COMMENTARY

Vulnerable and marginalized children: Who are they and how can we help?

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Before I proceed with the present commentary, which is broadly in the field of social paediatrics, I have something to confess: my name is Saleem Razack and I am a high-technology, all-the-beeps-and-whistles paediatric intensivist. I love analyzing the waveforms of central lines and contemplating the mysteries of sodium metabolism. By the end of the present commentary, I hope the reader will appreciate that even in this world of fascinating physiology, to be an efficacious and compassionate practitioner, I must integrate an understanding of the social determinants of health in my day-to-day practice, both as a physician-technocrat and as a teacher.

It is natural for those of us who work in child health to appreciate the links among social vulnerability, marginalization and health. To be a child means that one exists in some sort of social context that involves parents (or caregivers who stand-in in loco parentis), and the links between social context and health are often hiding in plain sight. They are there with the six-year-old child of Rwandan refugee parents, with limited access to quality primary care and frequent visits to the emergency room with asthma exacerbations (prematurity has a significant social determination) (1); they are there with the six-year-old child of an Inuit baby on high-frequency oscillatory ventilation, whose mother is 16 years of age (prematurity has a significant social determination) (1); they are there with the 26-week-old baby who stand-in in loco parentis, and the links between social context and health are often hiding in plain sight. They are there with the 15-year-old adolescent who attempted suicide after being ‘taxed’ (extorted for money) and bullied at school because he happens to behave effeminately (social discrimination and health).

So who are Canada’s vulnerable and marginalized children? They are children largely born into poverty and income disparity (with the vulnerability operating largely through associated social exclusion and discrimination). In a country like Canada, these children can be “camouflaged by the apparent affluence around them” (2). There is no standard definition of poverty in Canada, but the concept of ‘low income cut-off’ (families who spend 20% or more of their income after taxes on housing, food and other basic necessities than the average household expenditure) has been used. As of 2005, 1.2 million Canadian children (17.6%) were living in poverty by this definition (3). The country’s poorest children are most likely to be found in single-parent households (42% poverty rate), in Aboriginal families (40% poverty rate) and among new immigrants (40.4% poverty rate), versus a poverty rate of 18.4% for all Canadian children (4).

It can be hard to appreciate poverty in our affluent, first-world country, with its ‘universally’ accessible health care system. Journalist Ryszard Kapuscinski points out how these psychological barriers to appreciating poverty might work – “The products of poverty are fear and… the feverish dream, to tear oneself from it at all costs. To separate oneself from it by the tinted glass of a limousine, the wall surrounding a villa, a fat bank account…” (3). We may have trouble appreciating the social vulnerability created by poverty and marginalization, but as child health professionals, we are able to appreciate the very real effects of poverty and concomitant social exclusion on the health of our young patients. We see the outcomes of life in neighbourhoods with fighting and drug dealing (children from low-income families are twice as likely to live in such neighbourhoods), the impact of developmental disability (children from low-income families are twice as likely to be registered in special education classes than children from middle- or upper-income families) and the paradoxical rise in obesity among low-income children (three-quarters of children from low-income homes do not participate in organized sports compared with one-quarter of children from high-income families) (6).

So what can we, as paediatricians and child health professionals, do about it? A great deal, it turns out, but doing so will take no less than a paradigm shift in our understanding of the causality of disease, and it will have profound implications on the way we engage families and communities, and on the knowledge and skills we inculcate in the next generation of child health professionals. Not only will this need to include training that is successful at demonstrating the links between social determinants and health status, but also, given that the solutions to social vulnerability and exclusion are complex (requiring action in the social policy and political arenas), a shift in focus of skill-building that is more collaborative and team based.

When I was a critical care medicine fellow, a particularly sage supervisor of mine once said that bronchiolitis is not caused by the respiratory syncytial virus (RSV). This was a somewhat revolutionary statement, especially given that this was the middle of winter, and there were approximately six patients admitted and on mechanical ventilation with
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RSV bronchiolitis! What my supervisor was pointing out, of course, was an ecological model of disease causality; for an infectious disease, one needs to consider not only the agent, but also the host and the host's environment, in analyzing causality. In other words, not only RSV, but why this level of illness, in this particular patient, at this time? This way of looking at health, wellness and illness is at the heart of social medicine, and is a model that will have to permeate our thinking and our knowledge creation if we are to realistically address the factors that are making our vulnerable children sick. With a true ecological model, all of the factors that contribute to illness can be studied, understood and addressed.

Addressing marginalization will require a responsive and caring workforce and a progressive manpower policy on the part of government, regional health authorities and universities. There is a reason why new shingles tend to go up in middle- and upper-income communities – there are few incentives for new practitioners to set up practice in socially vulnerable communities (the highly politicized and important rural initiatives notwithstanding, although I would argue that the huge demographic of the urban poor have been largely forgotten in this debate). We need enlightened policies that promote practice among vulnerable communities (which also address issues of access, such as those encountered by nonstatus persons), and that include competitive remuneration and adequate infrastructure. The ‘best and the brightest’ often end up in our university centres, which usually means highly technical tertiary care medicine. Academic departments of paediatrics need to valorize practice and scholarship that is rooted in the community, so that the young paediatrician, whose practice population consists largely of children of refugees, can also develop and conduct research concerning the specific health problems of these children, yet be fully affiliated and appointed, with access to an appropriate community of scholarship (to give a hypothetical example).

