Due to her limited communication abilities, it is crucial for us to understand if the function of SIBs in this learner is significantly related to her seizures.

Literature Review

Autism is diagnosed based on challenges in two areas: persistent social-communication difficulties and restricted, repetitive behaviours or interests (APA, 2013). These autistic indicators combined with certain situations or co-occurring conditions can trigger SIBs in some autistic people (Moskowitz, 2023). SIBs can be defined as physical actions directed toward oneself that are likely to inflict tissue damage (Tate & Baroff, 1966). Berkson et al. (2001) introduced "proto-SIB" to distinct SIBs of the same form that does not inflict tissue damage. Topographies of SIBs may include head banging, ear banging, eye gouging, hand biting and excessive rubbing and scratching. SIBs can cause irreversible injury or death when the behaviour is not stopped (Schroeder et al., 1980). A recent meta-analytic study estimated a 42% pooled prevalence of autistic individuals engaging in SIBs (Steenfeldt-Kristensen et al., 2020).

There are several hypotheses offered as to why SIBs occur in autistic individuals. One of the most prominent models comes from the field of applied behavioural analysis. Carr (1977) suggested several hypotheses regarding the motivation for SIBs. The basic principle is individuals learn to associate the occurrence of behaviour with the consequence – behaviours are learned responses. The behaviour is more likely to occur again in the future as the consequence (usually a desirable outcome) is reinforced. This model proposes four functions of behaviour: provision of social attention, access to a preferred item or activity, an opportunity to escape an unpleasant or demanding situation or self-stimulatory. Carr also emphasised that biological or organic factors that could lead to physical conditions or altered pain thresholds should also be considered when trying to understand the motivation for SIBs. Interestingly, a study by Richards and colleagues (2016) shows autistic children who engage in SIBs are more likely to be less able and verbal. We can assume that SIBs may also arise to due communication barriers.

The International League Against Epilepsy (ILAE) defined epilepsy as a neurological disorder characterised by an enduring predisposition to recurring seizures (NICE, 2012). The prevalence of epilepsy in autistic individuals varies widely from 2% (Amiet et al., 2013) to 46% (Eriksson et al., 2012). In the largest studies, the prevalence rates ranged between 2.4% to 26% (Amiet et al., 2013; Jokiranta et al., 2014; Kohane et al., 2012; Viscidi et al., 2013; Mouridsen et al., 2011). The heterogeneous sample and inconsistent definition of epilepsy might be the cause for the differing prevalence rates reported in studies (El Achkhar & Spence, 2015).

Some people with epilepsy report being able to recognise signs of developing seizures well in advance (several hours or even days before the actual seizure). This is known as the prodromal phase – the duration from when early subjective symptoms begins before the actual seizure. Prodromes may include changes in mood, trouble sleeping, problems staying focused, confusion, anxiety, and tremor (Booth, 2021). It is estimated about 21.9% of individuals with epilepsy experience prodromes (Besag & Vasey, 2018).

For many people with epilepsy, the earliest sign of seizure activity is an aura. A study investigating the frequency of auras in generalised epilepsy reported that 64.3% of patients reported experiencing at least one form of aura before tonic-clonic seizures (Spencer, 2015). Auras, also known as the early ictal phase, can be defined as the initial components of a seizure that occurs before alteration or loss of consciousness. Contrary to prodromes, auras immediately precede a developing seizure. Auras may include weird tastes and smells, déjà vu, dizziness, hallucinations, flickering vision, pain in the head, arm or leg, nausea, and vision loss (Nakken et al., 2009). In 2017, the term aura is updated to focal aware seizure (Fisher et al., 2017). For some people, focal aware seizures may develop into another type of seizure (Johanson et al., 2008; Mula, 2014).

One of the complications regarding autism and epilepsy co-occurrence is that their phenotypes often overlap. Repetitive behaviours (stereotypies) can look like automatisms (involuntary movements occurring in focal seizures) which can make it difficult to distinguish between the two (Frye et al., 2023). There are certain events parents reported to be "typical seizures" but show no changes in electroencephalogram (EEG) (Kim et al., 2006). Contrarily, there are also studies showing that autistic individuals display EEG abnormalities in the absence of seizures (Schor, 2007; Chez et al., 2006). It is important to identify the co-occurrence of autism and epilepsy as autistic children with epilepsy show more gross and fine motor difficulties and independent living skills difficulties (Turk et al., 2009).

