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Proportions and Severity Levels of Anxiety among Children and Adolescents Presenting with Autism Spectrum Disorder in two Schools in Nairobi, Kenya.

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ABSTRACT

Autism is one disorder among a spectrum of disorders known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD). It is a general term that describes mental ailments that has diverse symptoms and characteristics. These include; restricted/repetitive patterns of behaviour, interests, and activities during the early developmental period. Others exhibit hyperactivity, aggression and anxiety. The individual's functionality is impaired requiring early intervention. Anxiety is a common comorbid and if left untreated affects the social functionality in ASD. This study looked at the proportion and levels of severity of the anxiety in a sample of 80 school children and adolescents with ASD. The goal of this study was to determine the levels, proportions and severity of anxiety among children presenting with ASD. The sample of 80 children and adolescents with ASD were observed and rated by their parents/teachers/caregivers using the Child and Adolescent Symptom Inventory (CASI) to measure anxiety. Eighty four percent of the total sample met cut-off criteria of at least one anxiety disorder. Anxiety was associated with poor coping skills and greater impairments in social reciprocity. Anxiety is a common comorbid in ASD which requires clinical assessment and treatment. It is important to those who deal with children and adolescent with ASD to understand the symptoms and management of anxiety both in school and other settings (home, social places).

Introduction

Autism is defined as a disorder beginning in childhood, marked by the presence of markedly abnormal or impaired development in social interaction, communication and a restricted repertoire of activity and interest (ICD-10-CM). Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. Globally, it is estimated that, one child in every 160 suffers from Autism (WHO, 2014). Studies conducted over the years have shown an increase in autism around the world.

Autism is one disorder among a spectrum of disorders known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD). It is a general term that describes mental ailments that has diverse symptoms and characteristics. ASD is said to be present in a wide variety of combinations, so individuals who have it, can exhibit any combination of the behaviours in any degree of severity as described in the DSM-5 (Weitlauf, McPheeters, Peters, Sathe, Travis, Aiello, Williamson, 2014). Individuals with ASD may only display the restricted/repetitive patterns of behaviour, interests, and activities during the early developmental period.

ASD is usually seen as a life-long diagnosis.

However, during various phases of development, the clinical picture often changes. For instance, there are children who fall just within the classification and who after some time can fall outside it (Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert et al., 2008).

Key predictors for long-term progression are language development (presence of communicative speech at the age of 5) and intelligence level. Early detection of ASD is important to reduce the problems and to promote the child's development. Early diagnosis of ASD increases chances for children to access early intervention services, which is fundamental to achieving positive outcomes as early on as possible (Lovaas, 1987; Reichow and Wolery, 2009; Rogers and Vismara, 2008; Boyd, Hume, McBee, Alessandri Anibal, Johnson, 2014; Magiati, Tay, & Howlin, 2012; Prior, Roberts, Roger, & Williams, 2011).

Anxiety disorders in children with ASD are highly reported and of concern in treatment (White, Attwood, & Scarpa, 2009). A study by White (2013) stated an age-related upsurge in the prevalence of anxiety disorders in a birth cohort that increased from 7.5% at 11 years of age to 20.3% at 21 years of age in USA. A similar report confirmed that rates of anxiety disorders increased with age, from 14.7% at 12–13 years, to 22.0% at 16–17 years of age (Costello, Egger, & Angold, 2004; Essau, Conradt, & Petermann, 2000).

The prevalence of anxiety problems in school-age children and adolescents with ASD is in the range of 40–45 % in the USA (White et al. 2009). This is noticeably higher than the incidence of anxiety disorders in epidemiological studies of children in the general population which was at 5–10 % to 31.9% (Costello, Egger, & Angold, 2004; Merikangas et al., 2010). Further, studies have confirmed higher anxiety levels in children with ASD than typical

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developing children (Bellini, 2004; Gillot, Furniss and Walter, 2001).

In an attempt to ascertain the prevalence of ASD in Africa, children with intellectual disabilities were screened in Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa by Lotter (1978) and found out that 9 out of 1312 children had ASD. The study also found out that, among other things, there were certain differences in the frequency of specific behaviours between African children and children from Western Europe and USA (Bakare & Munir, 2011;

Bernier, Mao, & Yen, 2010). While a recent review indicated that there was a discrepancy in prevalence of autism spectrum disorders across cultures and regions, a typical standard community based epidemiological data for the African sub-region was lacking(Springer, Toorn, Laughton, & Kidd, 2013; Zaroff & Uhm, 2011).

