Children in Need of Pharmacare

Medication Funding Requests at the Toronto Hospital for Sick Children

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ABSTRACT

Objectives: Although a national Pharmacare program ensuring access to and affordability of needed medications has repeatedly been cited as a priority to policymakers, 20% of families remain either uninsured or under-insured. The Hospital for Sick Children's Patient Amenities Fund (PAF) covers out-of-pocket medication expenses for inpatient and outpatient children. The research objectives were to 1) examine family demographics and socio-economic status (SES), the types of medications requested and government program process issues of PAF applicants in 1998 and 1999, and 2) describe trends in PAF requests from 1998 to 2000.

Methods: Data were extracted retrospectively from fund requests, charts and social work and discharge planning reports. Descriptive statistics were used to summarize the data and to examine time trends.

Results: Eighty-six applicants submitted 112 requests from 1998-1999. Most were for children with cancer, neurological disorders and transplant patients. Medication expenditures were \$22,408 in 1999, a 39% increase over 1998. Most requests came from two-parent nuclear families where one or both parents were employed. High deductibles, waiting time, application form complexity and request denials were cited as problems encountered with government drug plans.

Discussion: The findings suggest that for provinces that do not provide universal drug insurance programs, relying on a patchwork of government plans and community agencies may not be effective in ensuring easy and timely access to necessary medications for children.

La traduction du résumé se trouve à la fin de l'article.

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A national Pharmacare program ensuring access to and affordability of needed medications has repeatedly been cited as a priority to policymakers.¹ This goal has yet to be realized and debate continues regarding what constitutes optimal pharmaceutical policy in Canada.²⁻⁵ Of particular concern are the needs of vulnerable populations, such as children. A recent Health Canada study observed wide variation across the provinces in the provision of drug coverage to families.² Families without private drug plans face major financial burdens. Parents who are part-time workers and low income earners are more likely to be uninsured or under-insured. Children from families without private insurance rely on publicly administered plans and community agencies or must pay out of pocket.

Are pharmaceutical policies designed to provide coverage to families without a private drug plan working? In Ontario, gaining access to government plans can be complicated and time-consuming. Barriers to access for families exist in the form of cost-sharing through income-indexed deductibles and/or co-payments. Savings to the Ontario Drug Benefits program (ODB) resulting from cost-sharing may be offset by cost-shifting to the patient's family and to other health care sectors, a phenomenon that has been observed in other jurisdictions with government cost-sharing programs.^{4,6-9}

Few studies have examined the effect of pharmaceutical policies on child health. In the Ontario Bronchial Inhaler study, health service use, health outcomes and costs were investigated in adults and children with asthma, a chronic condition requiring long-term treatment with prescription medications.^{10,11} In a retrospective analysis which included 42 children from families with no drug plan, a significantly higher proportion of parents without drug plans reported delaying or not filling prescriptions for their children because of cost compared to parents with drug plans (31% vs. 13%, $p=0.002$).¹² Children from families without drug plans had significantly fewer visits to respiratory specialists with a trend toward fewer prescriptions and more Emergency Department visits. In a study of cost-sharing and medication use by children enrolled in five US drug benefit plans, Hong and Shepherd suggested that increasing the level of cost-sharing may

TABLE I
Publicly Administered Drug Plans Available in Ontario

Program	Eligibility	Characteristics
Ontario Drug Benefits program	<ul style="list-style-type: none"> Valid Ontario Health Card Receiving social assistance or Family/Disability Benefits 	<ul style="list-style-type: none"> Provides family access to ODB* formulary No annual deductible \$2.00 co-payment required for each refill Benefits end when social assistance ends
Trillium	<ul style="list-style-type: none"> Valid Ontario Health Card No private drug plan or private plan does not cover all drugs or all costs Large part of income is spent on prescription drugs Program open to all family members 	<ul style="list-style-type: none"> Provides family access to ODB formulary Annual deductible is \$150 to \$4,089, depending on household income and size Once deductible is paid, \$2.00 co-payment required for each refill No consideration given to expenses related to diagnosis Application form can be difficult to understand Yearly application, 4-8 weeks to process
Assistance for Children with Severe Disabilities	<ul style="list-style-type: none"> Based on annual family income Based on eligible expenses related to impact of condition on child's development and activities of daily living (i.e., feeding, cognitive function, motor skills) 	<ul style="list-style-type: none"> Provides access to ODB formulary \$2.00 co-payment required for refills Lengthy and complicated application process, involves 2 applications and interview with patient/family Can take months for application approval, especially in larger geographic areas Yearly review required
Homecare – Community Care Access Centres	<ul style="list-style-type: none"> Restricted to patients eligible for CCAC† services upon discharge Ineligible if patient has private drug insurance 	<ul style="list-style-type: none"> Patient receives access to ODB formulary for duration of homecare services only \$2.00 co-payment required for refills Benefits begin immediately upon discharge
ODB Section 8	<ul style="list-style-type: none"> Must already have ODB card, from any program Authorization is diagnosis-specific 	<ul style="list-style-type: none"> Approval is DIN-specific Detailed application must be submitted by physician to Drug Programs Branch Review and approval by Drug Quality and Therapeutics Committee required May take 4-8 weeks to be approved Approval granted for 12 months
Medical Services Branch, Federal Native Affairs	<ul style="list-style-type: none"> All Status Indians eligible 	<ul style="list-style-type: none"> Not all drugs covered Difficult to get special authorization for drugs not covered (no 'Section 8' benefit) Drugs covered may differ from ODB

