THE BURDEN OF PRENATAL EXPOSURE TO ALCOHOL: REVISED MEASUREMENT OF COST

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ABSTRACT

Background
In Canada the incidence of Fetal Alcohol Spectrum Disorder (FASD**)** is estimated to be 1 in 100 live births. FASD is the leading cause of developmental and cognitive disabilities in Canada. Only one study has examined the cost of FASD in Canada. In that study we did not include prospective data for infants under the age of one year, costs for adults beyond 21 years or costs for individuals living in institutions.

Objective
To calculate a revised estimate of direct and indirect costs associated with FASD at the patient level.

Methods
Cross-sectional study design was used. Two-hundred and fifty (250) participants completed the study tool. Participants included caregivers of children, youth and adults, with FASD, from day of birth to 53 years, living in urban and rural communities throughout Canada participated. Participants completed the Health Services Utilization Inventory (HSUI). Key cost components were elicited: direct costs: medical, education, social services, out-of-pocket costs; and indirect costs: productivity losses. Total average costs per individual with FASD were calculated by summing the costs for each in each cost component, and dividing by the sample size. Costs were extrapolated to one year. A stepwise multiple regression analysis was used to identify significant determinants of costs and to calculate the adjusted annual costs associated with FASD.

Results
Total adjusted annual costs associated with FASD at the individual level was $21,642 (95% CI, $19,842; $24,041), compared to $14,342 (95% CI, $12,986; $15,698) in the first study. Severity of the individual's condition, age, and relationship of the individual to the caregiver (biological, adoptive, foster) were significant determinants of costs ($p < 0.001$). Cost of FASD annually to Canada of those from day of birth to 53 years old, was $5.3 billion (95% CI, $4.12 billion; $6.4 billion).

Conclusions
Study results demonstrated the cost burden of FASD in Canada was profound. Inclusion of infants aged 0 to 1 years, adults beyond the age of 21 years and costs associated with residing in institutions provided a more accurate estimate of the costs of FASD. Implications for practice, policy, and research are discussed.

Key words*:* *Alcohol, pregnancy, cost, economic burden, fetal alcohol spectrum disorder*

In Canada the incidence of Fetal Alcohol Spectrum Disorder (FASD) has been estimated to be 1 in 100 live births.[1,2,3] Caused by prenatal exposure to alcohol, the disorder is the leading cause of developmental and cognitive disabilities in Canada's children, and its effect are life lasting.[1,2] FASD is an umbrella term describing a range of physical, cognitive, and behavioural disabilities that can occur in children exposed to alcohol during gestation. Within the overall category of FASD are three diagnostic terms: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), and Alcohol-Related Neuro-developmental Disorder (ARND). Although the individual with PFAS and ARND may not have all or any of the characteristic facial features or growth restriction seen in the full Fetal Alcohol Syndrome, the neurotoxicity resulting from prenatal exposure to alcohol can be as significant and disabling.[1-8]

In Canada, FASD is increasingly being recognized as a large public health problem with high potential for the prevention of future cases and for the prevention of excess disability. Updated and improved cost data on FASD is a research priority.

The cost burden of FASD has been measured in six studies.[9-14] Abel & Sokol[9] measured the economic cost of FAS from the perspective of the health care system and estimated that the burden of FAS in the United States was US $321 million in 1984, based on the average incidence of 1.9 FAS cases per 1000 live births. The incidence rate was on average, drawn from several prospective and retrospective studies. Components of costs included treatment of care of low birth weight babies with FAS; costs for surgical correction of FAS-related birth defects; care for those with moderate or severe cognitive disabilities; and the cost of semi-independent supervised support for mildly cognitively disabled patients with FAS who were 21 years of age or under.

In 1991, Abel & Sokol[10] again estimated the cost of FAS from the perspective of the health care system and produced much lower annual cost estimate of US $74.6 million, based on an incidence rate of 0.33 FAS cases per 1000 live births. This conservative estimate was derived entirely from prospective studies, which yield lower estimates of FAS incidence than do retrospective studies, in part because, unlike the retrospective studies, there are no prospective data for Native Americans and other racial/ethnic groups that may face a higher risk of being diagnosed with FAS. In addition, the cost of semi-independent supervised support for mildly cognitively disabled patients ages 21 and under was excluded from the later study, on the grounds that such care was generally required only after the age 21. Neither of the Abel and Sokol studies included costs beyond age 21.

