



Draw me your disease

Obstacles to palliative intervention for patients with noncancer diagnoses

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Upon receiving a cancer diagnosis, you immediately understand the gravity of the situation, and rightfully so, given that there are innumerable types, grades, and stages for which there is an entire gamut of outcomes. In your mind you have already begun creating an image of this cancer as a stain, a beast, a monster that you need to be rid of.

In contrast, when you receive a diagnosis of heart failure, chronic obstructive pulmonary disease, or kidney failure, the news might seem less threatening. You are told that there are good treatments, often consisting of a few pills or an inhaler. Sometimes all you need to do is change certain bad lifestyle habits. You consider it ridiculous that such chronic diseases could threaten your life. And yet a leaking heart, collapsing lungs, or petrifying kidneys do not sound less menacing to me than the beast of cancer.

So why, then, is there such a great disparity between the popular understandings of cancer and noncancer chronic diseases? Yes, the statistics associated with cancer are staggering. In fact, 1 in 2 Canadians will be diagnosed with cancer in their lifetimes¹—the equivalent of flipping a coin! But if 1 in 6 Canadians are currently living with heart, lung, or kidney failure,²⁻⁴ would you be willing to play Russian roulette?

Early integrated palliative care for all

Within our medical culture, palliative care was originally developed for patients with cancer and remains primarily focused on that population, although things are slowly beginning to change: by 2030 most deaths will be attributable to organ failure and physical and cognitive frailty. By 2017, cardiovascular disease was killing 53 000 Canadians per year, chronic pulmonary diseases nearly 13 000, and chronic kidney diseases nearly 3000.⁵ This is not far off from the 80 000 deaths per year caused by malignant neoplasms. The needs of patients with noncancer chronic diseases evolve over months and years based on the natural trajectory of the disease. Consequently, necessary resources become more difficult to access, predict, and distribute. The difficulty of prognosis, lack of funding and palliative expertise dedicated to noncancer chronic diseases, and the absence of concrete data to support palliative care for noncancer chronic diseases are all very real obstacles.⁶

Academic medical associations all agree that the burden resulting from noncancer chronic diseases is just as high as

that of cancers, if not higher. They agree that patients with heart failure, chronic pulmonary diseases, or chronic kidney diseases would benefit from early palliative intervention.⁷⁻⁹

Guiding patients in designing their own lives

As family physicians, what is our role in relation to these patients? We are well placed to understand their overall biopsychosocial state and to guide and arrange their specialized care. We have the prerogative to take a step back and promote a comprehensive approach. We have the obligation to combine curative and palliative approaches and use them in complementary ways rather than in opposition to one another. We must reflect upon how to apply endlessly evolving technologies while optimizing the risk-benefit ratio for our patients.

Of course, patients must be allowed to discuss their perspectives concerning their own medical care. Those discussions should occur while the patient is in a stable condition rather than while they are hospitalized or during emergency visits. Timing is also crucial: there are risks associated with bringing this up too late, and if you choose to discuss it early on it is important not to forget to periodically reevaluate decisions. The ideal environment for this discussion is at a family practice or outpatient clinic with an appropriate specialist present, while the patient is presenting with refractory symptoms but is stable. The discussion should be interdisciplinary to promote a comprehensive approach and decrease the unease that would be felt by a single professional while speaking to a patient and his or her family.

My year of enhanced skills in palliative care introduced me to fantastic mentors who helped me refine this very specific competency necessary to guide patients in designing their own lives, including their deaths. One of those mentors taught me a very simple but essential question for guiding a patient's decisions: which should be prioritized, quality or quantity of life? Little by little, more detailed discussions will follow (eg, palliative care plans concerning resuscitation, dialysis, artificial nutrition, and hydration). In that respect, the advance medical directives (AMDs) form can be a good guide. However, checking yes or no on the AMD form is not sufficient. In my opinion, this form should encourage respondents to develop their own thoughts concerning the guidelines and how to convey the essence of their life philosophy to their family members and providers

to guide them in their decision making should they become incapable of doing so.

Another mentor taught me how to use concrete terms when in discussion with patients. The expression “no prolonging of life,” while used often, is understood differently by different patients and should be avoided (or at least clarified). All evidence suggests that few people wish to remain in a vegetative coma. However, there is an entire range of care plans available between healthy and comatose states, from intravenous antibiotics to simple hospital transportation. Discussing concrete actions and care sites with patients allows them to visualize it all in a realistic way. Using expressions such as “maximum hospital care,” “maximum home care,” or “symptomatic or comfort care” gives both the physician and the patient a comprehensible reference point.

Conclusion

The task of discussing AMDs with our patients is already monumental, but there is even more to be done in transmitting that know-how to medical students and residents. The levels of care are discussed only very theoretically in university medical curricula. I had the opportunity to meet physicians who were very knowledgeable in this area and who generously shared that knowledge with me. However, for those who did not have such an opportunity during their training, there is no big secret: you must be humble and humane in your approach.

How then, in our chaotic world of endlessly piling workloads and backlogs, do we find the time? Hearts will continue to leak, lungs to collapse, and kidneys to

petrify. Every second counts. You must make the necessary time, both for your patients and for your learners. 🌿

Dr Nguyen completed the Enhanced Skills in Palliative Care Program at the University of Montreal in Quebec in June 2019, and will begin a family medicine group practice in the fall that includes palliative home care.

Competing interests

None declared

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