The Direct Cost of Autism and its Economic Impact on the Filipino Family

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ABSTRACT

Background. The increasing prevalence of autism has significantly impacted the health care spending of many families worldwide. To date, families from low to middle-income countries are burdened with out-of-pocket spending as their local health care systems have yet to incorporate autism-related services into the health care infrastructure.

Objectives. This study aimed to determine the direct costs of diagnosing and caring for children with autism and analyze its impact on the Filipino family.

Methods. The cross-sectional study consisted of a self-administered questionnaire that looked at parents' employment status, family income, and the direct costs for consultations, diagnostic tests, therapy, education, and medications. Study participants were parents living with their child diagnosed with autism, ages 2 to 6 years old at the time of the study.

Results. One hundred fifty-eight parents participated in the survey for the cost of care for children with autism. Sixty-seven (42.4%) of parents received government or subsidized medical services for their children's consultation and/or intervention, while the rest went to private centers or hospitals. The total costs for all evaluations that confirmed the autism diagnosis ranged from ₱1,356 to ₱44,634 and averaged ₱7,411.80 per child. Overall, the mean cost of interventions post-diagnosis, including therapy, education, medications, and developmental evaluations for the first year, was ₱38,868 or ₱3,239 per month (21% percent of the monthly expenditures for a household with an income of ₱15,000/month). The total cost of care per child was closely related to the family's revenue in the sample population. Families with higher incomes also had higher expenditures for autism-related services.

Conclusion. Autism imposes a significant economic burden on Filipino families, particularly the minimum-wage household earners who spent a higher proportion of their budget (21%) on autism-related services. The wide range of total costs for the care of the children in the study may be explained by the wide variability of the expenses for the services, differences in access to services, socioeconomic status, and the wide variation in needs of children with autism due to the nature of the condition.

Keywords: autism, direct cost, Philippines

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INTRODUCTION

Autism spectrum disorders (ASD) are a group of complex neurodevelopmental disorders marked by social skills and communication deficits, and interfering repetitive behavior. It is a lifelong disorder currently classified under pervasive developmental disorders. It involves qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviors.[1] The diagnostic criteria are described in the Diagnostic and Statistical

Manual of Mental Disorders DSM- Fifth Edition.[2] In the United States, the prevalence of ASD is reported at 1 in 54 children.[3] A systematic review and meta-analysis of the prevalence in mainland China, Hongkong, and Taiwan showed a pooled prevalence of childhood autism at 11.8 per 10,000.[4] There was, however, the significant heterogeneity among the studies, which may be attributed to different age groups studied and/or diagnostic criteria used. There are no prevalence studies for autism in the Philippines, but in 2012 it was estimated to affect at least 500,000 children.[5] The factors leading to the increase in prevalence worldwide are not fully known. Still, they include changing criteria, new diagnostic methods, dependence on existing registers, diagnostic substitution, and earlier and better recognition of the early signs of autism. However, the possibility of an actual increase in cases is not ruled out.[6]

Deokar et al. (2008) reported that the average individual health care expenditure for children and adolescents with autism and associated disorders has increased by approximately 20.4% from $4965 per patient in 2000 to $5979 per patient in 2004. The increasing prevalence of autism has negatively impacted the existing healthcare infrastructure in the US. Clinicians in the health care system are thus encouraged to understand and use the cost-effective approach that integrates autism services in taking care of individuals with autism and yet, at the same time, provide the necessary assistance.[7] A study done by Petrou et al. (2010) on the economic costs associated with childhood psychiatric disorders showed that for autistic disorder, there was a mean cost difference over the previous year of UK £6,745.3 (95% CI 2,232.9 - 11,257.7), higher among those with the autistic disorder than those without among children included in the EPICure study. The EPICure study is a whole-population longitudinal study of all infants born at 20 to 25 completed weeks of gestation in all 276 maternity units in the UK and Republic of Ireland from March to December 1995.[8] Another study, done in the US (Montes et al., 2008), showed that given the demographic and educational characteristics of parents of children with ASD ages six years to 10, they were expected to have an average income of $51,693.25 if their child had no ASD. The families, however, reported an average income of only $45,486.55. There is a difference of $6,206.70 or a 14% loss of revenue associated with having a child with ASD. Mothers of children with ASD earn 35% ($7189) less than mothers with another health limitation and 56% ($14,755) less than mothers with no health limitation.[9] Furthermore, children with ASD are 9% less likely to have both parents working than children with no health limitation. Thus, family earnings of children with ASD are 21% ($10,416) less than children with another health limitation and 28% ($17,763) less than those with no health limitation.[10]

