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## Speaking by Behavior: A Psychological Interpretation of Worrying Non-Autistic Behaviors in Adults with Autism Spectrum Disorder and Intellectual Disability

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Submitted 22/10/21, 1st revision 11/11/21, 2nd revision 02/12/21, accepted 23/12/21

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**Abstract:**

**Purpose:** The purpose of this article is to present the concept of a psychological interpretation of worrying behaviors in adults with autism spectrum disorder (ASD) and intellectual disability (ID) who have severe speech limitations or do not speak. These behaviors were called non-autistic because they do not belong to symptomatology of autism spectrum disorders.

**Design/Methodology/Approach:** Psychological interpretation of worrying non-autistic behaviors in adults with ASD and ID was under qualitative research. The interpretative phenomenological analysis (IPA) was used to find the meaning of worrying behaviors which were observed in of a person with ASD and ID from their perspective. In the interpretation from an external perspective, reference was made to professional experience, psychological theories and scientific research results of various problems occurring in this group of people.

**Findings:** Four types of themes (meanings) of worrying behavior in people with ASD and ID have been found. (1) "I want – I don't want to", (2) "too much – too little", (3) "something bad happened to me", (4) "something is wrong with me". Forms and functions of worrying behavior were also described.

**Practical implication:** This article will be helpful for caregivers working in institutions who have taken over or will take over from parents the care of adults with ASD and ID.

**Originality/ Value:** It is an original approach in non-autistic worrying behaviors in people with ASD and ID, as a way of speaking about their problems and using IPA to find their meaning.

**Keywords:** Autism, adults, intellectual disability, worrying behavior, interpretative phenomenological analysis.

**JEL classification:** I21.

**Paper Type:** Research study.

### 1. Introduction

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Adults with autism spectrum disorder (ASD) and intellectual disability ID, like other people, regulate their relationships with their surroundings through behaviors. Behavior depends on the current external situation, previous experience, current psychophysical state (Lewicki, 1974). In the case of adults with ASD and ID, it is necessary to consider the fact that the building of individual experience proceeded from early childhood on the basis neurological deficits specific to autism and global developmental delay, characteristic of intellectual disability.

On the one hand, disorders of brain functions led to problems with processing sensory information, with imitation, with compassion, guessing what other people think and feel, with planning, with motor, emotional, cognitive self-control, with combining elements into a whole. These aspects of autism cause people with ASD and ID to give the situation and its elements a different meaning that determines their behavior. On the other hand, intellectual disability caused a decrease in the level of functioning in all developmental spheres and limitations in social adaptation depending on the degree of intellectual disability (mild, moderate, severe, profound).

Among adults with ASD and ID, about 30% of them do not speak the rest have severe verbal limitations (Howlin *et al.*, 2004)<sup>2</sup>. They also have little ability in non-verbal communication (facial mimics, gestures, eye contact, body position) (Adams and Oliver, 2011). So, they cannot pass on their inner states to other people. They "speak" of their unmet needs, discord, fear, pain, mental and physical discomfort through their behaviors, e.g., outbursts of anger, screams, escapes, repeated words, questions, decreased or increased appetite, beating, pinching, pushing other people away, throwing objects, self-harm, squeaking, motor or voice tics, pollution, immobility. I called these behaviors worrying behaviors non-autistic, to distinguish them from the behaviors that are criteria for autism spectrum disorders.

Caregivers are not looking for an explanation as to why they behave in this way. They think that these behaviors in people diagnosed with autism are result from their autism. Also, clinicians may treat some worrying behaviors as belonging to the main disorder, reducing the chances of treatment of curable comorbidities (Rai *et al.*, 2018; Bakken *et al.*, 2010).

Meanwhile, in the repertoire of behaviors of people with ASD and ID, there are both behaviors resulting from autism spectrum disorders (autistic behavior) and behaviors with a different genesis (non-autistic behavior). This makes the picture of the functioning of an adult person with ASD and ID complicated, illegible, blurred (Sáez-Suanes *et al.*, 2020). The same behaviors can indicate different problems. Therefore, they require an interpretation aimed at understanding the meaning of disturbing behaviors.