Children and adolescents, who experience anxiety, may be predisposed to information processing, unhelpful thoughts, and physiological hyper arousal (Harkema and Coffee, 2014). Some symptoms however may look different from typical children. To offer necessary support in treatment, ASD awareness is crucial for practitioners both medics and paramedics (such as doctors, psychologists, social workers, teachers e.t.c). Further, the impact of anxiety is not only left to children but the caregivers and their families as well. Past research has found that having a child with ASD can be a source of stress for parents. Caregivers of children with ASD, especially mothers, have been found to experience higher levels of stress than both the general population and parents of children with other developmental disabilities. A study conducted in Kilifi, Kenya, noted that parents of children with autism are faced with emotional stress, guilt, financial hardships, and disrupted family relationships (Gona, 2010). The added perception of children with autism as possessed or cursed, in much of Africa, only worsens an already difficult family environment (Gona, 2010; Riccio, 2011).

Anxiety impacts children with ASD in various ways. Among the adolescence with ASDs, anxiety can evident itself in excess inflexibility, intense intolerance, and extreme avoidance of the various triggers associated with anxiety (Storch, Arnold, Jones, Ale, Wood, Ehrenreich-May et al., 2012). In children and adolescents with ASD, anxiety can cause increase difficulties with concentration, fatigue, disturbed sleep, and excessive irritability (Reaven, 2008). Additional symptoms include social confusion, heightened sensory defensiveness, weakness in perceiving emotions, negative or angry social interactions, and extreme difficulty with change (Ollendick and White, 2012). Lastly, youth may exhibit an amplified persistence to rules and routines, engage in high levels of repetitive behaviors, or present with increased amounts of silly or explosive behaviors (Dasari, 2012).

Anxiety is one of the most common disorders reported among young people (AACAP 2007). Higher rates of anxiety disorders have been reported in adolescence as compared to childhood in ASD population (Kuusikko et al., 2008; Weisbrot et al., 2005; White et al., 2009).

This creates awareness for those working with younger and the older children. Further, it alerts the practitioners(doctors psychologists, teachers e.t.c) that adolescents may have an extremely tough time expressing their anxiety, so that an upsurge in anxiety may manifest itself as an increase in challenging behaviour (Minahan & Rappaport, 2013).

This means that children may have difficulty expressing their emotion.

Therefore to offer a responsive intervention most needed, early identification of needs by screening for symptoms of anxiety is recommended (Mayes et al., 2011).

While separation anxiety disorder is less prevalent in adolescence as compared to childhood, other anxiety disorders such as generalized anxiety disorder and social anxiety disorder are prevalent (Reaven, 2011; Westenberg, Gullone, Bokhorst, Heyne, & King, 2007; White et al., 2009). Preferably, the assessment of anxiety disorders in ASD should be conducted using multiple informants and modalities on the grounds that children with ASD often do not show age-typical symptoms of anxiety (White et al., 2009).

This also reduces any possibility of bias or over-reporting of informants. This may strengthen findings especially in countries where assessment services have not been established such as Kenya, by use of multiple informants to validate the outcome.

Recruitment

To be eligible for the study, children had to be five to 21 years of age and meet the ASD criteria according to DSM-V and confirmed with the Autism Behaviour Checklist tool. There were 40 children recruited for this study (20 children from experimental school and 20 from control school).

One participant in the experimental school did not meet the ASD criteria and was excluded; one participant had worsening self-harm and the parents sought for close supervision off school. That left 40 participants in the experimental school.

In the control school all the 42 participants screened met the criteria. One relocated out Nairobi city had to change school; another one declined to take part in the study and was excluded from the study. Both experimental and control were left with 20 participants each (n=40) in the study and all completed the study. Due to limited schools with children with ASD, all the available cases that met the inclusion criterion formed the sample. The sample included the children and adolescents with ASD. Further, the schools for study were purposively selected and further randomly assigned to treatment MASSI (experimental) and no treatment (control).

Measures:

a. The Autism Behaviour Checklist (ABC)

The ABC is a 57-item informant-based measure of problem behaviours of individuals with developmental disabilities, rated on a 4-point Likert scale (Aman, Singh, Stewart, & Field, 1985). Based on split-half reliability, intra-rater reliability was reported as a Spearman-Brown coefficient of .94, and interrater reliability as 95% agreement (Krug et al., 1993).

b. Child and Adolescent Symptom Inventory-4 ASD Anxiety Scale (CASI-Anx; Sukhodolsky et al., 2008)

CASI was developed as a dimensional rating of overall anxiety severity (White, 2013) the CASI-Anx is comprised of 20 symptom DSM- IV based items. The CASI-Anx is completed by the parent or caregiver making it applicable where cognitive skills are deemed low (Sukhodolsky et al., 2008).

Results

The research investigated the proportions and severity levels of anxiety disorders among children presenting with ASD in primary and secondary school. The children with ASD are in primary and high school ranging from six years to 20 years. They are at different levels academically despite their mental and chronological age.

The outcomes show that children were generally assessed to have mild levels of anxiety.

