Helping MS patients help themselves

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Faced with an explosion of advances in medical science and information technology, the increasing focus on patient-centred care can at times be a challenge for practising physicians.

With our capacity to communicate with the masses instantaneously, are we allowing enough time for the high-quality research needed to validate the efficacy and safety of new interventions before releasing information to the public? What is the risk-benefit ratio of early dissemination of unproven interventions? When patients demand access to unproven medical approaches, are health professionals and our health system obligated to provide and support these choices? Is denial of such contrary to the goals of patient-centred care? And whose role is it to help patients understand the flood of information before them?

We are in the midst of a very public debate about a proposed treatment for multiple sclerosis (MS). *Liberation therapy,* introduced by Zamboni et al, involves endovascular treatment of the internal jugular or azygous veins in an attempt to reverse effects of chronic cerebrospinal venous insufficiency (CCSVI), which Zamboni has claimed causes or contributes to MS.[1] His research using noninvasive Doppler ultrasound imaging showed CCSVI in all MS patients and in none of the controls; sensitivity, specificity, and positive and negative predictive values were all reported as 100%.[1] But other studies have failed to replicate these findings,[2,3] and have concluded that more evidence is needed before a link can be established between CCSVI and MS.[4]

As news of this potential treatment spread, clinics offering liberation therapy opened in several countries. With Canada's high rates of MS, it is not surprising that many Canadians suffering from this incapacitating disease are among those seeking access to this intervention—and their family physicians are often identified as the main resource to help them understand what is unfolding and to achieve their goal of treatment.

The Canadian Institutes of Health Research (CIHR) takes the position that more evidence of a link between CCSVI and MS is needed before endovascular treatment is introduced in Canada. A CIHR expert working group is reviewing results of studies being carried out around the world, including 7 rigorous blinded studies undertaken by MS societies in North America. If the link is proven, the next step would be clinical trials on the safety and efficacy of the endovascular procedures, followed by recommendations for clinical applications. The Canadian Medical Association, the Association of Faculties of Medicine of Canada, the Canadian Society for Vascular Surgery, and the Executive Committee of the College of Family Physicians of Canada support the CIHR position and agreed to share it with our members. This information can be found at **www.cfpc.ca**.

Multiple sclerosis is a complicated disease. In some it is a primary progressive condition; in others it has a relapsing-remitting pattern that might or might not become progressive. A number of patients have reported symptom improvements following liberation therapy. The interest of others desperate for relief has, naturally, been piqued. But were these improvements related to the treatment, the natural course of the illness, or other factors?

Endovascular treatment is not without risk. Venous restenosis, thrombi, pulmonary emboli, hemorrhage, and migration of stents have all been reported. Patients experiencing troubling symptoms after being treated abroad have on occasion encountered difficulty accessing medical care at home.[5] The Registrar of the College of Physicians and Surgeons of Saskatchewan, Dr Dennis Kendel, offered this reminder: "We do expect physicians to respond to patients in need regardless of the previous treatments they have had, here or elsewhere."[5] He also made it clear that while care should never be denied, patients cannot demand particular tests or procedures. Patient-centred care does not mean physicians must agree to carry out specific treatments or tests suggested by patients. It does mean that we should listen to patients, be sensitive to their perspectives and needs, and ensure they have all the information necessary to make the best possible decisions. It also means we must not abandon them when they are in need.

The explosion of medical advances will continue, as will the rapid dissemination of information—validated or not. And patients will play an increasing role in determining their own care. But it will still be the personal family physician who will provide most of each patient's medical care, who will arrange and coordinate referrals, and who will be vital to helping each patient understand the information available and the choices to be made. Trusted lifelong patient–family doctor relationships ensure that patients are heard and that their input into care decisions is respected. The current challenges in MS treatment exemplify the importance of the role of the family physician in helping patients help themselves.

Cet article se trouve aussi en français à la **page 383.**

References

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