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Social stories as a support tool for children with autism spectrum disorder following distressing medical procedures – case studies

Historyjki społeczne jako narzędzie wsparcia dzieci z zaburzeniami ze spektrum autyzmu po trudnych doświadczeniach związanych z procedurami medycznymi – studia przypadków

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Abstract

Performing medical procedures in patients with autism spectrum disorder is associated with a high risk of intensified stress reactions. Difficulties in adapting to the requirements of medical care often lead to the use of physical restraint, which in the long term may increase anxiety and aversion toward medical staff. The aim of this paper is to present three case studies of children with autism spectrum disorder who experienced negative consequences of restraint during medical procedures and to discuss the therapeutic use of narrative strategies (social stories). Personalised narratives helped patients reorganise traumatic experiences, resulting in reduced anxiety and improved daily functioning. Clinical observations indicate that narrative strategies are a justified and effective method for minimising the negative effects of medical experiences. The article emphasises adherence to ethical standards of care, including proactive preparation of children and medical staff, and highlights the need for further research on effective communication with autism spectrum disorder patients.

Keywords: neurodevelopmental disorders, narrative therapy, medical trauma

Streszczenie

Przeprowadzanie procedur medycznych u pacjentów z zaburzeniami ze spektrum autyzmu wiąże się z wysokim ryzykiem nasilonych reakcji stresowych. Trudności tych pacjentów w dostosowaniu się do wymogów opieki medycznej niejednokrotnie wiążą się z koniecznością sięgania po środki przymusu, co w dalszej perspektywie może utrwalać u nich reakcje lękowe i niechęć wobec personelu medycznego. Celem pracy było przedstawienie trzech studiów przypadków dzieci z zaburzeniami ze spektrum autyzmu, które doświadczyły negatywnych następstw przytrzymania w trakcie procedur medycznych, oraz omówienie zastosowania strategii narracyjnych (historyjek społecznych) w terapii. W opisanych przypadkach wykorzystanie spersonalizowanych narracji pomogło pacjentom zreorganizować traumatyczne doświadczenia, co przełożyło się na redukcję lęku i poprawę codziennego funkcjonowania. Wnioski z obserwacji klinicznych wskazują, że strategie narracyjne stanowią uzasadnioną i skuteczną metodę minimalizowania negatywnych skutków procedur medycznych. W artykule podkreślono znaczenie przestrzegania etycznych standardów opieki, w tym proaktywnego przygotowywania dzieci i personelu medycznego, oraz wskazano potrzebę dalszych badań nad skutecznymi formami komunikacji z pacjentami z zaburzeniami ze spektrum autyzmu.

Słowa kluczowe: zaburzenia neurorozwojowe, terapia narracyjna, trauma medyczna

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INTRODUCTION

The specific characteristics of how individuals with autism spectrum disorder (ASD) function, including their way of communicating and difficulties in adapting flexibly to change(1), influence their behaviour in the context of medical care. ASD encompasses a broad range of clinical manifestations that vary in terms of language competence, intellectual abilities, and the severity of symptoms. Among patients with ASD, there is a frequent co-occurrence of other neurodevelopmental disorders, such as attention deficit hyperactivity disorder (ADHD) and intellectual disability, as well as somatic comorbidities, including epilepsy, allergies or chronic gastrointestinal conditions(2). This is associated with an increased frequency of contact between these individuals and medical personnel.

Children and adolescents with ASD often respond to medical procedures with greater stress, anxiety, or resistance than their typically developing peers(3). This heightened response may stem from factors such as sensory hypersensitivity, difficulties in predicting events, and a limited understanding of the situational context. Even routine diagnostic procedures, such as physical contact during an examination or injections, may be perceived by a atypically developing child as highly threatening and can lead to an escalation of defensive behaviours, which in some cases may necessitate the use of direct physical restraint(4,5).

Communication difficulties and increased anxiety in unfamiliar situations among patients with ASD may hinder the identification of the underlying causes of challenging behaviours and the selection of effective de-escalation strategies(6,7). Both physicians and medical students emphasise that the lack of adequate preparation for working with patients with ASD impedes the provision of effective and safe care. Furthermore, they point to the need for additional training and the development of coherent procedures for managing situations in which these patients exhibit acute reactions(4).