* Ontario Drug Benefits Program

† Community Care Access Centre

affect a parent's decision to purchase a medication for their child.¹³ If cost-sharing is too high, the parent will weigh the benefit of treating the child (and possibly foregoing the purchase of other household goods) against the cost of the medication. The final decision may not coincide with optimal medical management and may incur costs to other health sectors.

At The Hospital for Sick Children (HSC), an urban 374-bed paediatric academic health centre, the Patient Amenities Fund (PAF) was established to help families with the extra costs associated with a child's illness not covered by private insurance or government programs. Increasingly, the PAF is used to cover medications. Since funds for PAF come from charitable donations, the availability of funds is not guaranteed and the fund is limited in its ability to offset gaps in government programs.

Studies of pharmaceutical policy traditionally take a 'top-down' approach, assess-

ing the impact of cost-sharing on the utilization of medications and government expenditures in a population covered by a single payer. This study takes a novel approach by examining the characteristics of a sample of Ontario children with unmet medication needs. The research objectives were to 1) examine family demographics and socio-economic status (SES), the types of medications requested and government program process issues of PAF applicants, and 2) describe trends in PAF requests from 1998 to 2000.

METHODS

Requesting medication benefits from the PAF Program

HSC staff (nurses, physicians) refer families to a social worker if they are concerned about a family's psychosocial or financial circumstances. Needy families are expected to utilize existing programs, however hardship navigating public drug plans and

community agencies and the need to provide their children with medications without delay induce parents to apply to the PAF. Requests are reviewed and approved by the PAF Committee Chair. During the study period, virtually all requests were approved.

Data collection and analysis

The study was a retrospective descriptive analysis of all requests to the PAF from January 1, 1998 to December 31, 1999. There were 112 requests from 86 applicants during this period. The following variables were extracted from PAF request forms, social work and discharge planning reports and medical charts: patient information (sex, age, diagnosis, inpatient/outpatient status), family demographics and SES (residence, citizenship, family configuration, source of income), and medication information (drug name, dollar amount requested, drug plan status, drug plan process issues). The number and dollar

Figure 1. Patient Amenities Fund Medication Requests, 1998 to 2000

TABLE II

Sample Characteristics for PAF Applicants 1998-1999

Sample Characteristic	Number of Patients (%)
Age	
mean $\pm$ s.d.	7 $\pm$ 6 years
Sex	
Male	43 (50%)
Female	43 (50%)
Patient Status	
Previous inpatient	38 (44%)
Outpatient	33 (38%)
Inpatient	15 (17%)
Source of Referral to PAF	
Social worker	57 (66%)
Discharge planner	11 (13%)
Unknown	9 (10%)
Nurse	7 (8%)
Physician	2 (2%)
ICD-9-CM Category	
Neoplasms	19 (22%)
Nervous system	10 (14%)
Genitourinary	11 (13%)
Circulatory	9 (10%)
Musculoskeletal	8 (9%)
Metabolic	8 (9%)
Respiratory	7 (8%)
Congenital	6 (7%)
Other	8 (9%)

amount of requests for 2000 were also analyzed. Descriptive statistics (means, frequency distributions) were used to summarize the data. Where needed, categorical variables were created (e.g., diagnosis ICD-9-CM category, application problems noted). The study was approved by the HSC Research Ethics Board.

RESULTS

Public pharmaceutical programs in Ontario

The publicly administered Ontario drug programs are presented in Table I. One public plan option is the Trillium Program. Trillium has annual deductibles that vary from \$150 to \$4,089 depending on household income and family size. Families with members requiring multiple medications or families where several members require chronic treatment, experience a greater financial impact from cost-sharing than others. For the Trillium and Assistance for Children with Severe Disabilities (ACSD) programs, applications must be renewed yearly and the initiation of drug benefits is frequently delayed, causing hardship for children whose treatment must begin immediately. While ODB benefits associated with home care are available immediately upon discharge subsequent to a hospital admission, the benefits last only as long as home care is prescribed. When home care benefits are terminated, families must pay out of pocket for medications or submit applications to a government plan or community agency. The ODB Section 8 is not truly a drug plan, but a mechanism of last resort for obtaining access to medications not listed in the provincial formulary. It requires a detailed submission by the treating physician and approval by the Drug Quality and Therapeutics Committee.