Harwood & Napolitano[11] used a societal perspective and generated cost estimates of US $ 1.95, 3.2, and 9.69 billion dollars using alternative FAS incidence rated of 1.0, 1.67, and 5.0 per 1000 live births in the United States. Incidence rates were based on a review of prospective studies. Costs included estimates of the value of productivity lost as a result of cognitive disabilities, as well as the cost of treatment and residential care for patients of all ages with FAS.

Klug & Burd[12] estimated the mean annual cost per child with FAS, of 45 children aged 0 through 21 years of age, in North Dakota, USA. The researchers found that the annual cost associated with FAS per child was US $2342 more than the annual average cost of health for a child in North Dakota who did not have FAS (US $500 per year).

Rice, Kelman, et al[13] estimated the cost of FAS from the perspective of the health care system and placed the annual cost of treating the birth defects associated with FAS in the United States at US $1.6 billion, based on an incidence of 1.9 FAS cases per 1000 live births. The incidence was based on a review of several prospective and retrospective studies. Components of costs included the cost of care for FAS-related birth defects and cognitive disability, as well as the cost of residential care for patients over 21 years. The cost of residential care accounted for 8- percent of the total cost estimated.

Stade et al[14] measured the burden of cost of FASD at the individual-patient level of 200 children and youth, aged 1 to 21 years, in Canada and found that the cost per child was CD $14,342. Cost included estimates of Medical, Education, Social Services, and Out-of-Pocket expenses. Cost of FASD annually to Canada of children and youth, 1 to 21 years old, was $344,208,000.

The six studies reviewed demonstrate that the physical, behavioural, and cognitive sequelae of FASD are costly to treat and to rehabilitate, and may limit an individual's ability to contribute to society's productivity. The economic burden of FAS calculated in these studies provides impetus for implementing prevention and treatment strategies. However, there are several limitations to past research examining the cost of FAS. In the five American studies[9-13], past research estimates of costs are strictly limited to FAS and do not reflect costs of other alcohol related effects, which are more common. Thus, the results of these studies may significantly underestimate the economic burden associated with prenatal alcohol exposure. Precisely what costs should be measured and included in an economic evaluation depends on the perspective selected. In 4 of the 5 studies reviewed, the perspective chosen resulted in under-estimation of the total costs of FAS. Specifically, Abel & Sokol[9,10] and Rice, Kelman et al.[13] failed to include direct costs to the family/patient or productivity losses associated with prenatal exposure to alcohol. Klug and Burd[12] only measured medical costs and did not include cost of education, social services, productivity losses and others. Discrepancies in cost estimates obtained in past studies were due, in part, to the time horizon used in the evaluation. For example, Abel & Sokol did not include costs beyond 21 years of age. Rice, Kelman, et al, included the costs of treatment and care for individuals under the age of 22 years as well as residential care for all ages. Harwood & Napolitano[11], with the largest cost estimates, included treatment, care, and lost productivity for all ages in his research.[13] In the Canadian study conducted by Stade and colleagues[14], costs of children living in institutions and individuals who were homeless or in the judicial system, and prospective data for infants under the age of one year were not included in the study. Health care resource data were based on parent reports. Finally, it was extremely difficult to measure productivity loss of parents who reported a career change or lack of career opportunity.

METHODS

Research Design

Prospective cross-sectional research design was used.

Setting

This study was conducted in urban and rural settings throughout Canada.

Sample

Potential participants were elicited from parent support agencies across Canada. These agencies provide service to a heterogeneous population of over 1000 children, youth and adults with FASD and their parents throughout Canada. All participants in this study were diagnosed with FAS, PFAS, or ARND. The children, youth and adults with FASD varied in the following characteristics: age, gender, educational levels and abilities, ethnicity, and age of entry into their current home. Their parents also varied in terms of age, gender, marital status, education, and relationship to the child (adoptive, biological, and foster).

The current study did not include any participants interviewed in the 2003 study.[14] Two-hundred and forty (240) of the study sample included parents (biological, adoptive, or foster) of one or more children diagnosed with FAS, PFAS or ARND, aged 1 day to 53 years, who were currently living with their child, or responsible for the care and welfare of that child. Ten (10) participants were adults with FASD. All of the participants completed the Health Services Utilization Inventory – FASD (HSUI-FASD). A family member or social service worker helped 5 of the 10 adult participants with FASD complete the survey. The remaining 5 adult participants provided information such as medications, hospitalization records, ODSP forms and others.