Medical care for a neuroatypically developing child primarily requires the implementation of proactive measures, including adequate preparation both at home and within the healthcare facility, as well as tailoring communication to the child's developmental level. A crucial element in preparing a patient with ASD for a visit is ensuring predictability and providing the child with a sense of control, for instance through the use of schedules, visual aids, or personalised social stories(8,9). To the extent possible, the environment should be adapted to the child's sensory needs. Identifying these needs and preferences requires close collaboration with caregivers(10). Such measures allow for the reduction of the child's stress, anxiety, and resistance, thereby minimizing the risk of having to resort to direct physical restraint(8–10).

The use of physical restraint is considered an intervention of last resort, which should be employed only after other methods supporting cooperation have been exhausted and in situations where the safety of the patient or those around them is at risk(11,12). It should be recognised that the use of force to carry out medical procedures may lead to secondary traumatisation, which may hinder future therapeutic interventions(13). The data regarding the short- and long-term effects of using coercive measures on children with neurodevelopmental disorders is lacking. Furthermore, research concerning the diagnosis, treatment, and prevention of stress-related disorders in individuals with ASD remains limited(6,14). Existing evidence indicates that children and adults with ASD may be particularly vulnerable to the negative effects of stress and potentially traumatic events, and that available therapeutic models aimed at addressing the consequences of trauma require adaptation to the specific characteristics of functioning in this group of patients(6).

The therapeutic process aimed at processing traumatic experiences in children and adolescents developing on the autism spectrum can be framed within a four-stage model: acknowledgement of the experience, ensuring safety and skill development, processing the trauma, and moving beyond it (Charlton and Tallant, 2003, cited: Faccini and Allely(15)). This model provides a flexible clinical framework that requires individual adaptation to the patient's age, intellectual development, and communication skills, as well as the specific therapeutic modality employed in the intervention(15).

The first stage – acknowledgement – involves explaining the nature of the traumatic event in a manner adapted to the child's cognitive and linguistic abilities. In case of patients with limited or no functional speech, it is crucial to use augmentative and alternative communication (AAC) methods, such as picture-based systems (e.g. Picture Exchange Communication System) or speech-generating devices(15). In children with intellectual disabilities, abstract concepts are replaced with concrete examples and visual strategies. A vital component here is the psychoeducation of caregivers, aimed at preventing diagnostic overshadowing, that is, the misattribution of stress-related symptoms (e.g. those associated with traumatic experiences) solely to the characteristics of autism(15).

The second stage focuses on ensuring safety and skill development, aimed at restoring the patient's sense of predictability, control, and emotional stabilisation. While interventions for younger children (approximately 3–6 years old) focus on caregiver involvement and behavioural techniques(6), older children and adolescents (8–14 years old) are typically supported through cognitive behavioural therapy (CBT), including modified protocols targeting anxiety and trauma, such as Coping Cat(6). These modifications include the use of visual tools (e.g. anxiety scales or session schedules), extending the duration of therapeutic work, and incorporating sensory breaks. An important aspect of this stage is supporting the agency of patients by ensuring they have opportunities to communicate their needs and boundaries (self-advocacy).

The third, crucial stage is trauma processing. This stage is carried out using methods adapted to the patient's cognitive profile. Trauma-focused therapies recommended by the UK National Institute for Health and Care Excellence involve an element of processing the event, most commonly through imaginal exposure, which requires the patient to revisit and provide a narrative of the traumatic event[16]. In trauma-focused CBT adapted to the needs and abilities of children with ASD, the process of constructing a trauma narrative often relies on visual-symbolic techniques, such as social stories, drawing, puppet work, and digital tools[6]. Such adaptations serve to reduce the verbal load and enhance the patient's sense of security.

The final stage, defined as moving beyond trauma, focuses on consolidating coping strategies, strengthening self-efficacy, and preparing the child for situations that may trigger difficult memories. In work with individuals with ASD, this stage often leverages their special interests as a motivating and stabilising factor in the recovery process[15].

