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Perspectives in Pediatric Neurology

Pediatric Neurology Far From Home: Globalization, Guidelines, and Standards of Care

Peter M. Bingham MD [a,*], Biayna Sukhudyan MD [b], Artsruni Hakobyan MD, PhD [c]

[a] *Department of Neurology, University of Vermont, Burlington, Vermont*
[b] *Pediatric Neurology Department, "Arabkir" Medical Complex and Institute for Child and Adolescent Health, Yerevan, Armenia*
[c] *Yerevan State Medical University, "Surb Grigor Lusavorich" Medical Center, Yerevan, Armenia*

As the demand for, and the relative paucity of, our services continues to grow, pediatric neurologists around the world are increasingly moved to consider the educational needs of our colleagues in primary practice: how can we help them to use our services effectively by referring appropriately? How can we guide them to carry out patient education for common problems when education is the main intervention? How generalizable are the educational needs relating to pediatric neurology referral from one region to another? These questions formed part of the impetus for a Fulbright Scholar Project by the authors in Yerevan, Armenia.

The twentieth century history of the Armenian nation tells of one existential challenge after another—genocide, massive emigration, cultural repression during Soviet times, a massive earthquake. In addition to being the ancestral home to one of the author's "grandparents-in-law," Armenia's interest lay in its 1000-year-old history of religion, music, and medicine at a crossroad—the Silk Road, to be exact—of Eastern and Western societies. As an institution with over one millenium of history behind it, Armenian medicine, like the Armenian people, possesses an extraordinary adaptability and resilience.

Armenian Pediatric Neurology began in the 1970s when the Ministry of Health appointed the late Dr. Juletta Aylamazyan as the first chief child neurologist. Dr. Aylamazyan trained most of the approximately 25 pediatric neurologists working in Armenia, where this discipline has been academically and administratively linked to pediatrics, rather than neurology. A strong tradition of evidence-based neurology practice in Armenia derives in part from the work of the late Vahagn Darbinyan, whose training was supported by the Armenian Medical International Committee shortly after the earthquake of 1988.

A children's neurological hospital operated from 1988 to 2004, when a reorganization distributed its services to Surb Grigor Lusavorich Hospital. A division chair at Arabkir Medical Center and the Chief of Pediatric Neurology at Lusavorich Hospital report to the Medical School Dean (Yerevan State Medical University) and to the Ministry of Health, respectively.

With candidates starting at around 18 years of age, medical undergraduate training in Armenia lasts 6 years, after which an additional "intern" year gives the graduate permission to work as a general practitioner. After these 7 years, pediatrics or pediatric neurology specialization requires two or three additional years, respectively. Most medical graduates continue to pay tuition for a two to five year residency based in one of Yerevan's teaching hospitals and so face considerable financial pressures when choosing a specialty. A weak revenue stream, which contributes to the vulnerability of this specialty in other countries, undoubtedly aggravates low compensation and recruitment of pediatric neurologists in Armenia.

> *ICU. This infant, un-responsive and unable to inspire effective breath, has been on a ventilator for three weeks now. Bi-hemispheric and brainstem stroke. Would the doctors suggest to the parents that turning off the ventilator could now be a caring gesture?*

Armenian clinicians lack formal "Do Not Resuscitate" or end-of-life agreements, even for declaring brain death. Seeing the delicate mix of feelings provoked by these ICU scenarios in Armenia—Will the parents blame the doctors? Will the doctors know they did all they could?—our

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* Communications should be addressed to: Dr. Bingham; Department of Neurology; University of Vermont; Burlington, Vermont 05401.
E-mail address: peter.bingham@uvm.edu

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appreciation for the value of such formal agreements has deepened. It seems just a matter of time before Armenia imports guidelines for declaration of brain death from hospitals in the United States or Europe. On the other hand, Armenian hospitals lack consistent access to the technology (electroencephalography; EEG) that is sometimes needed to implement such guidelines. Pediatric intensivists and neurologists are keenly interested in increasing access to EEG for their sick inpatients.

