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Specificities of Anxiety in Children and Adolescents with Intellectual Developmental Disorder: Prevalence and Treatment

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Abstract **Review Article**

Individuals with Intellectual Developmental Disorder (IDD) face elevated rates of anxiety, challenging previous assumptions of immunity to mental health issues. Prevalence rates of anxiety disorders in this population can be as high as 84%, surpassing typical populations. Specific syndromes, genetic factors, and challenges in diagnosis are highlighted, emphasizing the need for tailored assessment tools. The SCARED questionnaire is identified as a valid tool. Psychological treatments, especially Cognitive Behavioral Therapy (CBT), show promise, but evidence is limited. Pharmacological treatments, including SSRIs, are used, but studies are scarce. This overview contributes to a more comprehensive understanding of anxiety in individuals with IDD and underscores the importance of targeted interventions.

Keywords: Anxiety – intellectual developmental disorder – intellectual disability- SCARED- specific intellectual developmental disorder.

INTRODUCTION

Anxiety, a complex emotional state characterized by apprehension, fear, and nervousness, can exert profound effects on the well-being of individuals and their families. While research has extensively delved into anxiety in typical populations, limited attention has been directed toward understanding anxiety in individuals with Intellectual Developmental Disorder (IDD).

Historically, it was widely assumed that individuals with IDD were immune to experiencing mental health issues, yet growing evidence has demonstrated otherwise. Elevated rates of mental health problems among individuals with IDD are now well established, challenging previous assumptions. Despite varying reported prevalence rates, research consistently indicates high comorbidity of mental health problems, often reaching 30-40% in this population.

Within the realm of typically developing children and adolescents, anxiety disorders frequently emerge as a prominent mental health concern). In contrast, efforts to establish corresponding prevalence rates of specific disorders, including anxiety disorders, among young people with IDD are still nascent. However, we now know that the prevalence rates can be as high as 84% and have been found to be significantly higher than in typically developing (TD) populations. As well as being associated with particular syndromes, e.g. Fragile X syndrome or Williams Syndrome, anxiety is also linked with a number of factors that are more common in the ID population. These include dysregulation of neurotransmitters; insecure attachment; exposure to negative life events, and limited social networks.

The recognition of the high prevalence of mental health disorders among young individuals with IDD has spurred interest in developing and evaluating measures tailored to identifying these disorders within this population. However, unique challenges arise when diagnosing mental illness in the context of Intellectual Developmental Disorder, including the phenomenon of "diagnostic overshadowing" and the atypical presentation of mental illness

This review seeks to shed light on a critically important yet often overlooked area of mental health research, ultimately contributing to a more comprehensive understanding of anxiety in this vulnerable population.

Intellectual developmental disorder:

DSM-5 TR characterizes Intellectual developmental disorder by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience. The deficits result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings. Intellectual functioning is typically measured with individually administered and psychometrically valid, comprehensive, and culturally appropriate tests of intelligence. Individuals with intellectual developmental disorder have scores of approximately two standard deviations or more below the population mean, including a margin for measurement error (generally ± 5 points). On tests with a standard deviation of 15 and a mean of 100, this involves a score of 65–75 (70 ± 5). Clinical training and judgment are required to interpret test results and assess intellectual performance

The Prevalence of Anxiety Disorders in Individuals with non specific Intellectual Developmental Disorder:

Considering the reported prevalence rates in literature, a wide variation was observed for anxiety disorders within this population, ranging from 3% (Stromme & Diseth, 2000) to 21.9%. Noteworthy disparities existed in rates of separation anxiety disorder, with higher figures found in studies concentrating on 5-year-olds (13.7%-17.6%), while investigations involving older children yielded lower percentages, ranging from 2.1% to 2.7%. Furthermore, a striking 10.8% rate of social anxiety disorder among 9-year-olds was reported by Green *et al*., (2014), in contrast to lower figures in studies encompassing a wider age range, ranging from 0.8% to 2.7%. Prevalence rates for generalized anxiety disorder exhibited a range of 0% to 5.4%. However, data on specific phobias, panic disorder, and agoraphobia were more limited, with generally lower rates, except for a specific phobia rate of 17.5% reported by Dekker and Koot (2003).