The effectiveness of interventions at each of these stages depends on the clinician's flexibility and their ability to integrate evidence-based protocols for treating the effects of (potentially traumatic) stress with the unique sensory, communicative, and developmental needs of the child with ASD. It is worth noting that research on the impact of adverse childhood experiences within the ASD population remains scarce[6,14]. Available evidence indicates that highly stressful events in children with ASD worsen their mental health and lead to negative structural changes in the brain[14]. Currently, there are no interventions with proven effectiveness specifically designed to address trauma-related stress in this patient group[6].

While social stories (social narratives) are a well-established, evidence-based method for supporting the social functioning of individuals with ASD, their application is gaining increasing recognition in the treatment of posttraumatic stress disorder. The structure of a social narrative involves combining a description of events with guidance on coping strategies, typically following a 2:1 ratio, where two-thirds of the content describes the objective situation and one-third provides concrete recommendations for desired responses and behaviours. The literature suggests that this technique can serve as a valuable adjunct to exposure therapy, specifically tailored to the unique cognitive needs of individuals on the autism spectrum[6].

In their literature review, Como et al.[17] indicate that social narratives are an effective behaviour modification tool because they allow the patient to anticipate the course of events and reduce anxiety associated with uncertainty. Due to their visual and structured format, social narratives help integrate difficult experiences, which is crucial, for example, in the process of desensitisation.

This study serves as a clinical complement to the issues addressed in the first part of this series, which focused on the ethical and legal aspects of minimising interventions based on direct physical restraint involving neuroatypical patients[18]. While the previous work provided a detailed discussion of proactive strategies for preventing challenging situations in medical settings (such as pre-visit preparation or the use of visual aids), the present article focuses on remedial interventions.

It presents three clinical cases of children with ASD, all of whom experienced negative consequences following physical restraint during healthcare delivery. In these patients, narrative strategies inspired by the concept of social stories, with the active involvement of their caregivers, were successfully implemented. The presented case studies illustrate the complex challenges faced by healthcare professionals and therapists working with children with neurodevelopmental disorders following exposure to potentially traumatic events. They provide a practical example of utilising narrative tools that can support clinicians and caregivers in the absence of structured, empirically validated therapeutic protocols specifically designed for this particular group of patients.

CASE DESCRIPTIONS

The case descriptions presented in the following section illustrate the application of narrative techniques in addressing the consequences of physical restraint used during medical procedures. The subjects were three patients with ASD under the care of a child psychiatrist and a behavioural psychologist.

To prevent the identification of the patients, personal data and certain descriptive details have been modified. Written informed consent for the publication of these anonymised data was obtained from the children's legal guardians.

Case 1

Piotrek, an 8-year-old boy diagnosed with childhood autism (F84.0 according to ICD-10)[19], functioning within the intellectual norm, was brought by his parents to a psychologist due to the sudden onset of intense health-related anxiety. Even minor pain, discomfort, or slight abrasions triggered severe fear and persistent reassurance-seeking that he would not require surgery or hospitalisation. The symptoms, described by his parents as excessive, obsessive, and interfering with everyday functioning, persisted over time, and the boy's anxiety gradually intensified.

During the diagnostic process, it was established that a year earlier Piotrek had fallen from a scooter and required stitches for a laceration of the eyebrow. Because of his protest and severe fear during the suturing procedure, Piotrek had to be physically restrained by medical staff. This highly stressful situation was not later discussed with him in detail.

The intervention utilised a narrative approach inspired by social stories. The parents were asked to provide a highly detailed description of the event from the boy's perspective; subsequently, together with the child, remembered details were added to the account. The narrative included a description of the situation as well as the emotions experienced by the child and their underlying causes.

The following narrative was developed for the purpose of the therapy.

A year ago, during the summer holidays, something unexpected happened while I was out for a walk with my friend Adam. I was wearing a helmet and riding my scooter. At one point the scooter bounced on a bump, and I hit my right eyebrow ridge on its frame. My glasses frame also broke. I felt the warmth of my blood. Adam took me home to my mom. Mom dressed my wound and said we had to go to the hospital because even though the wound was small, it might need stitches. I got very scared. I decided to take my tiger toy with me so it could give me courage. Mom drove me to the hospital, and on the way she explained what they would do. She said that maybe instead of stitches they would put on a special patch or glue the wound, because it was small, and if there were stitches, they would first give me anaesthesia so it wouldn't hurt. When we arrived at the emergency department, we first went to the window. A lady gave us a special number and told us to wait. I was very worried. When our number appeared on the screen, we went into a room where a paramedic asked me what had happened and how I felt. Then we went to another room where there was a doctor and a nurse. The doctor decided that the wound needed to be stitched, but that she would put in only one stitch, so she would not inject anaesthesia, but would spray a weaker anaesthetic on the wound. Mom was with me the whole time, but I was still very scared. They told me to lie down on a special table and not move. Even though I was very brave, I cried and even shouted. Someone held my legs and another person held my shoulders, and I had no way to escape. The stitching took a very short time, but it hurt and I was very upset and frightened.

