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Correlates of early assessment of neurodevelopmental disorders in Lebanon

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Children with neurodevelopmental disorders who receive early therapeutic interventions present a better developmental pathway than children who do not. Early assessment of neurodevelopmental disorders is the first step in this process. This study aims at describing the variables that are in play in the first assessment of children with autism spectrum disorder (ASD) or intellectual developmental disorders (IDD) in a mental health clinic in Beirut Lebanon. A total of 209 charts covering a period of two years were analysed. Demographic and clinical variables influencing early assessment of neurodevelopmental disorders were found similar to those identified in the international literature with one critical exception, the age at assessment. The average age for diagnosing ASD was four years and seven months and seven years and five months for diagnosing IDD. This finding supports the need for developing a comprehensive national strategy for the early identification of neurodevelopmental disorders.

Keywords: early assessment; autism spectrum disorder; intellectual developmental disorders; Lebanon

Neurodevelopmental disorders are a group of disorders sharing common genetic risks, cognitive impairments, and deficits. Autism spectrum disorder (ASD) and mental retardation fit under this meta-structure. These disorders have in common the early onset and a persistent course in addition to cognitive impairment and deficits (Andrews, Pine, Hobbs, Anderson, & Sunderland, 2009; Chen, Liu, Su, Huang, & Lin, 2007).

ASD is a diagnostic category that covers impairments in the areas of social development: Social interaction, communication, and repetitive behaviours. Asperger syndrome, Pervasive developmental disorder not otherwise specified, autistic disorder, Rett's syndrome, childhood disintegrative disorder will be officially under the ASD category in the next DSM V and ICD 11 classifications (Lord & Jones, 2012).

Recent studies have placed the prevalence of ASD at 6–7 per 1000 (Fombonne, 2009). DSM IV has reported the median rate in epidemiological studies as 5 cases per 10,000, and the reported rates ranged from 2 to 20 cases per 10,000 individuals, with rates of the disorder being four to five times higher in males than in females. Despite these discrepancies, either related to differences in methodology or to more refined diagnosis, the diagnosis of autism seems to be one of the most common in child psychiatry.

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Lebanon has no epidemiological studies in this particular domain. Only the Lebanese Autism Society, a national non-governmental organization (NGO) active in advocacy and research estimates the prevalence of ASD to be 3.3%.

Mental retardation is defined as an arrest in the intellectual development occurring before adulthood and disabling the social integration. Parents' associations and advocacy movements pushed towards an official change in the terminology to lessen the stigma on individuals with mental retardation. The WHO Working Group on ICD-11 suggested replacing Mental Retardation with intellectual developmental disorders (IDD). It defined it as 'a group of developmental conditions characterized by an extensive impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior and skills' (Salvador-Carulla et al., 2011).

Conservative estimates suggest a worldwide prevalence of IDD between 0.9% and 1.7%, with a rate that is three times higher in low- and middle-income countries than in high-income countries. IDD is frequently misdiagnosed, and is associated with poor access to health-care services. It has a major impact on functioning throughout the lifespan, and 40% of persons with IDD present with associated psychiatric disorders (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). The prevalence of IDD due to known biological factors is the same among children of upper and lower socioeconomic status. IDD due to certain etiological factors such as lead poisoning and premature births is more common in children of lower socio-economic status. Children from lower socio-economic status exhibit IDD with unidentified specific biological causation and it is usually in the milder form. In Lebanon, the most recent estimation of the Ministry of social affairs established the incidence rate of people with mental retardation at 4.1% (Romanos, 2000). According to the Ministry of health's estimations, children with IDD represent 25% of the population of children with special education needs (Ministry of Public Health, 2001).