Data Collection: Health Services Utilization Inventory – FASD (HSUI-FASD)

The Health Services Utilization Inventory (HSUI)[14] used in the first estimates of cost of FASD in Canada was modified to include other significant components of costs. The tool contained questions consistent with the questionnaire used in the 2003 study, but also included questions relevant for measuring the costs in infancy and in adulthood and the costs of living in an institution. The modified tool was reviewed by experts in FASD, including parents and professionals throughout Canada for content, face and construct validity.

The HSUI-FASD consisted of questions about the respondents' direct costs of medical care – hospital admissions, costs of surgeries, health professional services, medication; costs of educational services- home schooling, special schooling, infants stimulation or therapy program; costs of social services - respite care, foster care; cost of institutionalization; government pensions; adoption costs; and direct costs to parents parking and transportation costs, and costs of externalizing behaviours, and others.

The tool also included questions to assess indirect costs such as days missed from work caring for the child with FASD. Questions were restricted to a reliable duration of recall, such as 6 months for remembering a hospitalization, 3 months for a visit to a physician and 1 month for use of a prescription medication.[15]

Unit prices for services and care identified by the parents were collected separately, and total expenditures for services used were calculated. Unit costs associated with costs of treatment and care identified by parents in the "Health Inventory" were collected from various sources including Pediatric Hospitals across Canada; Ministry of Education, Ministries of Community and Social Services, Ministries of Health and Long-Term Care; Schedules of Physician Benefits; Provincial Drug Formularies and others.

Productivity losses were calculated by estimating loss of caregivers' wages. Finally, costs that are incurred because of the child's externalizing behaviours, which included acts of aggression such as damage to people/ property or stealing, were included in the total estimates of costs whenever possible. Costs were analyzed from the perspective of society, the provincial ministries of health and the patient. All costs incurred by parents and caregivers were assigned to the child as the unit of analysis. An incidence approach which begins at birth was used. All data were analyzed using Statistical Package for the Social Sciences (SPSS).

Data Analysis

The average direct costs associated with FASD at the individual level, from birth to 53 years, were calculated by multiplying the volume of resource use by the unit price for each service. Costs for recall intervals of various lengths were annualized by linear extrapolation. All costs were expressed in 2007 Canadian dollars.

Employed subjects were asked to report their salary within a $10,000 range, and the median was used in the calculation. Wages per day were estimated by dividing the annual salary by the number of potentially productive days per year (240). This is estimated by subtracting vacation time (10 work days) from the number of work days per year (260), resulting in 240 potentially productive days per year. For unpaid labour or those not reporting their salary range, a wage was imputed from sex-specific and age-specific means of the study sample.

Productivity costs were measured using the human capital approach. The Health Services Utilization Inventory elicited information about the number of days lost from work, over the preceding month, caring for the child with FASD. The number of days lost were multiplied by 12 to calculate time losses over a 12 month period. This number was then multiplied by the parent's average daily wage yielding annual productivity losses per child with FASD.

Expenses related to the child's externalizing behaviours, including acts of violence against persons, animals, and or property; and stealing were elicited directly in the inventory.

The contributions of key costs were categorized as:

1. medical;
2. education;
3. social services;
4. patient/family direct;
5. productivity losses; and
6. externalizing behaviours

Total unadjusted costs were calculated at the patient level by summing the costs for each child in each cost component. Societal costs were presented from the perspective of society, the government ministries and the patient.

A stepwise multiple regression analysis was used to calculate the average cost per case, controlling for explanatory variables. Variables which potentially influence cost, included severity of illness defined by degree of cognitive delay and behavioural problems, age of the child at diagnosis, relationship to the child (biological, adoptive, foster), age of parent, marital status, occupation of the parent, annual wage of the parent, ethnic group of the child and parent, and geographical setting. P values of <0.05 were considered significant.