When we were coming back from the hospital, mom said that I had been very brave and that she was sorry that it had been different from what she had explained to me.

The narrative was also supplemented with information regarding why the situation was handled incorrectly, along with a description of what might happen should the boy require hospital assistance in the future and how he could react. Reading the narrative several times with his parents brought about an immediate change in the boy's behaviour, indicating a reduction in the anxiety he was experiencing. Piotrek stopped excessively questioning health-related matters and was able to discuss the accident without visible symptoms of fear, using elements of the prepared description.

Case 2

Bartek is a 12-year-old boy diagnosed with childhood autism and moderate intellectual disability (F84.0, F71 according to ICD-10)[19]. His parents reported a problem with faecal soiling that had been occurring for about a year, even though toilet training had been completed when the boy was 6 years old. The problem began when the child developed persistent constipation. This condition, which posed a significant threat to his physical health, required medical intervention. According to the parents' account, the physician prescribed enemas. Unfortunately, due to a lack of skills in managing the child's fear and resistance, this procedure was occasionally performed by the parents using physical force to restrain Bartek. It must be emphasised that this was not part of the medical recommendations but rather an inappropriate reaction by the caregivers in a situation they perceived as a crisis. Despite the resolution of the constipation, Bartek continued to avoid using the toilet, associating it with previously experienced pain and discomfort.

This case may raise justified ethical concerns; however, it is presented as an illustrative example of a situation in which medical recommendations were implemented improperly and their consequences needed to be urgently minimised.

The aim of the therapeutic intervention was to provide psychoeducation for the parents and explain the coercive nature of their actions, restore the boy's sense of safety, reduce stress and the effects of the traumatic experience, and develop ethical strategies for further cooperation. As part of the intervention, based on a detailed description of the events, a simple narrative adapted to Bartek's intellectual level was created together with him and his parents.

A year ago, I started pooing in my pants. First I had constipation, which means the poop got stuck in my bottom and it didn't want to come out because it hurt. Sometimes I had an enema and it was very unpleasant. My parents held me and I didn't want that enema.

When you have constipation, it hurts a lot when the poo comes out. To avoid having an enema, I pushed the poop out by force and it hurt. It hurt because I had constipation.

Now I don't have constipation anymore. I poop almost every day. When no one is looking, I hide and poop in my underwear. I'm afraid to poop in the toilet because I don't want it to hurt. Now that I don't have constipation anymore, the poo comes out easier and it doesn't hurt. I poop in my pants because I am scared of the pain.

If I poop in the toilet, it will not hurt because I don't have constipation.

I can be brave, and even though I am scared, I can learn to poop again like my mum, dad, and (other family members).

I will learn to sit on the toilet and be brave. My parents will help me with this and they promised that if I am brave and learn to use the toilet, I will earn rewards: (list of rewards).

One of the objectives of the narrative was to neutralise the aversive association between the toilet and pain. After a week of daily readings by the parents, the caregivers reported a significant success – the boy began using the toilet for bowel movements once again. Moreover, spontaneously and in different situations, he expressed happiness about being brave; among other things, these were his first words spoken to his teacher when he returned to school after the summer break.

Case 3

Adam is a 6-year-old boy diagnosed with childhood autism (F84.0 according to ICD-10)[19], functioning within the intellectual norm. The boy requires regular blood draws due to allergies, which are important for monitoring his health and planning treatment. His parents reported difficulties related to these procedures – Adam exhibited intense anxiety and oppositional reactions, and previous experiences in which he had been restrained had created negative memories as well as strong protest and resistance to clinic visits.

As part of addressing the negative effects of the previous experience, the therapist, together with Adam and his parents, prepared a narrative adapted to his cognitive level.