Importantly, a salient observation is the significantly elevated occurrence of psychiatric disorders—occurring at least three times more often—in children and adolescents with intellectual developmental disorders compared to their typically developing counterparts. This discrepancy is particularly apparent for oppositional defiant disorder (ODD), attention deficit/hyperactivity disorder (ADHD), and anxiety disorders. This co-occurring phenomenon of anxiety disorders in children with IDD follows a pattern reminiscent of children with typical development. However, the reduction in separation anxiety disorder among children with IDD manifests over a longer time span compared to those with typical development.

Moreover, it's crucial to highlight that a substantial minority of children with IDD also contend with sensory impairments such as hearing deficits or visual impairments. These additional challenges tend to correlate with higher rates of anxiety as well.

It's worth noting that in the reported studies variations were observed based on the source of information, with higher prevalence reported when parents alone provide information compared to cases where both parents and youth contribute. This could be due to parents' own distress affecting their reports or the potential challenge in identifying psychological disorders when reported by youth with IDD themselves. The inclusion of youth as informants could enhance diagnostic accuracy**.**

According to age:

In 2015, a study was conducted in the United States, involving children aged 3 to 9, with or without developmental delays. This research took place across three universities: the University of California, Los Angeles, the University of California, Riverside, and Pennsylvania State University, encompassing 190 families (79.8% of the total enrolled).

In terms of the findings, children with intellectual developmental disorders (IDD) exhibited significantly higher anxiety scores on the CBCL (Child Behavior Checklist for Ages) across all ages except at 7 years. Furthermore, they demonstrated a notably higher likelihood of surpassing clinical cutoffs for Anxiety Problems on the CBCL at ages 8 and 9, as well as on the DISC Separation Anxiety subscale at the age of 5. Notably, there were no significant group differences in DISC Social Phobia (SoP) or Generalized Anxiety Disorder across any age, with both disorders showing low prevalence rates. Sex differences were not significantly observed in the percentage of individuals meeting CBCL anxiety criteria within either the IDD-TD status group, which aligns with studies of typically developing children indicating no sex differences during pre-adolescence.

Prevalence of anxiety in specific syndromes:

The prevalence of anxiety was notably high in Rett (73 %), 7q11.23 duplication (70 %) Cornelia De Lange Syndrome (CdLS) (64), fragile X (48 %), 22q11.2 deletion (40 %), CHARGE (37 %), 3q29 deletion (19 %) syndromes and Tuberous Sclerosis Complex (14 %), with the lowest prevalence in Down Syndrome (9%). It is striking that all syndrome prevalence estimates were higher than reports from general and ID of mixed etiology populations (4% and 5% respectively; James *et al*., 2018; Maïano *et al*., 2018; Mazza *et al*., 2020). These estimates indicate the importance of clinicians knowing the cause of ID to

inform the risk of a specific, common, and treatable mental health problem.

Specific anxiety diagnosis profiles:

Fragile X syndrome experiences high rates of anxiety disorder symptomatology, with approximately 70–86.2% meeting criteria for at least one anxiety disorder, yet common occurrences are noted for specific phobia and social anxiety (Cordeiro *et al*., 2011; Crawford *et al*., 2017; Ezell *et al*., 2019; Gabis *et al*., 2011; Groves *et al*., 2018). In the case of 22q11.2 deletion syndrome, the highest prevalence rate is for specific phobia, while OCD is prominent in CHARGE syndrome (Bertrán *et al*., 2018; Blake *et al*., 2005; Jolin *et al.,* 2012; La Spata, 2019). Individuals with 7q11.23 duplication syndrome exhibit experiences of social anxiety, separation anxiety, specific phobia, and selective mutism (Abbas *et al*., 2016; Mervis *et al*., 2012). Panic attacks are reported in 3q29 deletion syndrome, and selective mutism is found in Down syndrome (Pollak *et al*., 2019, 2020). Strikingly, there is a noticeable dearth of research delving into the presentation of trauma and PTSD in genetic syndrome populations.

