THE PREVALENCE AND CHARACTERISTICS OF PSYCHIATRIC DISORDERS AMONG ADOLESCENT BEDOUIN WITH MILD TO MODERATE INTELLECTUAL DISABILITY

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The aim of this study was to examine the prevalence and types of psychiatric disorders among Bedouin adolescents with mild to moderate intellectual disability. This is the first study ever conducted on this topic within the Bedouin community in the Negev in Israel. The issue of psychiatric disorders among adolescents with intellectual disability is a complex one in general and even more so among the Bedouin population in the Negev, because of the large number of intellectually disabled children and adolescents in this community.

The research population included 30 parents of 30 Bedouin adolescents with a mild to moderate intellectual disability attending a special education school in the Bedouin sector. The study used four research tools: the Schedule for Affective Disorders and Schizophrenia for School Aged Children (6-18 Years) Kiddie-Sads Present and Lifetime Version (K-SADS-PL); the Yale-Brown Obsessive Compulsive Scale (CY-BOCS); the Autism Screening Questionnaire (ASQ); and the Severity Scale of the Stereotyped Behavior Scale (SBS).

The research results confirmed the initial hypothesis that there would be a high rate of psychiatric disorders in the research sample. Research findings indicated that 77% of the adolescents had at least one psychiatric disorder during the evaluation. The most common of these were autism-spectrum disorders 70% (21); disruptive disorders 47% (14); attention deficit and hyperactivity 47% (14); and anxiety disorders 40% (12). Other psychiatric disorders of lower frequency were also found and discussed in the findings. It is essential to continue the work started in this research, of examining the kinds and rates of occurrence of psychiatric disorders, on a larger sample of the same population, as well as paying closer attention to the disorders that this research found to be less common. On the level of practical implications, the main recommendation of this research is the need to develop diagnostic services and psychiatric and educational care for children and adolescents with intellectual disability in the Bedouin community in the Negev.

The issue of psychiatric disorders among adults with intellectual disability is complex for several reasons. Firstly, there is a dispute as to the psychopathological definition of *intellectual disability*. Secondly, researchers and professionals in the field are still trying to understand the nature of the interaction between disability and psychopathology. Thirdly, there is insufficient evidence as to the reliability and validity of current DSM or ICD systems in the population (Einfeld & Aman, 1995). The fourth point is defined by Reiss (1994) who coined the phrase for the phenomenon whereby severe emotional problems may appear less important than they actually are, when viewed in the context of the debilitating effects of Intellectual Disability.

Carvill and Marston reinforce this point by emphasizing that symptoms of psychiatric disorder in people with intellectual disability may go undiagnosed for long periods because of *diagnostic overshadowing* (Carvill & Marston, 2002). In addition, most of the diagnostic criteria used to diagnose the normal population are based on verbal symptoms. The verbal component in the existing criteria may be rendered invalid when diagnosing children with limited verbal skills (Cooper et al., 2003).

Finally, it may be that due to the complexities and difficulties presented, psychiatrists and psychologists are inclined to diagnosing psychiatric disorders among adults with intellectual disabilities by relating them to emotional and behavioral symptoms as an integral part of the disability. There might also be a misdiagnosis of the disorders. Wrong diagnoses are connected to the fact that children

with intellectual disability express their symptoms less clearly (for example feelings of anxiety or depression) and present symptoms that are less familiar to child psychiatrists, for example, stereotypical behavior and self-injury.

Despite the above, study findings indicate that the prevalence of psychiatric disorders among children with intellectual disabilities is higher than among children without intellectual disabilities (Whitaker & Read, 2005; Emerson, 2003; Rutter et al, 1970). Einfeld and Aman (1995) state that intellectually disabled children are reported to have about two to four times the level of emotional disturbance compared to other children. There is also evidence that the rate of psychiatric disorder is higher for children with a greater degree of intellectual disability. Stromme and Diseth (2000) and Gillberg et al. (1986) found higher rates of psychiatric disorders among children with IQ levels below 50 or 60. A study by Gostason (1985) also provides evidence that the rate of psychiatric disorders is greater in people (both children and adults) with severe intellectual disability.

There are a number of disadvantages to the data based on the existing research findings: as of today, most studies on psychiatric disturbances among adults with intellectual disabilities relate to children and adults as one group without distinguishing between them. Another disadvantage of previous studies is that most of them were based on behavioral questionnaires that yielded numerical marks for a broad group of psychiatric symptoms. Only a few studies were based on structured psychiatric interviews leading to a clear psychiatric diagnosis (see e.g. Molteno et al., 2001).

