

The Not-So-Near Death of Autopsies in the U.S.

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NEUROLOGICAL DISorders are the most difficult to diagnose. While imaging and genetic testing has advanced tremendously over the past three decades, and our ability to diagnose has advanced with it, the truth of the matter is that we're not so good at identifying most neurodegenerative disorders in life that do not fit a clear pattern. Complicating the matter is the fact that it is not uncommon for different disorders to have identical clinical presentations. Probably the most common example is the problem of diagnosing dementia with Lewy bodies. This is quite simple if the patient with dementia also has clear-cut features of Parkinson's disease. But, if the dementia precedes the motor dysfunction the diagnosis is made correctly in only about half the cases if seen by a dementia specialist, and mostly diagnosed as Alzheimer's by other doctors, including neurologists.

Much rarer is the newly re-named disorder, "corticobasal syndrome," which had been called, "corticobasal ganglia degeneration," after initially being labeled as "cortico-striatal-pallidal degeneration with neuronal achromasia. "The first change was made for brevity's sake. The recent change was made when autopsies made clear that one third of the cases were actually unusual cases



of Alzheimer's disease, and not what they were expected to be. Occasional cases of Alzheimer's masquerades as other, rare disorders. In a few years we will see that much of what we believe about Parkinson's disease will be reframed based on pathological and genetic findings. Thirty percent

of people diagnosed with Alzheimer's disease by dementia experts are proven wrong at autopsy. We Parkinson's disease experts even misdiagnose Parkinson's disease about 10–20% of the time, especially during the early years. The point of these references to esoterica is to establish that neurologists are unable to make diagnoses in a fair number of cases, that we know a lot about what we don't know, but, like everyone else, don't know what we don't know, which is why autopsies are crucial if we are to make advances.

I am not very good at getting autopsies. I do get some, particularly when I think we may learn something of relevance to the family. I am less assiduous when the motivation is largely for me to be the primary recipient of the knowledge. Oftentimes I am more interested in knowing the true diagnosis than the family. It is meaningful to me to learn which of the several atypical parkinsonisms was the pathology, whereas the family finds the diagnosis of atypical

parkinsonism, which, despite being only a general term for a syndrome, adequate enough to understand the disease process, possibly do a Google search, etc. My local colleagues learn as well, but only an occasional brain autopsy will merit a case report.

Getting autopsies is not very easy, despite the extremely generous and hospitable nature of the neuropathology group at Rhode Island Hospital, which is where all brain autopsies are performed. It turns out that they do more than I thought, although less than they should. Autopsies, in general, are dwindling. In the U.S., in-hospital deaths were autopsied over half the time 50 years ago, but now only about 5%. Obviously, out-patient death autopsies are much less common, partly because the family rarely knows how to proceed, and if they contact the attending physician, that person usually does not know how to proceed. And, even if the doctor is me, the logistics are challenging and the family has to pay the funeral home to transport the body. Many funeral homes discourage the practice. I am not sure why in-patient autopsies are so uncommon, but I have a lot of thoughts on why outpatient post-mortems are rare. In UK, a recent medical article spoke of autopsies as being near extinct.

I think that one reason in-hospital autopsies are uncommon is that there is a fear of unwittingly revealing a deficit in medical care. Yet, it turns out that medical-legal data have shown that

autopsies generally *aid* the physicians in cases of alleged malpractice, even when the autopsy demonstrated an unrecognized, yet treatable condition. Decisions were based on standard of care for what were thought to be the problems at the time of treatment. In a recent article looking at this by the American Association of Anesthesiology, over 50% of the autopsies were thought to help the plaintiff while only 28% supported the malpractice allegations. I believe that another reason is that requesting an autopsy requires asking something from the bereaved relatives, which is always a difficult thing to do unless the illness was a great mystery that the family wants to understand better to achieve

closure. Perhaps most important is the common belief that little is to be gained from the autopsy, that with the current battery of highly sophisticated tests we know all we need to know, so why go to the bother and expense of a formal autopsy? This is remarkably incorrect, in general. For neurological cases, this is even more likely to be incorrect.

Complicating any attempts to increase autopsy rates is the absence of reimbursement for the pathology department for autopsies, a rather expensive undertaking, especially for brain disorders which often require extensive testing and large amounts of time as special stains get ordered to perform increasingly sophisticated testing.