RESULTS

Sample Characteristics

Two-hundred and fifty caregivers or adults with FASD participated in the study. Table 1 presents the children's characteristics. A document written by the diagnosing health professional or the primary physician confirmed the child's diagnosis. Table 2 presents the parents' characteristics. Figure 1 demonstrates the number and percentage of participants from the 3 geographical settings: Canada West, Central, and East. Canada was divided into 3 geographical settings, rather than provinces, due to the small sample size.

TABLE 1 Cost Study: Characteristics of the Children, Youth and Adults with FASD (n=250)

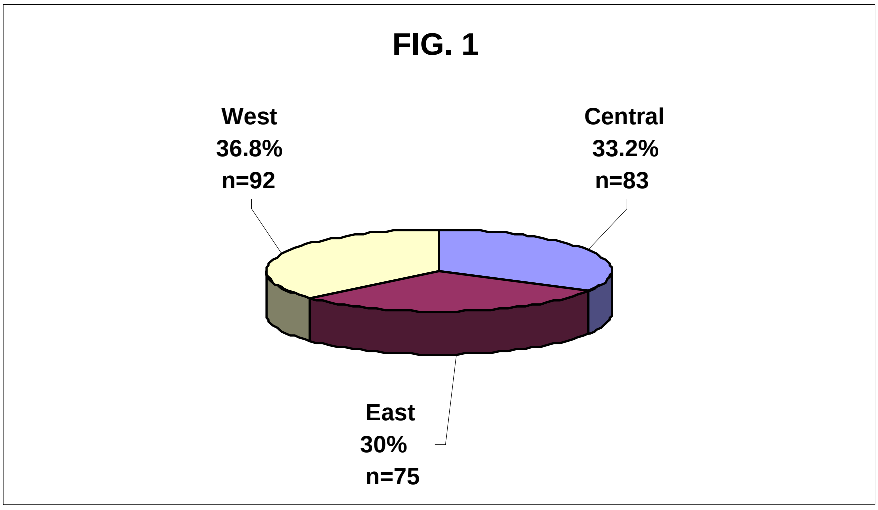
Characteristics	**Number**	**(%)**
Sex:		
Male	133	53%
Female	117	47%
Diagnosis:		
FAS	30	12%
PFAS	23	9%
ARND	197	79%
Cultural Group:		
Native-Canadian	102	41%
Euro-Canadian	120	48%
Asian-Canadian	16	6%
Jamaican-Canadian	12	5%
Age: (0 = Day of birth)		
0-2 years	20	8%
3-6 years	36	14%
7-12 years	60	24%
13-17 years	48	19%
18-21 years	36	14%
22-25 years	18	7%
26-35 years	12	5%
36-45 years	11	5%
45-53 years	9	4%
Relationship to Parent:		
Biological	36	14%
Adoptive	142	57%
Foster	62	25%
Self	10	4%
Severity of Disability *		
Mild Disability	108	43%
Moderate Disability	101	40%
Severe Disability	41	16%

***** The level of disability – mild, moderate, severe - was a clinical judgment determined by a health professional, in collaboration with the caregiver, based on deficits in intellectual, adaptive behaviour, and/or organ anomalies that significantly limited an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that is expected of the individual's age-level.

TABLE 2 Cost Study: Characteristics of the Parents (n=250)

Characteristics	Number	(%)
Gender		
Female	185	74
Male	65	26
Age (in years)		
< 20 to 30	12	05
31 to 40	46	18
41 to 50	64	26
51 to 60	66	26
> 60	62	25
Relationship to the child with FAS		
Biological	36	14
Adoptive	142	57
Foster	62	25
Self	10	04
Marital Status		
Married/Common-in-law	132	53
Single	53	21
Divorced/Separated	65	26
Occupation		
Employed Full	95	38
Part-Time	50	20
Unemployed	17	07
Full-Time Homemaker	25	10
Pension	38	15
Self-Employed	25	10
Average Annual Household Income		
$10,000 to $30,000	50	20
$30,000 to $40,000	62	25
$40,000 to $50,000	58	23
$50,000 to $60,000	45	18
more that $60,000	35	14
Preferred not to answer	00	00
Education		
Grade 7 to completion of Grade 12	55	22
Grade 13 (if applicable and/or Some University or Colleges)	88	35
Completed University or College	98	39
Post Graduated Work	9	4
Ethnic Group		
Native Canadian	102	41
Euro-Canadian	120	48
Asian-Canadian	16	06
Jamaican-Canadian	12	05

FIG. 1 Cost: Participants by Geographical Regions*



*West: Saskatchewan, Alberta, British Columbia, and the Yukon/North West Territories; Central: Ontario and Manitoba; East: Quebec, Newfoundland, New Brunswick, Nova Scotia

Direct and Indirect Costs

The contributions of the direct and indirect cost components from the perspectives of society, the Ministry of Health/Social Services and the patient are displayed in Table 3. From the societal perspective, the average unadjusted annual cost was $22,524 per child with FASD.