One day, I had to go for a blood draw to do some tests for my doctor. I went there with my parents by car. Mum and dad had told me everything about the blood test before. My parents promised that if I was brave, I would get a reward.

I waited outside the office for my turn. When I went inside, I got very scared, upset, and started crying. The nurse asked me to sit on my dad's lap. By then, I was already crying a lot and shouting that I didn't want to do it. Dad held my arm, and the nurse put a band on it that squeezed it.

When she took out the needle, I started to scream very loudly and kick my dad. I was very scared and didn't know what to do. Mum talked to me and tried to calm me down. Then she held my legs so I wouldn't kick anyone. The nurse pricked me in the arm. It hurt a lot. She couldn't take the blood because I was upset and shouting very loudly.

When they couldn't take the blood, two other nurses told me that I mustn't move or scream like that.

I kept crying and tried to escape from there, but I couldn't because mum, dad, and the nurses were holding me. I cried a lot and I really didn't want to be there.

Mom tried to calm me down, she took out her phone and turned on my favourite videos. At the same time, another nurse put a squeezing band lower down on my arm. Again, everyone held me tightly and said I couldn't move. The nurse pricked my hand, and the blood started to flow into a special container by the needle. I was still crying and screaming very loudly. It hurt, and I really wanted the blood draw to be over.

When the nurse finished taking my blood, she put plasters on me. I was still crying, and my arm hurt. Mum picked me up and carried me out of the office straight to the car. I kept crying and couldn't calm down. Since then, I have been very afraid of blood tests.

That was not a typical blood test because usually, no one has to hold anyone. My parents didn't know I would be that scared.

A blood test is a type of medical check-up. We do tests to see if someone is healthy and to know how to treat different illnesses, like allergies. I have allergies, so it is important for me to do the tests, which means drawing blood. The doctor will look at my blood in a special machine and check what I am allergic to.

I am afraid of blood tests because last time it hurt a lot, and the nurses and parents held me. But I can try to be brave and, even though I am scared, learn how to go through a blood test so that no one has to hold me and it hurts less.

Now, when my parents talk about blood tests, I remember that unpleasant situation when the nurses didn't listen to me and I was struggling.

My parents promised me that next time will be different and that we will plan visits to the clinic so I can learn to be brave. When I am ready, mum will buy a special cream so that the place where the nurse pricks me will not hurt so much.

I will go to the clinic to learn to be brave. My parents will help me with this.

The objective of this narrative was to label the child's experiences and the accompanying emotions, as well as to prepare him for the subsequent stages of exposure. The story was intended to be read by the parents, followed by planned steps of exposure and systematic desensitisation. These steps began with entering the clinic's waiting room, receiving a reward, and returning home. Subsequent steps included, among others: opening the door to the treatment room and saying hello; entering the office to look around; touching the chair; sitting in the chair; rolling up a sleeve; applying a tourniquet; and opening a syringe and needle brought by the parents. The immense openness of the staff and the parents' patience in conducting these successive exposure steps – combined with reminding Adam of key elements from the narrative – led to successful outcomes. At the time of writing this article (December 2025), the boy enters the nursing office, sits in the chair, requests that no one hold him, and allows for the application of the tourniquet and the opening of the equipment that will be used for future blood draws.

DISCUSSION

A growing body of research emphasises the importance of modifying the medical environment and providing systematic staff training as primary factors in reducing the use of physical restraint in the care of patients with ASD(18). The use of restraint can lead to physical injuries, heightened anxiety reactions, and a deterioration of the relationship between the patient and the healthcare system(4,13,20).

Despite well-established theoretical models describing the mechanisms of stress and coping, such as Lazarus and Folkman's transactional theory of stress(21), available data on the effectiveness of psychological interventions in mitigating the consequences of highly stressful medical events in children with neurodevelopmental disorders remain limited(6,14). This specifically concerns the impact of stress within the medical context, including the consequences of physical restraint used to save health or life. The few studies addressing the outcomes of potentially traumatic experiences in individuals with ASD do not yet allow for the formulation of clear, evidence-based recommendations for therapeutic interventions for this group of patients(6).