The autopsy “completes” the physical exam. Neither has yet become outdated, despite what some of our colleagues might think. ❖

Author

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Disclosures on website

Changes in the Maintenance of Certification (MOC) process have not gone far enough

To the Editor and my RI colleagues:

I am writing to seek your interest and support in asking the Rhode Island Medical Society to follow in the steps of the Massachusetts Medical Society¹ and many others in creating a formal resolution against the Maintenance of Certification (MOC) process being promulgated by the American Board of Medical Specialties. Grassroots efforts across the country have pressured the specialty boards into making concessions, but these changes have not gone far enough.

In the last two years, we have seen a group of well-respected physicians² create an alternative to the American Board of Medical Specialties, The National Board of Physicians and Surgeons, which has so far been accepted into 40 hospitals in the US.³ Oklahoma has enacted the first ever “Right to Care” legislation⁴ which states that MOC cannot be linked to licensure, reimbursement, hospital privileges or employment. Michigan and Missouri are now considering their own similar legislation. The AMA has called for an immediate end to any mandatory, secure recertifying examinations⁵ which is a major step, although it has also previously endorsed the idea of more intense Maintenance of Licensure to be enforced by the states⁶, a process which looked exactly like MOC with its self-assessment, assessment of knowledge and skills, and performance in practice.⁷

Though making a resolution against MOC is a small step, it is one brick in a much larger foundation, which has made the current progress we have seen possible. Most doctors who are required to complete MOC feel this is an important issue, and I have yet to talk to one who has not complained about this burdensome process. I believe this would be an issue where our medical society could be a strong advocate and voice for its doctors.

With a formal resolution like Massachusetts, we could then seek “Right to Care” legislation to prevent what has become mandatory participation in MOC for many doctors in RI. It is complicated with the many hospitals and insurers and will not happen overnight, but if we join together with physicians and medical societies nationwide, our voices do have power. Help ensure that MOC will never be linked to licensure, reimbursement, hospital privileges or employment. The time to act is now.

Please take a look at our petition and add your name if you haven’t previously:

<https://www.change.org/p/rhode-island-medical-society-create-a-resolution-against-the-abms-moc>

Sincerely,
Lisa Frappier, DO
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RI Physicians for Quality Care

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Medical Decision-Making for Unrepresented Patients

HERBERT RAKATANSKY, MD

A SIXTY-ISH-YEAR-OLD homeless man is admitted to the hospital with pneumonia and found to have COPD and cancer of the lung. Radiation and surgery are under consideration. He is forgetful and is unaware of any family. He has no friends and this is his first encounter with the medical system.



He is confused and lacks capacity to make decisions about his treatment.

A diligent search fails to discover any friends or relatives and did not reveal any cultural, religious or other values that might influence medical decisions.

Such cases are not common but pose difficult dilemmas when they occur. Without family, friends or a prior knowledge of their views on medical treatment, such persons are “unrepresented patients.” They have no advocates. The literature suggests that 5% of the 500,000 patients who die annually in ICU’s and 3–4% of patients in nursing homes are unrepresented.

Forty-three states have laws designating who can make medical decisions for patients who lack capacity and have not designated a proxy. Rhode Island (RI) is not one of these. RI has a statute designating a hierarchy of persons who can consent for an autopsy, but we do not have such a legal hierarchy for decision-making for live patients when there is no designated proxy. Generally

we designate close family or friends who may know the patient’s values and will be able to use the criterion of “substituted judgment” to make medical decisions. But there are no such persons for our patient.

A proxy who could apply the “reasonable person” standard is the

default option. But who is that person?

In emergency situations it is clear that treatment should be given. But in our case, where the treatment is urgent but not emergent, the only legal option is to seek a court-appointed guardian. This is not a realistic solution as that process is very time consuming (up to several months) and expensive (est. \$5000–\$8000). And often a willing guardian who can make timely informed decisions cannot be found.

The attending physician generally should not be the default proxy of record. In some states, including RI, the attending physician is prohibited by law from being an appointed proxy. However, 12 states allow the attending doctor to be the legal proxy although 7 of those impose significant limitations on them. A multi-disciplinary committee such as an ethics committee could serve in this role. Only 5 states, however, have laws that specifically empower such committees to make decisions about treatment. RI does not have such

a law. Three states (New York, Texas, Iowa) have laws establishing extra-institutional committees that may serve as proxies. In Florida, the “ultimate surrogate” is a clinical social worker and in Texas “a member of the clergy.”