Earlier investigations into anxiety within Williams syndrome demonstrate a consistent pattern, with high rates of generalised anxiety and specific phobias related to noise stimuli, blood, and injury (Gothelf *et al*., 2006; Royston *et al*., 2017). These specific diagnoses have been associated with phenotypic features of Williams syndrome, such as hyperacusis and frequent medical interventions due to complex physical health challenges.

Individuals with CdLS (Cornelia de Lange syndrome) typically have social anxiety-like behavior, often accompanied by high rates of selective mutism. However, more recent evidence suggests that individuals with CdLS may exhibit symptoms indicative of a broader anxiety spectrum, including generalised anxiety, separation anxiety, panic disorder, and agoraphobia.

Risk Factors:

Risk factors for co-occurring psychiatric disorders include the severity of cognitive, adaptive, and language impairments, socialization deficits, low family socioeconomic status, trauma, and having a single biological parent as a caregiver. Certain genetic syndromes are associated with increased rates of psychiatric and behavioral disorders. Few studies have examined the risk factors for psychopathology in children and adolescents with Intellectual Developmental Disorders (IDD). However, it is presumed that a similarity exists between the risk factors in this population and those without IDD. Intellectual developmental disorder is a risk factor for the development of anxiety disorders, having detrimental effects on the development of adaptive behaviors. Children and adolescents with IDD are also believed to have a biological vulnerability to psychopathological disorders, possibly due to pre- or postnatal conditions that caused the IDD (Wallander *et al*., 2006). Additionally, intellectual developmental disorder leads to deficits in the learning process, resulting in repeated failures. These negative experiences, coupled with a low sense of control, lead to higher expectations of failure, subsequently increasing anxiety. Difficulties in social adaptation and environmental stress management can also contribute to heightened anxiety in children and adolescents with IDD. Indeed, research indicates that individuals with IDD respond to stressful situations with higher levels of anxiety.

Furthermore, when a child's cognitive development deviates from the norm, parents may become anxious. Consequently, through imitation, the child might also develop anxiety. Family members and professionals often tend to infantilize and overprotect individuals with intellectual developmental disorders, leading to dependency, fear, and avoidance responses. As a result, they have fewer opportunities than those without IDD to develop emotion management skills. Negative life events are a significant risk factor for anxiety disorders in this population. Children and adolescents with IDD are also at greater risk of being evaluated and judged negatively by society, which serves as a source of stress. Moreover, families with a child having an intellectual developmental disorder are more likely to experience social and material disadvantages compared to families with typically developing children.

Logically, other risk factors, protective mechanisms, comorbid conditions, and consequences of anxiety disorders for the general population apply to the population with cognitive deficits. In terms of developmental trajectory, anxiety might be more pervasive and lasting in the IDD population than in the general population. The developmental pathway of anxiety disorders is potentially the same for children and adolescents with IDD as it is for those without IDD. Nonetheless, it is relevant to include risk factors more specific to this population.

Challenges Associated with the Assessment and Diagnosis of Anxiety Disorders in Individuals with Intellectual Developmental Disorder (IDD):

Certain characteristics associated with IDD complicate the diagnostic process concerning anxiety disorders, particularly communication and abstraction difficulties. Communication and abstraction difficulties can hinder access to cognitions during an interview, and the individual being evaluated might struggle to describe their own symptoms. Nonetheless, the classification of anxiety disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) is formulated based on symptoms presented by individuals

without IDD and relies, at least in part, on self-reported information. The criteria for anxiety disorders as defined in this diagnostic manual encompass cognitive aspects (e.g., distress, worries, anticipation), somatic aspects (e.g., hyperventilation, sweating, dry mouth, palpitations, muscle tension), and behavioral aspects (e.g., avoidance). However, their application, especially for cognitive criteria, requires the patient to possess a certain level of intellectual functioning that enables them to report elements related to internal factors (e.g., identifying irritability, suffering, dysfunction in daily life, etc.). A similar situation applies to ICD-11.

It's noteworthy that manifestations of anxiety in individuals with mild or moderate intellectual developmental disorder are similar to those observed in the general population. The most common characteristics recorded include aggressive behaviors, agitation, insomnia,

The absence of described anxiety disorders in individuals with profound IDD could result from the complexity involved in diagnosing a population incapable of verbally or non-verbally indicating their level of anxiety in response to certain stimuli.

