

Review: Report about the Liberation Treatment for multiple sclerosis

November 25, 2011

REVIEW

On July 8, 2011, CBC Television's The National [carried a story](#) from Kelly Crowe, its health reporter, on the death of a Canadian woman who had gone to the United States for a relatively new therapy for multiple sclerosis called Liberation Treatment.

[Multiple sclerosis \(MS\)](#) affects the ability of nerve cells in the brain and spinal cord to communicate with each other. The symptoms are wide-ranging and worsening. There is no definitive cause and no known cure.

[Liberation Treatment](#) involves angioplasty or the placement of a stent in certain veins in an attempt to improve the flow of blood draining from the central nervous system. The compromised flow of blood, known as chronic cerebrospinal venous insufficiency (also known as CCSVI or CCVI), was hypothesized in 2008 by Italian vascular surgeon Paolo Zamboni as playing a role in multiple sclerosis.

The new procedure is controversial. Research has been limited, criticized and unable to draw a causal link between multiple sclerosis and the venous insufficiency. Indeed, the procedure has been linked to serious health complications and deaths. That being said, it also has its proponents who believe it has provided relief from symptoms.

Canadian clinics do not perform the procedure, so those who want it must travel abroad for treatment. In June 2011, the federal government announced it will finance clinic trials to examine its safety and effectiveness. Those trials are not yet under way.

CBC News, in possession of medical records provided by the patient's family, indicated Maralyn Clarke underwent the treatment at a private California clinic. She experienced health difficulties upon discharge, including nausea, vomiting and severe headaches. She was taken back to hospital and found to have bleeding in her brain. A scan showed an irreversible brain injury. She was placed on life support and died five days later of a stroke.

“Maralyn Clarke is the second Canadian known to have died after having the procedure,” Crowe reported.

Dr. Barry Rubin, a Canadian vascular surgeon and part of the federal panel studying the therapy, said in the report that patients need to know about complications before they decide on treatment.

The report also heard from Dr. Michael Brant-Zawadzki, a prominent neurosurgeon and the executive medical director of neurosciences at the Hoag Memorial Hospital in California. He refuses to perform the procedure. Brant-Zawadzki said that physicians may think they’re helping patients, but “unconsciously there’s an enablement going on of what could become a self-harmful, if not truly self-destructive process.”

Crowe said Clarke’s husband said she would be alive if she hadn’t proceeded with the procedure.

The report featured another patient, Caroline McNeill, who had her veins unblocked in the same clinic and was returning to have it done again. “I think the benefits definitely outweigh it (the risk),” she said in the report.

Crowe concluded the report by noting experts agree all surgical procedures carry risk, but that because no one knew how many were undergoing the procedure it was impossible to gain an accurate understanding of the complication rate. She said experts felt it important to proceed with “rigorous scientific studies” to determine if Liberation Treatment works and is safe.

The complainant, Thomas Peterson, who has MS and has undergone Liberation Treatment, wrote July 20 with an extensive critique of the report as alarmist and biased. Among other things Peterson said the report:

- Failed to place the deaths in context of other treatment-related and MS-related deaths.
- Bought into the fear, uncertainty and doubt expressed by a medical establishment threatened by the loss of income from this lower-cost treatment.
- Distorted the claims of Liberation Treatment supporters.
- Ignored the moral questions of Liberation Treatment or the failure of existing therapy.

“The problem with your treatment of this issue is your unbalanced reporting,” Peterson wrote, adding that CBC should commit to “the whole truth, not just part of it,” and that its coverage “stresses the negative and largely ignores the alternative.”

Mark Harrison, the executive producer for The National, wrote back October 3 and disagreed. Harrison also apologized for the time it had taken to respond.

Harrison said CBC News had over the years provided “a wide range of stories on many aspects of MS and its treatment” but that this report was “very narrowly focused” on Clarke’s death.

“While it acknowledged the risks of the treatment, it also pointed out that a woman who had her veins unblocked at the California clinic a year earlier is intending to return to have it done again,” he noted.

Television news requires that information is at times compressed to fit the report, he said. “Inevitably, some things are left out, but that does not mean the story is biased or unbalanced . . . reporters cannot reasonably be expected to include all the information available in every story.”

Peterson wrote again October 19 that the report was too narrowly focused and insufficiently curious. MS patients routinely exchange information suspicious of the medical establishment.

“I do not question that in the past you have fairly and thoroughly covered the topic of multiple sclerosis. I would just like that fair and thorough reporting to continue into the future.” He reiterated the need to show the hazards of other treatments and to question why the procedure requires the unusual step of a clinical trial.

It was not clear if he was asking for a review by this Office, so he was asked October 20. On October 25 he wrote back to say his main objective was to get The National to attend to his concerns and that a review would not be needed. But he then wrote again November 7 to express concerns that the story continued to be featured online, so a review was started.

CBC Journalistic Standards and Practices policy calls for accurate, fair and balanced reporting that even-handedly and respectfully treats individuals and organizations involved in controversial issues. It requires that CBC not take a position on any matter of public debate.

On science and health reporting it states: *“In matters of human health we will take particular care to avoid arousing unfounded hopes or fears in persons living with or close to those living with serious illnesses.”*

CONCLUSION

This report was one of more than a dozen by CBC News on the subject of Liberation Treatment in the last year or so, following other media reports that claimed the treatment was a breakthrough.

In reviewing the stories I concluded that the overall thrust of CBC's journalism has been open-minded about Liberation Treatment, even if the reporting itself has suggested caution and skepticism about its proponents' claims and identified the need for greater scientific effort to shed light on its qualities. CBC has made room in its journalism to chronicle the success stories that flow from the Liberation Treatment hypothesis, but not at the expense of suspending a more substantial respect for scientific rigor.

In the absence of peer-reviewed studies and other qualitative science about Liberation Treatment, CBC and other organizations have no other responsible choice to the public than to avoid raising false hopes about it. CBC's journalistic policy demands that. The corollary of this approach is the responsibility to chronicle news associated with the topic while it remains a controversial matter of public debate, even if that casts a largely negative impression.

From my review I concluded CBC News had ample understanding of the issue, and of this particular personal story, to report what it did accurately and to do so without raising a false fear. Indeed, I suspect CBC's reporting has supplied MS sufferers with greater insight into the surgical risks of Liberation Treatment, and that well may be a good thing. And, given its effort to date, there is no reason to believe it will not see the story through to understand what the public can learn from the clinical trials of the procedure or any other significant developments.

News stories are finite chapters in a larger tale, and it can be frustrating to know certain information could have been included but wasn't. But I concluded that, given the nature of the format and its focus on this particular treatment, it was unnecessary to cite the consequences of other treatments (and non-treatment) as context to fulfill journalistic policy.

There was no violation of CBC Journalistic Standards and Practices.

Kirk LaPointe
CBC Ombudsman