

The Neurological Advocate?

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CLINICAL VIGNETTES

A twelve-year-old, immobile, tube-fed GMFCS Level V spastic quadriparetic child with cerebral palsy was brought to a neurology clinic for a scheduled follow-up visit. Examination of this child reveals multiple cutaneous lesions, which upon further investigation turn out to be rat bites.

A four-year-old child, the offspring of recent immigrants to Canada from a developing nation has a severe global developmental delay without apparent etiology despite detailed investigations including metabolic, genetic and neuro-imaging studies. At follow-up, it is made known that previous home educator and rehabilitation services visits have been suspended by local service providers due to an extensive cockroach infestation in the family's rental apartment.

A family on social assistance has a three-year-old child with global developmental delay receiving rehabilitation services (physiotherapy, occupational therapy, speech language pathology) from a local regional center. These services are terminated when they move to an adjacent region. At this adjacent region's pediatric rehabilitation center, their child is put at the end of the waiting list (approximately one year) for intake.

The above incidents are drawn from an academic pediatric neurology practice in a country that has ranked at the top of the United Nations Human Development Index nine times since 1990 and had a ranking of fourth overall most recently in 2008.¹ The incidents illustrate that even within the wealthiest and most blessed of nations, real disparities that obviously impact on health do exist. These incidents also illustrate the need to emphasize our role as advocates for our patients.

An advocate is one who speaks, writes, pleads or acts in support or defence or behalf of a person or cause. Recognized synonyms include; agent, champion, defender, exponent, partisan, promoter or proponent. An advocate engages in the action or process of advocacy. The word's origin lies in the 14th century and borrow directly from the Latin "advocare" meaning to summon that combines "ad" and "vocare" (to call or voice).²

Medical advocacy has many possible characteristics including informing, empowering, protecting, supporting and representing the interests and needs of the patient.³ This Editorial will focus on an additional feature generally assumed to be both non-contentious and beneficent; that is ensuring fair access to available resources.⁴

This feature is thought to be non-contentious because it reflects the practical application of the philosophical concept of "justice" that within the Canadian milieu has been operationalized as an accepted social construct of a distributive model that eliminates or minimizes bias.⁵ Within this model every individual has an equal right to available resources,

structured such that the greatest benefit accrues to those who are least advantaged naturally with respect to individual, social and economic attributes. While these principles appear to be accepted across the Canadian political and intellectual spectrum, the opening vignettes illustrate that implementation of lofty principles into practice may fall short of our ideals.

Poverty and social disadvantage play a bidirectional role in health and well-being. It is clear that whenever studied, social disadvantage acts as a risk factor in the genesis of chronic disease.⁶ Furthermore, within our International Classification of Functioning, Disability and Health (ICF) model of health, social and economic limitations function as potential barriers to access and participation.⁷ While at first glance this is discouraging, it needs to be recalled that these barriers may be far more modifiable than those underlying the biologically determined, and traditionally medically targeted, pathology responsible for organ based impairment that is the origin of individual disability.

The physician as advocate is not a novel conceptualization. The Canadian Medical Association's Code of Ethics explicitly states that "advocacy on behalf of the profession or public" is one of the fundamental responsibilities of being a physician.⁸ The same Code also articulates advocacy as a physician-based responsibility to society at large; "[The] profession's responsibility to society in matters relating to public health, health education, environmental protection, legislation affecting the health or well-being of the community".⁸ It has been stated that the public we serve as healthcare providers "expect physicians to advocate for their individual and collective well-being".⁹

As busy physicians caring for patients, how can we operationalize these responsibilities and expectations? First we need to be explicitly aware that our overall goal is primarily health promotion and well-being. We also need to be aware that social and economic factors, both at an individual and societal level, may act as mechanisms to create barriers to optimizing individual health. Thus we need to enquire, and make ourselves aware of, the social and economic factors influencing our patient's health status. Uncomfortable as it may be, we need to

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make enquiries regarding socio-economic status, employment, housing, custodial, financial assistance, criminal, immigration and mental health issues. Recognition of such issues impacting on health should prompt referrals to appropriate local resources as readily as does recognition of a medical issue outside our neurologic area of expertise prompts referral to an appropriate allied specialist. To correctly refer, we need to educate ourselves regarding what local resources are available and make necessary alliances that facilitate effective and rapid lines of communication with these resources. Simply writing a referral may not be a sufficient action to accomplish the best possible care for our patients. Taking the time to make contact can expedite service delivery and minimize possible barriers. We need to reformulate our conception from “allied” to “essential” elements of health services delivery. Such a reformulation would serve to highlight to our profession, the public and policy makers the need for ready availability of these services. We should not hesitate to get involved by providing written documentation of our patient’s health status and needs. We tend to underestimate the influence our diagnoses and considered professional opinions do have on bureaucrats that often serve as the gatekeepers of societal resources (i.e. educational, housing, financial, rehabilitation).

Advocacy as a collective professional group is challenging as political differences need to be respected and are essentially outside our purview as health professionals. We can however influence the policy process by our unique position as providers of healthcare who are well aware of actual circumstances and their consequences. Furthermore, once policy is established by an open political process, as it affects health we can collectively influence its implementation so that access to resources are fairly available and distributed. Collectively our voice does carry weight if it is articulated with reason and we do not appear to be advocating self-serving agendas that place physician needs above those of our patients.

Tensions do exist in being an advocate.³ There is a necessary tension between individual and group needs in an era of challenges with respect to resource allocation. There may also be conflicts between what can be considered an expected duty of physicians and what might be beyond reasonable expectation in an era of manpower limitations.

Such tensions are the natural consequences of having the choice of exercising our duty or responsibility to become involved. As such, they should not preclude our acting as advocates. Within the scheme of our professional goal to promote health and minimize disease, advocacy represents a duty that is potentially as effective, and certainly as important, as the prescription pad.

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