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Ethical and clinically humane end-of-life care for those living with dementia

Michael Gordon

Dementia is a complex and in many ways devastating disease. It affects not just the individual afflicted with the disorder but their family and friends in a way that is very unique: the witnessing of the loss of what is often construed as the 'essence' of the person they love. This loss encompasses among other things the ability to easily communicate, express feelings and apparently appreciate the nuances of the world around them. Much of the clinical focus of dementia is on diagnosis and treatment, during the various stages of the disease. Sometimes while groping for answers and improvements in care, it is forgotten that dementia has a terminal phase and the needs of the person and the family and friends during this latter stage of disease must be addressed within the context of clinical and palliative end-of-life care, so that the whole journey can be appreciated and dealt with in the most humane, ethically sound and compassionate manner possible [1].

Ac **Dementia** is a progressive decline in cognitive function that usually includes impairments in memory, judgment, use of words and behavior. It is most commonly seen in those afflicted with Alzheimer's and related diseases such as those that affect the small blood vessels in the brain

In contemporary medicine, much of the effort in addressing the challenges of **dementia** and those who are afflicted by it tends to focus on diagnosis, treatment and the pursuit of new methods of defining the nature of the deficiency. There is a growing

awareness of the psychosocial impact of dementia and the effect it has not only on those experiencing the illness but those in the role of informal care providers, who for the most part are close family members and friends.

In order to achieve optimum care for a condition that may take many years to fully develop and go through its various stages, many healthcare professionals traditionally become involved, in the initial stages, with the focus on diagnosis and the implementation of the limited treatments currently available. In the later stages, depending on the nature and degree of behavioral problems that often accompany the cognitive decline, there may be need for help from members of the psychological and psychiatric and social work disciplines [2,101]. Throughout the course of the disease, it is generally physicians and nurses who become the foundational healthcare professionals responsible for guiding patients and their loved ones through the complex challenges engendered by the disease with the support of those healthcare and social service professionals who may be best suited to address the psychosocial, spiritual and end-of-life issues that eventually occur in almost every situation [3].

Barriers to end-of-life discussions

There are many reasons that healthcare professionals and family members may not address the reality of end-of-life issues when dealing with dementia. One important factor is that in the early stages of the condition, it often takes a while before it becomes clear that one is dealing with such a condition as the symptoms may be subtle and variable. There is also a good deal of emphasis from the media as a reflection of those organizations that support research and treatment for dementia that cases be found as early as possible presumably because important clinical steps should or might be taken.

 It is imperative to discuss with patients and/or families the expected trajectory of dementia and what to expect in the later stages

It is very important to promote with families and their loved ones conversations about what the person living with dementia would prefer in the later stages of their life and what treatments they would prefer to reject

The current model of case finding, diagnosis and trying to be specific about the type of dementia (i.e., Alzheimer's vs vascular or Lewy body or one of the less common causes) is based on the model in much of medicine in which the core approach is

based on complaints by patients or families (as in the case of dementia) or some sort of clinical screening as part of general medical reviews if there is a reason to be at all suspicious that there may be some component of cognitive impairment.

With this current model, individuals who come under scrutiny are usually classified as 'normal' or suffer from one degree or other of cognitive impairment ranging from mild (which has its own constellation of symptoms and indicators) to moderate and severe or as some scholars prefer to use one of seven stages of cognitive function/impairment [2,101]. Once the diagnosis is established and the parameters and prognosis of the disease outlined and explained to family and patient, the following few years are usually spent with the family and patient learning how to cope with the gradual decline in intellectual capabilities and memory, and adapt to changes that may occur in personality and behavior. Depending on the course of the disease, the various adaptations may occur in a fashion that can be dealt with and the range of healthcare and social service providers may grow as the needs and complexities of the disorder progress [4,102].

Forever hope & the denial of reality

Whatever is going on, there is usually at the back of the mind of those involved with care, especially those as primary care providers, the hope that there will be a new medical treatment available that will alter the course of the disease or may in fact halt its progress and maybe even reverse its progression. Physicians in the field are often asked whether there are new treatments that have been found and family members often bring various supplements and other products either promoted through the internet or recommended by a friend or family member who has received information from one source or another [4,102].

As the years pass and the individual's condition deteriorates as it invariably does despite the use of those medications that have been found to have some beneficial effect on the symptoms or the trajectory of decline, it becomes apparent that the condition is entering a final phase of the disease process. One would think or might assume that somewhere along the way, healthcare practitioners would broach the subject with the family members and when possible with the patient, what they foresee as the condition progresses and what their preferences would be when difficult end-of-life decisions have to be made or difficult options presented by the array of treatments that acute care medicine has to offer for intercurrent



It is important to be clear as to who will be responsible for making the difficult end-of-life decisions as to which types of treatment to pursue with the understanding that it ideally should be based on an understanding of what the person living with dementia would prefer rather than what the substituted decision maker would prefer



Ethical decision making decisions based on foundational principles used within North American such as autonomy (respect for the person), beneficence (the commitment to do good or the right thing), nonmaleficence (the avoidance of unnecessary harm, justice, as in the sense of distributive justice, which is the fair apportionment of resources

Frank discussions about the limited benefits and risks and discomforts associated with artificial nutrition and hydration and cardiopulmonary resuscitation and their lack of efficacy but be discussed openly and sensitively with families and those living with dementia

events. These generally will have little impact on the final pathway of the disease process [5–7].

Terminal phase of dementia

As with many other conditions that fall under the definition of chronic disease and for which the approach of contemporary medicine has been their management rather than their elimination or cure, Alzheimer's disease and other forms of dementia has a terminal phase.