The current literature regarding SIBs in individuals with co-occurring autism and epilepsy shows that children with higher autism phenotype with co-occurring epilepsy display significantly higher maladaptive behaviours including SIBs (Viscidi et al., 2013). It is out of the remit of the study to investigate whether epilepsy plays a risk factor role for SIBs in autistic individuals.

Method

A functional behavioural assessment (FBA) on the possibility of a relationship between the presence of SIBs and seizures was conducted for 3 months during the 2022 Autumn term. An FBA is built on the premise that behaviours serve a communicative function – provision of social attention, access to a preferred item or activity, an opportunity to escape an unpleasant or demanding situation or self-stimulatory – for an individual (Kern et al., 2006). The staff working with the learner collected the Antecedent-

Behaviour-Consequence (ABC) data. All members of staff received training from their behaviour analyst.

Contrary to the traditional ABC data commonly utilised in schools using principles of behavioural analysis to record behaviours that challenge, we used the scatterplot. A scatterplot is generally understood as an interval recording method to identify patterns related to behaviours that challenge and specific periods. The scatterplot is a grid with time plotted on the vertical line divided into periods (Touchette et al., 1985). In this case study, two behaviours are being observed – the presence of SIBs and seizures. Our main priority is to identify the co-occurrence of SIBs and seizures in a 30-minute interval rather than if the behaviours are occurring at specific periods.

The count of the presence of SIBs is defined as all forms of SIB, regardless of leaving marks in a 30-minute interval, including hand and knuckle biting, knuckle hitting, head hitting, mouth hitting and head banging. The intensity of SIBs is categorised by three levels – Level 1: no mark; Level 2: leaves mark and Level 3: breaks the skin. The presence of SIBs is recorded every 30 mins (one session). If multiple SIBs occur in one session, the highest level of SIBs is recorded. If no SIBs occurred, it was recorded as '0'. The presence of a seizure is presented by shading the cell in grey which is also recorded every 30 minutes. Figure 1 illustrates an example of the scatterplot used for this learner.

	27/9/2022	28/9/2022	29/9/2022	30/9/2022	3/10/22	4/10/22	5/10/22	6/10/22
Time of day								
9:30-10:00	0	0	0	0	0	0	0	0
10:00-10:30	0	0	0	3	0	0	0	1
10:30-11:00	0	0	0	0	0	0	0	0
11:00-11:30	0	0	0	0	0	0	0	0
11:30-12:00	0	0	0	0	0	3	0	0
12:00-12:30	0	0	1	0	1	0	0	0
12:30-1:00	0	0	0	0	0	0	2	1
1:00-1:30	0	1	1	0	0	0	0	0
1:30-2:00	0	1	1	0	0	0	0	0
2:00-2:30	0	1	1	0	0	0	0	0
2:30-3:00	0	1	0	3	0	0	0	0
3:00-3:30	0	0	0	3	0	0	0	0

Figure 1: A scatterplot containing records of the intensity of SIBs and presence of seizures collected in 30-minute intervals. The numbers 0 to 3 represent the intensity of the SIBs and the grey-shaded cells represent the presence of seizure.

Results

Our case describes a 16-year-old autistic learner diagnosed with epilepsy and learning difficulties who often engages in various forms of SIBs. The aim of this study is to investigate a possible pattern between the presence and intensity of SIBs and presence of seizures. A total of 336 observations were collected in this study.

Table 1 demonstrates that 64% of seizures occur in the presence of SIBs. The highest count of seizures reported to occur (54.6%) in the presence of SIBs is Level 1 SIBs. However, higher occurrences of Level 2 and 3 SIBs are also reported in the absence of seizures, both at 62.5%. This is better illustrated in Figure 2. We can also see that 31 (10.4%) seizures occur in the absence of SIBs which means while we are observing high co-occurring of SIBs and seizures, the majority of the seizures actually occur in the absence of SIBs.

	Presence of seizure (n, %)			
Intensity of SIBs	**Absent**	**Present**	**Grand Total**	**Present : Absent ratio**
No SIBs	267 (89.6%)	31 (10.4%)	298	0.12
Level 1	10 (45.5%)	12 (54.6%)	22	1.20
Level 2	5 (62.5%)	3 (37.5%)	8	0.60
Level 3	5 (62.5%)	3 (37.5%)	8	0.60
Grand Total	287	49	336	
Level 1+2+3	10 (35%)	18 (64%)	28	

Table 1: Percentage of absence and presence of seizures depending on the intensity of SIBs (ranging from No SIBs to Level 3) and present: absent seizure ratio.

