Challenges in Understanding Functional Decline, Prognosis, and Transitions in Advanced Illness

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This article has 2 purposes: to inform the health care provider’s response to the common question asked by older adults with advancing illness, “How long do I have?” and to provide caregivers with a framework which can guide provision of care in advancing illness. Both purposes are addressed by exploring 3 major concepts associated with declining functional ability: (1) common functional changes and strategies to identify and manage these changes, (2) the extent to which prognostic tools provide insight for the prediction of rate of decline, and (3) the transitions in the focus of care that are required with advancing disease. Although the article is focused on the residential care setting the concepts examined can be applied more broadly to other practice settings such as palliative care. Declining functional ability is a common feature of the journey toward end of life. Irreversible decline in function is frequently accompanied by the resident and family’s need to understand the probable duration of survival and the caregiver’s need to adjust priorities for care. To better inform the clinician’s response to the question of “How long do I have?” prognostic tools which incorporate measurement and interpretation of declining function can be utilized to improve the ability to predict survival. A 10-step approach to formulating and discussing prognosis is presented to assist clinicians in predicting rate of decline and sharing difficult news. Finally, in recognition of how declining functional ability affects priorities for provision of care, a framework which advocates the shift in focus from function, to safety, and ultimately to comfort, is provided. **Key words:** duration of survival, hospice, palliative care, prognosis

Declining functional ability as a result of chronic disease and comorbidities can manifest itself in older adults experiencing difficulty in coping at home and in exhaustion of family members who struggle to adequately meet care needs. This scenario often necessitates a move to residential care. Most of these elders are in the final stages of their lives and it is not uncommon for an individual to require the specialized services of multidisciplinary palliative care practitioners.

There are times when the question of “how long will I live?” is asked by the patient, family, and health care providers. This article addresses issues which may inform the health care provider’s response to this question by focusing on 3 areas: (1) common functional changes and strategies to identify and manage these changes, (2) the extent that prognostic tools provide insight for the future, and (3) the transitions in the focus of care that are required with advancing disease. Although the article is focused on the residential care setting, the concepts explored can be applied more broadly to other settings.

**WHAT ARE THE CHALLENGES?**
The move to residential care for those with chronic illness is filled with challenges such as: loss of privacy, loss of control and freedom, having to ask for help, and not being viewed or known as the same person that they used to be. Although many of these features have already been experienced with chronic illness, their intensity is magnified as a result of the realization that they will likely die in residential care.

The decline toward the end of life may be slow, rapid, or unpredictable. Health care providers need to be adaptable in adjusting to the pace of change of each individual so as to ensure the right care is provided by the right person, at the right time, at the right place. Researchers have tried to determine functional trajectories in the elderly to identify what factors contribute to functional decline. Elderly persons with advanced frailty and multiple comorbidities tend to follow a slow and progressive decline, particularly those with dementia, who demonstrate a higher level of disability in the final year of life. All members of the health care team need to identify residents who are approaching the end of life and appropriately adjust care. For example,
for the physical therapist (PT) who is typically focused on maintaining or improving function, prognostic information is particularly important in determining when and how to readjust the focus from restorative approaches to those on the basis of compensation and the ultimate acceptance of declining function. Typically residents and their families hope for and seek improvement in function. Consequently, many find it very difficult to accept that improvements in functional mobility may not be possible even with extensive discussions about goals that allow the resident to visit home or go out for a special event. The family may be focused on the goals of increasing strength or functional ambulation and may not fully engage in the plan for the resident to return home at their current level of function. This dissonance in goals can result in tension.

There are many potential situations in which these clashes between family members and residents and health care providers about the degree of medical intervention may occur. What may seem an unacceptable risk or burden to the care team may conversely be very important and perceived as necessary to the family and the resident to feel that they are doing something to improve their frail health. Clarity regarding changes in goals during declining function is obviously critical to prevent the clashes.

Other factors such as cultural differences may also impact end-of-life care. Withdrawing or withholding care is uncommon in traditional Asian cultures and family members are expected to protect and care for the vulnerable.4 Also, decisions of care in this culture may or may not involve the resident but rather may be predominantly made by the family members. Power imbalance among family members may also affect understanding and care planning for the terminally ill resident. Withholding or withdrawing care in North American or European countries is more common than in Asian countries.5 In addition, asynchrony in cultural or spiritual beliefs between members of the multidisciplinary team and the resident and family, or if the organization does not value cultural competence, may result in a strain on the relationships within the team and between the resident/family and ultimately affect the goals of care.

