

PATH: A New Approach to End-of-life Care

Due to advances in medical care, aging patients have survived the accumulation of many chronic diseases, including dementia. In an effort to help foster decision making and plan ahead to meet the challenges of end-of-life care in dementia, two physicians created the PATH model, a process which promotes careful consideration of the complex issues relevant to frail older adults nearing the end of their lives.

By Paige Moorhouse, MD, MPH, FRCPC; and Laurie Mallery, MD, FRCPC

Programs that foster individualized decision-making and care planning are required due to the increased prevalence of dementia and frailty in Canada's aging population. To address this need, we developed a standardized program, the Palliative and Therapeutic Harmonization (PATH) process, to help promote careful consideration of the complex issues relevant to frail older adults nearing end of life. The program's goal is to empower patients and their families to learn about their health issues in order to improve medical

decision-making. The following article reviews the need for better end-of-life care in dementia, and how the PATH model meets this need.

Improving End-of-life Care

The frailty tsunami is coming. Over the next 30 years, the Canadian healthcare system will treat an unprecedented number of older adults who, due to advances in chronic medical care, have survived the accumulation of many chronic diseases, including dementia. Thus, the hallmark of the aging population is frailty, an accumulation of multiple health deficits.¹ Despite terminal frailty, many older individuals receive highly aggressive care that has little chance of success and results in prolonged suffering before death.^{2,3} As such, consideration of how we deliver end-of-life care is essential.

Evidence-based medicine falls short. Most older adults with dementia also suffer from other chronic health conditions and are

therefore underrepresented in scientific studies. Complex medical treatments that work well for healthier populations may have less benefit for frail adults who are vulnerable to the adverse effects of treatment and have fewer years of life to experience treatment benefit if it occurs.

Unfortunately, clinical practice guidelines for end-of-life care designed for chronic conditions are often disease-specific/single-system-based and do not provide guidance about how to understand prognosis when more than one chronic illness is involved. Even clinical practice guidelines for severe Alzheimer's disease (AD) may fail to make specific recommendations about end-of-life care for dementia.⁴ Similarly, most risk scores are designed to estimate the risk of mortality associated with an intervention (*i.e.*, cardiovascular surgery), but do not address outcomes, such as institutionalization or permanent loss of function, which many patients consider to be fates worse than death.⁵ This lack of

Paige Moorhouse, MD, MPH, FRCPC

Assistant Professor, Geriatric Medicine
Capital District Health Authority,
Dalhousie University
Halifax, Nova Scotia

Laurie Mallery, MD, FRCPC
Professor, Geriatric Medicine
Capital District Health Authority,
Dalhousie University
Halifax, Nova Scotia

Table 1

Pre-palliative Era of Cancer Care vs. Current End-of-life Care for Frail Older Adults

Pre-palliative Era of Cancer Care	Current End-of-life Care for Frail Older Adults
<ul style="list-style-type: none"> Information regarding diagnosis withheld 	<ul style="list-style-type: none"> Complexity of comorbidities and lack of applicable evidence-based medicine may lead to avoidance of prognosis discussions
<ul style="list-style-type: none"> Lack of awareness of palliative care in cancer 	<ul style="list-style-type: none"> Lack of awareness of implications of frailty Lack of attention to how frail patients die
<ul style="list-style-type: none"> Comfort care may be withheld leading to patients dying in pain 	<ul style="list-style-type: none"> Comfort care may be withheld leading to patients dying in pain
<ul style="list-style-type: none"> “Cure culture” 	<ul style="list-style-type: none"> Futile treatments may be offered
<ul style="list-style-type: none"> Spiritual approach at odds with medical care of the dying 	<ul style="list-style-type: none"> Insensitivity to the needs of the dying patient and his or her family

evidence-based guidelines and frailty-relevant risk scores can lead to uncertainty about how healthcare providers should discuss prognosis and lead to inconsistencies in how information is communicated to patients and caregivers.

Dementia is often not recognized as a terminal illness. It should be noted that the progressive and terminal nature of dementia³ may not be addressed during routine care. In particular, for individuals with dementia, the risk of adverse outcomes associated with hospitalization, surgery or other medical interventions^{6,7} may not be identified as a central focus for care planning. As a result, more aggressive care may be chosen for patients with advanced dementia when compared with non-demented patients with a similar life expectancy.⁸

By nature of their medical complexity, frail patients with dementia are often cared for using team-based models. Although team-based care requires multiple specialized skill sets to evaluate health, the task of assembling the timeline of health in a trajectory, as well as realistic prog-

nosis is not normally the responsibility of any single team member. As such, the team may not recognize the terminal decline in function, cognition and mobility.

