Improving end-of-life care

Editor's Note: This article is the second in a series related to age research being conducted within Lakehead University's Centre for Education and Research on Aging & Health (CERAH).

BY JILL MARCELLA
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HOW IS it that people benefit from health research? At times, seeing how research is put into action is not clear. Research is continually taking place in every area imaginable. Have you ever asked yourself, "How do I, or the people around me, really benefit from health research?" Some benefits are obvious and receive a lot of media attention, for example, creating new medicines, cures, diagnostic tests, or guidelines for healthy eating and lifestyles that reduce your risk for certain diseases.

Other areas might not be as apparent and do not receive the same kind of media attention. Improving the quality of life for people dying in long-term care is one of the areas less talked about.

The Social Sciences and Humanities Research Council has funded a five-year project titled Improving the Quality of Life of People Dying in Long-Term Care. This program of research, in partnership with St. Joseph's Care Group and the Municipality of Halton, is now in its fourth year. The research has been developing palliative care programs in LTC homes by engaging long-term care staff, residents, families and community organizations.

When the Quality Palliative Care in Long-Term Care Alliance began, approximately 40 per cent of residents living in a long-term care home died each year. In 2011, 50 per cent of the residents had died.

This increase is not reflective of poor care but rather is reflective of the frailty and complex health conditions of residents now entering long-term care homes. Our advances in home care for seniors means that residents who enter long-term care homes are of advanced age, often 100 years-plus, and needing extensive amounts of care. The new residents are often approaching the end of their lives.

Many people are unaware that residents living in long-term care homes can remain there until the end of their lives; residents do not have to transfer to an acute care facility or a hospice unit for end-of-life care. Residents and family members can be supported by a palliative approach to care in the resident's home.

Providing care at end-of-life has become vital to long-term care practice. The Quality Palliative Care in long-term care program of research has been supporting long-term care homes with the creation of interprofessional palliative care teams; providing training, education and developing evidence-informed strategies to guide clinical practice. These are all components to supporting a new palliative care culture in long-term care.

Two of the research homes have formed interprofessional palliative care teams. These team members have the role of being a resource of palliative care information and they share their knowledge gained through palliative care training and education with other staff.

When the long-term care homes indicated that more training and education in palliative care was needed for staff, our research completed a needs assessment and created unique education and training opportunities targeted at these needs. Examples of education included improving communication skills for talking with families about death and dying, and strategies to support people with their grief after a resident dies.

Each of the long-term care homes that are study sites in the research has developed many evidence-informed strategies to guide practice. For example, one of the homes has implemented the use of a clinical tool that will identify residents who are transitioning to end-of-life and would benefit from having a family conference to discuss palliative care. Two of the homes are evaluating how the use of new pain screening tools increases the frequency of staff reporting and documenting when a resident has pain.

The last home has evaluated the benefits to staff, families and volunteers of having palliative care rounds facilitated by their pain and symptom management consultant. These examples of research in action are directed towards improving the quality of life of residents dying in LTC homes while building the capacity of the staff who are delivering this care on the frontline day to day.

Jill Marcella is acting research project co-ordinator for the QPC-LTC project.

SUBMITTED PHOTO

Nadia Thatcher, left, and Jackie McDonald assist a resident of Bethammi Nursing Home. Many long-term care facilities are working toward improving the quality of life for residents.

Patient trial of proposed MS treatment announced

THE CANADIAN PRESS

TORONTO — A long-awaited Canadian trial of a controversial experimental treatment for multiple sclerosis has been given the go-ahead and will soon begin recruiting patients, Health Minister Leona Aglukkaq said.

Aglukkaq, in Halifax for a meeting with provincial and territorial health ministers, said about 100 MS patients will be enrolled in the trial to assess the safety of the procedure to unblock narrowed neck veins and its efficacy in improving MS symptoms.

The condition — dubbed chronic cerebrospinal venous insufficiency, or CCSVI — has been proposed as a possible cause of MS by Italian vascular surgeon Paolo Zamboni.

More than three years ago, Zamboni hypothesized that narrowed and twisted veins in the neck and chest create a back-up of blood in the brain, resulting in iron deposits that could cause the brain lesions typical of MS.

The disease causes the destruction of myelin, the protective sheath around nerves throughout the body, leading to progressive physical and cognitive disability. An estimated 55,000 to 75,000 Canadians have MS, and the county has one of the highest rates of the incurable disease in the world.

