The Virtual Hospice

An Interview with Dr. Michael Harlos

Lydia Lee, President and Board Chair of COACH and Dr. Michael Harlos

Dr. Michael Harlos, Medical Director, Palliative Care Program & Pediatric Palliative Care Service, Winnipeg Regional Health Authority; Professor & Section Head, Palliative Medicine, University of Manitoba, was honoured with the Clinician Leadership Award by COACH in 2011 for his work as the Clinician Leader of the Canadian Virtual Hospice. This award is given annually to a clinician who has shown outstanding leadership in advancing the use of health information communication technology (ICT) and informatics in clinical practice resulting in improved provider and patient experiences and outcomes.

A highly experienced and widely respected palliative care physician, researcher and educator, Dr. Harlos was a key member of the team that conceived and designed Canadian Virtual Hospice (Virtual Hospice). This internationally award-winning website provides information and support about palliative care, loss and grief. The driving force behind the Virtual Hospice Ask a Professional (AAP) feature, Dr. Harlos has pioneered effective clinical communication in an area fraught with complex symptom management and emotional distress. The AAP feature made Virtual Hospice the world's first web-based platform directly linking the public with healthcare specialists online.

Dr. Michael Guerriere, co-editor of *ElectronicHealthcare*, recently interviewed Dr. Harlos. What follows is an excerpt from their conversation:

MG: As an initiator of the Canadian Virtual Hospice, can you provide us with some history on where the concept of using technology to communicate with patients originated?

MH: In the early 2000s, Harvey Chochinov[1] had a vision of a platform that would provide support and information to Canadians about palliative care. I remember the phone call from Harvey asking if I thought it was a good idea – of course I thought it was a great idea!

The vision was to make information available online, both static and interactive. We found a huge variation in the availability and quality of information about end-of-life care and felt there was an opportunity to provide quality, evidenced-based information. If you go beyond an urban setting, the availability of teams with expertise in palliative care is limited. It requires someone who's had extra training and a focused career in palliative care – something you are unlikely to find in a small town. There are doctors and nurses who take great care of people at end-of-life, but specialist expertise is often not available. The stats produced by the Canadian Hospice Palliative Care Association show that only approximately 30% of Canadians have access to palliative care, depending on where they live.

To address the limited resources available online, we brought together a team of nurses and physicians to create a repository of articles on communication, pain management, symptoms, and so forth. Soon after, we had a social worker, a spiritual care specialist and ethicists join our team to help address broader issues around end-of-life, including ethics, spirituality, physical and emotional considerations.

We felt good online content was important because patients and families, especially when they are vulnerable, may find it challenging to differentiate between reliable and unreliable information. As for the interactive component, "Ask a Professional" allows people to post questions to the website. These questions are then reviewed and answered by our professional group within three working days. The questions are quite challenging and from varied sources: 40% are from healthcare professionals, 40% from the patient's family and 20% from patients themselves.

MG: Was "Ask a Professional" a component of Virtual Hospice from the beginning? What challenges have you experienced with this feature?

MH: Yes, "Ask a Professional" has been part of the website since its launch in February 2003. There have been a number of interesting challenges over the years.

We have successfully navigated the jurisdictional issues that derived from variations in policy between the Colleges of Physicians and Surgeons in each province with regards to communicating about patients in other provinces.

The Canadian Medical Protective Association (CMPA) expressed concerns about supporting physicians working for the Virtual Hospice because it was a big unknown. On the other hand, the Canadian Nursing Protective Society was extremely supportive from the start. We have been able to address medical liability coverage through private insurance supplementing CMPA coverage.

I see Virtual Hospice as a way to explore what is inevitable: that online communication is going to be a way that people seek help. It is a bit naive to think that electronic support of patients and families doesn't exist in healthcare. There are families e-mailing doctors and doctors e-mailing back, and doctors who put things up on the Web for their patients. It's happening now. Despite this reality, if physicians or nurses in this country want to learn about the nuances of online interaction with patients – and there are clearly a lot of subtleties and considerations involved – where would they go?

Another challenge is responding to vague or poignant inquiries. The questions asked by the healthcare professionals are often difficult because they've tried everything possible and are now seeking guidance. In such situations, we have to be mindful of what our role is: to educate and inform. For example: when physicians or nurses ask a question, often they present it as a case: "I have a patient who has pain related to nerve compression that I can't get on top of; can you give any suggestions?" or "I've got someone with nausea that I can't control." We don't have a lot of history, so we don't know everything that's been tried. Therefore, we start with a background overview: a mini textbook chapter. Then we narrow down to the options they have, so we can provide support. Often we'll do a literature search and reference our recommendations with research articles and papers.

