

Death literacy – Educating ourselves on the inevitable



Sparrow – by Robert Pope, 1989, acrylic on canvas, collection of Art Gallery of Nova Scotia

- by Dr. Kelly Fenn

Talking about dying is hard, but it won't kill you.

Perhaps you have heard about health literacy – the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services to make health decisions.

But what about death literacy? Death will happen to each of us. Understanding and normalizing this shared human experience can better prepare us for the road ahead. Like health literacy, death literacy is the practical know-how to gain access to, understand and make informed choices about the end-of-life. It directly shapes the decisions we make about the care we receive as well as our ability to care for others.

In becoming death literate, one can better understand what palliative care is all about. Palliative care about living well with a life threatening condition – relieving suffering and distress related to serious and incurable illness. The goal is to improve quality of life for both the patient and the family.

As a palliative care physician, I have been thinking about how we can better prepare our communities with the knowledge and skills to have meaningful discussions and decisions about death and dying. But before those conversations can take place, each of us can begin by understanding our own beliefs, discomforts and fears about death.

Part of my work is to help individuals and families make plans to support, care for, and manage serious health issues. We often think about health problems like advanced cancer, HIV/AIDS, end stage COPD as synonymous with palliative care. Sometimes people think that palliative care is purely end of life care, something that starts when “nothing else can be done”.

The misconception that palliative care is limited to diagnostic labels or end of life care only persists in part because education and conversations about death and dying don't often happen at our kitchen tables, around the office, or with our friends. They are happening in times of crisis, when urgent decisions must be made, the stakes are high, and our emotional capacity is limited.

The reality is that a palliative approach to care can offer a range of options, from relieving pain and supporting people to live well regardless of their diagnosis or condition, to information about a disease and its common trajectory, to end of life care in a hospice or home setting. Palliative care can be offered alongside treatments aimed at controlling disease, and can be a tool to increase the quality of life for people living with chronic health issues.

Palliative care is about whole person care, harm reduction, compassion, symptom management, and connecting people with the resources they need in the face of health uncertainty. Palliative care is a team-based model at the heart of the work of family physicians and primary care providers, community nurses and paramedics, PSWs, and also includes the integral fabric of family and caregivers.

Whole person care – doesn't that sound like the kind of care we all want from our system? Research studies have shown that a palliative approach to care can increase the patient's sense of connection, belonging and meaning – improving quality of life for patients with terminal illness while also increasing their life expectancy. This model meets patients as whole people, rather than just focusing on their diagnoses which enables care that reflects the needs and goals of the patient rather than the limitations of our healthcare system.

Something I often come across in my practice is the comment that a patient or family is “not ready” for palliative care yet. I try to use this as an opportunity to educate patients and families about what a palliative approach can offer them. In fact, the most meaningful part of my job is the privilege of being with families at their most vulnerable, helping them understand their diagnosis and trajectory, what is to come, and identify what is important to them in the face of health challenges.

As our communities age and the proportion of our population within the “frail elderly” segment increases, we need to increase understanding of death literacy and the role of a palliative approach to care through public education. In the abstract, I believe everyone agrees that it is a good idea to become informed about decision making relevant to death, dying, loss, and health care because it makes you think about what is important to you in the end.

What I am proposing is that we begin to educate ourselves, our loved ones, and our community about death and dying. Normalizing something allows us to become more comfortable with it, even if at first it feels awkward or uncertain. It makes you ask the hard questions. Having taken some time to reflect about how you want to live while you're still on this big blue and green marble might help you plan ahead, and at least guide what you won't want done, for example, having a feeding tube inserted when you are no longer able to swallow or have a meaningful interaction with your family and friends and depending entirely on others for your basic care needs.

If I haven't convinced you yet, there are other good reasons to be informed about death and dying that might speak to those with death aversion. Research has shown that knowing a little bit about the dying process can really change how you experience the illness, grief, and bereavement (for the better). Rather than it taking

you off guard when the hard stuff happens – as it inevitably will – spending some time thinking about what you want your last years or months look like can be a tool to get to know ourselves better. Making decisions when we are stressed does not always lead us to decisions that are in line with our values and desires. Not everyone has the chance to spend some time thinking about dying while they are living, so if you are one of the lucky ones that has that time, I encourage you to use it.

Our healthcare system – or perhaps we should call it our sick care system - does not explicitly acknowledge that we support individuals who have a strong probability of dying in the immediate weeks, months, or short years. Perhaps if people felt more comfortable with death and its inevitability it would allow us to speak up about what we want to see to improve health and well-being at the end of life. This might help reorient services that reflect the kind of integrated care we need when the stakes are high. It might also inspire you to make plans around the legal, practical and medical issues that matter to you before it catches you off guard,

Let's create a culture where being informed about the matters of death and dying is seen as important. Palliative care is everyone's responsibility.

Remember, talking about dying is hard, but it won't kill you.

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1 <https://abclifeliteracy.ca/health-literacy/>

2 <https://theconversation.com/death-literacy-why-its-important-to-talk-about-dying-184087>

3 <https://getpalliativecare.org/handouts-for-patients-and-families/>

Suggested reading - [Speak Up Canada](#)