A study in the Philippines (Pulhin-Dacumos et al.) looked at the direct cost of care for children with ASD ages 2 to 6 years. The mean initial cost of diagnosis was ₱7,325 which included professional fees, diagnostics, and evaluation by therapists. The average cost of follow-up services, including medical and educational services, was more than ₱114,440 annually, with the highest expenses seen during the first year because of the more frequent therapy sessions compared to the succeeding years. Therapies and educational interventions comprised 87% of the total cost of care for the first year. Cost of care was significantly associated with both parents' family income, occupation, and educational attainment, with increased expenditure seen in higher socioeconomic status. Private patients spent as much as seven times more than charity patients for services post-diagnosis.[11]

MATERIALS AND METHODS

This was a cross-sectional survey that was part of a study on the parents' perception of autism and their health-seeking behavior.[12] The study consisted of 4 parts: a qualitative study, questionnaire development, quantitative research, and economic analysis. The survey questionnaire was adopted from a previous local unpublished study by Dacumos. The questionnaire was pre-tested together with the questionnaire for the parental perceptions part. The parents were recruited through institutions in and around the National Capital Region—parent organizations, schools, clinics, therapy centers involved in caring for children with autism.

Participants of this study were parents living with their child/children who has/have been diagnosed with autism, aged 2 to 6 years old, when the study was conducted. The survey was limited to parents of children with autism in this age group to minimize potential recall bias. The child must have been diagnosed with autism by a child development specialist—psychiatrist, child neurologist, developmental pediatrician, or a team comprised of the above. If a parent has two children with autism, the parent was asked twice to relate their perceptions, understanding, and experiences for each of them.

Direct costs, all the expenses related to the diagnosis and care of children with autism, were measured. The survey did not include indirect costs such as earnings and opportunity losses. Cost of services when given in a charity setting was computed based on a study done in five government tertiary hospitals in 2007, which determined an outpatient consult to approximate ₱378 (or 8 US dollars [USD] using the 2007 average peso-to-dollar exchange rate of ₱46.08 = USD 1).[13] Unfortunately, the same data was not available from the Philippine General Hospital, which would have reflected the actual cost for our study population more closely. The cost of developmental pediatrics consult in a government hospital was multiplied by four since a new patient consult takes an hour and a half, which is 4 to 6 times the usual general pediatrics consult duration.

Data were encoded in Microsoft Excel. A coding manual was created to facilitate encoding. Statistical analysis

was done using Stata12 software. Descriptive statistics were reported in means and proportions. Associations between categorical variables were tested using Chi-square statistics. For continuous variables, correlation analysis was done.

The authors submitted the study protocol for technical review and approval from an adviser from the Department of Clinical Epidemiology. This study was part of the requirements for the course CE 201: Fundamentals of Clinical Economics and Health Social Science. The participants in the study were assured of confidentiality. Informed consent was obtained from all participants in all phases of the study. Recruitment was done by an investigator who had no professional relationship with the participants. No intervention nor remuneration was given to the participants, but appropriate referrals for management were made when requested. Participants were also allowed to attend one of two lecture series on various autism-related topics organized by the researchers. Admission to the said forum was free. This study was approved by the University of the Philippines – Manila Research Ethics Board.

RESULTS

One hundred fifty-eight parents were included in the cross-sectional survey for the cost of care for children with autism. The survey was adapted from a previous study done by Pulhin-Dacumos in 2007. Of the 158 parents surveyed, 67 (42.4%) received government or charity medical services for consultation, intervention, or both for their children, while the rest went to private centers or hospitals.