Components of Direct Costs

Components of direct costs from the societal perspective included medical, education, social services and out-of-pocket costs. As illustrated in Table 3, education (28%) and medical services (35%) represented the greatest percentage of costs. It is striking that families pay 25% of the total costs.

TABLE 3 Average Annual Cost of FASD per Case

Component	Societal Cost ($) % of total	Ministry of Health/Social Service Cost ($) % of total	Patient Cost ($) % of total
Direct Costs: Medical			
Hospitalization	$ 1,445.45	$ 1,445.45	N/A
Emergency Room/Clinic Visits	$ 660.82	$ 660.82	
	$ 2,106.27	**$ 2,106.27**	N/A
Visits to Health Professionals			
Family Doctor	$ 301.15	$ 301.15	N/A
Orthopedic Surgery	$ 67.68	$ 67.68	
Urologist	$ 46.10	$ 46.10	
Allergist	$ 6.08	$ 6.08	
Pediatrician	$ 241.65	$ 241.65	
Psychiatrist	$ 892.00	$ 892.02	
Occupational Therapist	$ 444.12	$ 352.00	$ 92.12
Physiotherapist	$ 91.00	$ 91.00	$ 00.00
Speech Therapist	$ 58.54	$ 28.31	$ 30.23
Psychologist	$ 737.39	$ 122.00	$ 615.39
	$ 2,885.73	**$ 2,147.99**	**$ 737.74**

Medical Devices	$ 416.02	$ 282.00	$ 134.02
Medication Dispensing Fees	$ 56.00	$ 47.50	$ 8.50
Prescription Medications	$ 800.00	$ 592.00	$ 208.00
Non-Prescription Medication	$ 218.08	N/A	$ 218.08
Diagnostic Tests	$ 148.00	$ 148.00	N/A
	$ 1,638.10	**$ 1,069.50**	**$ 568.60**
TOTAL	**$ 6,630.10**	**$ 5,323.76**	**$ 1,306.34**
Direct Costs: Education			
Home Schooling	$ 198.50	$ 198.50	N/A
Special Schooling	$ 3,237.60	$ 3,237.60	N/A
Residential Program	$ 1,600.00	$ 1,000.00	$ 600.00
Post-Secondary Education - Tutor	$ 64.00	N/A	$ 64.00
Job Education	$ 160.00	$ 160.00	N/A
TOTAL	**$ 5,260.10**	**$ 4,596.10**	**$ 664.00**
Direct Costs: Social Services			
Respite Care	$ 151.84	$ 151.84	N/A
Foster Care	$ 2,000.40	$ 2,000.40	N/A
Institutionalization	$ 1,654.95	$ 1,654.95	N/A
ODSP	$ 143.34	$ 143.34	N/A
Legal Aid	$ 125.00	$ 125.00	N/A
TOTAL	**$ 4,075.53**	**$ 4,075.53**	
Out-of-Pocket			
Transportation per visit	$ 152.16	N/A	$ 152.16
Parking	$ 162.00	N/A	$ 162.00
Externalizing Behaviours	$ 2,500.12	N/A	$ 2,500.12
TOTAL	**$ 2,814.28**	N/A	**$ 2,814.28**
TOTAL DIRECT COSTS	**$ 18,780.01**	**$ 13,995.39**	**$ 4,784.62**
Indirect Costs			
Productivity Losses	**$ 1,430.65**		
TOTAL COSTS	**$ 20,210.66**		