To address these issues, some authors suggest adaptations of DSM or ICD diagnostic criteria. These adaptations aim to facilitate the diagnostic process and depend on the severity of the individual's cognitive and adaptive limitations. They primarily involve using behavioral equivalents, taking into account the individual's cognitive and adaptive functioning. Consequently, for certain symptoms, direct observation of the individual's behaviors (or behavioral changes) is proposed instead of relying mainly on self-reported internal content, especially for individuals with severe and profound disabilities. For example, even though a person with severe to profound IDD might not be able to report the sensation of shortness of breath, it can be observed by others. It's important to note that all diagnostic criteria for anxiety disorders in the DSM-5-TR are considered applicable to individuals with mild to moderate IDD, often with very slight modifications.

In addition to the difficulties associated with IDD characteristics, several challenges can be related to the diagnostic process, including diagnostic overshadowing (clinicians attributing symptoms to the IDD diagnosis itself rather than a concurrent disorder), exaggeration of baseline levels by family members or professionals, diagnosing a mental health disorder for a phenomenon appropriate to the individual's developmental level, or psychosocial overshadowing effects (for a more detailed presentation). Moreover, it's important to emphasize that evidence-based knowledge in the field of assessing and diagnosing anxiety disorders in individuals with IDD is limited.

Assessment tools for anxiety disorders in intellectual developmental disorders (IDD):

As previously mentioned, the use of criteria, such as the DSM or ICD, may underestimate anxiety in IDD due to the reliance on items requiring verbal response and/or the description of emotions, and atypical presentations of anxiety such as self-injurious behavior. Consequently, an individual may not meet the diagnostic threshold and therefore be 'counted' within a prevalence rate but be experiencing anxiety that is impacting their quality of life.

Currently, there are no consensus guidelines for assessing anxiety in individuals with IDD, stressing the need for the consideration of issues such as the method of assessment (observation, diagnostic interview, rating scales), who completes the assessment (self, proxy), assessment outcome (symptoms/behaviors vs. diagnosis), and exploration of frequency, severity, and impact of anxiety to determine clinical significance. Clinicians need to be aware of these factors when assessing mental health in IDD and use multi-method assessment to elucidate the clinical presentation. Researchers should strive to develop tools created and validated specifically for different groups to improve the validity of diagnosis and prevalence estimates.

The SCARED is a valid and clinically useful tool for assessing anxiety in children and youth with IDD who have similar characteristics to the sample used, and who may also be eligible for specialized clinical treatment. The Screen for Child Anxiety Related Disorders (SCARED) is a 41-item self-report questionnaire to measure symptoms of anxiety in children and adolescents (aged 9 to 18 years old) widely used in clinical and research settings. The SCARED is based on the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition Revised (DSM-IV-R); however, the symptoms also correspond to those in DSM-5. There is an initial and previous version of 38 items, and these findings suggest that the SCARED yielded five factors: somatic/panic, general anxiety, separation anxiety, social phobia, and school phobia in the child version (SCARED-C) and in the parent version (SCARED-P). In addition to these versions of SCARED (38 or 41 items), there are two other versions that examine a greater number of anxiety-related disorders. The SCARED-R (66 items) is a measure with nine subscales: Panic Disorder, Separation Anxiety Disorder (including school phobia), Generalized Anxiety Disorder, Social Phobia, Obsessive-Compulsive Disorder, Post-Traumatic Stress Disorder, and three types of Specific Phobias (animal phobia, situational-environmental phobia, and blood-injection-injury phobia). The SCARED-71 is a version adding five further social phobia items that refer to aspects of social phobia such as fear of interaction with familiar people, fear of being evaluated, and psycho-physiological aspects of social phobia. SCARED has been adapted to various languages, including German,

Arabic, Chinese, Spanish, Italian, Persian, Portuguese, or Serbian.