Cost for Initial Diagnosis (Table 1)

For consultations with medical specialists, charity patients spent from 0 to 60 pesos per consult, while private patients spent from ₱200 to ₱12,000 for a consult. For all charity consults, the parent-reported cost (0 to ₱60) was replaced with ₱378 to represent the actual cost to the hospital.[13] Majority of the consultations leading to the diagnosis involved general pediatricians who refer to specialists to confirm the diagnosis. Professionals who can confirm the diagnosis of autism are developmental pediatricians (majority of the consults), psychiatrists, neurologists, clinical psychologists, and SPED specialists with training on evaluation. The professional fees of these specialists showed a wide variation, with private general pediatricians having a fee of ₱100 to ₱3,000, private developmental pediatricians having a fee of ₱1,500 to ₱10,000, and private clinical psychologists having a fee of ₱7,500 to ₱12,000. Parents were made to report all the consults leading to the confirmation of the diagnosis of autism. The majority of the children receive the confirmed diagnosis of autism after just one consult with a specialist (82.9%). At the same time, the rest required a second or even third consult because the condition may still be evolving, or the family wished to seek another opinion.

Since autism is a diagnosis made clinically based on the DSM-V criteria, no laboratory test is required to confirm the diagnosis. However, certain tests are ordered when it is important to rule out other differential diagnoses and comorbidities based on clinical suspicion. The most common diagnostic test is a hearing evaluation (29.7%), followed by electroencephalography, or EEG, at 24.7%. Other tests

Table 1. Cost for initial diagnosis

	Mean (Pesos)	Standard Deviation (Pesos)	Range (Pesos)
General Pediatrician	545.71	546.81	100 to 3,000
Developmental Pediatrician	1,989.20	1,293.60	1,500 to 10,000
Other specialists*,**	4,157.50	4,677.28	100 to 12,000
Total Cost of Professional Fees	3,368.86	3,228.56	478 to 20,800
EEG*	2,416.67	2,889.56	100 to 15,000
Hearing Evaluation*	1,942.98	1,644.34	100 to 15,000
CT scan*	5,314.19	5,165.73	350 to 7,500
MRI*	11,277.78	6,941.10	3,000 to 19,700
Lead Analysis*	6,000.00	4,242.62	3,000 to 12,000
Other diagnostic tests***	3,841.67	5,502.58	50 to 7,500
Total Cost of Diagnostics	2,350.13	5,633.50	0 to 35,500
Occupational Therapy*	846.43	711.58	100 to 4,000
Speech Therapy*	787.31	998.34	300 to 8,000
Physical Therapy*	1,148.22	707.36	378 to 2,500
Total Cost of Evaluation by Therapists*	1,629.81	1,639.12	378 to 10,000
Average Cost for Initial Diagnosis	7,411.80	7,849.13	1,356 to 44,634

* *Computed average only for that availing of test or service*
** *Other specialists – neurologist, psychiatrist, clinical psychologist, SPED specialist*
*** *Other tests – chromosomal analysis, unspecified laboratory test*

carried out for children were Computed Tomography (CT) Scan (4.4%), Magnetic Resonance Imaging or MRI (5.7%), lead analysis (2.5%), and chromosomal analysis (1.9%). For diagnostic tests, parents spent an average of ₱2,350.13 per child (0 to ₱35,500). Not all children underwent laboratory testing.

Before starting the formal intervention, therapists perform initial assessments on the children. The cost for the first assessment of therapists before starting formal intervention ranged from ₱378 to ₱8,000 and averaged ₱1,629.81 per child.

The total costs for all initial evaluations leading to the confirmation of the autism diagnosis ranged from ₱1,356 to ₱44,634 and averaged ₱7,411.80 per child.

Cost for Intervention and Follow-ups (Table 2)

The majority of the children in the study are undergoing occupational therapy (67.5%) and speech therapy (54.4%). A small group is undergoing physical therapy (4.3%) and Applied Behavior Analysis or ABA (6.3%). The cost for therapy ranges from ₱100 to ₱3,000 per session per child.

