A Five-Year Review of Referrals to the Developmental Pediatrics Section of a Major Tertiary Hospital

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ABSTRACT

Developmental disabilities involve a delay in development based on that expected for a given age level or stage of development.1 These impairments which originate before age 18 are expected to continue indefinitely and constitute a substantial impairment that may create a burden to the family and society. In a developing country like the Philippines, it is a public health problem that remains largely undetected and neglected. Local attempts to organize more systematic diagnostic services are needed.

Objectives. To review the referrals made to the Section of Developmental Pediatrics for evaluation and to describe the demographic and clinical patterns of the more common developmental disabilities identified.

Methods. This was a retrospective study based on the clinical census of patients seen over a five-year period from January 2004 to December 2008 by the Section of Developmental Pediatrics.

Results. Referrals made to the Section of Developmental Pediatrics were usually seen during the first decade of life, were mostly males and were usually referred for developmental delay. The three most common developmental disabilities identified were mental retardation or global developmental delay, autistic spectrum disorders and cerebral palsy.

Key Words: developmental disability, mental retardation, global developmental delay, Autistic Spectrum Disorders, Cerebral palsy

Introduction

Developmental disabilities are conditions characterized by physical, cognitive, psychological, sensory, adaptive, and/or communication impairments manifested during development.[2] In a developing country like the Philippines, it is a public health problem that remains largely undetected and neglected. However, local attempts to organize more systematic diagnostic services only began in 1961 at the Child Development Unit located at Ward 12 in the Department of Pediatrics, Philippine General Hospital (PGH). Since the focus of the pediatric health system then was on the existing morbidity of infectious diseases, this small office unit was not utilized as intended.

The advent of the 1980s heralded the wave of these "new morbidities" which recognized not only the upsurge of developmental and behavioral disorders but better awareness and more clamor for services. The need for a more comprehensive evaluation of these children and adolescents then became an urgent concern. Subsequently, to address the need, the Multidisciplinary Child and Adolescent Unit (MCAU) of the Department of Pediatrics began its services at the PGH Out-Patient Department in 1987 with the first fellowship program in Developmental and Behavioral Pediatrics established simultaneously.

The MCAU combined the existing Child Developmental Unit and the Adolescent Services of the Department of Pediatrics. In 2000, it was eventually reorganized as the Section of Developmental Pediatrics and became a separate unit from the Adolescent Service. It remains to be the largest provider of charity diagnostic services for children and adolescents with developmental and behavioral disabilities in a tertiary government teaching hospital in the country to date. The primary goal of this Section is to provide holistic and multidisciplinary diagnostic services and has for the past 20 years evaluated over 20,000 patients. In addition, the Section of Developmental Pediatrics also receives referrals from the Child Protection Unit (CPU) and the inpatient services from the different clinical departments.

The general objective of this paper is to review the referrals made to the Section of Developmental Pediatrics (MCAU) for evaluation during the past five years. The specific objectives of the study are 1) to describe the demographic and clinical profile of children and adolescents referred to the Section of Developmental Pediatrics (MCAU) and 2) to describe the types and clinical patterns of developmental disabilities and behavioral disorders identified.

Materials and Methods

This was a retrospective study based on the census of all the child and adolescent consults (old and new cases) seen by the Section of Developmental Pediatrics (formerly the Multidisciplinary Child and Adolescent Unit) from January 2004 to December 2008. The data obtained from the census included: age, sex, reason for referral, type of disability and how the disability presented in terms of age of manifestation, sex, and subtypes identified.

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Results

Demographic and Clinical Features

The total number of referrals evaluated by the Section of Developmental Pediatrics between January 2004 to December 2008 are shown in Table 1. Outpatient consults accounted for the majority of referrals seen by the Section. Consults from the CPU were mostly made to determine the developmental status of cases of child abuse or neglect, while inpatient referrals included a variety of pediatric admissions in different wards that were under medical or surgical treatment, such as bilateral cleft and palate with mandibular duplication from the Department of Otorhinolaryngology (ENT) or an ovarian new growth from the Department of Obstetrics and Gynecology (OB-GYN) whom the attending clinicians perceived to have developmental delays.