Currently our largest RI health care system instructs attending physicians faced with caring for an unrepresented patient to call “risk management.” We need an approach in RI that will better serve these unfortunate folk.

A new law (effective August 2016) in Colorado (CO) offers guidance. The law works as follows:

Lack of capacity must be confirmed by an independent examiner.

A doctor (other than a doctor involved in the care of the patient) may be appointed proxy with the consensus of the ethics committee.

For routine treatment (formal informed consent not required) the proxy may act independently.

For treatments requiring formal informed consent both the proxy and the ethics committee must sign the informed consent.

For end-of-life treatment involving withholding or withdrawing treatment, a second independent medical opinion from a physician (not the proxy) and the consensus of the ethics committee must be obtained.

This law applies to all medical institutions in CO, including nursing homes,

assisted living facilities and community-based health services. If the designated doctor proxy is willing, he/she may continue as a proxy in all of the other care facilities and systems. If the consensus of the ethics committee is required and there is no such committee in the other facilities, the hospital committee may continue in its role to support the patient.

Since there is no law in RI that addresses these issues, we have several options.

We could try to get a law passed as the initial effort. Such legislation would likely address the issue of the hierarchy of medical proxies when family and friends are available as well as the process to assist unrepresented patients. Such an effort is likely to be lengthy, expensive and afflicted with unintended legislative consequences.

However, we could more easily incorporate processes to protect the unrepresented patients into the policies of our

institutions. A protocol based on the CO law, incorporated into the policy structure of hospitals, would be inexpensive and effective in dealing with this significant issue. Acting in concordance with hospital policy, the doctors caring for an unrepresented patient could enhance timely medical decision-making. And by acting in accordance with official hospital policy doctors may receive significant legal protection. This would be a benefit for patients, and would result in significant financial savings. Patients would get prompt, medically appropriate treatment and the administrative costs of dealing with the legal issues of unrepresented patients would be reduced.

Our small size and relatively few hospitals offer a unique opportunity for the competing medical systems in RI to cooperate on a non-controversial issue and establish a uniform policy for all RI medical institutions. Doctors working

in multiple institutions would always know the rules as would the institutions, and the designated proxy (if willing to do so) and the ethics committee could continue to serve in their roles in other institutions or settings, further benefiting both patients and institutions.

Finally, if a single agreed-upon policy to protect unrepresented patients were adopted by the various medical institutions and endorsed by the RI Hospital Association and the RI Medical Society, the legislature then might be convinced to create legislation incorporating these already effective policies and thus ensure the legal protection of these most vulnerable members of our society.

And that, after all, is our real goal. ❖

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Errata

R I Med J (2013). 2016 Sep 1;99(9):27-30.

ERRATUM Sex Trafficking Assessment and Resources (STAR) for Pediatric Attendings in Rhode Island.

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Abstract

BACKGROUND: Domestic minor sex trafficking (DMST) victims have unique medical and mental health needs and present frequently for medical attention. Little is known about the reported training, screening, comfort and knowledge of DMST among pediatricians in Rhode Island who likely encounter these patient victims without knowing.

METHODS: An anonymous electronic survey sent to Rhode Island Hospital staff physicians from November 2014 through January 2015.

RESULTS: Of the 109 participants, the majority reported no training, screened no patients for DMST in the past year, did not know any resources available and had limited knowledge and comfort with this pediatric patient population.

CONCLUSIONS: Rhode Island pediatricians of various specialties do not feel adequately prepared to identify and respond to a DMST patient population. These findings inform the need for increased training and education on DMST in our medical community. [Full article available at <http://rimed.org/rimedicaljournal-2016-09.asp>, free with no login].

KEYWORDS: commercial sexual exploitation of children; domestic minor sex trafficking; training; victim

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The Rio 2016 Polyclinic – An Athlete-Centered Experience in the Olympic Village

CLIVE W. BRIDGHAM, MA, DC, DACBSP, ICSSD

AT FIRST, BEING A MEMBER of the sports medicine team at the Rio 2016 Olympic Games was like being a mouse in a huge maze of corridors, offices, entries and exits – not to mention protocols. It quickly became an athlete-centered, check your ego at the door experience.