Although cranial magnetic resonance imaging (MRI) can be done, they often require hospital transfer, and 3-T imaging is not available. In individuals with brain infection, hydrocephalus, stroke, head trauma, and headache, pediatric neuroradiologic interpretation is highly variable. Considering that pediatricians and pediatric neurologists commonly seek international review of cranial MRIs, it is apparent that Armenian radiologists would benefit from further international training in pediatric neuroradiology.

Lesson learned

Formal end-of-life agreements, when consonant with regional ethical principles, can not only promote teamwork among specialists, but can also help control costs of intensive care in medically futile cases. The internet offers channels to improve the distribution of health technology and to further international educational needs in specialty medicine.

Lecture Hall, Yerevan State Medical University. "So, if we don't have EEG data, should we not call it a 'seizure' when the infant has a seizure? What should we say?"

In this Soviet-era lecture hall for some of Yerevan's neonatologists, the lecturer is aiming to shatter the notion of a neonatal seizure as something you can diagnose by eye. The physician audience believes in a scientific approach to diagnosis and, like many US neonatologists, mistakenly treat all seizure-like newborn behaviors as epileptic. The lecturer is attempting to bridge a gap that is in part a legacy of the Soviet health-care system: while that system emphasized prevention of infectious diseases with massive screening and check-ups along with widespread use of basic diagnostic technologies, it also effectively discouraged collaborative work among specialists dealing with noncommunicable diseases by separating them into different hospitals.[1]

Lesson learned

Some relatively simple tools and cross-disciplinary training can make a large impact on medical care in resource poor areas.

Neurology Clinic. This 7 month old has decreased visual interaction, increased flexor tone emerging over the last 3 months. Although the specialist has no records from the referring clinician, a brain MRI has been done, and it shows leukodystrophy. The interview takes place standing in one corner of a colorful, windowed playroom, and another family watches and listens from the other side. We move over to the second family; now they are lit with the first family's gaze.

Clinicians lack a centralized medical record, and correspondence among clinicians regarding clinic visits or hospital stays lacks consistency. Such discontinuities inevitably interfere with the care of children with chronic, developmental problems, and contribute to client distrust of clinicians. The working relationship among pediatric neurologists, general practitioners, and related specialties will undoubtedly benefit from improved communication networks and medical records. In contrast to this communication difficulty, medical interviews in Armenia may often be conducted with a startling "transparency," or lack of confidentiality.

Lesson learned

Technology availability may exceed basic infrastructural needs in medical systems (e.g., a working medical record). International medical exchange often means adjusting to different ground rules, including those regarding confidentiality practices. Globalization of medical care—like medical tourism—will inevitably test stake-holders' capacity to abide different communication practices and standards.

Clinic, a small Armenian village. This bright, 11 year old girl cracks her hands, so much that the knuckles have become sore and swollen. As she demonstrates the gesture, she looks down, like she has just done something wrong. With an interpreter and her primary doctor standing by, the American doctor asks a few questions—who is worried about this? (mom); why? (bad for my hands). Eventually, she admits that her knuckles hurt, but she cannot stop. Today the news passed through her village: there is an American doctor—bezheeske—seeing patients at the polyclinic. And so her physicians ask: what would you do? The 4 hours and 12 patients could have been back in Vermont: parents concerned about their children's tics, their angry, un-disciplined ways, their headaches, their reading problems. They eye the visitor's black bag, which has nothing in it to address these problems.

The Armenian Health Care system, which performed relatively well during the Soviet era, faces financial challenges, in that entitlements to primary care and medication for the most vulnerable (children, the elderly and disabled, poor, injured military) are not sustainable.[2] As in post-Soviet Russia,[3] the post-Soviet Armenian medical system's health safety net has been inadequate for many families.

At the same time, the tertiary pediatric hospitals are in the middle of a transition that recapitulates similar practice changes in the United States: common pediatric problems that previously prompted referral (e.g., febrile seizures) are increasingly handled by pediatricians. Other areas of improved evaluation and referral by general practitioners include macrocrania, tic disorders, neonatal encephalopathy, and breath-holding spells. This transition will support continuing access to pediatric neurologists.

Lesson learned

In Armenia, as in the United States, expectations of specialists are often inordinate, mismatched to our expertise, but relate to cultural and systemic themes within our health-care systems. Although we need to define our scope,