Figure 1 shows the sex distribution per year and indicates that there is a strong male predilection, an average of 64 % over the past five years. In 2004, the total number of referrals did not tally because the genders of the inpatient and CPU consults were not included.

The average age of referral, as shown in Table 2, was one to five years and 11 months (41.7%), followed by six to nine years and 11 months (33.4%). More consults were made in the first decade of life; older patients comprised only 22% of consults.

The reasons for referral of new patients are shown in Table 3. Developmental delay was the most common reason for referral, followed by speech delay, hyperactivity, school difficulties and baseline developmental assessment for high-risk cases. Other less common reasons included other aspects of behavior like inattention, aggression and unusual patterns.

The top three developmental diagnoses based on the total number of referrals made over the past five years are shown in Table 4. Mental retardation/global developmental delay was the most common developmental disability identified followed by autistic spectrum disorders and cerebral palsy. The other developmental disabilities included attention deficit hyperactivity disorders (ADHD), hearing impairment and a variety of other conditions like learning disabilities and developmental language disorders. There were a few cases for high-risk follow-up who had typical or normal development.

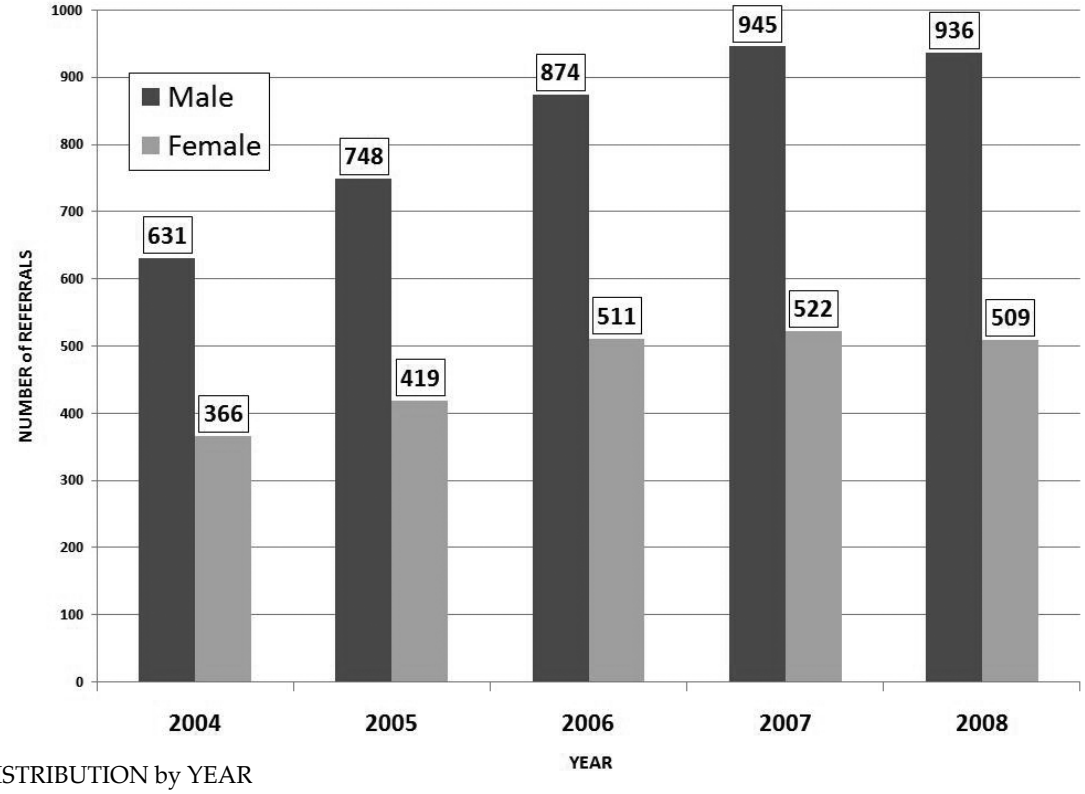

Figure 1. SEX DISTRIBUTION by YEAR

Clinical Patterns of Developmental Disabilities

The demographic and clinical patterns of new cases of the top three developmental disabilities from 2005 to 2008 are listed in Table 5. Missing data were noted in 2004, and as such this year was not included in this analysis.