A diagnosis distinguishing between mental disorder and intellectual disability in early childhood is particularly difficult since the child is still developing and experiencing frequent changes. It is also difficult to reach a diagnosis because the information received from the surroundings is not clear-cut. Obtaining a definitive diagnosis for adolescents is also difficult due to the nature of adolescence as a period of complex developmental challenges that often constitute a crisis for many of those with an intellectual disability.

In Israel, there is a lack of information about the prevalence of psychiatric disorders among adolescents with an intellectual disability for both the Jewish and the Arab populations. An examination of the subject among the Bedouin population in the Negev is even more complex since there is only partial information regarding the number of intellectually disabled children within this community. Existing information regarding the percentage of children with special needs in the Arab population mentions 9.7% compared with 7.6% for the Jewish population (Or-Noy, 2007). It can be assumed that this rate actually underestimates the true rate among the Arab-Bedouin population of the Negev due to the difficulty of conducting diagnostic tests and poor awareness among the population (for more information about the difficulties in diagnosing children with special needs within the Bedouin community, see Manor-Binyamini, 2007). In addition, a significant number of children in the Negev Bedouin population have intellectual disabilities, the main reason for this being the tradition of marrying within the tribe and even within the family (Raz, Atar, Rodnay, Shoham-Vardi & Carmi, 2003). Bedouin villages are characterized by lower than average family income in Israel, and the acute socio-economic distress of numerous Bedouin families is another contributing factor to intellectual disability (Lithwick, 2002, p. 2).

In this context, it is important to point out the research findings of Koskentausta et al. (2007), who state that low socio-economic status of the family increased the risk of disruptive behavior. A diagnosis can contribute to the clinical and educational care system, other support services, and to continued research in the future (Cooper et al., 2003). Also, a better understanding of the ways in which psychiatric disorders are expressed in people with intellectual disabilities can give insight into the nature of both psychiatric disorders and intellectual disabilities. This kind of understanding in the Bedouin sector is essential. Researching the subject will facilitate raising awareness of diagnostic issues and subsequent work towards more standardized and improved clinical diagnostic practices.

The goals of this research are, first, to examine the prevalence of psychiatric disorders among adolescents with mild-moderate intellectual disability in the Bedouin sector, and secondly, to examine the types of psychiatric disorders among this population. The hypothesis of this research is that there will be a high rate of psychiatric disorders in the study sample – Bedouin adolescents with intellectual disability.

Method

Research Participants Population

The research population included adolescents with mild to moderate intellectual disabilities who attended a special education school in the Bedouin sector. The students were defined as having intellectual disability according to the following definition of the Ministry of Education, based on the Israeli Welfare Law: Care of the Mentally Retarded (2000):

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

The school attended by the research participants had 14 classes with seven students in each. There were a total of 98 students in the school. The research participants had been officially diagnosed as having mild or moderate intellectual disability as determined by the Ministry of Education. The Chief Scientist of the Ministry of Education authorized the study. The adolescent students themselves were not interviewed, only their parents. It is important to point out that the reliability and validity of psychiatric interviews with intellectually disabled children and adults have not yet been confirmed from a research point of view. Consequently, most of the studies of this population relied on reports by the parents or professionals providing them with support services and therapy. Furthermore, it can be difficult to elicit psychopathology when a person has limited verbal communication skills with which to describe inner emotional experiences. Hence the assessor must heavily rely on informant information (Cooper et al., 2003).

Thus, the present study also relied on informant information from the parents. Out of the 98 sets of parents of the students in the school, 30 agreed to be interviewed (31%). The aim of the study was explained to the parents in a personal meeting (one parent was interviewed from each set of parents) and they gave their consent to be interviewed. All the interviews were conducted in the parents' homes or tents, which presented unique challenges for this study and special research preparation for several reasons.

First, Bedouin custom does not welcome psychiatrists in the community. Bedouin society is traditional and secluded and views strangers entering their villages with suspicion. This meant that comprehensive preliminary work was needed before entering the villages where the interviews were to take place. For each village, the researcher made contact with the local leaders and obtained their cooperation. Secondly, physical access obstacles had to be overcome due to the lack of paved roads and due to difficult weather conditions – extreme heat in the summer, and mud and rain in the winter. In addition, locating the tents and houses of the study sample according to maps of the settlements required on-the-spot orientation skills.