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<sup>2</sup> For comparison, 30% of people with ASD without ID is minimal verbally (Lerner *et al.*, 2018).

## **2. Methodology**

Psychological interpretation of worrying non-autistic behaviors in adults with ASD and ID is in qualitative research. The aim of the qualitative approach is to discover the meanings that the subject gives to events, their causes, or effects, to recognize of the process of giving meanings, to understand his attitude to reality and to himself (Straś-Romanowska, 2010). Interpretative Phenomenological Analysis (IPA) was used to reach the meanings of worrying behaviors (Pietkiewicz and Smith, 2012).

The subject of qualitative analysis/interpretation are most often transcriptions of data from an in-depth interview and self-descriptions. However, because the most of persons ASD and ID do not speak or have severe speech limitations, the subject of this analysis can be only their behaviors. Also, the questions of interpretation: *why?* (the question of the cause) or *for what?* (the question of the purpose) a person behaves in a worrying way, must be directed to her/his behaviors. Complementary questions: *from when?*, *where?*, *how often?* *how long?* directed to worrying behaviors are also important.

The subject of the IPA were the worrying behaviors in five adults with ASD and ID (3 men and 2 women), aged 36 – 43 years, which appeared in a person since he or she left the family home and lived in a permanent care home (2 people, since 10 and 12 years), in a protected apartment (1 person, since 13 years) or attended a day care home (2 people, since 14 and 12 years). All these places were intended for people with ID and did not offer specialized services for people with ASD. The method of obtaining these behaviors was observation – direct participating or non-participating. These kinds of observation took place in various situational contexts: during family rehabilitation stays, classes in care centers, various celebrations at home and institutions or everyday situations when I was together with person with ASD and ID. The observational data I also obtained indirectly from parents, caregivers, therapists when they asked me to help them understand the behavior that was worrying them.

In this way, I collected 33 units of worrying behaviors that I interpreted (a unit could consist of one worrying behavior, e.g., bites the wrist, or from several behaviors, e.g., walks back and forth, hits his hand on the cheek, pulls with the nose).

In the interpretation of worrying behaviors I used (1) information about a person with autism and ID, whom I have known since he/she was kids: gender, age, level of severity of autism, level of intellectual disability, level verbal, state of health (co-occurring diseases, medications used), changes in a person's life situation, history of worrying behaviors, traumatic events in the past (e.g., violence, losses, hospital stay), (2) situational context (3) the literature on the subject: psychological theories i.e., learning mechanisms, the relationship between the value of arousal and the efficiency of action and mental integration, the alarm response mechanism, difficult situations,

(3) the results of research conducted among adults with ASD and ID on emotional disorders, psychosomatic disorders, affective diseases and somatic diseases, (4) my professional experience.

### **3. Findings**

The use of APA to uncover the meaning of observed worrying behaviors in a person with ASD and ID (unit level) has led to the distinction (at the inter-units' level) four themes that they "talk about" through their worrying behaviors. There are: (1) "I want – I do not want", (2) "too much – too little", (3) "something bad happened to me", (4) "something is wrong with me".

#### **3.1 Theme 1: "I want - I don't want"**

In adults with ASD and ID, worrying behaviors with self-aggression e.g., beating on the cheek, biting the wrists or with aggression, e.g., pushing the caregiver, hitting him, throwing an object are often observed. To understand these behaviors, it is important to determine whether they have given a person with autism something important to them, e.g., already the twentieth Barbi doll, attention, staying at home, wearing this blouse, watching TV or, on the contrary, avoided something, e.g., getting dressed, washing, leaving the house, waiting, taking the medication. If the answer is yes, it means that these behaviors are learned on the basis on the mechanism of instrumental conditioning.