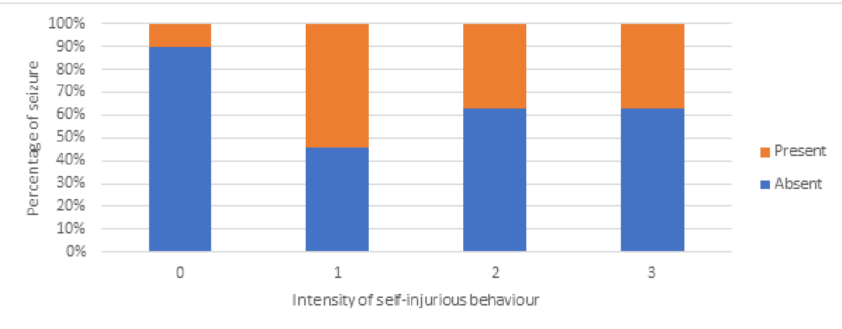

Figure 2: A compound bar chart presenting the percentage of presence and absence of seizures in the different intensities of self-injurious behaviour.

Altogether, we can assume that there is no clear pattern between the presence and intensity of SIBs and seizure (i.e., engagement in SIBs does not necessarily communicate a developing seizure). This finding is supported by a recent study by Buono et al. (2020) whereby there is no correlation between the frequency and intensity of SIBs and seizure frequency in participants diagnosed with intellectual disability (ID) and epilepsy. In a previous study on the same matter by Buono et al. (2012), when a group with co-occurring ID and epilepsy were compared with a group of only ID, there are no significant difference between the prevalence of SIBs. This implies that the presence of epilepsy did not confer a risk factor for SIBs. With that being said, the evidence from these studies may only partially support our findings due to the difference in our main subjects. The author did not manage to find specific studies regarding epilepsy as a risk factor for SIBs in autistic individuals.

From our results, we can assume that either a) engagement in SIBs has an entirely different function to communicating a developing seizure in this learner (which may be unlikely as can be seen from the 54.6% co-occurrence of Level 1 SIBs and seizures) or b) the sample size is simply too small for us to draw a correlation.

There are also several other factors needed to be considered. Upon discussion with staff familiar with this learner, they reported that reminding the learner that they can “lie down” when she starts to engage in SIBs (presumably due to developing seizure) will usually stop the behaviour. However, due to the nature of the scatterplot, this intervention cannot be recorded. Moreover, this reminder from the staff also becomes a confounding variable and therefore may influence our results. Other than that, due to the learner’s severing epilepsy, the learner started on a new trial of anti-epileptic drugs. Anti-epileptic drugs have been known to induce hyperactivity, depression, psychomotor deficits, and aggression (Tsiouris, 2001) which may lead to more SIBs or seizures.

As mentioned in Introduction, it is also observed by the staff that extended nap periods may lead to seizures hence, moving forward, it might be worth collecting data on the period and duration of sleep the learner had at school. Furthermore, it is also recommended that data on learner’s menstrual cycle should also be collected as SIBs are often used by autistic individuals to communicate pain (Richards et al., 2016; Carr, 1977) and it is important to identify if menstrual pain is one of them.

Discussion and conclusion

This study set out to investigate the possible pattern between the presence and intensity of SIBs and seizures in a 16-year-old autistic learner diagnosed with learning difficulties and epilepsy. Most individuals with epilepsy reported feeling prodrome signs or auras before experiencing a seizure (Spencer, 2015; Tuchman & Barker, 2017; Booth, 2021), however, due to this learner’s limited communication abilities, we suspect that SIBs tendencies may be her way of communicating signs of a developing seizure. Our findings did not manage to find a clear pattern between the presence and intensity of SIBs and seizures in this learner. However, this study has outlined several limitations and recommendations to further explore the function of SIBs in this learner including collecting more data for a bigger sample size, change in medication and to include data on sleep and menstrual cycle moving forward.

There are multiple variables needed to be accounted for such as sleeping patterns, menstrual cycle and medication interactions in order to fully understand the interaction of autism and epilepsy in this learner. Ultimately, what can be taken from this case study is behaviour is multi-functional. For example, Level 1 SIBs could be a need to communicate difficulties related to seizures but may also communicate the need to lay down, access to tangible items, obtain attention, or escape. Moving forward, it might be worth studying if different intensities of SIBs communicate different functions for this learner. Other than that, this study would also benefit from the parents being involved in collecting data (tracking the same behaviour and seizures at home). Additionally, an interobserver agreement between the staff working with this learner is also recommended to ensure consistent quality of data.

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