The students in the study were aged 12-21; there were 21 boys and 9 girls. All of the subjects were Bedouin from different tribes; some were from permanent known settlements while others were from unknown encampments scattered throughout the Negev. Out of the 30 adolescents who participated, 71% had genetic syndromes such as fragile-x, velocardiofacial, Down and Williams syndrome. The rate of genetic syndromes in the study sampling is higher than the rate reported for populations of children and adults having mild-moderate intellectual disability in other studies. This is because of the unique characteristics of the population in this study (Manor-Binyamini, 2007).

Research Tools

Four research tools were used in this study: Schedule for Affective Disorders and Schizophrenia for School Aged Children (6-18 Years), Kiddie-Sads-Present and Lifetime Version (K-SADS-PL); the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) for children; the Autism Screening Questionnaire (ASQ), and the Stereotyped Behavior Scale (SBS)

Schedule for Affective Disorders and Schizophrenia for School Aged

Children (6-18 Years): Kiddie-Sads-Present and Lifetime Version (K-SADS-PL).

A certified psychiatrist who translated the English diagnosis into Arabic interviewed all the parents. In cases where for certain categories of symptoms in the screen interview there were suspicions about the diagnosis, the full version of the relevant interview was offered for the same possible diagnosis. Psychiatric disorders present that were not included in the interview were evaluated using screening questions based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000). The DSM was used even though previous literature has

demonstrated that it has certain limitations when used with adults with intellectual disabilities. Despite criticisms, mental health professionals use the DSM-IV widely and there have been a number of attempts to modify it for use with subgroups, such as adults with intellectual disability.

Two child and youth psychiatrists analyzed a summary of the information collected from the diagnostic process, and the diagnosis was presented by consensus according to the DSM-IV-TR.. *The Yale-Brown Obsessive Compulsive Scale (Y-BOCS) for children* was passed on to parents as a semi structured interview. The questionnaire has become the most widely used assessment instrument for evaluating the severity of symptoms in obsessive-compulsive disorder (McKay et al., 2003).

The questionnaire is composed of five items for obsessions and the same five items for compulsions. The five items are: time spent, interference, distress, resistance, and control. A severity scale of zero to four is used to give marks for each of the items. The three marks from the conclusion were calculated. These included obsessions (0-22), compulsion (0-20), and a general mark (40). This questionnaire is reliable and valid for studies on adults with genetic syndromes expressed as an intellectual disability (Dykens, 2004).

Autistic symptoms were evaluated using *The Autism Screening Questionnaire* (ASQ). This questionnaire is structured in such a way that one of the parents can fill it in without guidance. It contains 40 questions. Every item in the questionnaire receives a mark of one (for the existence of deviational behavior) or zero (for the absence of deviational behavior), the total number of points ranging from 0-40. The questionnaire is valid for distinguishing individuals with Autism Syndrome Disorder from individuals with other psychiatric and developmental disorders and from individuals with learning disabilities (Berument et al, 1999). Marks of 15 or more in this questionnaire distinguish between children/adults with autism spectrum disorders and those without. There is a sensitivity of 0.85, specific of 0.75, and a positive prediction of 0.93.

The Stereotyped Behavior Scale (SBS) consists of 24 items, each item describing one kind of stereotypical behavior. On this scale, zero indicates absence of a behavior while three indicates a degree of behavior defined as severe. Behavior evaluation was based on the interview with the parents. The SBS has good internal consistency and high reliability. High correlations were found between this questionnaire and other scales that check stereotypes, such as the 'Stereotypy' scale of the Aberrant Behavior Checklist (Rojahn et al. 2000).

Results

As the first study of its kind, most of the data it presents at this initial stage relate to the examination of prevalence and distribution of disorders by type. The distribution of highly prevalent types of disorders in the study population is shown in Table 1.

Table 1

Distribution of the most prevalent types of disorders among adolescent Bedouin with mildmoderate intellectual disability

Diagnosis	Study Findings
	N=30 (number of participants)
Psychiatric disorder (any type)	77% (23)
Autism spectrum disorder	70% (21)
Disruptive disorder (any type)	47% (14)
Attention and hyperactivity disorder	47% (14)
Anxiety disorder (any type)	40% (12)
Specific phobia	17% (8)

Out of the sample, 77% were described as having at least one psychiatric disorder at the time of the evaluation. The average number of psychiatric disorders per subject was 2.1. Only one significant difference was found between boys and girls: impulse control disorders were found among boys, but not among girls: fourteen percent of boys compared with zero percent of girls.