Table 1: Social Demographic Characteristics of the Study Population (n=20)

Background Variables	Labels	Control School		Experiment School		Overall	
		Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Sex	Male	13	65.0%	14	70.0%	27	67.5%
	Female	7	35.0%	6	30.0%	13	32.5%
Level of Schooling	Junior	11	55.0%	8	40.0%	19	47.5%
	Middle	3	15.0%	6	30.0%	9	22.5%
	Senior	6	30.0%	6	30.0%	12	30.0%
Age	< 10 Yrs	5	25.0%	7	35.0%	12	30.0%
	10-14 Yrs	7	35.0%	6	30.0%	13	32.5%
	15-19 Yrs	6	30.0%	4	20.0%	10	25.0%
	20 - 24Yrs	2	10.0%	3	15.0%	5	12.5%
Parents		Number	Percent	Number	Percent	Number	Percent
Religion	Protestants	15	75.0%	15	75.0%	30	75.0%
	Catholic	5	25.0%	5	25.0%	10	25.0%
Marital status	Married	19	95.0%	19	95.0%	38	95.0%
	Single	1	5.0%	1	5.0%	2	5.0%

Table 2: Levels of Severity of Anxiety amongst Children Presenting with ASD at Baseline

Category	**Anxiety Level**	**Control School**		**Experimental School**		**p-value**	**Kappa Coefficient**
		Number	**Percent**	**Number**	**Percent**		
Parent	Low	6	30.0%	2	10.0%	0.127	-0.143
	Mild	14	70.0%	16	80.0%		
	Moderate	0	0.0%	2	10.0%		
	Total	20	100.0%	20	100.0%		
Teacher	Low	4	20.0%	1	5.0%	0.184	0.000
	Mild	12	60.0%	9	45.0%		
	Moderate	3	15.0%	8	40.0%		
	Severe	1	5.0%	2	10.0%		
	Total	20	100.0%	20	100.0%		
Overall	Low	10	25.0%	3	7.5%	0.048	-0.063
	Mild	26	65.0%	25	62.5%		
	Moderate	3	7.5%	10	25.0%		
	Severe	1	2.5%	2	5.0%		
	Total	40	100.0%	40	100.0%		

However, scoring by teachers showed cases of children and adolescents severe anxiety levels at 5% (1) in the control and 10% (2) in the experimental schools. There is an association between school type and anxiety levels ($p = 0.048$). However, this association doesn't exist when assessment of the teachers and parents are performed differently ($P>0.05$).

At baseline, the majority of the respondents had Mild Anxiety based on their Anxiety status despite the fact that 91.3% of the sample had moderate and high presentation of ASD. This indicates that level of ASD does not positively correlate with level of anxiety.

In Africa, as noted earlier there is limited research work in this area. Although anxiety is a comorbid in ASD, it is not a highly prevalent comorbid condition in association with autism spectrum disorders among African children (Bakare & Ikegwuonu, 2008; Belhadj et al., 2006). This finding corroborated with observation made by Mankoski et al. (2006) in their study in Tanzania. Similarly, this study found that anxiety in ASD was not easily recognized by the caregivers.

Variations do exist as shown by literature originating from Africa on symptoms presentation and comorbid conditions (Bakare et al., 2011; Lotter, 1980). Further findings of many studies in Africa show a low level of knowledge and awareness about ASD among the general populace and health workers, thereby compromising early recognition of the disorder (Bakare et al., 2008; Bakare et al., 2009; Igwe et al., 2010; Igwe et al., 2011; Maulik & Darmstadt, 2007; Riccio, 2011). Additionally, the diagnosis of anxiety especially in ASD is complicated (Joshi et al., 2010; Leyfer et al., 2006; White, 2010). Thus, lack of awareness explains further why anxiety and social skills deficit continue to receive no attention in identification and treatment as well.

Anxiety disorders actually does exist in the African children with ASD as observed in this study. The nature of African culture which is more accommodative, interactive and working interdependently lacks the definition of anxiety (Bakare et al., 2008; Sue & Sue, 2008; Trembath et al., 2005). Therefore, the relationship between ASD and anxiety disorders among African children exists and there is need to identify those with anxiety disorders and push for their treatment.

Further, it is important to note that although culture is an aspect that has recently drawn interest worldwide as worthy noting in ASD presentation across borders (Bakare et al., 2011; Lotter, 1980).

Clinical implications

The impact of anxiety not only affects the child but the parent and teacher as well (Green, 2007; Gona, 2016; Weiss & Lunsky, 2013). Withdrawing these children from social life or locking them up in houses does not help to lower anxiety or better their social skills (Riccio, 2011). Further, parents give up their livelihood to give care to their children, which in the Kenyan setting could lead to ASD symptom severity and therefore the development of anxiety disorders (Khasakhala, 2012).

This study found that the caregivers/parents and teachers of children with ASD might benefit greatly from more awareness about anxiety symptoms and its association with social skills deficits and education, and the importance of psychosocial treatment.

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