Research indicates that patients with ASD not only experience potentially traumatic events more frequently but also exhibit distinct neurobiological and hormonal responses to severe stressors compared to neurotypical individuals(14). These biological predispositions mean that in cases of traumatic stress, standard intervention techniques primarily based on verbal communication and abstract processing require modification(6,14). Patients with ASD need, among other things, a specific approach to communication, which should be integrated into every stage of medical care(18,22).

Data from genetics, epigenetics, and neuroimaging suggest that early stressful experiences may lead to lasting changes in brain structure and functioning and may exacerbate co-occurring mental disorders in individuals with ASD(14). Symptoms of ASD may additionally make it more difficult to recognise signs of stress, including traumatic stress in the form of PTSD(6). This highlights the need for an individualised clinical approach that takes into account the subjective sensitivity of autistic individuals to difficult experiences. Understanding these complex interactions is essential for developing more effective forms of support that could reduce the long-term consequences of trauma and prevent the escalation of difficulties later in life in this group of patients(6,14).

Processing traumatic experiences is one of the core elements of trauma-focused therapy(16), and social stories are indicated as a form of intervention particularly suited to the specific functioning of individuals with ASD(6,15,17). Traditional therapeutic methods recommended as first-line interventions for typically developing individuals with PTSD symptoms, such as trauma-focused CBT or prolonged exposure, may be difficult or impossible to apply in patients with ASD, both for ethical reasons and due to their specific characteristics. In this context, narrative exposure therapy, which involves constructing a coherent narrative of traumatic experiences, is recommended by the American Psychological Association as a second-line strategy for patients with PTSD without co-occurring ASD(23). The use of visual supports and the creation of narratives in the form of social stories, developed in collaboration with caregivers and the patient, may represent an adaptation of established trauma-focused therapies, contributing to their increased effectiveness among children with ASD(6).

In this context, social stories cease to be merely a simple educational tool and can become a form of narrative exposure therapy tailored to the specific characteristics of ASD. The effectiveness of this method, observed in the cases described, is linked, among other things, to the process of safely experiencing emotions(15). In neuroatypically developing patients, a lack of understanding regarding the intentions of medical staff often leads to medical procedures being interpreted as acts of aggression. Social stories allow giving meaning to these events by providing a logical justification for the adults' actions and the emotions experienced by the child, which directly addresses the first stage of the therapeutic model – acknowledging the experience(15).

The analysis of Piotrek's case shows that it was the lack of "closure" and discussion of the situation that led to increasing anxiety. The use of a personalised narrative allowed for cognitive reorganisation of the memory. In turn, Bartek's case illustrates the mechanism of neutralizing an aversive association (toilet–pain), which, in the presence of intellectual disability, was possible thanks to a structured and simple form of communication. Adam's case, on the other hand, shows that a social story can be part of an intervention, serving, among other things, as a framework for gradual desensitisation. In this way, social stories become a reparative tool, enabling the continuation of necessary medical care without escalating the patient's resistance. Key factors in the therapeutic success of the applied methods include individualisation (tailoring to the linguistic level) and the involvement of caregivers as safe guides through difficult memories.

Although the presented results are based on case study methodology and subjective caregiver reports, they provide important arguments for implementing narrative methods to minimise the effects of difficult experiences related to medical procedures in children with ASD, even long after the event occurred. Despite methodological limitations, the conclusions described are consistent with preliminary recommendations reported in the literature(6) and justify further research on the effectiveness of narrative interventions in this group of patients.

SUMMARY

Despite the documented vulnerability of individuals with ASD to developing PTSD, there is currently insufficient evidence regarding the effectiveness of therapeutic interventions specifically designed for this patient group(20,24). Preliminary data suggest that social narratives can be effective when working with children with ASD in the context of medical procedures(17). In light of the potentially traumatic nature of medical interventions, this article underscores the role of narrative techniques, such as social stories, in minimising adverse outcomes for children with ASD, providing a foundation for further research into effective ways to support this patient population.

Conflict of interest

The authors do not report any financial or personal connections with other persons or organisations which might negatively affect the content of this publication and/or claim authorship rights to this publication.

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Author contribution

Original concept of study; collection, recording and/or compilation of data; critical review of manuscript: KP. Analysis and interpretation of data; writing of manuscript; final approval of manuscript: PS, KP.

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