A sub-analysis comparing the expenditures for therapy for children 2 to 6 years of age (n = 38) and children above six years of age (n = 120) shows a higher expenditure in the younger group (average of ₱16,086.45 vs. ₱6,678.08 annually per child).

Of the 158 children, 103 (65.20%) are enrolled in a special education program, while only 4 (2.5%) are enrolled in a regular school. 32.2% are not enrolled in any educational program. Expenditures for educational interventions range from 0 to ₱387,600 and average ₱17,299.49 annually per child. The actual cost of education in government schools was not reflected in the survey. Parents whose children are enrolled in a public SPED placed "0" to indicate that the tuition is free.

A sub-analysis comparing the expenditures for educational intervention for children 2 to 6 years of age (n= 38) and children above six years of age (n=120) shows a higher expenditure in the older group (average of ₱23,259.68 vs. ₱3,417.50 per child annually).

The majority (96.8%) of patients are not taking prescription medications. Five (3.2%) are taking antiseizure medications, and an equal proportion (3.2%) are taking anti-psychotic drugs (Risperidone or Abilify). Seventeen (10.7%) parents reported giving their children food supplements and other biomedical treatments (e.g., chelation agents, antioxidants, etc.). Parents reported the actual costs of the medication in unit price, which the researchers converted

Table 2. Cost of interventions for the first year after diagnosis

	Number of Visits per Month			Cost of Therapy per Session (Pesos)		
	Mean	SD	Range	Mean	SD	Range
A. Therapy						
Occupational Therapy*	4.25	3.76	0 to 20	368.62	489.10	200 to 2,000
Speech Therapy*	2.38	2.77	0 to 12	505.58	322.94	200 to 3,000
Physical Therapy*	0.23	1.03	0 to 8	426.29	219.51	100 to 800
Total Costs for Therapy (Annual)				13,108.37	23,403.23	0 to 144,000
				Cost of Annual Tuition Fee (Pesos)		
				Mean	SD	Range
B. Educational Interventions						
SPED*				15,348.06	32,329.22	0 to P157,750
ABA*				62,520	49,578.78	600 to 150,000
Other educational intervention*,**				44,253.64	78,903.69	250 to 279,600
Total Costs for Educational Interventions				17,299.49	47,801.30	0 to 387,600
				Cost of Medications per Year (Pesos)		
				Mean	SD	Range
C. Medications / Supplements						
Prescription Medications / Vitamins / Food supplements				6,412.73	29,046.57	0 to 240,000
	Number of Consults per Year			Cost of Consults per Year (Pesos)		
	Mean	SD	Range	Mean	SD	Range
D. Developmental Monitoring						
Developmental Pediatrician						
1st year from diagnosis (N=158)	0.89	1.05	0 to 6	2,048.01	2,928.27	0 to 18,000
2nd year from diagnosis (N=158)	0.52	0.84	0 to 4	951.54	1,961.48	0 to 10,000
The average cost for follow-up services and needs for the 1st year after diagnosis				***38,868.61***	***72,224.87***	***0 to 500,400***

* *Computed average only for those availing of service*

** *Other educational interventions – regular school, tutorials, social thinking, playschool*

to monthly, then annual costs. The cost of medicines averages ₱6,412.73 per child annually.

There is a trend of decreasing follow-up rates in the years succeeding the initial evaluation. For the first year following the initial diagnosis, only 54.5% went for re-evaluation or follow-up. In the second year, only 25.9% went for a follow-up. The decrease in expenditure for developmental follow-up and re-evaluation followed the decline in follow-up rate. In the first year, parents spent an average of ₱2,048.00 per child; in the second year, an average of ₱951.54 per child.

Overall, the mean cost of follow-up interventions including therapy, education, medications, and developmental evaluations for the first year was ₱38,868.61 which is 5.2 times the expenses for the initial assessment. This amount translates to an average of ₱3,239 a month (21% percent of the monthly expenditures for a household with an income of ₱15,000/month). This imposes a significant financial burden on at least 55% of the families in the study whose monthly income fell below ₱15,000 monthly.