Dr. Anthony Traboulsee, medical director of UBC Hospital's MS Clinic, will lead the $6-million study, which will be conducted initially in Vancouver and Montreal. Medical and ethical approval is also being sought for parts of the trial to be conducted in Quebec City and Winnipeg.

"It's going to be a randomized-control study where patients who have the presence of CCSVI will be randomly selected to either have the venoplasty, which is dilation of the vein, or a sham treatment, which is not an actual dilation, just a pretend dilation," Traboulsee said from Vancouver.

"And after a year, the groups will switch so that everybody eventually gets the dilation of the vein."

A venoplasty to widen veins is the same technique as an angioplasty used to expand coronary arteries; a tiny balloon is fed into the blood vessel, then expanded.

None of the participants will know which treatment they received or during which half of the study, Traboulsee said.

"The patients won't know when they're getting the dilation, the first time or the second time, so it doesn't bias their interpretation of benefit," he said.

Thousands of Canadians with MS have reportedly travelled to clinics outside the country, paying thousands of dollars for the vein-dilating procedure since Zamboni's theory first made headlines in late 2009.

Many patients — but by no means, all — reported their symptoms had improved following CCSVI treatment, fuelling insistent calls by MS patients and their advocates to allow doctors to perform the procedure in Canada.

But with several deaths and complications attributed to the vein-widening surgery — and studies on CCSVI around the world showing mixed results at best — an expert medical panel advised Ottawa to first mount a clinical trial to test Zamboni's theory.

Traboulsee's group, whose study design was chosen from among three proposals, said the research is meant to establish both safety and efficacy of the treatment.

"Safety is really important. We've been surveying patients who have gone out of the country for the treatment and we found a complication rate of 11 to 12 per cent. That's what patients are reporting," he said.

"My impression is it's mostly related to stents and we're not going to be using stents in our study. We don't think the stents are the best idea at this point."

Stents are small mesh cylinders that are inserted into blood vessels to keep them propped open. Their use in veins is controversial, as the stents can cause blot clots or migrate from their original site in some cases. Even Zamboni does not advocate their use in his CCSVI treatment.

"There has been a lot of controversy around it," Traboulsee said of the procedure. "That's why I think it's important to move this forward and get some final answers to it.

"Because so many Canadians are going out of the country to have this procedure done, if we don't bring some resolution to it soon, we won't be able to give people the information they need to make safe, informed decisions."

Dr. Alain Beaudet, president of the Canadian Institutes of Health Research (CIHR), said MS patients will be drawn from the three provinces where the research is being conducted.

Beaudet said the study is among only a handful worldwide that are blinded, randomized-control trials, the gold standard of medical research.

"Which is critical here because we're wondering if it's a true effect. Is it a placebo effect? Is there really an effect?" he said from Halifax.

"I think we're getting to the point where we need to know one way or the other, and I hope that this will bring us the answer that we're all after."

The case against male circumcision

BY W. GIFFORD-JONES M.D.

THE DOCTOR GAME

WHY ARE so many male circumcisions still performed when we all agree that female circumcision is a barbarous act?

Now, the American Academy of Pediatrics says the benefits of male circumcision outweigh the risks. But, if newborns had a say in the matter, they would use the following reasons to shout a big "NO" to this mutilating procedure, unless religious or cultural reasons require it.

Circumcision doesn't just snip off a small piece of skin. Rather, it removes a large surface of foreskin measuring three to five inches in length, about half of the total skin of the penis! Also, inside the foreskin there's a band of tissue that acts like an accordion. Its gliding motion is needed to trigger sexual reflexes and pleasure.

The foreskin is not just skin. Dr. John Taylor, a Winnipeg pathologist, reported in the British Journal of Urology in 1996 a new anatomical finding. Taylor and his colleagues discovered a "ridged band" that runs around the inside of the foreskin. Microscopic examination shows this skin is loaded with blood vessels and nerves. So what is being amputated is a large part of the sexual function of the penis.

Never forget that nature placed the foreskin in that area for a good reason. It's therefore a sound rule not to mess around with nature.

Don't buy the argument that circumcision decreases urinary infections. Infections primarily occur in the first year of life and can be avoided by improved hygiene. This is a lame excuse for decreasing the pleasure of sex for the next 80 years or more.

Don't accept the theory that circumcision decreases the risk of penile cancer as this is an extremely rare malignancy. After all, no one recommends that all female breasts be removed for fear of malignancy.

