Many highly industrialized countries such as Canada face a rapidly aging population. Accordingly, this means that there are new end-of-life challenges and procedures that must be discussed, debated, and hopefully resolved. One issue particularly worthy of addressing is how later stages of diseases such as dementia are broadly considered and the implications of these conceptualizations. It is imperative, then, that age-related illness and end-of-life care be more closely and openly discussed and understood among health care professionals and the public.

Knowledge and awareness of Alzheimer’s disease and other causes of dementia has increased among health care professionals.

Abstract

Physicians and other health care providers have learned to approach end-of-life care issues in individuals suffering from malignant disease quite effectively. Palliative approaches are widely accepted for this population. In contrast, individuals suffering from end-stage dementia may also benefit from suitably tailored palliative care which is much less often considered or provided. It is incumbent on health care professionals responsible for treating those with end-stage dementia to offer palliative care. This must be preceded by proper discussions between afflicted individuals, their families and their health care providers to assure that they understand the progress and prognosis of end-stage dementia.

Keywords: dementia, palliative care, end-of-life care

About the authors

Michael Gordon, MD, MSc, FRCP, FRCP Edin, Medical Program Director, Palliative Care, Baycrest Geriatric Health Care System; Professor of Medicine, University of Toronto, Toronto, ON.

Natalie Baker, MSc, Project Coordinator, Baycrest Geriatric Health Care System, Toronto, On.
and the general public in recent years. This is, in part, thanks to the efforts of those organizations (e.g., Alzheimer’s Society of Canada) committed to assisting the public in addressing the challenges associated with the care of those with dementia and to outlining interventions that may be of assistance to patients and their families. It is also due to the development and marketing of medications that can ameliorate symptoms and the course of diseases that cause dementia.

Even if these initiatives were motivated partially by the pharmaceutical industry’s financial interests, the ultimate result is that it is now part of the normal discourse in health care to identify individuals with evidence of cognitive impairment and to focus on interventions that might be of value to all those involved.

At first, it may seem a bit counterintuitive to frame the more recent spotlight on end-of-life issues in a positive light. An aging population and the accompanying abundance of age-related issues translate into the reality that many more people are living longer than ever before. There was a time when there was not a significant need for discussions regarding end-of-life issues and for guidelines that are clearly laid out for caregivers and medical professionals. In the past, individuals had a much steeper end-of-life trajectory after falling ill in old age. Now, thanks to significant medical advances, patients spend an average length of 4.5 years in a long-term care facility.

Typically, physicians use a curative model when dealing with patients who have end-stage dementia. Their focus is on the diagnosis and treatment of the patients’ conditions and symptoms, highlighting both the physicians’ and the families’ typical underlying concern for prolonging human life. Consider the fictionalized case below.

“Mary’s” Case
Mary was an 88-year-old woman admitted to a complex continuing care facility from an adjacent long-term care facility because of a pulmonary tract infection. She had dementia and had gradually declined in function during the preceding 4 years, having lived for 3 years in a retirement home that was part of the multilevel care program of the facility. She had dementia and had gradually declined in function during the preceding year, and her attending physician was aware of her declining function and general disability. She had difficulty in recognizing people and was at...
times prone to confusing close members of her family. In terms of the basic activities of daily living, Mary needed help in all aspects of care, from eating (e.g., she often kept food in her mouth for long periods of time before either swallowing or spitting it out) to hygiene, being by this time doubly incontinent.

Her family was distraught over her decline and continued to search for treatments that might improve her cognition and decrease her risk of infection. The focus was essentially on keeping their mother alive. Though never actually having had this particular conversation with her, they had rejected in principle any thought of artificial nutrition and hydration as they believed that was not what she wanted. End-of-life preferences in general were never discussed with their mother when she was able to engage in such matters because her family had thought that this kind of conversation would be too painfully upsetting for her.

After what seemed to be a recovery from the aspiration pneumonia, Mary experienced another similar episode, and the attending physician asked the family what they would like to do. Searching for guidance, the family asked the physician for the options; she outlined various interventions including some imaging studies and blood work that might help “diagnose” the problem. The physician did not, however, bring up the option of palliative care. Finally, with another course of antibiotics and limited symptomatic treatment to address what appeared to the family to be severe shortness of breath and agitation with difficulty breathing, the patient succumbed to her illness. The physician explained that she had been reluctant to use morphine, other than in very small doses, to decrease the respiratory symptoms, because “she could not do anything that would seemingly be responsible for ending the patient’s life prematurely.”