This message is therefore clearly related to a goal that people with ASD and ID are not able to achieve on their own, and are also unable to express it in words, or their words are not respected by the environment. Thus, they express the goal with undesirable behaviors, which, because the negative reinforcement used by caregivers, become an effective way to achieve it (Zimbardo *et al.*, 2010). To recognize this message, it is important to analyze the current situation and know the history of reinforcements.

Aggressive and self-aggressive behavior, too often interpreted from the perspective of applied behavioral analysis (ABA), in some cases may be the result of psychological trauma (Siegel, 2018). They can also be analogous to expressing emotions or emotional anxiety (Adams and Oliver, 2011).

#### **3.2 Theme 2: "too much - too little"**

For mental health, it is important that the psychological load (emotional, sensory, motivational) is moderate, because then the mental integration and performance efficiency reaches the highest level. A moderate psychological burden is therefore an optimal load (Jankowski, 1994).

Too high values of load lead to psychological stress, which causes a decrease in mental integration and decrease in the effectiveness of activities but is additionally responsible for the disorganization of behavior. Changes are a significant source of too high arousal for people with ASD and ID because these people have a low tolerance of changes<sup>3</sup>. Changes which are short-term and recurring e.g., transfer from a family home to a group apartment can cause single short-term emotional reactions, e.g., motor tics (pulling the nose, shaking the head and shoulders, blinking) or vocal tics (humming, waning, hissing) or repetitive questions.

Short-term changes that arouse strong fear (e.g., waiting in the doctor's waiting room) can cause disorganization of behaviors (anxiety inhibition/ withdrawal, aggressive behavior, self-aggressive behavior, regressive behavior, fixation behavior, outbursts of negative emotions). Adults with ASD and ID treat changes in their life situation as a loss or threat (Morgan, 2004). These changes, e.g., leaving the family home and moving to a protected apartment, moving out of a sister/ brother, death of a loved one, also can lead to disorganization of behaviors but also to persistent neurotic behaviors (e.g., nail biting, teeth grinding, mutism).

Too little psychological burden prolonging over time also becomes unbearable emotional. The autistic person is then in a situation of deprivation (e.g., sensory, emotional, cognitive, motor). Therefore, behaviors appear whose purpose is to achieve an optimal level of arousal. They perform one of two functions. The first function is to provide direct stimulation (self-stimulation) sensory (e.g., scratching, listening to the same album repeatedly) or kinesthetic stimulation, mainly by performing stereotypical activities (e.g., repeated movements with the fingers of the hands, going back and forth, moving objects). The second function involves gaining/forcing attention from caregivers and "provoking events". This function is characterized by behaviors such as: demanding frequent hygienic procedures, meals, regression behaviors, e.g., soaking, as well as self-harm, which can be a form of self-stimulation or a way to obtain stimulation, e.g., attention.

### **3.3 Theme 3: "something bad happened to me"**

Some of adults with ASD and ID experienced of the traumatic event in the past. Such an event is physical violence, sexual harassment or abuse, traffic accident. Such an experience can manifest themselves immediately after the event in the form of behaviors that are symptoms of anxiety: crying, anxiety, tremor, faster breathing, sweating for no apparent reason or in confrontation with specific objects, people, situations. Symptoms of anxiety can also be stereotypical body movements (rocking, spinning, going back and forth), repeating the same sounds, words, asking the same questions repeatedly. In people with ASD and ID, more often than in people with ID

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<sup>3</sup> *Sensory hypersensitivity, which is also a source of high arousal, is one of the diagnostic criteria ASD in the DSM-5.*

alone, anxiety can manifest itself by running away or hiding from specific objects or situations (Cervantes and Matson, 2015). Experiencing a traumatic event can cause far-reaching consequences, affecting the further course of life of a person with ASD and ID. The sense of danger is not related to cognitive function (analyzing the situation), but to the physiological response. The situational context is also remembered, and its elements can lead to an alarm response in situations that are not threatening, but some element is similar (LeDoux, 2000; Jastrzębowska-Tyczkowska, 2017).