Another factor that may impact end of life care is the cognitive status of the resident. The resident’s and family’s degree of understanding of the resident’s health and ability to state preferences for care is important in achieving consensus on intervention related goals. Residents with multiple chronic diseases frequently experience a “cascading series of multiple ailments” where one issue seems to lead to another.6 This situation is often compounded by a significant loss of the personal power to manage one’s own life.

Adjusting to chronic illnesses involves 3 cognitive and emotional tasks: (1) comprehension of the losses, (2) creative adaptation to the losses and integration and (3) acceptance of the revised sense of self.6 This model notes that the first 2 tasks of comprehension and creative adaptation are stressful and preferences for care and making are likely to be unstable and changeable during these times. Thus a resident arriving in care may be still in the process of adapting to the massive changes in their life and will have challenges in understanding and decision making.

Cognitive impairment, present in the majority of the residents in residential care, impairs their ability to participate fully in the adaptation to chronic illness as well as their degree of comprehension and capacity to make decisions. The ability to cope with physical decline and multiple losses will decline with advancing disease of any kind as many of the coping skills required to succeed necessitate intact cognition.

In developing the goals of care for a patient with dementia, it is key for family members to understand the prognosis. A recent study showed that families that understood the prognosis of their loved-one’s dementia were far less likely to have the resident undergo burdensome interventions in the last 3 months of life than those who lacked this awareness.6 The same study noted that although families had learned about complications and prognosis of dementia it was not necessarily from the physician. Team members were equally effective in helping the family to understand and thus all have a role.

Despite the commonly held belief that cognitive impairment may decrease a person’s ability to participate in an active PT program, Montagnini et al7 reported that patients with cognitive impairment in a palliative care unit made greater gains in function than those without cognitive impairment. Although this relatively greater degree of improvement may be due to the fact that the patients with cognitive impairment had perhaps a larger window to improve, it also indicates that physiotherapy interventions can be effective in these residents. Indeed, patients with a terminal illness and cognitive impairment demonstrated improvements in activities of daily living with a structured PT program focused on strengthening and balance.6,10 This is an important finding as cognitive impairment in the resident who is experiencing a reduction in strength and balance typically has a significant impact on fall risk and safety. Thus, physiotherapeutic interventions to enhance strength and balance in this population can be appropriate and effective in reducing fall risk.

One consequence of cognitive impairment is that the resident is often unable to describe pain and discomfort. They usually can answer whether they have pain “now” but cannot describe its current intensity or quality nor reliably report a change in these features. Consequently, team members must rely on nonverbal cues from the resident to assess the resident’s response to interventions and pain management.

Another consideration related to cognitive impairment is the ability of the resident to participate in decision making.
WHAT HAPPENS WITH FUNCTIONAL DECLINE?

Decline in performance or functional status can occur at any point in life and is not necessarily indicative of impending death. Various disabilities or physical challenges occur with illness. These disabilities/challenges may persist, improve or progress over short or long time periods. With an advanced progressive illness, functional decline is inevitable as death moves from the distant to imminent horizon.

In the hospice palliative care setting, such decline has been recognized as important for survival prediction, criteria for referral and registration criteria with hospices, as well as for family and health care system resource planning.

Measuring functional change in these populations of individuals with advancing frailty, dementia or neurological disease is a challenge because of the slowly progressive nature of these illnesses. Moreover, measuring change is complicated by the paucity of PT relevant outcome measures that are appropriate for the frail elderly in the residential care setting. Outcome measures commonly used in the geriatric population include: the Time Up and Go test, the Berg Balance scale, the Hierarchical Assessment of Balance and Mobility and the Elderly Mobility Scale. A particularly challenging problem is the lack of sensitivity of outcome measures to change in a population that is already in the lower end of the spectrum of functioning.

A tool that is sensitive to change in the frail elderly with chronic illness would be very helpful to guide PT practice from the “maintain/improve” paradigm to that of “compensation and adjustment.” Giuliani et al identified physical performance characteristics that may detect individuals in assisted living and long-term care that are at risk for adverse health outcomes. They concluded that physical measures such as grip strength, walking speed, chair rise, and balance could be used to identify increased risk of nursing home placement and functional decline and fracture, but not for predicting mortality, in the population of assisted living residents.