Existing Strategies for Care Planning

Most published communication strategies for care planning are designed for cancer care. In addition, medical literature detailing how to communicate with patients and their families is not evidence-based, and has not been validated for use in frail older adults with dementia. In light of these shortcomings, randomized trials are needed to determine whether interventions to improve communication about end-of-life care, specifically in frail patients with dementia, can improve patient outcomes.⁹

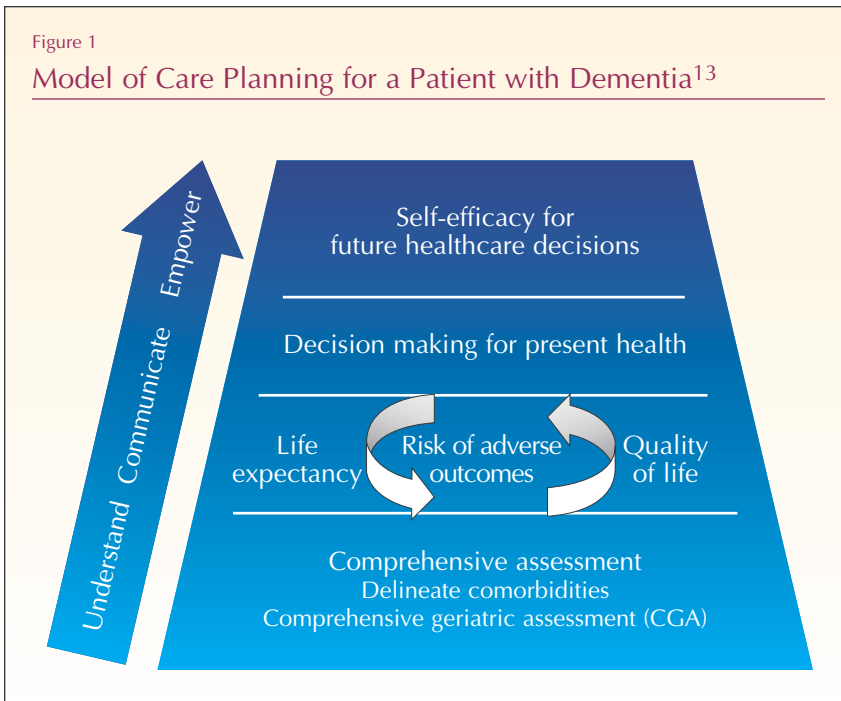
The current models of communication pose many challenges when implemented in patients with dementia and frailty, including end-of-life care planning, the “ask-tell-ask” model, and the creation of advance directives to guide future care (Table 1).

End-of-life care planning is frequently discussed when patients have moderate-to-severe stage dementia, and the substitute decision maker is prominently involved in the decision-making process. Traditional models of communication advocate that healthcare professionals begin by gathering information about the patient’s values and goals, and then use this information to contextualize the goals of care,¹⁰ which requires asking questions such as, “What is your biggest fear?” These questions may be difficult for substitute decision makers to answer on behalf of the patient with dementia.

Ask-tell-ask model. Many of the recommendations about how to communicate with patients and families advocate that healthcare professionals spend most of the time listening rather than talking, a method also known as the “ask-tell-ask” model.¹¹ This approach seems patient-centered, but assumes that the substitute decision maker has already been provided with the information needed in order to make a decision, which is often not the case.¹² For frail older adults with dementia, providing infor-

Figure 1

Model of Care Planning for a Patient with Dementia¹³



mation about the prognosis associated with each illness and their sum takes considerable time and is not well remunerated. As such, families may not be aware of the poor prognosis associated with dementia and frailty.

Guiding future care. Traditional models advocate the creation of advance directives to help guide future care. Substitute decision makers and care providers alike may be lulled into a false sense of security that the present advance directive will clarify the future goals of care. Although advance directives may be helpful in a single system illness, where the foreseeable decision points and interventions are easier to anticipate, they fall short in those with frailty and dementia whose list of possible scenarios is endless.

Furthermore, commonly used terms, such as “heroic measures,” have different meaning depending on the baseline quality of life (QoL) that they are meant to restore. For exam-

ple, a procedure such as intravenous rehydration that is generally considered routine may be considered a heroic measure in the terminal stages of dementia, where it has a limited chance of improving health, but a significant chance of prolonging death and suffering.

Meeting the Challenges of End-of-life Care in Dementia

The issues previously described demonstrate the need for better recognition of frailty through systematic evaluation and better communication of the results of such evaluations. The PATH process is a model of care planning for frail older adults with dementia based on four key principles:

1. Research shows that substitute decision makers want detailed information about overall health and prognosis from healthcare providers, even in the face of uncertainty.¹³

2. It is the responsibility of healthcare providers to anticipate and communicate the impact of each health condition on the patient’s overall health, QoL and the risk/benefit of interventions when discussing care-planning decisions.
3. Healthcare decisions should only be made after full disclosure of this information (above).
4. An organized approach to information gathering and provision can help substitute decision makers make informed choices.

These principles were used to develop a model of care planning characterized by three patient encounters: understand, communicate, and empower (Figure 1).¹³

Understand. The PATH process begins with an understanding of the full scope of illness severity, achieved through standardized evaluation of health domains encompassed by a comprehensive geriatric assessment (CGA; Table 2).