A traumatic experience in the past can lead to the following disorders: posttraumatic stress disorder (PTSD), Psychogenic non-epileptic seizures (PNES), Self-injurious behaviors (SIB).

People with autism may be more likely to experience real physical violence, as an easy victim, e.g., beating, sexual harassment, harassment, holding, isolation, but also psychological, e.g., ridicule, bullying (Haruvi-Lamdan, 2018). A person with ASD and ID is unable to say that something has happened that has aroused severe fear. He talks about this changed behavior. When worrying behaviors such as mood, sleep and attention deficit disorders are exacerbated, persist, and closely match the criteria for PTSD, it should be considered that the person has experienced a catastrophic event (Kupferstein, 2018).

PNES are a conversational emotional disorder that may resemble any type of epilepsy, but PNES is not associated with abnormal brain activity (Russell, 2006; Brown and Reuber, 2016; Jędrzejczak, 2016). PNES are rarely diagnosed in people with ASD and ID because they resemble outbursts of rage. The cause of seizures are traumatic experiences that have taken place more than once in the distant past. Such an event may have been unnoticed or intentionally concealed by caregivers. Seizure behaviours are usually treated by caregivers as voluntary and controlled behaviours that are deliberately directed against them (Anzellotti *et al.*, 2020). These behaviors cannot be interrupted by any persuasions, prohibitions on the part of caregivers. They do not require intervention, but to ensure physical security (Sala, 2020).

In the diagnosis of seizure outbreaks, it is necessary to consider both the significance of recent events in the light of distant trauma and psychological stress in the current situation, as a trigger for PNES (van Ool *et al.*, 2018).

It was found that after experiencing a traumatic event, there was a higher incidence of self-deeming behavior in people with autism with limited language skills than among those who spoke in complete sentences (Kildahl *et al.*, 2020). Depressed mood and SIB may be associated with the presence of untreated pain (Summers *et al.*, 2017). Self-damaging behaviors can also have an instrumental function, e.g., to get something, e.g., attention or avoid something, e.g., a trip to a permanent residence facility. Because people with ASD and ID learn over time to associate SIB with what follows (Summers *et al.*, 2017).

### **3.4 Theme 4: "something is wrong with me"**

People with ASD and ID with an average age of 42.9 years were burdened with these diseases to the same extent as those aged eighty in the population hospitalized in the geriatric ward. It increases the burden of co-occurring diseases: age, reduced autonomy, and increased polypharmacy (Miot *et al.*, 2019). The three most common chronic diseases in this population are, gastrointestinal (56%), mental (40%), neurological (37%) (Croen *et al.*, 2015). Symptoms of gastrointestinal disorders may be unusual and visible only as a change in behavior (Sala *et al.*, 2020). Adults with autism aged 40 years and older were more likely to have seizure disorders, constipation, hypertension, hypothyroidism, urinary incontinence. In this age group, 4.2% required a cane or walker, 10.7% required a wheelchair. In the middle of adulthood, people with autism can meet ailments from the locomotor system (degenerative joint diseases, osteopenia), which hurt, not allowing a longer state, walking (Fortuna *et al.*, 2016).

Some somatic diseases, such as stomach and intestinal disorders, gastric and duodenal ulcer, heart disease, tachycardia, asthma, atopic inflammation of the skin, rheumatoid arthritis, some types of obesity, erosions or stomach ulcers, teeth grinding can have an emotional basis. They occur because of not very large but repetitive psychological loads, the consequence of which is permanent psychological stress. Psychological stress is associated with a sense of danger, which is very common in people with autism (Mayer, 2000). Because people with ASD and ID cannot describe the symptoms or indicate the painful spots in their body, usually the disease is diagnosed too late. The pain, physical discomfort they feel is manifested in worrying behaviors which caregivers do not associate causally with physical ailments.