High-technology tertiary care medicine also possesses many opportunities to identify and address the ecology of social vulnerability. Those of us that work in that environment can appreciate the metaphor of ‘collision’ when thinking of social vulnerability and high-technology medicine, whether that be the child with central alveolar hypoventilation who is tracheostomized and ventilated and unable to go home due to lack of supports, or the 16-year-old Cree heart transplant recipient in whom the risks and benefits of a traditional lifestyle ‘in the bush’ have to be weighed. There is much for us to work on collectively with the communities we serve to understand health and wellness in these technological times. To do so usefully, we will need to organize our thinking and knowledge generation ecologically.

A changed approach to the way we understand disease and the way we deliver care will require a new skill-set for tomorrow’s paediatricians. Not only will they have to be adept at understanding how observations about populations can be applied to single patients (the epidemiological approach), but also how individual patients’ particularities (social context, host factors) can be implicated in disease and wellness. In addition to the competent application of science to clinical care, they will need to possess some understanding of history and of the social world, and the roles of these two forces in creating the conditions that promote illness among socially vulnerable children. They will need to develop skills in working with a behaviourally, culturally and socioeconomically diverse population. They will need to practice models of care that are empowering of the communities they serve, and that value and promote interprofessional collaborations. Indeed, both the Royal College of Physicians and Surgeons of Canada (7) and the Accreditation Council for Graduate Medical Education (in the United States) (8) have recognized the importance of these skills in residency education, and have explicitly defined domain-specific training competencies in advocacy and the social determinants of health, which are used as accreditation standards for residency programs.

Moving from the care of specific patients and families to concern for the health status of whole communities, tomorrow’s paediatricians will need a keen understanding of the process of advocacy, and will need tools to impact on health policy and organization. Our training needs to galvanize and inspire this group such that, regardless of their ultimate practice trajectory, collectively, they will see themselves as part of a common community of practice, with shared goals vis-à-vis population health, and where some individuals in that community possess the requisite skills to be advocacy champions. It is not within the scope of the present commentary to provide specific advocacy recommendations (these are readily available on the Canadian Paediatric Society or American Academy of Pediatrics Web sites, among others). Rather, the goal of the present paper is to encourage dialogue on what constitutes the necessary conditions that must be put in place now for the training of tomorrow’s child health professionals, so that they may have the skills to impact on health and social policy to meaningfully improve the lives of socially vulnerable children. The root causes of social vulnerability, such as access to affordable housing, or working with fair wages, cannot be easily addressed on the individual level and will require coordinated advocacy for policy change on the part of our profession, in respectful collaboration with the communities we serve.

The present commentary has had social ‘vulnerability’ as its dominant concern. No discussion of social vulnerability would be complete without recognition of its flipside – social ‘resilience’. Thus, our understanding of the factors that contribute to vulnerability in specific social situations would be incomplete and perhaps not intellectually honest without an attempt to understand resilience in the same situation. It is only through this balanced approach that we will fully engage communities in partnerships, by not only identifying weaknesses and problems, but capitalizing on strengths as well.

Paediatrics is all about maximizing the life potential of the developing human. We can choose to simply nudge it along here and there, or, by understanding the pervasive impact of social context on health, we can choose to be catalysts of tomorrow’s promises.
REFERENCES

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A Paediatric Expert Advisory Committee

Increasingly, health products and food regulatory bodies around the world are turning attention toward the safety of children. Health Canada, in keeping with this trend, has formed a Paediatric Expert Advisory Committee. It will provide the Department with expert advice on how to better protect the health and safety of children, and pregnant and nursing women in keeping with the work of the Health Products and Food Branch.

As its Chair, I am pleased we are getting this work underway and there is much to be done. The Committee has 15 members and their expertise include paediatric specialists, university professors, pharmacists, researchers, representatives from industry and patient groups, not-for-profit organizations and parents. Fellow Committee members are: Dr Noni MacDonald (Vice-Chair), Dr Stephanie Atkinson, Dr Benoit Bailey, Dr Max Coppes, Ms Laura Lee Dupuis, Dr Lorella Garofalo, Dr Gideon Koren, Ms Mary Lye, Dr Stuart MacLeod, Ms Patricia Malloy, Dr Gary Pekeles, Ms Laurie Proulx, Ms Patricia J Rennie and Dr Ellen Tsai. We had an introductory orientation meeting in February 2009, and our next meeting is set for November 2009.

Some of the complex questions the Assistant Deputy Minister of the Health Products and Food Branch will task our Committee to examine focus on the current challenges with health products, ie, drugs, medical devices, biologics including vaccines and natural health products – to develop, test, evaluate and label with appropriate information for safe use in children – issues needing input from industry, clinicians, parents and regulators. The Committee will also focus on food safety issues and nutrition guidance targeted toward this group.

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