Paediatric palliative care and the social determinants of health: Mitigating the impact of urban poverty on children with life-limiting illnesses

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Despite Canada's highly praised universal health care system and strong social safety net, approximately 15% to 19% of Canadian children live in poverty (1,2). In the past decade, Toronto (Ontario) has witnessed a significant rise in child poverty, from 16.3% in 1990, to 28.8% in 2005 (3). Furthermore, Toronto has experienced a huge increase in the number of 'high-poverty neighbourhoods' (HPNs), from 30 to 120 neighbourhoods since 1981 (4), a trend that has been slowly increasing in Canada's major cities.

Social epidemiology and the social determinants of health illustrate the influence of social and economic factors, such as income distribution, unemployment/job security, housing, education and disability, on health outcomes. There is sufficient evidence to demonstrate that individuals of lower socioeconomic status are at increased risk for morbidity and mortality, thus highlighting social inequities in health status (5).

In spite of these startling facts, there is a dearth of Canadian research examining the intersection of poverty and paediatric palliative care. We know little about the prevalence of poverty among children with life-limiting illnesses (LLIs), nor do we know how the experiences, quality of care, access to services, and the quality of life and death of impoverished children differ from the experiences of children with LLIs who are of a higher socioeconomic status. To understand the prevalence of poverty among Toronto children who were followed by palliative care at a paediatric hospital, we conducted an epidemiological five-year review and found that 62% of these families lived in HPNs. This finding is similar to those of a groundbreaking study (6), in which it was revealed that 58% of all Toronto children were living in an HPN.

From observing our patient populations, we know that the social determinants of health have significant implications for children living with LLIs, as illustrated by the following example:

> *An infant living in a single-parent household in Toronto with three older siblings, ranging from four to 17 years age, was diagnosed with a genetic disorder that had a life expectancy of two months to two years. This family resided in a small two-bedroom apartment without adequate space for bedrooms or the baby's medical equipment. The family had been on the subsidized housing waiting list for two years. Their lives were further complicated by language barriers, unemployment and low socioeconomic status. Given the complex care and limited life expectancy of the baby, their refugee claimant status, along with their inadequate financial and housing situation, greatly increased the family's stress during an exceedingly vulnerable time.*

Caring for a child with an LLI can be described as a highly intimate and excruciatingly daunting dance. The emotional, social and financial well-being of all families is thrown into turmoil, with newly arrived immigrant families, single-parent families and low-income families experiencing even greater hardship. These subpopulations are more likely to confront problems with housing and employment, and with accessing government financial assistance programs. Furthermore, they tend to be more isolated from family and community supports, and may experience cultural/language barriers to accessing social services.

The experiences of poor Canadian children with an LLI are not widely understood or documented. The little we do know from studies conducted in the United States reveals that impoverished children: are at higher risk for receiving unequal care, including hospice and paediatric palliative care (5); have reduced access to pain management (7); are less able to afford necessary medication (7); are less likely to access information or social and community-based interventions (8); and are more likely to die in hospital despite their preference for palliative care at home.

The high rate of poverty among children with LLIs poses unique challenges to families and health care providers. In addition to caring for a very sick and dying child, parents who are of lower socioeconomic status also have to worry about paying for utility bills and noncovered medication, feeding their families, applying for financial programs that they may or may not be eligible for, finding work that accommodates the ill child's medical appointments, hospital admissions and 24 h care, overcoming language barriers to access health care services and finding housing that works as a home-hospital setting.

Holistic care is the cornerstone of palliative care, but families who experience significant socioeconomic hardships may not receive care at all, let alone holistic care. Many improvements are required in paediatric palliative care to adequately address the needs of the urban poor and other marginalized groups. For example, in our setting, medical practitioners commented that they did not have an in-depth understanding of how a seriously ill child's social environment impacted the child's and family's well-being, illness progression, death and grief. Most providers have little personal experience with serious illness or poverty and, in the case of hospital health care practitioners, little opportunity to provide care to children at home and, consequently, do not possess the necessary tools with which to understand the child's home and social environment. By examining the link between social inequalities and child health outcomes as they relate to palliative care, we can find ways to improve access to palliative care, offer choices regarding location of death, reduce psychosocial stress on family caregivers, reduce financial burdens and offer culturally competent care to improve the quality of life, and to better cope with death and grief.