Early intervention is highly recommended in neurodevelopmental disorders. Its benefits have been established across all areas of the child's development. The more intense the intervention, the greater the gains despite variability in outcomes within groups of children treated (Symes, Remington, & Brown, 2006).Long-term improvements in brain development and in cognitive functions and IQ have been registered (Anderson et al., 2003; Barnett, 1995; Boocock, 1995; Guralnick, 1998; Young, 1996). The association between parents' well-being, early intervention, and better developmental outcomes in children with disabilities has been illustrated in longitudinal studies (Hauser-Cram et al., 2001). Furthermore, implementation of early childhood development programmes can be an excellent economic investment to society (Heckman, 2004; Shonkoff, 2009; van der Gaag & Tan, 1998).

Early intervention being a strategic step, early identification and early assessment becomes a pivotal point in determining developmental outcomes in persons with neurodevelopmental disorders. Early and accurate assessment and diagnosis of ASD and IDD positively impacts the course of the treatment plan and the parents−child dynamic.

A review of 29 studies pertaining to the early identification of ASD found early impairments in social, behavioural, and communication development, such as the usage of vocalising and gestures to regulate the interactions and the behaviour in infants less than two years of age. Also, a significant number of repetitive behaviours and restricted interests were found in toddlers above the age of two. Finally, poor receptive and expressive language skills were detected in children aged between two years and six months and three years (Boyd, Odom, Humphreys, & Sam, 2010).

In addition, research has found that children with ASD as well as children with IDD show higher rate of aggressive behaviour, stereotypic behaviour, and self-injury behaviours and this between the age of 17 and 36 months (Medeiros, Kozlowski, Beighley, Rojahn, & Matson, 2012). For infants and toddlers with IDD, aside from chromosomal abnormalities and syndromic features that make the diagnosis much more evident, delays in early development are indicators. Studies pointed at sensible periods in the early development of a child. The 9, 18, and 30 months of age have been identified as key moments in detecting any delay or impairment. The age of nine months is sensible for motor and early communication skills development. At 18 months hindrance in communication and language development are usually apparent as well as delays in motor skills. At 30 months of age, motor, language, and cognitive delays can for the most part be recognised (American Academy of Pediatrics, 2006).

It happens that an infant or toddler with a general developmental delay shows impaired communication patterns. The question then will be whether the symptoms are more likely to be understood under the ASD or the IDD profile. Communication difficulties come first among the alarming signs to detect ASD (Fountain, King, & Bearman, 2011). Osterling. Dawson, and Munson assumed that a differential diagnosis can be established at one year of age. They have videotaped observations of three groups of 12-month-old children who have been diagnosed later either with ASD or with IDD or were found with no psychopathological diagnosis. The infants with ASD looked at others and oriented to their names less frequently than infants with IDD. The infants with ASD and those with IDD used gestures and looked at objects held by others less frequently and engaged in repetitive motor actions more frequently than typically developing infants (Osterling, Dawson, & Munson, 2002).

In summary, predictors of ASD or IDD can be recognised as early as at the age of 12 months. Nonetheless, parents seek help mainly after the age of 12 months unless the signs are too obvious or a comorbid medical or genetic condition is associated with the neurodevelopmental disorder.

Identifying the variables that affect early diagnosis helps in developing prevention and early intervention policies that will in turn lessen the economical and societal burden of the disorders. As opposed to children living in urban areas, children living in rural areas and having developmental problems are at higher risks of being unrecognised or undiagnosed because of the limited access to medical services. Low socioeducation and socioeconomic status of parents affect their early identification of warning behavioural and neurological signs. In addition, the age of the mother when the child is born and him being first child or not influence her ability to detect early signs of developmental dysfunctions. (Frenette et al., 2011; Fountain et al., 2011).

The most common primary diagnosis given to children who develop later into ASD is the diagnosis of attention deficit and hyperactivity disorder (ADHD). IDD is the earliest primary diagnosis given to children in comparison to the age at diagnosis for children with ADHD or ASD (Frenette et al., 2011). Although IDD in children show in significant impairments with adaptive and cognitive functioning, those impairments are usually accompanied with other complications such as mental-health problems, sleep disorders, challenging behaviours, and physical-health problems (McKenzie & Megson, 2002).