Residents admitted to residential care are typically defined as “dependent”. They may be able to participate in exercise programs that target functional or therapeutic walking, strengthening programs focused on sit-to-stand exercises and on those incorporating seated or standing strengthening exercises. The resident’s participation in mobility can still be maximized by maintaining his or her ability to weight bear with or without mechanical assist. Unfortunately, an acute illness or reduction of nutritional intake may tip the balance resulting in the resident quickly becoming dependent for all aspects of care. An acute illness, in conjunction with a chronic diagnosis such as congestive heart failure or dementia, may result in total dependency for a resident. If the acute illness can be quickly treated the resident may be able to maintain or return to a previous functional level without further decline in mobility. If it cannot be medically managed, the decline in function accelerates.
PROGNOSTIC MODELS

Most models in palliative care for estimating survival prediction include changes in functional or performance status. This seems obvious in that decline and approaching death (other than sudden death from heart attack, trauma, or massive stroke) involve progressive physical changes that are common and expected. As mentioned previously, a key limitation in utilizing these models is their reliance on “population-based” data rather than data specific to an individual. Some prognostic models are appropriate for the subset of “already identified hospice or palliative patients” where a more reasonable estimate of survival can be made than is the case in the general population of older adults with advanced chronic disease.

It is important to recognize, however, that relying solely on the clinician’s impression of prediction of survival is fraught with both over- and underestimations and consequently many clinicians are wary of prognosticating. Yet the desire and needs of the resident, family and health care team to provide some information is underscored by the increasing use of advance care planning and family conferences where decision making hinges in part on how long the resident may live. Interestingly, overestimation of survival may be more common in cancer patients and underestimation in noncancer patients. However, simply leaving the prognosis at “who knows?”, “I don’t play God,” or “everyone is unique” results in a vacuum of information for those surrounding a loved one.

An overall disease contributing to most of the functional decline of the resident can usually be identified. Beginning with that primary illness, an “anchor” point can provide general survival estimates based on staging (eg, 1-, 5-, or 10-year survival). Thus, survival statistics for breast cancer are different than those for pancreatic cancer, and those for Alzheimer dementia have a general trajectory different than those for end-stage renal disease or Amyotrophic Lateral Sclerosis.

Using this disease-based information, Lunney et al have categorized illness trajectories into 4 types: sudden death, cancer, organ failure, and “dwindling” trajectories. These categories have been incorporated into several frameworks, such as the Gold Standards Framework in the UK, for defining care. An Australian model identifies 5 phases: stable, unstable, deteriorating, terminal, and bereavement. However, in a recent study of 383 patients reporting the course of disability in the last year of life, Gill concluded that although 5 changing functional status patterns were identified—(progressive disability, accelerated disability, catastrophic disability, persistently severe disability, and no disability)—there was no predictable pattern based on the actual condition or illness leading to death. These variations are seen in Figure 1.

Functional assessment tools currently used in palliative care include: Karnofsky performance scale, palliative performance scale (PPS), Eastern Cooperative Oncology Group performance status, functional assessment staging, Edmonton frail scale, and the frailty index. Some tools incorporate additional measures to create prognostic models such as the Changes in health, end-stage disease and signs and symptoms (CHESS) in the resident assessment instrument, palliative performance index score, dementia prognostic index, Seattle Heart Failure Model. Prognostic tools include symptoms that have been shown to have predictive value such as delirium, persistent tiredness, weight loss, shortness of breath, dysphagia, and skin breakdown. A few others have utilized laboratory markers including white blood cell count, lymphocytes, lactate dehydrogenase, albumin, C-reactive protein, and others. The outputs of these prognostic tools usually involve Kaplan-Meier graphs, life expectancy tables or more recently nomograms to show percentage survival at points in time.

Figure 1. Disability trajectories in the last year of life. As shown, most of the conditions earlier included all 5 types of disabilities. Although the majority of patients with advanced dementia had persistently severe disability in the last year, almost one-third had a different trajectory. Frailty had a wide range of deficits. Reprinted with permission from Gill et al. Copyright 2010 Massachusetts Medical Society.