Unfortunately, the healthcare professions and the public has not yet adjusted to that fact in the way they have incorporated the acknowledgement of the terminal phase of many types of malignant disease [7]. This lapse in preparation of patients and the families for the inevitability of the terminal phase of the various forms of dementia often results in late-stage medical interventions that rarely change the trajectory of decline and death but interfere with the potential for a gentle death or one without the negative repercussions of contemporary technologically based medicine [7,8].

Ethics, palliative & end-of-life care & the late stages of dementia

The primary ethical based challenges that face those in the late stages of dementia include; the uses of artificial nutrition and hydration, the limits of acute-care interventions for intercurrent diseases especially of the infectious type, and the benefits if any of cardiopulmonary resuscitation [9–14,103].

Artificial nutrition and hydration is one of the most difficult challenges that are faced by family members when the person they are caring for is no longer able to take in sufficient nutrients to sustain them. One often hears from loving family members, 'I cannot just let him starve.' The drama of the concept of withholding what is deemed to be the most basic acts of love and devotion is not easily overcome, and certainly not in a time of crises that is often the case if the person should stop eating during an acute medical illness [9–11].

"How can you not treat pneumonia? No one dies of pneumonia any more."

This is another of those emotionally laden statements that one hears when a loved one suffers from an intercurrent event such as pneumonia or urinary tract infection, two of the more common conditions that



Palliative care care directed to symptom management during the terminal phase of a disease, in contrast to acute and curative care that is suitable during the earlier stages of many diseases

afflict frail elders in the later stages of dementia. It is true that we normally are successful in the treatment of such infections in younger, healthier individuals, and may get a response to antimicrobial treatment in late-stage dementia, but the benefit is often transitory. Eventually, another infection occurs, usually with a more resistant organism and in the grand scheme of things the trajectory of the dying phase of this stage of dementia is delayed only marginally. The effect on the person is often the need to transfer from home or a long-term care facility that has become like a home to an unfamiliar acute-care facility or unit so that parenteral fluids and antibiotics can be provided [12].

The most dramatic of the late-stage decisions appears to be with the issue of cardiopulmonary resuscitation [103,13,14]. ‘How can I just let my mother die when she might be saved?’ is the way the question is often phrased. It is not helpful that for the layperson the understanding of cardiopulmonary resuscitation often comes from the media, which has misrepresented the benefits of the intervention. From healthcare providers the issue is one of not being able to just observe death occurring without appearing to ‘do something’. It is sometimes easier on the conscience and when explaining to loved ones of a person’s death that “everything that could be done was done” meaning that an attempt at resuscitation was made but to no avail. For some families, that provides them with a good deal of solace as they come to terms with the loss of a loved one. The alternative scenario of a ‘quiet end with no suffering’ may sound attractive to some but does not always satisfy the need to have made attempts at the saving of life.

Framing end-of-life care in a positive supportive manner

When framing an approach to end-of-life care for those living with dementia, it is important for all involved, healthcare professionals and families, to understand the disease process, the toll it takes on all concerned and the limits of modern medicine. For those more philosophically inclined, one can also invoke the ‘meaning of life’ in the absence of meaningful communication and social connection to one’s world and one’s loved ones but that is for another discussion [15].

From the ethical perspective, the importance of end-of-life care and the decision-making around it, the aspect of loss of autonomy and the need, responsibility, duty and burden of decisions being made by surrogate decision-makers cannot be ignored. This is very difficult to do in the absence of knowledge through discussion and clear indicators by the



End-of-life care that care provided during the downward slope of the dying trajectory. It often will include clinical principles of palliative care but also the acknowledged psychosocial and spiritual components with the clear understanding by all that the dying process has begun and that should be the focus of care and caring

person with the dementia at some time in their life when they could express their wishes to those who will decide for them. Sometimes, indirect indicators exist but these are often harder to interpret than clear expressions of choice when it can be explored, discussed and internalized by those who will ultimately have to make those difficult decisions especially during crisis situations [16].

The importance of having the conversation

The most important steps that can be taken by healthcare professionals involved in the care of those experiencing dementia, especially during the earlier stages, is to discuss openly, preferably in the company of important family members and other who may be acting in a surrogate decision-making role what a person's preferences would be under certain circumstances that are likely to occur some time in the future. This does not have to be done within the context of a written living will or advance directive but for some people such a framework helps them approach the subject in a less threatening manner. For others, the discussion alone allows them to express their innermost feelings and values to those who love them and who would want to act in the best spirit of representing their wishes and desires and values.

If such discussions have not occurred, the next option is for the surrogate decision-makers to discuss with the help of a knowledgeable and trusted healthcare professional, what the trajectory of the end will look like and prepare themselves mentally for those decisions that are likely going to be necessary. The support of a trusted healthcare professional in this stage of the disease process is very important in achieving the goal of comfort and compassion at the end of life: a goal we should all strive for in the last stages of this very devastating disease.



Summary

- Dementia is a devastating illness that affects millions of elders worldwide.
- Most families faced with a diagnosis in a loved one spend much of the energies in the quest for effective treatments even when told that other than the few ameliorating medications available, little will change the course of the disease.
- It is often forgotten or not understood that all causes of dementia have a terminal phase of the disease.
- There must be a concerted effort by clinicians to prepare families for the difficult decisions that face them when dealing with a loved one with dementia.
- Ethically sound and clinically suitable decisions have to be part of the framework by which late dementia in a loved one is addressed by families and healthcare professionals, which must include the consideration of palliative care approaches in the later stages of the disease.

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