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Our epidemiological review and the observations from our clinical practice offer pertinent clinical and policy insights regarding how to improve the inequities and hardships experienced by poor families. We encourage all paediatric care providers (PCPs) to inquire about the socioeconomic background and well-being of the families of children with LLIs in their care by thoroughly assessing the family's basic needs. Our research team is working to adapt a Child Poverty Assessment and Resource Tool (adapted from Morinis, Bloch, Ford-Jones & Levin and the Social paediatrics Working Group, Toronto, 2012, <www.healthprovidersagainstpoverty.ca>) for use in paediatric palliative care. This tool asks targeted questions regarding a family's ability to meet financial obligations, care for a seriously ill child, feed their children, pay for medications and live in a safe and clean environment (Appendix). Although PCPs are skilled in managing difficult conversations regarding health and illness, they may be uncomfortable discussing a family's financial situation. While 'wish foundations' are plentiful and provide meaningful experiences for children with terminal illnesses, more resources are needed to support basic living costs that are exacerbated by caring for a child with an LLI. PCPs should develop a comprehensive knowledge of community and government resources available to families.

Our clinical experiences and study findings led us to conclude that families living in poverty need advocates to promote policy and funding changes. For example, current policies regarding special priority housing for gravely ill persons are failing families who face extraordinarily long wait times and changing eligibility requirements. If families prefer to remain at home for long-term and/or end-of-life care, PCPs may need to advocate with regional and/or provincial supporting housing associations to ensure that their homes are safe, accessible and affordable.

Single-parent families may need advocates to help them access subsidized day care for well siblings to enable the single parent to focus on caring for the ill child at home.

In Ontario, newly arrived immigrants are required to wait three months before accessing health care funding. This policy needs to change because it results in devastating health costs to families coping with LLIs. Even when families can afford private insurance, most do not qualify for private coverage because of pre-existing health conditions.

We recommend that hospices for children be situated within or near neighbourhoods and also within easy access to public transportation to promote family engagement, and to meet the needs of low-income families. The services provided in hospices must also be accessible to families and provide easy access to appropriate interpreters and, when possible, staff who reflect the communities they serve.

Even when services and resources are available, virtually all families coping with an LLI experience difficulties in learning about and accessing the myriad agencies, ministries and departments that deliver those services. These difficulties are exacerbated by socio-economic factors. Having a 'one-stop shopping' model of palliative care would ease the access to services and resources for families who are coping with an LLI.

In conclusion, we recommend that hospital and community palliative care-based service providers assess the socioeconomic and demographic characteristics of the communities they serve to improve practice and access to care. Health care systems, social planners, families and governments need to work together to develop a greater understanding of how social determinants of health, such as poverty, impact the families in their care to find ways to reduce the impact of social inequalities on children with LLIs.