Early Intensive Intervention

It is important to note how many preschoolers (2 to 6 years of age, n = 43) are receiving the prescribed amount of intervention. Among this group, only 2 (4.6%) received the intensive intervention (at least 30 hours of formal intervention per week). At the study time, eighteen (42%) received no form of intervention after being diagnosed, while the rest received less than 30 hours of intervention per week. Only 20 children (36%) were enrolled in an educational program. Overall, this age group underwent only 10 to 16 hours of intervention per week.

Overall Costs (Table 3)

When the costs were totaled from the initial evaluations up to the study, the overall costs ranged from ₱1,434 to ₱506,278 and an average of ₱48,505.13 per patient.

Figure 1 shows the percentage distribution of costs for caring for a child with autism. The highest cost is spent on education (37%), followed by therapy (28%), medications (14%), initial evaluations (11%), developmental monitoring (5%), and diagnostic tests (5%).

Net Present Value of Costs (Table 4)

Table 4 shows an illustrative example of the 10-year direct costs for the care of a child with autism based on actual inflation rates for the Philippines in the past ten years.

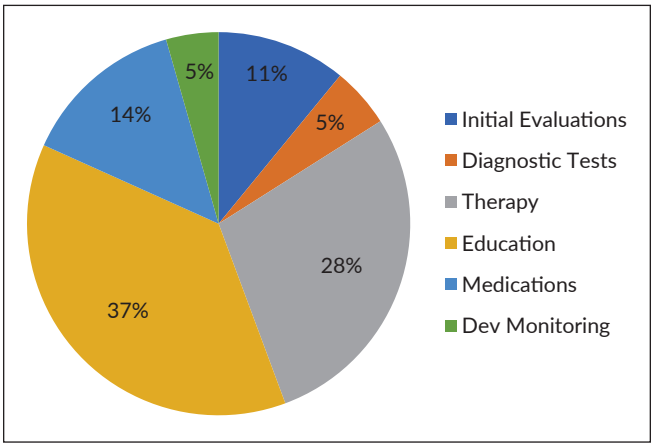

Figure 1. Percentage distribution for direct costs of care.

Table 3. Summary of mean total costs of caring for children with autism (n = 158)

	Mean Costs per Child (Pesos)	Standard Deviation (Pesos)	Range (Pesos)
Professional Fees for Initial Diagnosis	2,667.35	3,316.44	378 to 21,800
Diagnostics	2,350.13	5,633.5	0 to 35,500
Initial evaluation by therapists	1,692.81	1,639.12	378 to 10,000
Maintenance services by therapists *(annual)*	13,108.37	23,403.23	0 to 144,000
Educational Interventions *(annual)*	17,299.49	47,801.3	0 to 387,600
Medications *(annual)*	6,412.73	29,046.57	0 to 240,000
Professional Fees for Developmental Monitoring *(1st year up to present)*	4,272.74	7,156.24	0 to 32,500
All costs	48,505.13	76,314.13	1,434 to 506,278

Table 4. 10-year forecast of the cost of care of a child with autism based on actual Philippine inflation rates from 2009 to 2018

	2009 Cost (NPV, 3.2% IR)	2010 Cost (NPV, 4.1% IR)	2011 Cost (NPV, 4.8% IR)	2012 Cost (NPV, 3.0% IR)	2013 Cost (NPV, 2.6% IR)	2104 Cost (NPV, 3.6% IR)	2015 Cost (NPV, 0.7% IR)	2016 Cost (NPV, 1.3% IR)	2017 Cost (NPV, 2.9% IR)	2018 Cost (NPV, 5.2% IR)	Total
Initial Evaluations for Diagnosis	7,411.80										460,227.63
Maintenance Costs	38,868.61	40,462.22	42,404.40	43,676.54	44,812.13	46,425.36	46,750.34	48,152.85	49,549.28	52,125.85	