Mental Retardation/Global Developmental Delay

Of the 1,305 new cases, 43% were one year to five years and 11 months of age. There were more males than females. Although there was a wide scatter of cases among

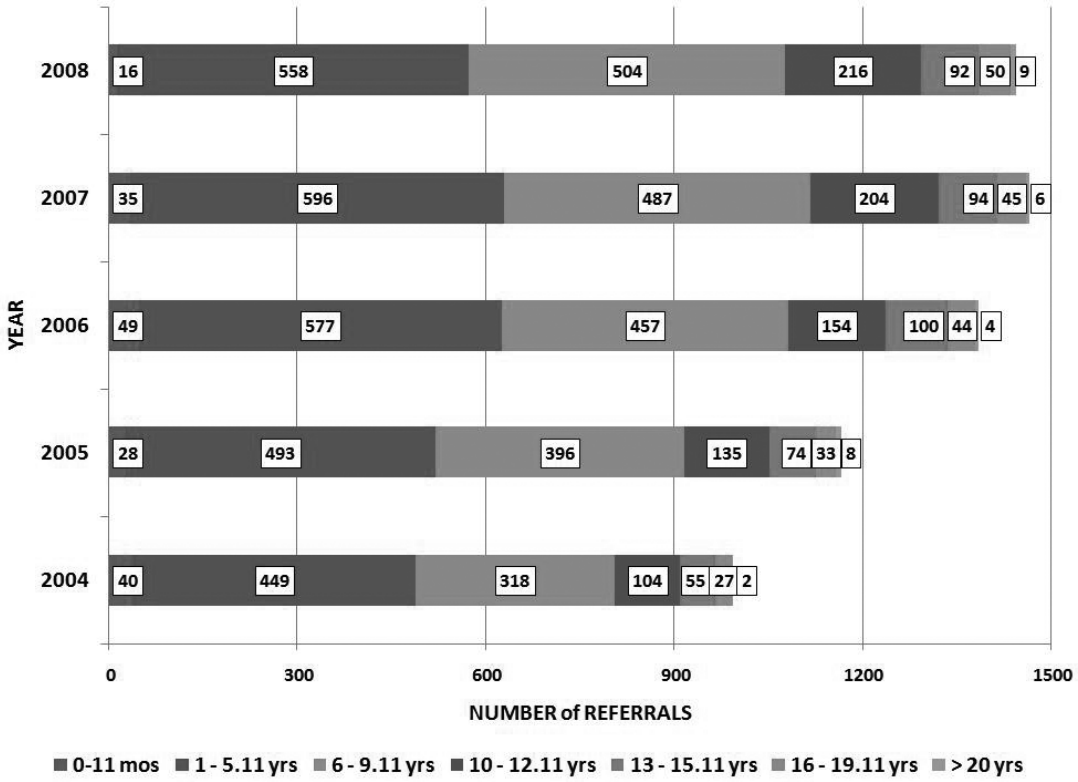

Figure 2. AGE DISTRIBUTION by YEAR

Table 1. Consults seen at the Developmental Pediatrics Section

Patients Seen	2004	2005	2006	2007	2008
OPD Consults	997 (95.3%)	1113 (95.4%)	1421 (96.9%)	1329 (96.0%)	1395 (96.5%)
InPatient Referrals	10 (1.0%)	7 (0.6%)	2 (0.1%)	5 (0.4%)	7 (0.5%)
CPU	39 (3.7%)	47 (4.0%)	44 (3.0%)	50 (3.6%)	43 (3.0%)
TOTAL	**1046 (100.0%)**	**1167 (100.0%)**	**1467 (100.0%)**	**1384 (100.0%)**	**1445 (100.0%)**

