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Anxiety in people diagnosed with autism and intellectual disability: Recognition and phenomenology

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ABSTRACT

Anxiety seems to occur frequently in individuals with autism, but varying prevalence estimates indicate uncertainties in identifying anxiety, especially in those with intellectual disability (ID). The present study explores the recognition of anxiety symptoms and aims to provide suggestions for the assessment of anxiety in individuals with autism and ID.

Two separate samples, a community sample of 62 individuals and a clinical sample of 9 individuals, were assessed with anxiety items from a screening checklist. Each item's scores were analyzed. In addition, in the clinical sample, checklist results were compared with clinical assessments.

The results indicate that anxiety can be recognized by symptoms similar to those in non-autistic individuals, but signs of physiological arousal seem difficult to recognize in this population. The results imply inclusion of general adjustment problems in order to identify individuals with anxiety problems by using a checklist. For diagnostic purposes, the use of an individual anxiety assessment seems indicated.

1. Introduction

Anxiety is assumed to occur frequently in individuals with autism[1] (Ghaziuddin, 2005; Howlin, 2000; Lainhart, 1999; Luscre & Center, 1996; Tantam, 2000). Reports of high prevalence rates have contributed to the growing awareness of anxiety as disorders separate from autism, and to the important implications of identifying anxiety disorders in addition to the diagnosis of autism for the conceptualization and treatment of these individuals (Gillott, Furniss, & Walter, 2001; Green, Gilchrist, Burton, & Cox, 2000; Matson & Nebel-Schwalm, 2007; Morgan, 2006). Overall, the most frequently occurring anxiety disorders in children and adolescents with autism appears to be specific phobia, generalized anxiety disorder, separation anxiety, obsessive compulsive disorder, and social phobia (MacNeil, Lopes, & Minnes, 2009; White, Oswald, Ollendick, & Schahill, 2009). However, the prevalence estimates of anxiety disorders in people with autism vary extensively (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). For example, vary reported rates in two recently published review studies between 7% and 84% (MacNeil et al., 2009; White et al., 2009). Thus, there seem to be differences and uncertainties about how anxiety may be recognized and diagnosed in these individuals.

The close relationship between autism and anxiety (Morgan, 2006; Weisbrot, Gadow, DeVincent, & Pomeroy, 2005) has led to diagnostic overshadowing (i.e. the tendency to overlook comorbid mental health problems in the presence of a

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[1] In the present paper, the term autism is used synonymously with autism spectrum disorders.

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disability; Mason & Scior, 2004). The tendency to attribute anxiety symptoms such as distress symptoms to the autism condition per se may indicate that these symptoms are overlooked, considered as less significant than the effect of the disability, or misinterpreted (Lainhart, 1999; MacNeil et al., 2009). For example, anxiety symptoms such as panic attacks and obsessions may be misinterpreted as behavior problems that are directly related to autism (Tsai, 2006), and frequent and repetitive questioning may be interpreted as signs of anxiety, or verbal rituals, or abnormal communication (Ghaziuddin, Alessi, & Greden, 1995).

Symptom overlap between anxiety and other psychiatric disorders may also contribute to the difficulties in recognizing anxiety symptoms in individuals with autism and intellectual disability (ID) suffering from other psychiatric disorders, including depression, OCD or psychosis. The association between anxiety and other psychiatric disorders, particularly depression, is well-documented in general psychiatry (Davidson, 2002; Gelder, Lopez-Ibor, & Andreasen, 2003). Anxiety symptoms coincide with depression, obsessive compulsive disorder (OCD) and psychosis and their frequency is positively related to the severity of the mental illness (Alden & Crozier, 2001; Lindenmayer et al., 2002; Regier, Rae, Narrow, Kaelber, & Schatzberg, 1998; Schneier, Johnson, Hornig, Liebowitz, & Weissman, 1992). Similar relationships between different psychiatric disorders have been assumed to occur in people with autism or ID (Dekker & Kooth, 2003; Ghaziuddin, 2005; Kim et al., 2000; Lainhart, 1999) and these assumptions have been supported by recent findings (Helverschou, Bakken, & Martinsen, 2009). Thus, it is likely that anxiety symptoms occur in many individuals with autism and psychiatric comorbidity.