Arriving on my first assignment day was a transportation maze. I was living with friends in Logoa, where the rowing and kayak events took place. I opted to take a taxi, as I had no idea of the public transportation logistics of walking to buses which took you to subways which took you to more buses and more walking. My taxi arrived 15 minutes late and the driver didn't know where the Olympic Village (OLV) was. After 50 minutes and driving in circles,

we found an entrance, but the security guards wouldn't let the taxi into the restricted area. We were stopped with a huge bus honking behind us. I got out of the taxi and fortunately one of the guards spoke enough English and let me get on the bus, which was authorized to go into the outer perimeter of the village. I walked toward some volunteers and asked for directions to the Polyclinic. Passing through security with credential check, metal detector, and x-ray examination of my official volunteer carry bag, they pointed me in the right direction.

After a fast walk/jog, which seemed like an eternity, I arrived at the Polyclinic, where we had our introductions and meetings of the physical therapies team of physios, chiros, and osteos. We

then toured the clinic, which included many specialties: dentistry, ophthalmology, emergency room, orthopedic sports medicine, podiatry, osteopathy, massage therapy, and of course chiropractic.

The complex also included two state-of-the-art MRIs, one digital x-ray, a cryo pool room, a rehab room with an anti-gravity treadmill, conference, storage and IT rooms, as well as lounges and reception areas.

There was a room for orthotics and support braces for ankles to shoulders, a chiropractic table room, an osteopathic table room, and our main area for physical medicine: the physio room with 12 treatment tables and state-of-the-art physio machines for ultrasound, ems, laser, cryo/compression, and hot moist packs. There was also a Swiss machine for intense pulsed ultrasound. The one exception was that no acupuncture was allowed in the clinic. The physios were allowed to perform mobilization but





only the chiro and osteopaths were allowed to perform manipulation.

During the first few days, the early morning hours were relatively quiet with only an easy flow of returning athletes, so it was watch and learn and figure out what specialty we each were as we were all dressed the same and our credentials made no differentiation as to our degrees. It was an adaptive process on all sides, learning the subspecialties of each provider. Watching the team develop understanding and work together was a great experience. The chiropractic team provided treatment to all athletes requesting their services, from any country's team in any sport.

We saw a wide variety of treatment needs, with many athletes being referred to us for neck, low back and extremity conditions. It was great being able to make a difference in these athletes' lives. We helped them achieve their goals by getting them back into play after an injury, or helping them perform at their optimum level by making sure that their body was functioning at 100%.

Our teams were divided into two shifts. On my first day there were only about 2,500 people housed in the OLV, by midway through my rotation the OLV swelled to at least 11,000 occupants. Athletes accompanied by their team doctor or team physio were allowed direct access and could either work with us or independently.

I found many team physios and some team MDs were very interested in referring and watching chiropractic services. Pleased athletes spread the word about the clinic and soon the volume increased exponentially. Once the athlete was in the physio treatment area interdisciplinary referrals were allowed and encouraged, providing the athletes with a world-class experience. My first day shift ended at 3 p.m. with a debriefing and a team Rio cheer.

There are so many people to thank for their years of work in making the Rio 2016 Polyclinic the success that it was. Of special note are Dr. Marcelo Botelho, the lead chiropractic physician and Felipe Tadiello, coordinator of physical therapy services. Many people were

exposed to chiropractic services for the first time. Many new friendships were formed and old acquaintances renewed.

It is amazing what happens when you have a dedicated team of professionals who are athlete-centered treating the finest athletes in the world. This has been a dream for my entire chiropractic career, and was 30 years in the making. It is the highest level of sport, and a total honor to be a part of the sports medicine staff. It was truly a world-class experience, well worth the time to learn how to navigate the mazes I encountered. ❖

Author

Dr. Clive W. Bridgham, a chiropractic sports medicine specialist and director of the Barrington Chiropractic and Sports Medicine Clinic, was one of the 17 chiropractors from eight countries chosen by the Rio 2016 Organizing Committee to serve in the host medical services during the Olympics and Paralympics. For three weeks, from July 29 to August 11, Dr. Bridgham and colleagues worked in a multidisciplinary polyclinic open to all athletes, coaches and officials.