Table 2. Age Distribution by year

Age	2004	2005	2006	2007	2008	AVERAGE
0-11mos	40 (4.0%)	28 (2.4%)	49 (3.5%0	35 (2.4%)	16 (1.1%)	2.7%
1-5.11 years	449 (45.1%)	493 (42.2%)	577 (41.7%)	596 (40.6%)	558 (38.6%)	41.7%
6-9.11 years	318 (32.0%)	396 (33.9%)	457 (33.0%)	487 (33.2%)	504 (34.9%)	33.4%
10-12.11 years	104 (10.5)	135 (11.6%)	154 (11.1%)	204 (13.9%)	216 (14.9%)	12.4%
13-15.11 years	55 (5.5%)	74 (6.3%)	100 (7.2%)	94 (6.4%)	92 (6.4%)	6.4%
16-19.11 years	27 (2.7%)	33 (2.8%)	44 (3.2%)	45 (3.1%)	50 (3.5%)	3.0%
> 19 years	2 (0.2%)	8 (0.7%)	4 (0.3%)	6 (0.4%)	9 (0.6%)	0.4%

the different categories from mild to severe-profound retardation, most of those identified could not be classified by severity because of the lack of or absence of confirmation using IQ or psychometric evaluation.

Autistic Spectrum Disorders

Of the 357 new cases, 54% were also one year to five years and 11 months of age. There were also more males than females. Classic autism or the autistic disorder was the most common type identified in 85% of the cases.

Cerebral Palsy

Of the 204 new cases, 63% were also one year to five years and 11 months of age. There were also more males than females. Seventy-eight percent (78%) were of the spastic type and most were in the spastic quadriplegic category.

Discussion

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (US Department of Health and Human Services) defines a developmental disability as: a severe,

Table 3. Reasons for Referral by year

Chief Complaint	2004	2005	2006	2007	2008
"Batang Isip"	5	3	4	4	1
"Di makausap"	0	0	0	0	1
"Makulit"	4	1	0	0	3
"Malambot ang leeg at paa"	1	0	0	0	0
"Sariling mundo"	4	4	0	0	0
Aggression	0	0	1	0	0
Articulation Problem	1	0	0	0	0
Behavioral Changes	0	0	2	1	4
Cannot Recognize	0	1	0	0	0
Developmental Delay	72	112	188	228	165
Developmental/Baseline assessment	44	9	20	16	123
Difficulty expressing self	0	0	0	0	1
Disruptive Behavior	0	5	3	2	0
Habitual Pulling of Hair	0	1	0	0	0
Head Banging	0	1	0	0	0
Hyperactivity	45	56	55	66	62
Inattention	0	4	4	10	2
Motor Delay, Unable to Walk	4	7	12	36	12
Odd Behavior	5	9	6	6	4
One-sided Weakness	0	0	1	1	0
Poor Class Performance	0	0	6	0	0
Poor Eye Contact	0	0	2	2	4
Poor Head Control	0	1	2	0	0
Poor Hearing	1	4	0	0	9
Poor Memory	0	0	3	0	0
Poor Social Skills	0	0	0	0	1
Reading Problem	1	1	0	0	0
Regression of Speech	0	0	1	11	1
School Difficulties	17	22	17	29	11
Sexuality Problem	0	0	1	0	0
Sleeping Difficulties	0	1	0	0	0
Slow Learner	0	7	8	5	10
Small Head	0	0	1	0	0
Spastic Extremities	3	3	5	0	1
Speech Delay	90	115	122	141	100
Speech Problem	0	1	6	20	0
Staring Episodes	0	0	1	1	0
Tantrums	2	0	0	0	1
Unable to Write	0	0	0	0	3
Unresponsive	0	0	0	0	1
Not Stated	1	0	130	0	0
TOTAL	**1046**	**1167**	**1385**	**1467**	**1445**

chronic disability of an individual that: 1) is attributable to a mental or physical impairment or combination of mental and physical impairments; 2) is manifested before the individual attains age 22; 3) is likely to continue indefinitely; 4) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and 5) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.[3]

Approximately 51.2 million people, or 18%, in the United States have a disability with roughly 11% of children ages six to 14 affected. The National Center for Birth Defects and Developmental Disabilities estimates that one in every 33 babies in the United States is born with a birth defect. [4]

The Philippines, with a projected population of 85 million in 2005, reported its total disabled population to be close to one million in 2000 (~ 1.23%), with most cases identified in Luzon, the most populated island (National Statistics Office, 2000).[5] Of those identified, most (78.6 %) were adults and most were physically handicapped with only 21.4% below 19 years. The relatively low prevalence particularly in our own pediatric population may be due to inadequate, inefficient detection and surveillance in communities. A comprehensive neurodevelopmental evaluation of those who may be referred for proper identification is sadly lacking since there is a limited number of facilities that offer this option in the country.