Lebanon lacks mental-health policy. The situation of children and adolescents in need of mental-health services has not been comprehensively assessed and no accurate information is available. The WHO (2010) reports pertaining to Lebanon mentioned that the ratio of mental-health provider per 100,000 population is as follows: 1.5

psychiatrists; 0.2 other medical doctors; 1.8 nurses; 2.2 psychologists; 0.5 social workers; 1.2 occupational therapists; and 7.5 other-health or mental-health workers. Mental-health services are mainly covered by private hospitals and private community services, or by NGOs. The estimated number of bodies providing mental-health care to children and adolescents is 30 NGOs offering educational and medical services to persons with neurodevelopmental disorders and 2 psychiatry services in 2 private hospitals in Beirut (Khoury & Tabbara, 2012). A few clinical psychologists have their own private practice. This pictures the paucity of resources and may give the reader the background to understand the results of the current study.

Methods

Participants

The data for this study were collected retrospectively. Charts of patients visiting the child development clinic at the Department of Psychiatry at the American University of Beirut Medical Center for a period of two years were reviewed. The child development clinic is the first in the country in providing assessment services. It receives patients from all regions of Lebanon and the Arab countries. A total of 209 children between the ages of 1 and 12 years who have been clinically diagnosed with either ASD or IDD were considered eligible for entry into the study.

Instruments

We designed a checklist to collect information on gender, age at diagnosis, birth order, parental marital status, number of children in the family, residence, family environment, presence of a medical condition, family history of neurodevelopmental disorders, and source of referral.

In parallel with the clinical naturalistic observation and the interview with the parents, we used the Autism Diagnostic Observation Schedule to diagnose autism and to determine its severity level. We also used the Wechsler battery of tests to assess intellectual abilities: The Wechsler Preschool and Primary Scale of Intelligence – Third Edition for children two to seven years and the Wechsler Intelligence Scale for Children – Fourth edition for ages 7 –12 years. For children who have not developed their language and for those who were not raised in an English-speaking family, the Wechsler Nonverbal ability test was used.

Measures

Twelve variables possibly affecting the early diagnosis of ASD or IDD were assessed. We have grouped them into two categories.

Six demographic variables: these included gender, birth order, parental marital status (married, divorced, at least one parent deceased), number of children in the family, area of residence (Beirut, other areas in Lebanon, or regional), and family-related childhood adversity (which included violence or neglect in the family).

Six clinical variables: these included age at diagnosis (early age of diagnosis was defined as those children who have been diagnosed at six years or younger and late diagnosis as 7–12 years), presence of a medical condition (epilepsy, seizures, genetic disorder, etc.), chief complaint: behavioural problems (hyperactivity and stubbornness), cognitive problems (learning delays and lack of attention and concentration), or communication problems (language delay or impairment, isolation, lack of responsiveness when called or invited to play), family history of neurodevelopmental disorders, source of referral (parents, physician, or teacher), and severity of the condition (mild, moderate, or severe).

Statistical analysis

Data were entered and analysed on SPSS version 17.0. Differences in means of continuous variables between IDD and ASD were determined by using Student's *T*-test and analysis of variance. Differences in proportions of non-continuous variables between the two groups were determined using chi-square test.

Results

Demographic characteristics

The sample comprised 100 children with IDD and 109 children with ASD. The gender distribution was borderline significant between the two groups ($p = 0.05$) with the majority in both groups being boys (67% for IDD and 79% for ASD). Children with IDD significantly reported higher rates of family-related childhood adversities (29%) than children with ASD (13.8% for ASD) ($p = 0.007$). The two groups did not differ in parents' marital status, birth order, and residence (Table 1).

Table 1. Differences in demographic characteristics between IDD and ASD.