Symptoms of anxiety fall into two main categories: cognitive and somatic (DSM-IV, APA, 1994; ICD-10, WHO, 1992, 1993). Somatic symptoms (i.e. signs of arousal such as hyperventilation, sweating, and shivering) are assumed to be easily recognized by an observer (Doctor, Kahn, & Adamec, 2008), although it is not known whether this is the case with individuals with autism. However, the cognitive aspect (i.e. the subjective experience of anxiety such as personal distress and worries) is difficult to recognize in individuals with autism and ID, since the only true measure of cognitive anxiety is through the person's own report of feelings of uneasiness and discomfort. Most individuals with autism and ID have difficulties in reporting the information needed to identify their anxiety problems due to their particular comprehension and communication difficulties (Gillott & Stranden, 2007; Kim et al., 2000; MacNeil et al., 2009; Melville et al., 2008; Tsai, 2006; Tsakanikos et al., 2006).

Higher prevalence rates of anxiety have been reported in the more cognitively able individuals with Asperger syndrome and pervasive developmental disorder not otherwise specified, than in individuals with autistic disorder and ID (Gillott et al., 2001; Kim et al., 2000; Sukhodolsky et al., 2008). These findings may indicate that anxiety problems are related to cognitive ability and the autism spectrum disorder subgroup (White et al., 2009). However, the special difficulties encountered when recognizing anxiety in mentally lower-functioning individuals, and the lack of specific methods for assessing anxiety in this population (MacNeil et al., 2009), may have led to underreporting and too low prevalence estimates of anxiety in individuals with autism and ID.

To sum up, the problem of recognizing anxiety in people with autism and ID is related to at least four factors: (1) diagnostic overshadowing between autism and anxiety (Lainhart, 1999; MacNeil et al., 2009; Tsai, 2006), (2) idiosyncratic or atypical anxiety symptoms (Lainhart, 1999; Myers & Winters, 2002; Stavrakiki, 1999; Tantam, 2000), (3) overlap between anxiety and other co-occurring psychiatric disorders in autism (Helverschou et al., 2009), and (4) the necessity of relying on indirect measures (observation or informant accounts) in low-functioning individuals because of their comprehension and communication difficulties.

In the present study, these obstacles are taken into consideration. The study explores the recognition of anxiety symptoms in individuals with autism and ID, and aims to provide recommendations for assessment of anxiety problems in this population. Two separate samples, a representative sample and a clinical sample of people with autism and ID were assessed with anxiety items from a screening checklist including items considered to cover both physiological arousal and the cognitive aspect of anxiety. The aim was to explore whether physiological arousal, which was the assumption, was more easily recognized than the cognitive aspect of anxiety in these individuals. In the clinical sample, assessment by checklist and reports on anxiety symptoms obtained in a comprehensive diagnostic process were compared. The aim was twofold: (1) to explore whether assessment by a screening checklist is sufficient to identify the individuals with anxiety problems, and (2) to examine in more detail how anxiety is manifested in these individuals. In particular, the anxiety symptoms that are most frequently reported (i.e. typical anxiety symptoms or more unusual expressions) were examined. Based on previous reports (e.g. Lainhart, 1999; Myers & Winters, 2002; Stavrakiki, 1999; Tantam, 2000) there is reason to suppose that descriptions of many idiosyncratic and atypical anxiety symptoms are revealed by clinical assessment.

2. Method

2.1. Participants

The community sample consisted of all persons above the age of 14 years registered with an autism spectrum diagnosis and ID in the specialized health services in Nordland County in the northern part of Norway. All registered persons and/or their guardians agreed to participate. The sample comprised 62 participants (45 males and 17 females) with an average age of 23.9 years (range 14–57 years) which represent approximately .04% of the population (Statistical Yearbook of Norway, 2006). Thirty-two participants were estimated to have mild or moderate levels of ID, and 30 to have severe levels of ID. All