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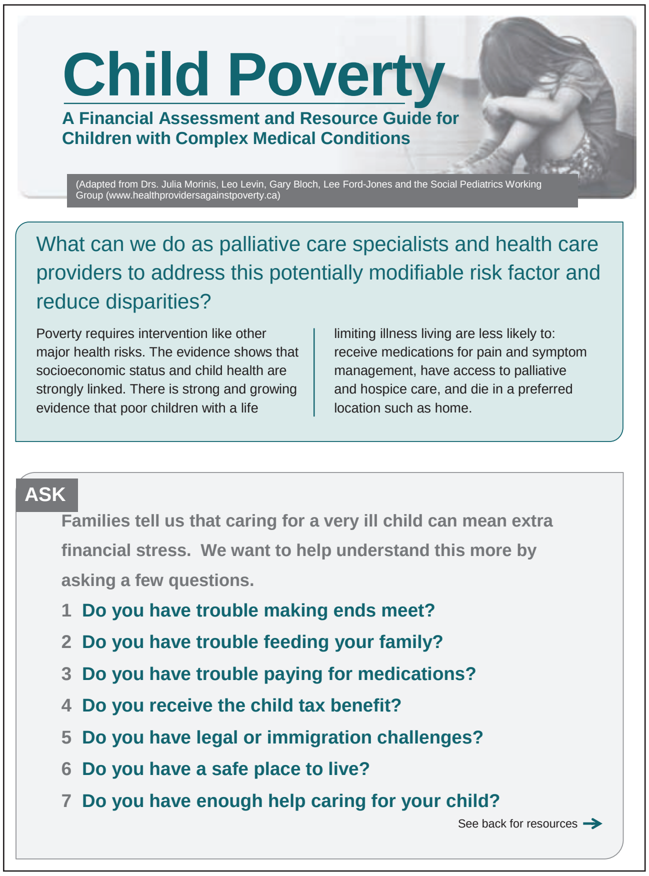
APPENDIX



Child Poverty

A Financial Assessment and Resource Guide for Children with Complex Medical Conditions

(Adapted from Drs. Julia Morinis, Leo Levin, Gary Bloch, Lee Ford-Jones and the Social Pediatrics Working Group (www.healthprovidersagainstpoverty.ca)

What can we do as palliative care specialists and health care providers to address this potentially modifiable risk factor and reduce disparities?

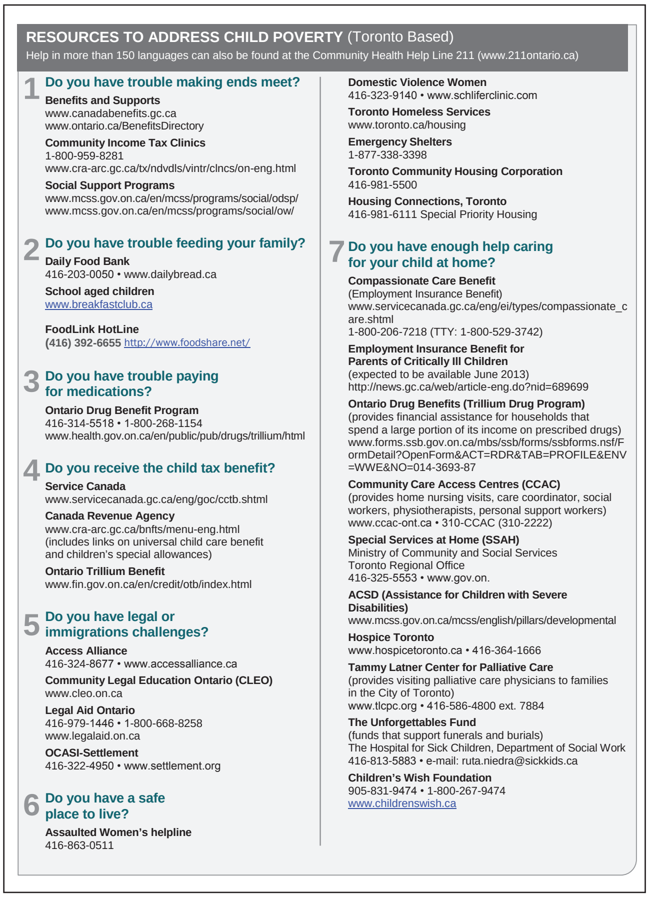
Poverty requires intervention like other major health risks. The evidence shows that socioeconomic status and child health are strongly linked. There is strong and growing evidence that poor children with a life limiting illness living are less likely to: receive medications for pain and symptom management, have access to palliative and hospice care, and die in a preferred location such as home.

ASK

Families tell us that caring for a very ill child can mean extra financial stress. We want to help understand this more by asking a few questions.