The most prevalent diagnosis was autism spectrum disorder. Seventy percent (21) of the participants in the study answered the criteria of the DSM-IV-TR for autism spectrum disorders, i.e. 70% (21) of the participants scored 15 (or higher) on the autism-screening questionnaire, 15 being the cut-off point for autism spectrum disorders. An interesting finding was that some of the adolescents belonging to this

group had co-morbidities. These included: oppositional defiant disorder 50% (15), general anxiety disorder 40% (12), and stress disorder 20% (6). Co-morbidity was clearly higher in this sub group (average -2.9, standard deviation -1.9) than in those without this disorder.

In addition, the score for obsessive-compulsive disorder was clearly higher among adolescents with autism-spectrum disorder than those without (average = 15.7, standard deviation = 5.3 compared with an average of 10.0, standard deviation = 5.1, z=2.8, P0.01). A significant correlation was also found between the scores on the Autism Screening Questionnaire and on the Stereotyped Behavior Scale (r=0.33, P 0.01). Other highly prevalent diagnoses were disruptive disorder, in 47% (14) cases, and attention deficit hyperactivity disorder, in 47% (14) cases. Combined disorder was found among 17% (5); attention deficiency was found among 13% (4),; and hyperactivity-impulsivity was found among 7% (2). Anxiety disorders were found among 40% (12). Overall, the most common symptoms among the autistic children were: any anxiety disorder 33% (10), separation anxiety 13% (4), and generalized anxiety 17% (5). Bipolar affective disorder was found among 3% (1), and enuresis among 7% (2).

Anxiety disorders existed among 14% (4) of the participants in the study (boys only) 13% (4) fulfilled the criteria for impulse control disorder (trichotillomania); 10% (3) for intermittent explosive disorder; 3% (1) for pyromania, and only 7% (2) of the participants for psychotic disorders: schizophreniform disorder for one participant, and psychotic depression for the other. One type of panic was reported by 23% (7) of the participants, but the panic included adaptive disabilities among only 20% (6) of the participants and fulfilled the criteria of the DSM-IV-TR for specific phobia. The most common phobias were fear of the dark 17% (5); fear of loud noises 13% (4); anxiety caused by factors in their natural environment 7% (2), and animals 7% (2). Thirteen percent (4) answered the diagnostic criteria for obsessive-compulsive disorder. The most common symptoms in this group were aggressive obsessions, repetitive questions, repetitive actions, and somatic obsession.

The average number of obsessions for each participant in this sub group was 2.6, and their average severity according to the Yale-Brown Obsessive Compulsive Scale questionnaire for children in the interview was 9.7. The average number of compulsions (standard deviation) was 3.2 and their average severity was 12.5%.

The findings of this study regarding aberrant behavior show oppositional defiant disorder 13% (4) and behavioral disorder 10% (3). In addition, disorders having low prevalence were found: bedwetting 10% (3), tic disorders 7% (2), eating disorders 7% (2), suicidal thoughts 3% (1), suicide attempts 3% (1), and impulse control disorder 3% (1).

Discussion

This is the first study in the Bedouin sector to examine the prevalence and characteristics of psychiatric disorders among adolescents with intellectual disability. The data are based on examining the division of the types of disorders compared with existing research data about this research group. The lack of data regarding the adolescent population with mild to moderate intellectual disability within the Bedouin sector in Israel does not enable a comparative evaluation. Therefore a comparison with previous literature was made.

In the study, psychiatric disorders were found at a rate of 77% among these adolescents. The initial hypothesis, that the percentage of psychiatric disorders among adolescent Bedouins in the Negev would be higher than the percentages presented in literature on adolescent groups with intellectual disability, was reinforced in this study: in the literature, the incidence of psychiatric disorders was reported to be 45.1% (clinical diagnosis) or 52% (DC-LD diagnosis) (Cooper et al., 2007). It may be that the high rate presented in this study, which included only adolescents, is derived from the unique characteristics of the population studied, or, as explained by Dykens (2002), in some adolescents with mental retardation there are also biological vulnerabilities that mediate increased risk of psychopathology.