Trends in Patient Amenities Fund requests

The trends in requests for funds from 1998 to 2000 are depicted in Figure 1. Panel A indicates that during 1998, requests for funding to pay for prescription medications increased over time, culminating in a total of 42. The total number of requests rose by 55% to 70 requests in 1999 and was sustained in 2000 with a total of 65 requests. The highest quarterly

number of requests was observed in the 4th quarter of 2000. Panel B depicts the quarterly dollar amount of funding requests. There was a 39% increase in PAF medication expenditures between 1998 to 1999, from a total of \$16,100 to \$22,408. The average amount of money disbursed per request was \$383 in 1998 and \$320 in 1999. In 2000, despite a high number of requests, total expenditures were \$10,855 and the average dollar amount was \$167. This reduction was not based on any HSC policy to reduce the amounts disbursed and reflects the actual value of requests.

Patient sample and medication request characteristics

Sample characteristics are provided in Table II. Most applications (44%) were for previous inpatients and 38% were for outpatients. Since medications are available to inpatients, the 17% of the sample so classified were likely children who required funding to pay for medications upon discharge. There was a wide diversity in diagnostic conditions. In 1998-1999, 49 different diagnoses were recorded among the 86 applicants. Most requests were for children with cancer, usually acute forms of leukemia. Other common disorders included seizures, renal failure, cardiac conditions requiring transplant and juvenile rheumatoid arthritis.

Table III provides additional request information. Typically, a request was for 2 prescriptions, but varied from 1 to 6. The distribution of monetary requests was skewed; there were several requests over \$1,000 for transplant patients and the largest disbursement was for \$2,335. For patients classified as inpatients, there was little delay between the day of the prescription and the day the request was submitted. For previous inpatients and outpatients for whom data were available, the largest proportions of patients filed their requests within 5 days of a prescription.

Table IV presents limited but revealing information regarding socio-economic status. Most children (84%) came from two-parent families. Interestingly, in 63% of families, one or both parents were employed. No data were available for 20% of the sample and it is conceivable that some of these families had one or both parents employed. These data suggest that 'working poor' families with no private

TABLE III

Medication Request Information for PAF Applicants 1998-1999

Request Characteristic	Result
Medication Requests 98-99	Number of Patients (%)
1 request	70 (81%)
2 requests	10 (12%)
3 requests	5 (6%)
7 requests	1 (1%)
Number of Medications per Request	
Mean $\pm$ s.d.	2 $\pm$ 1 medications
Minimum, maximum	1, 6
Money Provided per Request	
Mean $\pm$ s.d.	\$344 $\pm$ \$398
Minimum, maximum	\$12, \$2,335
Time Between Prescription and Request	Number of Requests (%)
Previous inpatient	
0 to 5 days	20 (43%)
6 to 10 days	2 (4%)
11 to 30 days	6 (13%)
More than 30 days	3 (7%)
Unknown	15 (33%)
Outpatient	
0 to 5 days	14 (30%)
6 to 10 days	2 (4%)
11 to 30 days	5 (11%)
More than 30 days	2 (4%)
Unknown	23 (50%)
Inpatient	
0 to 5 days	17 (85%)
6 to 10 days	1 (5%)
11 to 30 days	1 (5%)
More than 30 days	1 (5%)

TABLE IV

Socio-economic Characteristics for PAF Applicants 1998-1999

Socio-economic Characteristic	Number of Patients (%)
Family Configuration	
Nuclear/blended	72 (84%)
Single parent	8 (9%)
Separated/divorced	4 (5%)
Other	2 (2%)
Source of Income	
Both parents employed	18 (21%)
Father only employed	28 (33%)
Mother only employed	8 (9%)
Both parents receiving benefits	4 (5%)
Father only receiving benefits	6 (7%)
Mother only receiving benefits	4 (5%)
Both parents no income	1 (1%)
Income unknown	17 (20%)

TABLE V

Applications to Ontario Government Drug Plans for PAF Applicants 1998-1999

Application Characteristic	Number of Patients (%)
Type of Program Applied for*	
Assistance for Children with Severe Disabilities	30 (30%)
Trillium	27 (27%)
Ontario Drug Benefits Plan Section 8	15 (15%)
Ontario Drug Benefits Plan – social assistance	13 (13%)
Community Care Access Centre (home care)	3 (3%)
Did not apply	12 (12%)
Program Application Status	
Approval pending	61 (71%)
Approved	10 (12%)
Not approved	3 (3%)
Did not apply	12 (14%)
Application Problems Noted	
No problem mentioned	41 (48%)
Takes too long and/or high deductible	21 (24%)
Not listed or not approved	11 (13%)
Has to be renewed annually	1 (1%)
Not applicable (did not apply)	12 (14%)

* Some patients applied for more than one plan

health insurance constitute the majority of PAF applicants.