We have to make sure that we're clear about our role and are not critical of the care being provided, while at the same time empowering caregivers to provide more effective care.

One of the more poignant cases I remember was a teenage girl whose father had just been diagnosed with a rapidly progressive incurable condition and wasn't expected to live more than a couple of weeks. She wanted to know how she could help her father and particularity her mother, who was having a lot of trouble with the news and wasn't talking about it. You might wonder why would someone come online to ask this of strangers. But soon you realize, really, why not? Who is she going to go to? Neither parent is in a good position to help her, as those are the people she's worried about. She could try calling her parents' doctor and saying, "I'm worried about my Mom," but she would likely find it challenging to make such contact, and the physician may have concerns about speaking to her without her parents' consent. While she may find support in her friends, they would not be likely to be able to advise her on the needs of her parents. When you think of it, there aren't many choices for someone like her.

In answering a question like that, we need to make sure that she understands the whole spectrum of possibilities: It may be that her mother wants to be strong and not burden others with these issues. Or it could be the other extreme, where she is in real trouble and needs some help urgently. Responding to such a question would likely take 2-3 hours to write and edit, as you would want to be so attentive to the content.

So to summarize, questions are very wide ranging and often very poignant, and if they're clinical questions, they can be pretty challenging.

MG: Where is most of your clientele based?
MH: Our clientele reflects the size of the population in each province, with the exception of Manitoba. Manitoba is disproportionately represented because we're located here and the healthcare team in a small Manitoba town would know all about us because we present at local conferences. But Ontario is number one, Manitoba is second, followed by BC and Quebec. We also get occasional questions from Nunavut and remote areas.

MG: Do you have any clientele based outside of Canada?
MH: We get many, many visitors – over 1,000 hits a day in a busy month from all over the world. But people outside the country can only access the static information. We don't have "Ask a Professional" enabled for residents outside of Canada because of liability issues. Our insurance coverage would not extend outside of Canada.

MG: How do you market this service to the public?
MH: Most of our marketing efforts are within Canada. We publish articles in magazines and set up a booth at various conferences and fairs. We also promote through the Canadian Hospice Palliative Care Association or other websites.

MG: How do you see palliative care evolving? What challenges would you face if you were to expand your practice?
MH: When I teach our residents, I often say that palliative care is the only specialty that addresses a condition with a lifetime prevalence of 100%, which is death. There will never be an absence of demand for end-of-life information and for skill in managing it, regardless of what new cures and treatments emerge. I think we're just barely scratching the surface of what we could do for people.

The two big needs I'd like to address are those of Pediatrics and First Nations. If we had the resources – both human and financial – it would be really nice to have a pediatric element to the Canadian Virtual Hospice where a 10-year-old could go with appropriate supervision to learn about issues related to death and dying, but in an age-appropriate and interesting kind of way. Often people use games or interactive storytelling to communicate to younger age groups. Developing content focused on supporting First Nations communities would be a challenging but important initiative. In Canada we struggle with addressing basic palliative needs, let alone culturally diverse palliative needs. Moreover, it's very hard to deliver comprehensive palliative care to a remote community lacking in health resources. There are many improvements that can be made in addressing end-of-life issues for First Nations.

Another big gap we currently face is in providing palliative care in long-term care settings. In Winnipeg last year, 1,800 to 2,000 people died in long-term care facilities, of which we were involved with only a small percentage. Could the Virtual Hospice be a resource for them? That is a possibility.

We are always working on developing our website. One thing we've recently done is "how-to" vignettes. We've had a lot of nurses from the Winnipeg Regional Health Authority (WRHA) specializing in palliative care who work closely with our Clinical Nurse Specialists to put together vignettes for families on how to do a bed bath, how to turn someone in bed without hurting your back, how to help them out of bed. Eventually, all the basic support on palliative care is going to be available in downloadable format.

In the end, the challenge remains the limitations of financial and human resources. Any time we have a big initiative that is likely to bring more users to the site, those of us who are responsible for responding to questions are half excited and half nervous about it, as it may be hard to keep up with an increase in volume.

MG: Are there metrics to show how much palliative care is used by the community? Have these metrics been used to obtain funding for virtual hospice practices?
MH: I don't think there are published metrics available. One can find literature to quantify sudden unexpected deaths versus progressive illness to determine the target population for palliative care. In general, if you are conducting a needs assessment, progressive illness almost always has a recognizable palliative phase. Palliative care may have a role in sudden unexpected mortality, as well. People dying from sudden events such as a stroke or trauma may not always need to be cared for in a critical care environment, depending on goals of care. They should have access to a palliative care unit.