The most common finding in this study was an autistic disability 70% (21). This finding is uncommonly high compared with the corresponding figures in the literature, which fluctuate between 8.7% (Emerson, 2003) and 21.9% (Dekker & Koot, 2003). However, this finding is not surprising, because other researchers have also reported autistic behavior to be more prominent in persons with intellectual disability (Hardan & Sahl, 1997; Koskentausta et al., 2001).

It is interesting to note that the severity of the autistic symptoms explains 39% of the variance of obsessive-compulsive symptoms. Kanner & Eizenberg (1957) noted that children with autism desire similarity, which is expressed in their engagement in rituals. It is also worth mentioning that children with neurogenetic syndromes related to intellectual disability, such as Prader- Willi, and velocardiofacial syndrome, have high rates of autism-spectrum disorders. It is, therefore, important to look for genetic syndromes and autism-spectrum disorders together among adolescents with intellectual disability.

The common high incidence of autism-spectrum disorders found in this study is compatible with the ethological and pathophysiological brain paths, which are seemingly common for both obsessive-compulsive and autism-spectrum disorders, as reported in a study by Bejerot (2006, 2007) and Gross-Isserhoff et al. (2001). The study findings showed that attention deficit and hyperactivity disorders were also highly prevalent, occurring in 47% (14) of the cases. In comparison, Koskentausta, Livanainen, and Almqvist (2001) reported 12% of hyperactive behavior in children with intellectual disability. The findings of this study regarding aberrant behavior were oppositional defiant disorder (13.8%) and other behavioral disorders (4.6%), which were lower than the corresponding rates reported in the literature (Stromme & Diseth, 2000: Emerson, 2003; Linna et al., 1999).

Limitations of the Study

The study presented in this article has several limitations. First the sample was small. Also, all psychiatric evaluation was carried out only by interviewing the parents. No clinical evaluation of the adolescents was conducted, and neither was information collected about the parents or the members of the team working with the adolescents. An evaluation of the adolescents and the members of the team working with them would have provided additional important information and would have strengthened the diagnoses found in the study. Another limitation was the lack of a control group of adolescents in the Bedouin community who did not have intellectual disability. A comparison with a control group would have enabled an evaluation of the prevalence of different psychiatric diagnoses among adolescents with intellectual disability compared to adolescents without intellectual disability in this community.

Conclusion

This is the first study made on this subject in the Bedouin sector in the Negev, Israel. The results show a very high incidence of psychiatric disorders among adolescent Bedouin with intellectual disability (77%). The hypothesis that there would be a high incidence of psychiatric disorders in this population was confirmed in the sample. Such high incidence suggests that psychiatric disorders in this population are under diagnosed. This finding is groundbreaking for the simple reason that this group has not been studied before. This study also had important practical implications for the participants of the study sample, who had never been diagnosed by a psychiatrist or any other professional before the study, and were referred for treatment following the study's findings,

Overall, the current research has several implications. Firstly, it emphasizes the need for developing diagnostic services and psychiatric and educational care for children and adolescents with intellectual disability in the Bedouin sector. Diagnosing psychiatric disorders in populations with intellectual disability is a complex and time-consuming task since they often fail to communicate their hardships clearly. This causes professionals to sometimes mistakenly interpret the behaviors and hardships they express. Without a diagnosis, adolescents with a learning disability do not receive psychiatric and behavioral care that addresses their problems, or receive treatment that suits neither their needs nor their diagnosis. Therefore, it is recommended to provide the multi-disciplinary teams in special education schools with the following information: characteristics of the disorders commonly found in this study, the questions that need to be asked and behaviors to be expected, so that they can give students an initial diagnosis. Alternatively, they could be trained to use a structured survey, which would constitute an initial diagnosis. A diagnosis is the first step that provides a basis for continuing treatment for this population.

Secondly, it would be beneficial to give a course on the aspects of psychiatry for populations with intellectual disability as a first step in training specialists to diagnose the population with intellectual disability within the Bedouin sector. Extensive educational programs also need to be encouraged. There is clearly a need for further research that will extend the study sample to the populations of two other schools in the Bedouin community, and compare the present study's findings with a control group of adolescents in this community who do not have intellectual disability. Finally, there is a need for

methodologically sound studies of children with special needs in the disparate Bedouin community who do not attend special education schools.

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