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<table>
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<th>Disease-Specific</th>
<th>Example Models</th>
<th>Variables</th>
<th>Outputs</th>
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<tr>
<td>Cancer and noncancer</td>
<td>PPS</td>
<td>Used in cancer and noncancer. 5 factors mobility, disease, self-care, intake, and consciousness.</td>
<td>Life expectancy table, Kaplan-Meier-graph (KM) and nomograms.</td>
</tr>
<tr>
<td></td>
<td>PIMOA&lt;sup&gt;42&lt;/sup&gt;</td>
<td>Nondisease specific. Variables include male, ADL, dependency at discharge, comorbidities, lab (CR, Alb).</td>
<td>1-year mortality based on PIMOA score.</td>
</tr>
<tr>
<td></td>
<td>MRIS&lt;sup&gt;43&lt;/sup&gt;</td>
<td>Used in newly admitted nursing home residents. Uses 11 variables to create score.</td>
<td>5 groups with 1-year mortality rates</td>
</tr>
<tr>
<td>Cancer</td>
<td>PaP</td>
<td>Used in cancer with KPS, CPS, lab, and symptoms.</td>
<td>Kaplan-Meier-graph (KM) with 3 groups of 30-day chance of survival</td>
</tr>
<tr>
<td></td>
<td>PPI</td>
<td>Used in cancer with PPS, intake, edema, dyspnea, and delirium.</td>
<td>3-group survival KM-graph.</td>
</tr>
<tr>
<td></td>
<td>LCPM</td>
<td>Lung cancer. Uses pulse, toileting, feeding, living will, tissue type, liver metastases, and pain.</td>
<td>8 score groups with mortality in days for 50% and 80% admitted to a hospice</td>
</tr>
<tr>
<td></td>
<td>ICMRM</td>
<td>All cancers except hematologic category. Uses ECOG, duration of disease, type of hospital admission, lab (HgB, LDH).</td>
<td>Sum of hazard ratios for each variable.</td>
</tr>
<tr>
<td></td>
<td>CPS</td>
<td>Used in cancer in palliative care unit. Uses ECOG, metastases, and 5 symptoms.</td>
<td>1- and 2-week survival.</td>
</tr>
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<td></td>
<td>ECOG-PS</td>
<td>Often used in North American oncology studies. ECOG has 6 levels from 0 to 5 based on 3 factors: ambulation, extent of disease, and self-care.</td>
<td>Oncology treatments often limited with decreasing ECOG level</td>
</tr>
<tr>
<td></td>
<td>KPS</td>
<td>Often used in European oncology studies. Eleven levels using ambulation, extent of disease and self-care.</td>
<td>Oncology treatments often limited with decreasing KPS level</td>
</tr>
<tr>
<td>Heart failure</td>
<td>SHFM&lt;sup&gt;44&lt;/sup&gt;</td>
<td>Used in CHF with Web tool to adjust factors. Variables include 6 clinical, 6 meds, 5 diuretics, 6 lab and 4 devices.</td>
<td>1-, 2- and 5-year mortality on a dynamic KM-graph depending on inputs.</td>
</tr>
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<td></td>
<td>HFRSS&lt;sup&gt;45&lt;/sup&gt;</td>
<td>Uses 11 factors in CHF with age, 2 vital signs, 3 lab, 5 comorbidities.</td>
<td>5 categories with 30-day and year mortality.</td>
</tr>
<tr>
<td>COPD</td>
<td>MRC Dyspnea Scale&lt;sup&gt;46,47&lt;/sup&gt;</td>
<td>Uses 5 levels of dyspnea</td>
<td>5-group survival KM graph</td>
</tr>
<tr>
<td>Dementia/Alzheimer's</td>
<td>FAST</td>
<td>Use 7 stages with stage 7 recognized by NHPCO as appropriate for palliative care.</td>
<td>No survival reports.</td>
</tr>
<tr>
<td></td>
<td>DMI&lt;sup&gt;48&lt;/sup&gt;</td>
<td>Noncancer excluding stroke or nonprogressive dementia. Variables include age, KPE, marital status, anorexia, and KPS/anorexia interaction.</td>
<td>6-month survival.</td>
</tr>
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<td></td>
<td>MODA&lt;sup&gt;49&lt;/sup&gt;</td>
<td>A series of 14 tests divided in 3 sections</td>
<td>Predicts speed of cognitive decline</td>
</tr>
<tr>
<td>Frailty</td>
<td>CHESS&lt;sup&gt;27,50-52&lt;/sup&gt;</td>
<td>9-items: vomiting, dehydration, leaving food uneaten, weight loss, shortness of breath, edema, prognosis &lt;6 months, decline in cognition, decline in AD</td>
<td>1-2-year survival KM-graphs with 6 levels</td>
</tr>
<tr>
<td></td>
<td>Advanced Illness Index (All)&lt;sup&gt;53&lt;/sup&gt;</td>
<td>Uses 11 variables within physical function, geriatric syndromes, health care utilization, special equipment use, self-care deficits, caregiving responsibilities, and general health problems.</td>
<td>Predicted &gt;90% of those at risk who died within 2 y whereas &gt;90% of those not at risk lived more than 3 years.</td>
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<td></td>
<td>EDMont Frail Scale&lt;sup&gt;32,33&lt;/sup&gt;</td>
<td>Uses variables: cognition, general health status, functional independence, social support, medication use, nutrition, mood, continence, functional performance [requires mobility using Time up &amp; Go]</td>
<td>Each item assigned 0, 1, or 2 points; then added for total possible 17 points.</td>
</tr>
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<td></td>
<td>PACE&lt;sup&gt;54&lt;/sup&gt;</td>
<td>Program of All-Inclusive Care for the Elderly uses 8 risk factors for frail persons in the community.</td>
<td>Predicts 1- and 3-year mortality risk</td>
</tr>
<tr>
<td>ALS</td>
<td>ALSFRSr</td>
<td>12 items rated from 0 to 4 resulting in a total ALSFRSr score range from 0 to 48.</td>
<td>2-year KM-graph with 4 levels</td>
</tr>
</tbody>
</table>