	Diagnosis		
Characteristic	IDD	ASD	*P*-value
N	100	109	
Gender			
Boys	67%	79%	0.05
Girls	33%	21%	
Birth order			
First	59%	64%	0.7
Later	36%	32%	
Twin	5%	4%	
Number of children in family (mean ± sd)	2.1 ± 1.1	1.9 ± 1.0	0.2
Parent marital status			
Married	93%	96%	0.2
Divorced	5%	1%	
Deceased	2%	3%	
Family-related childhood adversity	29%	14%	0.007
Residence			
Beirut	56%	49%	0.3
Outside Beirut	12%	19%	
Outside Lebanon	32%	32%	

Clinical characteristics

Children with ASD seem to present for clinical assessment at a younger age (4.7 years) than children with IDD (7.5 years) ($p < 0.001$). The vast majority of children with ASD (80%) were assessed before the age of seven years (47% of them at age two–three years). This was significantly different from children with IDD half of whom were assessed before the age of seven years (12% at age two–three years). In addition, age at first assessment differed between children residing in rural and urban areas. The majority of children residing in urban areas underwent assessment early (i.e. at age below six years; 92.5% for ASD, and 66.1% for IDD). However, the majority of children residing in rural areas underwent assessment at the age of seven years or higher (81% for ASD and 100% for IDD). The chief complaint upon first visit for clinical assessment differed significantly between the two groups ($p < 0.001$). About two-thirds of children with IDD presented for cognitive problems, one-third for behavioural problems, and none for communication problems. Besides, the majority of children with ASD presented with communication problems (72.5%) and the remaining for behavioural (11.9%) or cognitive (15.6%) problems (Table 2). In each group, the chief complaint did not differ by gender ($p = 0.4$ for IDD and $p = 0.6$ for ASD). Children with IDD had about five times more medical conditions than autistic children ($p < 0.001$). The two groups did not differ in the severity of disorder and family history (Table 2).

We wanted to check if the age at first visit of clinical assessment is correlated with the severity level of the disorder on one hand and if the chief complaint and the referral source are correlated on the other hand.

Table 2. Differences in clinical characteristics between IDD and ASD.

Characteristic	IDD	ASD	*P*-value
N	100	109	
Age at first visit (mean ± sd)			
≤six years	7.5 ± 3.2	4.7 ± 2.5	<0.001
7–12 years	51%	80%	<0.001
Assessment age category			
Behavioural	49%	20%	
Behavioural	36%	12%	<0.001
Behavioural	64%	16%	
Chief complaint			
Behavioural	0%	73%	
Behavioural	50%	49%	0.2
Behavioural	42%	36%	
Severity level of condition			
Behavioural	8%	16%	
Behavioural	13%	39%	<0.001
Behavioural	42%	35%	
Referral source			
Behavioural	45%	26%	
Behavioural	16%	14%	0.6
Behavioural	52%	11%	<0.001

Table 3. Differences in age at first visit by severity of condition, chief complaint, and referral source.

	Diagnosis			
	IDD		ASD	
Characteristic	*N*	Mean ± sd	*N*	Mean ± sd
Severity level of condition				
Mild	53	5.2 ± 2.7	50	10.1 ± 2.1
Moderate	39	3.9 ± 1.8	42	4.9 ± 1.6
Severe	17	5.0 ± 3.0	8	4.9 ± 1.6
P-value	0.03		<0.001	
Chief complaint				
Behavioural	13	5.6 ± 3.1	36	4.8 ± 1.7
Cognitive	17	6.5 ± 2.9	64	9.1 ± 2.8
Social	79	4.1 ± 2.1	0	0.0 ± 0.0
P-value	0.001		<0.001	
Referral source				
Physician	43	4.1 ± 2.2	13	7.9 ± 3.1
Teacher	38	4.3 ± 2.0	42	6.8 ± 3.2
Family	28	6.2 ± 3.1	45	8.1 ± 3.1
P-value	0.001		0.1	

Children with moderate and severe IDD had similarly a significantly lower age of first visit than children with mild IDD, behavioural problems being the main reason for referral. The source of referral, being parents, teachers, or physicians, did not differ for children with IDD. For children with ASD the youngest age of referral was for difficulties in communication and social interactions, regardless of the severity level of the disorder. A younger age of first visit was associated with being referred by a physician or a teacher (Table 3).