Currently, the source of most data on developmental disabilities in children and adolescents has been limited to the census of developmental pediatric clinics of tertiary hospitals where there are trained subspecialists in developmental and behavioral pediatrics.

This retrospective study of cases seen by the Section of Developmental Pediatrics of the Philippine General Hospital

Table 4. Top three consults by year

Diagnosis	2004	2005	2006	2007	2008
Mental Retardation/GDD	279 (28.0%)	319 (27.3%)	419 (30.3%)	720 (49.1%)	691 (47.8%)
Cerebral Palsy	113 (11.3%)	108 (9.3%)	146 (10.5%)	133 (9.1%)	
Autistic Spectrum Disorder	196 (19.7%)	235 (20.1%)	294 (21.2%)	285 (19.4%)	295 (20.4%)
Attention Deficit/Hyperactivity Disorder					137 (9.5%)

Table 5. Pattern of Distribution between 2005 and 2008

	Cerebral Palsy			GDD/MR			Autistic Spectrum Disorder		
Age	**Male**	**Female**	**TOTAL**	**Male**	**Female**	**TOTAL**	**Male**	**Female**	**TOTAL**
0-11mos	8	7	**15**	34	38	**72**	0	0	**0**
1-5.11	87	42	**129**	339	218	**557**	160	33	**193**
6-9.11	25	16	**41**	184	153	**337**	101	27	**128**
10-12.11	7	2	**9**	71	78	**149**	19	4	**23**
13-15.11	5	5	**10**	41	81	**122**	9	1	**10**
16-19.11	0	0	**0**	14	44	**58**	2	1	**3**
>20	0	0	**0**	3	7	**10**	0	0	**0**
			204			**1305**			**357**

For CP	
Spastic Quadriplegic	**122**
Spastic Diplegic	**19**
Spastic Hemipegic	**18**
Athetoid	**15**
Mixed	**7**
Dyskinetic	**1**

For ASD	
Autism	**304**
PDD-NOS	**41**
Rett	**3**

For MR/GDD	
Unclassifed	**439**
Mild	**24**
Mild-to-Moderate	**51**
Moderate	**10**
Mod-to-Severe	**19**
Severe	**22**
Severe-to-Profound	**78**
Profound	**19**

over the past five years shows that about 1,300 children and adolescents are referred every year. Patients who want to be evaluated have to wait at least six to eight months.

This study may describe but might not truly reflect the community setting where more cases may exist.

Studies of developmental disabilities in children and adolescents report higher rates among males. This is also true in all age groups across the five year period included in this study. Although there is extensive literature, both speculative and empirical, on postulated differences between males and females in association with rates of particular types of disorder, very little is known about the mechanisms that underlie these differences.[6] In certain developmental disorders such as autism, the male predominance has been quite significant, as published by Wing in 1993, which showed that the rate is higher in boys than in girls with a ratio of 4-5:1.[7]

Most (78%) of the children seen were in their first decade of life. This trend has been constantly observed over the past five years despite the differences in the total number of yearly consults. This large range in the age bracket may be more indicative of the type and/or severity of disabilities diagnosed.

In children with severe mental retardation, for instance, the lags in development may be apparent as early as a few months of age, particularly when dysmorphic features are also present. Those with mild to moderate retardation usually present during the preschool years or in primary school because of challenges in academic performance.[8]

Cerebral palsy, a physically apparent motor disability usually presents during the first year of life when developmental events like head control, sitting up or walking do not appear as expected.

Autistic spectrum disorders also manifest on the average during the preschool years for the more severe cases because of the absence of language and communication but may also appear later, during the middle school years, as social issues for more functional patients.