Fifty percent of adults with ASD and ID surveyed have additional mental problems (Croen *et al.*, 2015, Bakken *et al.*, 2010). One of them is depression. Because depression is potentially curable, its diagnosis in people with ASD and ID and treatment may give the opportunity to reduce stress and improve quality of life (Rai *et al.*, 2018). The observational indicators use to diagnose depression. Psychotic depression in people with ASD and ID is more likely to manifest as vegetative disorders than depressed mood. Signs of depression can be trouble sleeping, increased or decreased appetite (Ghaziuddin *et al.*, 2002). At the beginning of development of the disease, depression may also manifest itself in non-specific agitation, irritation, irritability, aggressive behaviors that can obscure depression, especially when such behaviors have already appeared in each person, but in a much lower intensity and occasionally, e.g., situationally (Rola, 1996).

Psychiatrists do not associate such behavior with depression and usually administer sedatives. In the case of depression, pharmacological treatment is necessary directed not at autism, but at depression, as an additional disease. Depression can also occur

suddenly, as a psychotic episode caused by a threat situation related to, for example, beating, sexual harassment.

An additional result of the interpretation was the distinction of four functions of non-autistic worrying behaviors: (1) they can be an emotional/motor response to the physical environment, other people's behaviors and negatively assessed situation, (2) they can express an internal physical or mental state, (3) they can be a way to obtain/avoid something, (4) they can be symptoms of various disorders somatic, psychosomatic, emotional, neurological, mental in people with ASD and ID.

#### **4. Conclusions, Interpretative Procedure**

Interpretation triggers the noticing of behavior, changes in the previous behavior of a person with autism, or an increase in already occurring disturbing behavior. Worrying behaviour should be described in detail as they were observed. Before proceeding to the interpretation of worrying behavior, it is necessary to collect information about a person with ASD and ID, gender, age, level of severity of autism, level of intellectual disability, speech level, current state of health (co-occurring diseases, medications used), current life situation, changes in life situation, history of disturbing behaviors, traumatic events in the past (e.g., violence, losses, hospital stay). Not once you need to complete the information - turn to family members of other people caring for a person with ASD and ID, reach for documentation or plan further observation.

##### **4.1 Steps of Interpretation**

**Step 1:** Indication to which category of worrying behavior the observed behavior belongs to (e.g., “beats on face” belongs to self-aggressive behavior).

**Step 2:** Concretization

- a. formal features of worrying behavior - from when they occur, duration, frequency, dynamics of severity,
- b. situational context of behavior – whether situations when worrying behavior occurs are similar in something/ no connection with the situation is observed, new situation, new elements in known situation,
- c. how the caregiver behaves before, during, after disturbing behaviors.

**Step 3:** Profound changes in the life situation of a person with autism (change in the life situation caused that a person with ASD and ID found himself in difficult situation, (e.g., moving, moving out siblings, divorce of parents).

**Step 4:** Traumatic events in the past of a person with ASD and ID (physical violence, abuse, sexual harassment, traffic accident, hospital stay) that could be linked causally to worrying behaviors.

**Step 5:** Formulation of preliminary meanings of worrying behaviors using based on the **themes** presented in this article.



**Step 6:** Choosing (after discussion) the meaning of worrying behaviors, i.e., what a person with ASD and ID said through worrying behaviors.

#### **4.2 Omissions/Errors of Interpretation**

- will stop at assigning disturbing behavior to the category of worrying behavior
- applying only functional analysis to the so-called difficult behaviors,
- treating non-autistic worrying behaviors as belonging to the criteria for autism spectrum disorders,
- not including other people's behaviors preceding or following worrying behavior.

### **5. Practical Implications**

Year by year, the number of adults with ASD and ID is increasing. In addition, there will be more people who will have to leave the family home and live in a permanent residence facility. This article will be helpful for caregivers working in institutions who have taken over or will take over from parents the care of adults with ASD and ID. Caregivers need psychological knowledge to understand worrying behaviors in people in ASD and ID. Then their professional activities will be more adequate to the needs, goals, expectations, health state of people with ASD and ID.

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