Determinants of Cost

A stepwise multiple regression analysis was used to calculate the average cost per case, controlling for explanatory variables. Table 4 illustrates that severity of the child's condition, age of the child and relationship to the child significantly impacted on costs associated with FASD. Table 5 presents the adjusted annual costs for severity of disability: As expected, cost increased with the severity of illness. Table 6 outlines the adjusted costs according to age. Specific categories of resources are consumed as the child with FASD goes through life: The youngest age is characterized by utilization of health care, social services related to foster care costs; while in the older children costs are predominantly related to educational needs, externalizing behaviours, and the need for institutionalization. The average annual costs appear to decrease in late adolescence, beyond the age of 18 years. Table 7 demonstrates that costs of children in care are greater than costs for adoptive and biological caregivers. A regression analysis was used to arrive at an adjusted average total annual cost for individuals diagnosed within the Fetal Alcohol Spectrum, from day of birth to 53 years, in Canada. Specifically, when adjusted for severity of disability, age, and relationship to the child, the summary adjusted value of average annual costs was $21,642 (95% CI, $19,842; $24,041).

TABLE 4 Determinants of Costs from Societal Perspective

Variable	F	P
Severity of Disability	41.04	<0.001
Age of Child, Youth, Adult	31.02	<0.001
Relationship to Child, Youth, Adult	14.06	<0.001
Geographical Region	3.92	NS*
Age of Caregiver	3.88	NS*
Occupation of Caregiver	3.01	NS*
Education of Caregiver	1.62	NS*
Cultural Group of Child, Youth, Adult	0.10	NS*
Marital Status of Caregiver	0.08	NS*

*NS=Not Significant

TABLE 5 Adjusted Annual Costs per Individual with FASD According to Severity of Disability

Disease Severity	n	Mean	95% CI
Mild	122	$10,009	$ 5,445 $15,221
Moderate	84	$17,345	$15,012 $19,432
Severe	44	$31,234	$22,341 $40,368

TABLE 6 Adjusted Annual Costs per Individual with FASD According to Age

Age Range (Years)	n	Mean	95% CI
0 to 2	20	$30,222	$26,302 $38,222
3 to 6	36	$26,544	$23,666 $30,328
7 to 12	60	$28,666	$25,446 $32,832
13 to 17	48	$20,201	$16,997 $24,885
18 to 21	36	$16,544	$14,888 $18,234
22 to 25	18	$16,232	$14,666 $18,002
26 to 35	12	$15,998	$14,021 $18,112
36 to 45	10	$14,689	$12,888 $16,681
46 to 53	10	$14,810	$12,664 $16,988

TABLE 7 Adjusted Annual Costs - According to Relationship to the Individual with FASD

Relationship to Child/Adult with FASD	n	Mean	95% CI
Biological	36	$8,8225	$7,868 $10,001
Adoptive	142	$10,886	$9,563 $14,390
Foster	62	$16,355	$15,999 $16,884
Self	10	$15,002	$14,002 $16,022

DISCUSSION

Current and Past Research

This study has illustrated that the burden of prenatal exposure to alcohol is profound. The adjusted annual costs per child/youth with FASD, aged 0 to 53 years, in Canada were $21,642. The largest single component of costs was education costs and medical costs accounting for 28 % and 35 % respectively. The current study attempted to overcome the limitation of past research by including estimates of costs for infants from day of birth to 1 years, cost of adults beyond the age of 21 years and costs associated with children residing in institutions. Most past studies provide estimates of the total cost of FASD to the nation. Only two studies[13,14] have estimated the average cost associated per case of FASD, and only one study has been conducted in Canada.[14]

These per case estimates will be more helpful in providing guidance as to what policies and interventions for prevention and treatment of FAS are appropriate. Case-specific costs provide more information, such as what types of costs are incurred at different ages, which can be used for developing programs and services.

Determinants of Cost

Severity of the disability impacted on the cost of FASD. This is in keeping with clinical findings, as individuals with FASD who have severe cognitive and behavioural disabilities will require more specialized educational services, and health services such as psychologists, occupational therapists, community workers and others. Similarly, children with organ anomalies will require more hospitalizations and other medical services.

Age of the child impacted on the cost of FASD. Costs for children 0 to 3 years were higher than in all other groups. This reflects the costs of specialized stimulation programs, and the use of health specialists such as occupational therapists, physiotherapists, developmental pediatricians and cost of hospitalization in the neonatal period. Costs began to plateau between the ages of 17 to 25 years, and in the 45 to 53 age group were the lowest. Clinical data suggest that there is not only a lack of services for the older age groups but an inability of young adults, and adults with FASD to access services due to their cognitive executive functioning difficulties, and often because they did not want to accept services..