Fewer patients were seen in early and middle adolescence in this review, possibly because of a coexisting adolescent clinic in the same hospital, which also receives disability referrals, or because of the diminishing lack of motivation and increased hopelessness in families who take care of older disabled individuals.[9]

The most common reason for referral over the past five years was developmental delay. It is a common problem in child health and, as such, is the most frequent reason for referral of a child for subspecialty evaluation.[10] It is a documented disturbance in one or more of the recognized developmental domains like motor (gross or fine), speech and language, cognitive, adaptive or activities of daily living. The office evaluation of the young developmentally delayed child has a number of objectives including precisely categorizing the delay subtype together with rationally selecting investigations for determining a possible underlying etiology. It may be due to a variety of reasons which include, among others, mental retardation, autism spectrum disorders and other multi-handicapping conditions.

Speech and language delay is an umbrella term that covers a range of conditions in early childhood. This occurs when the speech and language skills of a child are delayed relative to other skills either in the absence of a clear etiology or in most cases when associated with delay in other domains as a result of a clear etiology like hearing loss or learning difficulties.[11]

Attempts to classify developmental disabilities have been based primarily on the specific domain of development greatly involved. Traditionally, this is represented by conditions such as mental retardation, autism and cerebral palsy. Accardo and Capute have proposed a diagram that represents an interaction among these three primary diagnoses which depict the motor end (cerebral palsy), the cognitive end (mental retardation) and communicative end (autistic spectrum disorders) of the spectrum.[12]

Developmental problems are thus divided into various subtypes that capture a group of children who share impairments and mandate a common approach to diagnostic evaluation and management.

The three most prevalent developmental disabilities described in this review have been well recognized as chronic global concerns that have a serious impact on families. Certain demographic trends and patterns of the more commonly reported disabilities in this review parallel, to a certain extent, those described in the literature.

Global developmental delay refers to a disturbance in an individual child across one or more domains and reflects difficulties in intelligence and cognition in the young child less than five years of age. Mental retardation refers to a range of standardized IQ scores from 70 to 75 as the upper limit with significant limitations in adaptive abilities. As

presently conceptualized, both global developmental delay and mental retardation represent predominantly clinically defined and recognized symptom complexes that are characterized by significant limitations both in intellectual functioning and in adaptive behavior. The statistical prevalence of mental retardation is approximately 2 to 3% although the actual prevalence may be closer to 1%.[13] Eighty-five percent (85%) of the mentally retarded population are usually in the mild range with IQ scores from 50-55 to 70. The three most common identifiable syndromes are fetal alcohol syndrome, fragile X syndrome and Down syndrome.

Autism spectrum disorder (ASD) is an umbrella term that describes a complex developmental disability that profoundly interferes with normal communication, social interaction, or behavior, usually before the age of two or three years. Prevalence estimates vary, but ASDs may affect as many as two to six per 1,000 children, making it the most common childhood disorder after mental retardation.[14] It is widely accepted that there is a male predilection for this disability. Early detection and intervention are critical since education and treatment can alter the disabling trajectory of autism.

Cerebral palsy (CP) is the most common cause of childhood disability in Western countries with an incidence of 2 to 2.5 per 1000 live births. Classification is based on the change in muscle tone, anatomic region of involvement and severity of the problem. Approximately 70 to 80% of children with CP are spastic.[15] The diagnosis of CP can be challenging, and may need to be confirmed by an experienced practitioner, ideally a developmental pediatrician, child neurologist or psychiatrist. It is important not to make the diagnosis too early in infancy, especially when the signs are not severe, as resolution of early neuromotor abnormalities does occur, particularly in premature infants.

Exclusion of genetic/metabolic disorders presenting with CP-like findings is important.

Conclusion and Recommendations

This review showed that selected demographic characteristics as pertaining to the age at referral and the male predilection seemed constant not only in the total number of patients seen but also in the three most common developmental disabilities identified. However, there are to date not only limited diagnostic services and few existing and sustainable programs with limited levels of care for selected disabilities.

This study contributes to our baseline understanding of developmental disabilities in the local setting and recognizes the need for a more comprehensive developmental evaluation program with proper documentation, perhaps in the form of a registry. Recognition and more in-depth interpretation of the different patterns and needs of developmental disabilities are a necessary component if a collective effort is to be made in creating resources for these children and adolescents.

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