Discussion

It is clear from this fictionalized anecdote that Mary’s physician did all that she could do to respond to the wishes of Mary’s family and to prolong their mother’s life. In fact, this is exactly the issue that needs to be examined: in essence, Mary’s quantity of life was favoured over her quality of life. While this is certainly understandable from a cultural, religious, or even simply emotional perspective (families often have an instinctive desire to keep their loved ones alive for as long as possible), there are many detrimental effects of solely taking this curative, interventionalist...
First, the effectiveness of using an aggressive medical approach in dealing with end-stage dementia must be questioned when patients have to endure high levels of discomfort for a relatively low return on the medical intervention. Evidence has shown that end-stage dementia is associated with a poor prognosis, and these invasive treatments have been shown not to significantly improve the duration of life.\textsuperscript{7,8} Thus, the downside of these medical advances and the resulting unrealistic priority to sustain or lengthen life is that, paradoxical as it sounds, a patient’s suffering may be worsened and prolonged by medical procedures and treatments.

Next, there is also the issue that in former generations, putting death in a social, cultural, or religious context (as opposed to a primarily medical context) helped

\begin{itemize}
  \item Mostly cancer
  \item Mostly heart and lung failure
  \item Mostly frailty and dementia
\end{itemize}

\begin{itemize}
  \item Healthy
  \item Chronic, progressive, eventually fatal illness
  \item Chronic, consistent with usual role
\end{itemize}

\begin{figure}
\caption{The course of common chronic diseases until the time of death}
\centering
\includegraphics[width=\textwidth]{figure1.png}
\end{figure}

to give the dying process meaning for the terminally ill person and his or her family. Now there is such a focus on medical treatments that conversations and decision making about the dying process seem even harder to initiate than before.

There has been a kind of medicalization of death in contemporary society, creating almost a universal conspiracy of silence surrounding issues that talk directly about the process of death and dying. There is often a lack of communication when it comes to discussions about the natural course of the diseases causing dementia and the ultimate likely terminal stage of the disorder (Figure 1). Ideally, early on in the disease trajectory there should be dialogues between patients, their families, and the physicians responsible for care regarding important planning and decisions about end-of-life care. When only silence occurs, often a series of aggressive medical interventions take place, followed by shock and denial when the terminal stages of dementia approach. There is typically little preparation for or communication about how to approach the care needs at this point in the progression of the disease.

On the other hand, the medicalization of death may offer opportunities to improve the end-stage dementia process. There is the option of taking a palliative care approach, which places the alleviation of pain, other clinical symptoms, and suffering as the main objective. While this is a quite widely known and accepted approach in terminal cancers, for example, it has yet to reach the same widespread usage and acceptance in Alzheimer’s disease and related dementias. Part of the reason for this is that dementia is not typically conceptualized as a terminal illness.

Whereas other terminal illnesses have a relatively quick, predictable decline, the trajectory of decline in dementia can be slow and variable. This speed factor may account for some of the denial around issues of death, the hesitancy to label dementia as a terminal illness, and the lack of communication surrounding treatments that may be most suitable for this stage of illness. This silence and the accompanying barriers it creates results in physicians who do not yet have the confidence to implement some of the palliative care approaches for patients (e.g., appropriate administration of a narcotic to help reduce suffering).

**Conclusion**

Education and awareness are necessary to break the silence around issues of end-stage dementia and, more generally, about the process...
End-Stage Dementia and Death

Summary of Key Points

Canada’s rapidly aging population means that there are new end-of-life challenges and procedures that must be discussed, and hopefully resolved.

Typically, physicians use a curative model when dealing with patients who have end-stage dementia, which may result in favouring quantity of life over quality.

The effectiveness of using an aggressive medical approach in dealing with end-stage dementia must be questioned when patients have to endure high levels of discomfort for a relatively low return on the medical intervention so as not to worsen and prolong the patient’s suffering.

A kind of medicalization of death in contemporary society has created an almost universal conspiracy of silence surrounding issues of death and dying. There is often a lack of communication among patients, families, and physicians about the natural course of the diseases causing dementia and the ultimate likely terminal stage of the disorder.

Taking a palliative care approach, which places the alleviation of pain, other clinical symptoms, and suffering as the main objective, may improve the end-stage of dementia for the patient and their family, as it does for those with other terminal illness.

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Clinical Pearls

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