Relationship to the child significantly influenced cost. This was largely associated with the cost of children in care. Unlike the 2003 study[14], children under the age of 1 year were included. The majority of infants in this study were not residing with a biological or adoptive family, but in the care of a child protection agency. In addition, biological parents and adoptive parents raising children of any age could identify general services needed for their child but were not able to access or pay for services as readily as foster parents.

The current study was not designed to estimate the costs at the population level. Costs were calculated at the individual-patient level. However, given the need for National costs to illustrate the cost significance of this disability, the cost of FASD was calculated. The prevalence of FAS and related effects is still poorly understood because researchers have used varying diagnostic criteria and methods of identifying cases, and numbers of diagnostic centres are limited. An estimate of the prevalence FASD in Canada is 1 in 100 people. The number of people from day of birth to 53 years in Canada is approximately 24.29 million.[16]

Therefore, the estimate of FASD in the "birth to 53 year age group" in Canada is 242,906 individuals. The adjusted annual cost of FASD in Canada for ages 0 to 21 years at the individual level is $21,642 (95% CI, $19,842; $24,041). Therefore, the annual cost of FASD to Canada of those 0 to 53 years of age with FASD is $5.3 billion (95% CI, $4.12 billion; $6.4 billion).

Study Limitations

While the study did not draw a random sample of children with FAS, the sampling plan included multiple areas of Canada and all children (parents) agreeing to participate were enrolled. Generalisability of the findings to the larger Canadian population is supported by the heterogeneity of the sample. The study did not include individuals who were incarcerated at the time of data collection, and thus may have lead to a somewhat lower cost estimate. The study was limited to children and adults from day of birth to 53 years.

Implications to Practice and Research

FASD is a public health priority in Canada with significant potential for prevention of future births of infants exposed to alcohol during their gestation, and for the prevention of the lifelong disabilities associated with FASD. Updated and improved cost data provided by this study is further impetus for clinical and policy decision-makers to allocate more funds to the prevention of FASD.

The costs components in the first year of life demonstrated not only the financial burden in the beginning of life, but the potential psychological burden to the infant. These infants are often placed in care before moving to a permanent home and family, may require painful and complex surgeries and/or specific medical or physical therapies, and they may have to cope with developmental delay. The components of cost in the first year of life with their associated psychological burdens demonstrate how essential it is to prevent this disability. The decreased costs associated with FASD in late adolescence and adulthood demands an evaluation of availability, access and utilization of services for these age groups.

The study findings illustrated that 25 % of total costs were paid by the caregivers caring for their child or family members with FAS. Policy makers and health and social service professionals should be aware of this substantial long-term economic impact of prenatal exposure to alcohol and should be sensitive to the financial constraints faced by parents. In addition, given the high adoption rate among this population, it is essential that infants prenatally exposed to alcohol be identified so that potential parents will not only be prepared of the potential special needs of the children but also be prepared for the potential costs. It is essential that financial support for specialized programs be provided by adoption agencies if needed.

Although this research attempted to overcome limitations of earlier studies, methods used to collect cost data continue to require further research and development. For example, it remains difficult to accurately measure productivity loss of parents of children and of adults with FAS. Parental reports of lost income due to career change or lack of career opportunity because of the child's disability could not be measured. It is difficult to determine the productivity loss of adults with FASD. Some adults with FASD in this study did work despite their level of disability. Environmental factors with lack of supports and lack of appropriate jobs, as well as late diagnosis may have contributed to loss of productivity of the majority of adults with FASD. A study focusing specifically on productivity losses is needed.

Studies which look more closely at the factors of why costs differ between foster, biological and adoptive families are needed. Future studies which include cost data of incarceration would more completely illustrate the economic burden of prenatal exposure to alcohol. Finally, studies that examine the cost benefit of programs for preventing the birth of a child with FASD are needed. Similarly, cost benefits of programs to promote better outcomes for these children must be conducted.

CONCLUSION

Study results demonstrated the cost burden of FASD in Canada was profound. Inclusion of infants aged 0 to 1 years, adults beyond the age of 21 years and costs associated with children residing in institutions provided a more accurate estimate of the costs of FASD. It is anticipated that this revised estimate of the burden of cost associated with prenatal exposure to alcohol may benefit children and youth with FASD.

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