The CGA has been widely used in geriatric medicine and is associated with improved QoL and survival.^{14,15} The assessment helps overcome poor recognition of the need for end-of-life care by providing a macroscopic view of current health and illness trajectory. Information for the CGA is gathered from a comprehensive review of the medical chart, collateral history from a family member or caregiver, physical examination and cognitive testing, including the Mini-Mental State Examination (MMSE),¹⁶ the Frontal Assessment Battery,¹⁷ the Brief Cognitive Rating Scale (BCRS),¹⁸ and the Functional Assessment Staging Tool (FAST).¹⁹

At the end of the first patient encounter, the PATH assessor meets with the patient and decision maker to briefly introduce the dementia stage and level of frailty, schedules a second encounter to discuss the findings in more detail, and provides educational materials to take home. The educational materials provide patients and their substitute decision makers with the opportunity to review the concepts of dementia, prognosis, frailty and the PATH model through narrative and descriptive writing. If the patient is not able to participate in the decision-making process, the decision maker may participate in subsequent PATH visits on their behalf.

Communicate. The second PATH encounter is a structured interview designed to communicate a detailed description of the stage and prognosis of each comorbidity, and subsequently describe how each comorbidity contributes to frailty. Particular focus is given to dementia, as it is a progressive condition and affects the risk/benefit balance of treatment for other comorbidities. The provision of information about dementia staging helps care providers and decision makers achieve a common understanding of where they are in the trajectory of dementia and what to expect in the future. All discussions and decisions arising from these discussions are documented, and copies of care plans arising from decisions are available to take home. This approach differs from traditional models of care planning because the focus is on providing information and allowing the decision maker to express their treat-

Table 2

The Domains of the CGA^{14,15}

- Cognition: memory, executive function, emotion and behavioral symptoms
- Mobility: transfers and ambulation, falls, balance
- Function: instrumental and basic activities of daily living
- Nutrition: appetite, weight loss, bowel and bladder function
- Social situation: living arrangements, formal and informal assistance, and caregiver stress
- Comorbidities
- Medications

ment preferences within the context of overall health and prognosis.

Of note, the encounter may involve intense emotions and catharsis. PATH participants often describe that they are hearing information about disease progression and prognosis for the first time, and although the content of the discussion can be upsetting, almost all participants indicate that the process is useful for future care planning. A nurse-led debriefing session follows the discussion of frailty and prognosis to ensure that decision makers' questions are answered. Further written materials are provided to support the information relayed about dementia staging. Time between the second and third PATH encounter is not always possible, but allows the decision maker to consider the overall health of the patient with dementia and formulate questions for the next visit.

Empower. The final PATH encounter is designed to give decision makers the skills needed to make foreseeable and unforeseeable decisions about future care. The session builds upon the first two visits by encouraging decision makers to apply newly learned concepts, such

as frailty, dementia and prognosis, and begins by discussing foreseeable care planning decisions for dementia, including resuscitation, artificial nutrition and hydration, antibiotics and surgery.

The potential effect of each intervention on cognition, mobility, function, symptom control and QoL are discussed within the context of the current dementia stage, as well as projected decline. Care planning decisions for other comorbidities, such as dialysis for chronic kidney disease, are also discussed when applicable. Due to the fact that unforeseen health crises can arise, decision makers are provided with a framework (Table 3) of questions that will help them gather the information they need to make informed decisions in an organized manner. To plan ahead, the framework is applied to hypothetical health crises pertinent to the patient. The framework questions are then provided in a wallet-sized card that can be carried with the decision maker for future use. Furthermore, written narrative materials describing how other decision makers have worked through health crises using the framework

Table 3

PATH Decision Framework

Questions to Ask During a Health Crisis

1. Which health conditions are easily treatable? Which are not?
2. How many patients are diagnosed as frail? How will frailty make treatment risky?
3. How can symptoms be safely and effectively managed?
4. Will the proposed treatment improve or worsen function and memory?
5. Will the proposed treatment require time in hospital? If so, for how long?
6. Will the proposed treatment allow more good quality years, especially at home?
7. What can we do to promote comfort and dignity in the time left?

questions are provided. Decision makers are also encouraged to contact their PATH assessor when faced with difficult decisions so that they can work through the framework questions together.

Implementation of the PATH Model

The PATH process requires active participation and reflection on the part of the decision maker and therefore may not be appropriate for all

decision makers. Currently, we request consent from the patient or decision maker to participate in the process at the time of referral. To ensure communication of the results of the PATH process, a typed summary of each encounter is mailed to the primary-care physician and other pertinent care providers (including specialists), which is uploaded to the patient's electronic medical record, where available.

The PATH model was originally

implemented in an outpatient clinic setting, but has been modified for inpatient consultations in a tertiary care and community hospital, as well as long-term care facilities. The primary variables have been the time allotted for each encounter, the total number of encounters, the support personnel providing initial assessment or debriefing, patient/family satisfaction, and the types of decisions that are made.

Limitations of the model. The PATH process has not yet completed formal validation in a randomized control trial, but neither has the current status quo of advising patients to endure complicated medical therapies based on care-planning strategies developed for single-system illness. However, the model is in accordance with recent studies that demonstrate providing information and education about the risks and benefits of intervention can influence decision makers' preferences in a positive way.²⁰

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