Discussion

The current retrospective study showed that figures obtained from Lebanese patients are for the majority of the variables similar to the results of international studies. Demographic factors such as the difference between urban and rural area had been significantly influential in the early assessment of the disorders. The main symptoms that had driven the attention of the referral sources are, respectively, social interaction problems for the diagnosis of ASD and delay in skills acquisitions for the diagnosis of IDD. The current study showed also in line with the international literature that children with IDD present more frequently with associated medical conditions than children with ASD. In addition, the more severe the symptoms are, the earlier the diagnosis for both diagnoses.

Nonetheless, the age at first assessment in Lebanon is until now higher than the age at first assessment in western countries. In fact, most of the children with ASD have been assessed before the age of seven at an average age of four years and seven months while the first signs of autism are apparent either at 12 months or at 30 months. As for the children with IDD, the average age of assessment was seven years and five months. However, only half of them underwent assessment before the age of 7 despite the fact that the developmental markers are usually visible before the age of 30 months. In our sample, ASD was identified at an earlier age than IDD. This may be due to the awareness campaigns addressing the identification of ASD systematically implemented in Lebanon through all media. We may also hypothesise that physicians and teachers are more aware of the necessity of referring to clinical psychology services for children with ASD than they are about children with IDD in Lebanon.

Conclusion

The early identification of neurodevelopmental disorders in children is a crucial step towards implementing early interventions programmes. It requires a series of actions: awareness campaigns, availability of screening tools, and presence of mental-health services in urban and rural areas. The current study tried to point at a critical gap in the field of early assessment of neurodevelopmental disorders. It is the first of its kind in the country and opens the door for extended research towards reaching the design and implementation of specific mental-health strategies.

Notes on contributors

Leyla Akoury-Dirani received her PhD in clinical psychology and psychopathology from Paris 5 University. Since 1987, she has been with the Saint Joseph University of Beirut as maître de conference in different departments. She held academic and administrative positions as the director of the Institut Libanais d'Educateurs at Saint Joseph University. She played a pivotal role in creating the university curricula for speech therapy and psychomotor therapy professionals in Lebanon. Since 2009, Dr Akoury-Dirani has been with the department of psychiatry at the American University of Beirut as an assistant professor – child and adolescent psychologist. In parallel with her clinical work with children and adolescents, Leyla Akoury-Dirani conducted several researches in the field of child and adolescent mental health in Lebanon and worked actively to establish a new trend in dealing with children with neurodevelopmental disorders, developing early intervention programmes for them and including them into the regular education mainstream. Dr Akoury-Dirani established the first therapeutic and special education programme for children with autism spectrum disorder and she is till now very active in supporting the development of this particular field. Dr Akoury-Dirani is currently a member of the working group established by the WHO to revise the ICD-10 classification on Mental Retardation. She is also the president of the Lebanese Psychological Association, an association that aims at paving the road for better practices and researches in the field of psychology in Lebanon.

Mariana M. Salamoun received her BS in biology in 1999 and BA in psychology in 2002 from the American University of Beirut, Lebanon. In 2010, she completed her MA in clinical psychology at Haigazian University, Lebanon. She also did a one-year internship in clinical psychology at the American University of Beirut Medical Center. She worked at the Institute for Development Research Advocacy and Applied Care (IDRAAC) as a research associate and general coordinator for seven years (2004–2011). She taught graduate courses in psychology at Notre Dame University, Lebanon, as a part time instructor for a year. Currently, she is a Humphrey Fellow sponsored by the Department of State at the School of Public Health at Johns Hopkins University, Baltimore, Maryland.

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