Among the broad-based measures identified in evaluation studies, the Developmental Behaviour Checklist (DBC) and the Nisonger Child Behaviour Rating Form (NCBRF) emerged with the strongest support for the psychometric properties of their respective subscales measuring anxiety symptoms. These broad-based measures offer the potential to assess anxiety, alongside a range of other behavioral and emotional problems. These measures also have the advantage of being designed for the target population and thus reflecting the experience and expression of behavior and emotional problems specifically within this cohort. However, while both the DBC and NCBRF may provide a reliable and valid measure of anxiety symptoms, their capacity to screen for anxiety disorders remains unknown.

Neither the Reiss Scales for Children's Dual Diagnosis (RSCDD) nor the Psychopathology Instrument for Mentally Retarded Adults have been sufficiently evaluated as measures of anxiety in young people with ID, with only one study meeting criteria for inclusion in this review for each measure. Thus, further work is needed to evaluate the reliability and validity of these anxiety measures in this population. The Baby and Infant Screen for Children with Autism Traits' Anxiety and Repetitive behavior subscale also lacks an evidence base in samples without autism spectrum disorder, and importantly does not offer a measure of anxiety that is distinct from repetitive behavior.

Treatment of Anxiety Disorders in Individuals with Intellectual Developmental Disorder (IDD):

Psychological treatment:

When it comes to the psychological treatment of anxiety disorders, the literature predominantly relies on adaptations of anxiety treatments for the general population, primarily for Cognitive Behavioral Therapy (CBT). In contrast to the extensive literature available on treating anxiety disorders in the general population, there is limited empirical evidence regarding interventions for individuals with Intellectual Developmental Disorder (IDD). In fact, IDD has typically been an exclusion criterion in research investigating the effects of psychotherapy.

However, recent studies showed that CBT interventions had a positive impact on anxiety severity in both children/adolescents with ID. Results indicated that CBT could be effective for individuals with mild ID and anxiety, with positive outcomes extending to overall functioning, distress levels, quality of life, and mood. Notably, studies suggesting the most promising results tended to be recent and methodologically rigorous, incorporating various cognitive and behavioral CBT components.

Adaptations of CBT techniques were applied to participants with ID across studies, such as involving parents/support persons and using simpler language. Yet several studies lacked detailed descriptions of modifications, challenging replication efforts.

The flexibility of CBT delivery was beneficial, accommodating participants' age and cognitive capacity. While cognitive restructuring was effective, participants with moderate ID benefited more from a simplified approach, involving thought replacement and visual aids. The use of cognitive strategies tailored to individual cognitive capacities and comorbidities was highlighted.

Although these findings were encouraging, the lack of control groups and methodological limitations limited the conclusions drawn.

Pharmacological Treatment:

There have been no new studies on pharmacologic treatment of anxiety or depressive disorders in children with ID/IDD since 1999, and the treatment approach continues to be similar to that for children without ID/IDD. For depression and anxiety in children with ID/IDD, selective serotonin reuptake inhibitors (SSRIs, i.e. fluoxetine and sertraline) continue to be the treatment of choice due to their evidence for efficacy in typically developing youth. Alpha agonists (clonidine, guanfacine) and beta-blockers are sometimes used for the management of anxiety. However, there are no trials investigating the use of these medications for this indication in children with ID/IDD. Benzodiazepines are not generally recommended for the treatment of chronic anxiety in children with ID/IDD due to concern for potential heightened sensitivity to behavioral side effects such as disinhibition.

CONCLUSION

Anxiety remains one of the most common disorders in typically developing children and youths, and when it comes to people with intellectual developmental disorders, the numbers are much higher. However, despite this prevalence, research in this population is not progressing to the same extent as in typically developing individuals. Although attempts have been made to create tools to assess anxiety in this population, problems still persist.

Having lower cognitive ability appears to put children at greater risk for anxiety compared to typically developing peers. Preliminary results are mixed regarding whether anxiety presents as the same disorder in children with or without ID. Children with ID exhibit similar increases in anxiety during early elementary years, though their initial anxiety rates are higher. Additionally, anxiety may often co-occur with attention or hyperactivity problems in children with ID, underscoring the importance of screening for anxiety in

this population, particularly when behavioral problems are present.

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