1 **Do you have trouble making ends meet?**
2 **Do you have trouble feeding your family?**
3 **Do you have trouble paying for medications?**
4 **Do you receive the child tax benefit?**
5 **Do you have legal or immigration challenges?**
6 **Do you have a safe place to live?**
7 **Do you have enough help caring for your child?**

See back for resources →



RESOURCES TO ADDRESS CHILD POVERTY (Toronto Based)

Help in more than 150 languages can also be found at the Community Health Help Line 211 (www.211ontario.ca)

1 **Do you have trouble making ends meet?**

Benefits and Supports
www.canadabenefits.gc.ca
www.ontario.ca/BenefitsDirectory

Community Income Tax Clinics
1-800-959-8281
www.cra-arc.gc.ca/tx/ndvdls/vintr/clncs/on-eng.html

Social Support Programs
www.mcss.gov.on.ca/en/mcss/programs/social/odsp/
www.mcss.gov.on.ca/en/mcss/programs/social/ow/

2 **Do you have trouble feeding your family?**

Daily Food Bank
416-203-0050 • www.dailybread.ca

School aged children
www.breakfastclub.ca

FoodLink HotLine
(416) 392-6655 http://www.foodshare.net/

3 **Do you have trouble paying for medications?**

Ontario Drug Benefit Program
416-314-5518 • 1-800-268-1154
www.health.gov.on.ca/en/public/pub/drugs/trillium/html

4 **Do you receive the child tax benefit?**

Service Canada
www.servicecanada.gc.ca/eng/goc/cctb.shtml

Canada Revenue Agency
www.cra-arc.gc.ca/bnfts/menu-eng.html
(includes links on universal child care benefit and children's special allowances)

Ontario Trillium Benefit
www.fin.gov.on.ca/en/credit/otb/index.html

5 **Do you have legal or immigrations challenges?**

Access Alliance
416-324-8677 • www.accessalliance.ca

Community Legal Education Ontario (CLEO)
www.cleo.on.ca

Legal Aid Ontario
416-979-1446 • 1-800-668-8258
www.legalaid.on.ca

OCASI-Settlement
416-322-4950 • www.settlement.org

6 **Do you have a safe place to live?**

Assaulted Women's helpline
416-863-0511

Domestic Violence Women
416-323-9140 • www.schliferclinic.com

Toronto Homeless Services
www.toronto.ca/housing

Emergency Shelters
1-877-338-3398

Toronto Community Housing Corporation
416-981-5500

Housing Connections, Toronto
416-981-6111 Special Priority Housing

7 **Do you have enough help caring for your child at home?**

Compassionate Care Benefit
(Employment Insurance Benefit)
www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
1-800-206-7218 (TTY: 1-800-529-3742)

Employment Insurance Benefit for Parents of Critically Ill Children
(expected to be available June 2013)
http://news.gc.ca/web/article-eng.do?nid=689699

Ontario Drug Benefits (Trillium Drug Program)
(provides financial assistance for households that spend a large portion of its income on prescribed drugs)
www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ACT=RDR&TAB=PROFILE&ENV=WWE&NO=014-3693-87

Community Care Access Centres (CCAC)
(provides home nursing visits, care coordinator, social workers, physiotherapists, personal support workers)
www.ccac-ont.ca • 310-CCAC (310-2222)

Special Services at Home (SSAH)
Ministry of Community and Social Services
Toronto Regional Office
416-325-5553 • www.gov.on.

ACSD (Assistance for Children with Severe Disabilities)
www.mcss.gov.on.ca/mcss/english/pillars/developmental

Hospice Toronto
www.hospicetoronto.ca • 416-364-1666

Tammy Latner Center for Palliative Care
(provides visiting palliative care physicians to families in the City of Toronto)
www.tlcpc.org • 416-586-4800 ext. 7884

The Unforgettables Fund
(funds that support funerals and burials)
The Hospital for Sick Children, Department of Social Work
416-813-5883 • e-mail: ruta.niedra@sickkids.ca

Children's Wish Foundation
905-831-9474 • 1-800-267-9474
www.childrenswish.ca

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