In building our Palliative Care program in Winnipeg, we estimated the number of community nurses we needed to support patients in their homes, and the physician resources as well. We have gradually expanded our program over time. In my view, health regions should have a specialist who knows how to do palliative care, manage complex symptoms and support people at home. Even if the numbers are low, the need is still there.

MG: Can you help me understand the funding model: how is Virtual Hospice supported from both a

technology and human resource standpoint?

MH: From my understanding, the two main sources of funding are the Federal government and the Canadian Partnership against Cancer. There were others that provided support in the early days, as well. The WRHA provides funding for the physicians and other members of the Virtual Hospice team. Within nursing, there's a full-time nursing position dedicated to the Virtual Hospice.

We require a fairly unique skill set to support the Virtual Hospice – you have to be able to write pretty well, understand boundaries within the scope of practice, and have some intuition about how to approach sensitive issues. You have to be able to write at a level that patients and families understand, yet is technical enough that it's informative to professionals, as it is quite likely that the patient or family is going to share the answer with their doctor. For example, a response might be, "Well it sounds like you're having a lot of pain in your leg, and this might be caused by bone troubles, nerve troubles and soft tissue troubles. Now I'm just wondering if some of the pain that you've just described is more like a nerve-type pain and this is something that you'd need to check with your healthcare team. Here are the medication types that doctors tend to use." So you need people who can craft an informative answer that will help both the physician and the patient.

MG: There are many emotional challenges for a professional in the palliative care business. How do you manage it personally?

MH: I've been doing this now for almost 21 years, and it's an area of medicine that either fits for you or doesn't; you either love it or you don't. I fell into it quite accidentally. I agreed to cover the palliative care service 20 years ago when the Medical Director retired and I committed to fill in for the three months until they hired a replacement. I was working in Geriatrics at the time, so it sort of stuck to me – it was clinically very challenging and personally rewarding.

Patients in a palliative circumstance have complex pathology and often challenging medical conditions. When you know that you've made a difference in a person's life, it's quite rewarding. The key is, when you spend the whole day watching people face end-of-life, it makes you think about what's important in your life, so you hopefully take good care of yourself and value your family time.

In the last six years, I've focused on pediatric palliative care, which presents its own unique challenges and rewards. The first 15 years of my career helped me learn to be mindful of what I need to take ownership of and what I cannot take ownership of in supporting patients and their families in such difficult circumstances. What I own is an obligation to be strong clinically, to be supportive of the patient and the family, to be helpful, to be informative, and to be supportive of patients at home if they want to be at home. But I cannot own the sadness. If you work in palliative care and get too intensely caught up in it, you must reframe your view or find a different line of work.

MG: What e-initiatives have you been involved with other than Virtual Hospice?

MH: The other main websites I have worked on are palliative.info and the Canadian Network of Palliative Care for Children. I'm by no means a web designer, but back in the early 2000s I was involved in a lot of e-mail discussion on palliative care, and people across the world would share cases and ask for advice. People kept asking me for the bookmark list I used, so I ended up creating the palliative.info site to hold such information. Soon after, the website evolved into an open source repository where I uploaded presentations by me and my colleagues for public use. I've been to conferences and seen my slides used by others, and I think it's great! It's a good way to share information.

MG: What advice would you give to other clinicians who want to incorporate more virtual aspects into their practice?

MH: That's a great question! First of all, I would say do it and I would absolutely support it. I do it all the time in Pediatrics where families just need to have contact to address questions but don't have the time to spend hours trying to track you down. But be informed about the policies and procedures that are out there with regards to communicating electronically, notably those of the provincial College of Physicians and Surgeons and the Canadian Medical Protective Association.

Any time you explore something new, it's always wise to be honest and open about potential risk. If things aren't going well, what will you do? If I were exploring that with my patients, I might say, "We're going to give this a try; it's possible that I might be overwhelmed with 50 e-mails a day and I won't be able to answer, but we're going to try it for two or three months and see how it goes and then re-evaluate." It's like any e-mail conversation: be mindful that everything you write is forever, so don't be disparaging, flippant or inappropriate. I would say explore the policies and procedures, the jurisdictional restrictions and the standards of virtual practice before getting started. **EH**

Endnote

[1] Dr. Harvey Max Chochinov is internationally recognized as a leader in palliative care research. He is a Professor of Psychiatry, Community Health Sciences, and Family Medicine (Division of Palliative Care), University of Manitoba, and Director of the Manitoba Palliative Care Research Unit, CancerCare Manitoba.