(https://knoema.com/atlas/Philippines/Inflation-rate) NPV, net present value; IR, inflation rate

DISCUSSION

The researchers were only able to analyze the direct cost of care for autism-related services. Healthcare expenses in the Philippines are primarily out-of-pocket. Among the significant issues related to the care for individuals with autism is the economic burden on the affected families. This study shows that ASD is associated with a substantial financial burden, with half of the families in the study having to shunt 21% of their income for autism needs. Among the lower 30 percent income groups for Filipino households in 2018, this amount is more than twice the spending for housing (8.1% of total income) and one-third of the expenditure for food (58.2% of total income).[14] This burden goes beyond the expenses of having the child diagnosed. While many families even have to save up for the confirmation of the diagnosis, the cost for the maintenance services poses a much bigger problem. So is the case for the children, who, after being diagnosed early, still lose the benefit of early intensive intervention due to financial constraints.

The vast range of the total costs for the care of children with autism may be explained by the following: 1) variability of costs for the services; 2) non-uniformity of access to services, 3) socioeconomic status, 4) and the variability in the needs or levels of support required by the children in the spectrum of autism (from mild to severe cases). The total cost of care per child increased with higher socioeconomic status in the sample population. Families with higher income spent more on intervention and monitoring than those with lower income. This finding is compatible with the costing study done by Dacumos, where private patients were shown to spend as much as seven times more than charity patients.

Because there is minimal insurance coverage for the needs of children with autism and other developmental disabilities, most families spend out-of-pocket to care for their children with autism. This explains why more affluent families can pay more for intervention and monitoring and why many children did not receive intervention despite being diagnosed.

Early intensive intervention can spell the difference between being functional and being a burden to the family throughout the individual's lifetime. Being the latter will incur more costs and opportunity losses for that individual with ASD and the ones providing care. A compelling argument for giving early intensive intervention is the associated costs with non-treatment or sub-optimum treatment.

Childhood autism has been shown to significantly impact parents' productivity and earnings. A US study that compared parental hours of work and earnings among parents of children with ASD, other health limitations, and no health limitations showed that parents of children with ASD earned 35% less than parents of children with other health limitations and 56% less than parents of children with no health limitation. Weekly work hours were also 5 hours less than children with no health limitation.

An equal percentage (67%) of children undergo therapy and educational intervention, but the latter increases the overall cost. The higher costs of tuition explain this. These figures show that the therapy and educational needs of children with exceptionalities are currently underserved.

The decreasing rate of follow-up for developmental monitoring show several things: 1) that the costs associated with follow-up hinder parents from bringing their children, 2) parents may not fully understand the value of continued monitoring, or 3) parents do not feel the need to follow-up after confirming the diagnosis, especially when they see signs of improvement in their children.

Coming up with actual data on the cost of care for children with autism is fraught with limitations. Since there is limited insurance coverage, the researchers had to rely on parental reports, which is subject to recall bias. Moreover, the range of expenditures may not reflect the children's actual needs but is reflective more of the family's spending capacity or access to the services.

CONCLUSION

The care system for children with autism is fragmented, with gaps widened by the economic burden imposed by this lifelong condition. It is crucial to elucidate the state's role in caring for children with autism and other developmental disabilities and push for more comprehensive insurance coverage for these individuals. Requiring insurance companies to cover autism services will reduce families' financial burdens associated with their children's health care expenses. Early diagnosis can genuinely lead to early intervention and optimum outcomes.

In a country with limited resources, other accessible, continuous, and culturally relevant forms of low-cost intervention should be developed. These may include parents' and caregivers' training and home and community programs so that children can continue to receive appropriate and timely intervention in a wider variety of settings.

A comprehensive costing analysis that will include indirect costs such as productivity and opportunity losses will give us a complete picture of the economic impact of autism. Multi-sectoral action needs to be taken, policies need to be formulated, and programs need to be designed and implemented to address the financial burden of caring for persons with autism.

Statement of Authorship

All authors contributed in the conceptualization of work, acquisition and analysis of data, drafting and revising and approved the final version submitted.

Author Disclosure

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