Table V presents families' experiences with government drug plans. Eighty-eight

percent were in the process of applying for one or more government plans. Most of these applications were to the ACSD and to Trillium, plans which are associated with delays and application complexity. At the time of application to the PAF, 71% of the sample were waiting for approval for a government plan. Although problems with the application process were not systematically captured in social work reports or patient charts, 25% of cases documented problems such as "takes too long", "high deductible" and "annual renewal required".

DISCUSSION

At one large children's hospital in Canada, an increase in the number of medication requests and expenditures over time was recently observed. Most requests came from two-parent nuclear families where one or both parents were employed but did not have access to private drug plans. In most cases, immediate funding was required to purchase a necessary medication while the family waited for applications to provincial programs to be processed. In other cases, the PAF was the only option available for families to purchase medications that were not listed on the ODB formulary. These results suggest an inability of government plans to provide timely access to necessary medications for families without a private plan, some of whom may constitute the 'working poor'. Failure of government plans to provide sufficient coverage to this segment of the population is of concern, since lower SES is associated with poorer health outcomes in children.¹⁴⁻¹⁷ If working poor families have lower SES, then their need for medications could be greater than higher income families with private plans.

There is concern that if the pharmaceutical benefits provided to Canadian families are inadequate due to excessive cost-sharing or bureaucratic delays, this will result in deleterious health effects. Children are dependent on parents, teachers and informal caregivers to ensure access to health care and medications. Given this reliance on others, it is important that health policies facilitate rather than deter optimal medical management by removing financial barriers. In the US, where private health care is predominant, the problem of

uninsured children led the federal government to establish the Children's Health Insurance Program. This allows individual states to extend health services and medication coverage to children with no private insurance.¹⁸ While Canadian children face no financial barrier to receiving physician services, the problem of under-insurance for needed prescription medications persists.

A number of study limitations were present. The study was retrospective and data on income, education and occupation were lacking, making it difficult to verify SES. Nevertheless, available data on family configuration and income source provided insight into the SES of the sample. The analysis focused exclusively on PAF requests and did not examine the overall ability of provincial drug plans to serve uninsured or under-insured children in Ontario. Only the medication needs of families who made PAF requests were included. The characteristics of patients who received medications in the form of free samples or other sources were not captured. This segment of the population should be included in future studies.

This research suggests Ontario drug plans are limited in their ability to provide timely access to prescription medications, especially for the 'working poor'. The ongoing debate about the mix of public and private services in our health care system and the use of user fees must not over-

look the needs of vulnerable populations. Future policy research should be directed at ways of reducing financial barriers and impediments to improve access to needed medications for children.

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RÉSUMÉ

Objectifs : Bien que les décideurs évoquent périodiquement l'urgence d'avoir un programme national d'assurance-médicaments universellement accessible et à prix abordable, 20 % des familles demeurent inassurées ou sous-assurées. Le fonds de commodités pour les patients (PAF) du Hospital for Sick Children rembourse aux familles les dépenses en médicaments pour les enfants malades hospitalisés et ambulatoires. Notre étude visait 1) à examiner les données démographiques et le statut socio-économique des familles, le genre de médicaments demandés et les problèmes rencontrés par les demandeurs du PAF en 1998 à l'égard des formalités administratives du programme gouvernemental; et 2) à décrire les tendances des demandes PAF de 1998 à 2000.

Méthode : Les données ont été extraites rétroactivement des demandes PAF et des diagrammes et rapports de planification des services de travail social et des autorisations de sortie. Nous avons fait appel à la statistique descriptive pour résumer les données et en étudier l'évolution dans le temps.

Résultats : Quatre-vingt-six personnes ont présenté 112 demandes en 1998 et 1999. La plupart concernaient des enfants greffés ou atteints de cancers ou de troubles neurologiques. Les dépenses en médicaments représentaient 22 408 \$ en 1999, en hausse de 39 % par rapport à 1998. La plupart des demandes venaient de familles nucléaires où au moins un des deux parents travaillait. Les franchises élevées, la période d'attente, la complexité du formulaire de demande et les demandes refusées comptaient parmi les obstacles à surmonter pour se prévaloir des régimes gouvernementaux d'assurance-médicaments.

Discussion : Ces résultats portent à croire que les provinces qui n'offrent pas de programme universel d'assurance-médicaments doivent se fier à des régimes gouvernementaux et à des organismes communautaires disparates, ce qui n'est peut-être pas une manière efficace d'assurer un accès facile et rapide aux médicaments dont les enfants ont besoin.

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