Studies show that circumcision decreases by 15 per cent the risk of contacting HIV and genital herpes. But it has no effect on decreasing the risk of gonorrhea. This advice may make sense to those wandering from one bed to another. But not to others who practice responsible sex. Why should all suffer for others' irresponsible behaviour?

Circumcision rarely presents complications. But if one occurs, it's nevertheless a 100 per cent hit. Moreover, the world's medical journals are full of reports dealing with a variety of surgical mishaps that are not an "act of God," but due to human errors.

A primary problem is the incorrect use of the circumcision clamp. In some cases too much foreskin is pulled into the clamp causing injury to the penis. In other cases there's severe injury to the urinary tube (urethra). This may result in difficulty passing urine or development of a urethral fistula causing urine to be discharged through an abnormal opening. Some of these injuries are not apparent following discharge from hospital as a fistula takes weeks or months to make its presence known. And on rare occasions part of the penis has been amputated. As Harvey Cushing, one of Harvard's great surgeons, once remarked, "There's no such thing as minor surgery, but there's a lot of minor surgeons."

How many men today would need an erectile dysfunction drug (ED) if a circumcision had not been done. I don't know how many angels can dance on the head of a pin, nor do I know the answer to this question. Nor does anyone else. But it's my bet that this procedure has had a reasonable effect on the sale of ED drugs.

In 1996 The Canadian Pediatric Society recommended that circumcision should not be routinely performed. It plans to reconsider this advice in the next year. Let's hope it first reads the Canadian Charter of Rights and Freedoms and the United Nations Declaration of Human Rights, then decides it's a needless, brutal procedure that violates newborn rights.

Circumcision is not a life and death situation. So unless it's required for religious or cultural reasons, this decision should be made when an adult can decide whether or not he wishes it done. I believe many newborns would say Amen to that.

The Doctor Game runs each Tuesday in The Chronicle-Journal. Dr. Ken Walker (aka W. Gifford-Jones) has a private practice in Toronto. Please send comments to info@docgiff.com or visit docgiff.com.

Doctors call on Ottawa to rethink refugee health cuts

THE CANADIAN PRESS

TORONTO — Pregnant women and their babies are among those experiencing the worst fallout from Ottawa's decision to scale back funding for refugee health care, says a group of doctors protesting changes to the program.

Canadian Doctors for Refugee Care said Thursday that three months after cuts to the Interim Federal Health Program took effect, it is marred by confusion, unnecessary costs and compromised care.

The physicians group has been documenting dozens of patient cases since the changes to the program were announced June 30, including that of a young female refugee claimant left pregnant after being used as a sex slave. The woman, 18 weeks' pregnant, has no IFH coverage for obstetrical care.

"The IFH Program is in disarray and being mismanaged and the health of all refugees is being placed at risk," said Dr. Philip Berger, chief of family and community medicine at St. Michael's Hospital in Toronto.

"It appears to be disproportionately affecting pregnant women and their babies, because there's a time limit by which they need medical care, obviously," Berger said in an interview, explaining that claimants must wait up to six weeks for health coverage after seeking refugee status.

"So we know of independently confirmed cases — we've spoken to health-care providers directly — where women are in their very last four weeks of pregnancy and cannot get any care and are advised to just show up at an emergency department when they go into labour."

Six such cases have been seen at one small clinic alone in the last three months, the group said.

"The government is telling some of the most vulnerable members of society they are not eligible for important, possibly life-saving health coverage," said Dr. Meb Rashid, medical director of the Crossroads Clinic at Women's College Hospital in Toronto.

Other cases documented by Canadian Doctors for Refugee Care include:

• A man requiring urgent eye surgery to prevent blindness is refused IFH coverage because he is said to be an "illegal migrant expected to leave the country." His doctor performs the surgery anyway. Ten days later, he receives notification from Citizen and Immigration Canada that he is eligible to apply for permanent residency status.

• A refugee claimant, 36 weeks' pregnant, is told by her obstetrician to bring in $3,000 for her next appointment because the IFH will no longer provide insurance for her pregnancy and delivery. Weeks later, following an investigation, the program admits a mistake as made and the woman will be covered.

The doctors organization wants the federal government to reconsider its changes to the program — and it's also calling for the Standing Committee on Citizenship and Immigration to thoroughly evaluate the impact of reductions in refugee health coverage.

"Physicians will continue to track individual patient cases and report back on our findings," Rashid said in a statement. "We are not going away until the government does the right thing and completely reverses these reckless health-care cuts."