Abbreviations: AII, advanced illness index; ALSFRSr, ALS functional rating scale-revised; CHESS, changes in health, end-stage disease and signs and symptoms; CHF, congestive heart failure; CPS, cancer prognostic scale; DMI, dementia prognostic index; ECOG-PS, eastern cooperative oncology group-performance status; FAST, functional assessment staging; HFRSS, heart failure risk scoring system; ICMRM, intrahospital cancer mortality risk model; KPS, Karnofsky performance scale; LCPM, lung cancer prognostic model; MODA, milan overall dementia assessment; MRC, medical research council; MRIS, mortality risk index score; PACE, program of all-inclusive care for the elderly; PaP, palliative prognostic score; PIMOA, prognostic index for 1-year mortality in older adults; PPI, palliative prognostic index; PPS, palliative performance Scale; SHFM, Seattle Heart Failure Model.
which is a Web-based tool with a dynamic Kaplan-Meier survival graph which adjusts to lab and medication changes entered. Doberman et al. reviewed 5 prognostic tools for end-stage dementia including Functional Assessment Staging, mortality risk index, and PPS, and concluded that PPS and mortality risk index are perhaps better than the more common Functional Assessment Staging. Residential care teams are encouraged to review these tools for potential use in their practice settings.

Intuitively, it might appear that multiple comorbidities would result in a shorter prognosis. One of the first palliative prognostic tools to test comorbidities is the Prognostar. The study involved 422 cancer and noncancer patients who were either registered with or consulted by a palliative care program. Somewhat unexpected is that, when functional status, illness trajectory, clinician prediction, and symptoms were incorporated, the Charlson comorbidity index was not significant. The strongest predictors by far were clinical prediction, functional status and primary illness; a lesser degree of association was seen with age, gender, illness trajectory, and symptoms. Because most of these patients were already deemed “palliative,” the nonsignificance of comorbidities may be because of referral bias. It is also unclear whether similar findings would be seen in a residential facility setting. Another area of study is the identification of sentinel events that may signal major change in the resident’s condition and herald imminent death. Clearly, this area of research holds promise for informing clinician predictions of the anticipated course for a given resident with chronic disease.

It is important to acknowledge, however, that current survival prediction models for chronic disease do not capture all relevant factors. Does a “fighting spirit” alter longevity? Some data suggest that indeed the will to live is related to survival. and mortality risk index are perhaps better than the more common Functional Assessment Staging. Residential care teams are encouraged to review these tools for potential use in their practice settings.

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The final aspect in understanding prognostication is recognizing that it is not an “event” but a “process.” With regular reassessment of the patient, complications, treatments, and goals of care, the prognosis will change—either longer with stability or shorter with functional or other parameters, which indicate decline toward death.

WHAT TRANSITIONS OCCUR AND SHIFTING FOCUS OF CARE?

There is little research to guide care for the “oldest of the old” or those with multiple comorbidities. Almost all the studies exploring effectiveness of interventions exclude those who are older or near the end of life. As a result, if the goals of care are based on management of multiple diseases there may be potential conflicts over disease guidelines with the result of undertreatment of symptoms (eg, pain) and an overtreatment of disease (eg, rigid blood glucose control in diabetic patients with advanced dementia).

A “palliative approach” to care in a residential setting aims to “improve the quality of life for older adults with life-limiting illness and their families by reducing their suffering through early identification, assessment and treatment of physical, psychological and spiritual needs.” This is consistent with a call for basing our care on patient goals and preferences as opposed to the management of individual diseases. This type of care makes particular sense in older adults in residential care as many of them suffer from unmanaged physical symptoms such as pain and report different symptoms from younger patients. A palliative approach to care can be started early in the disease and will benefit everyone, even those with very uncertain prognosis.

A palliative approach encourages primary care clinicians to build palliative care knowledge skills and attitudes into their normal processes of care. It focuses on symptoms and quality of life as opposed to following disease indices and using guidelines aimed at modifying chronic disease. The outcomes are based on measures of the resident’s quality of life and the family satisfaction with care and support as opposed to length of life and disease metrics.

Defined objectives and guidelines for a palliative approach in residential care were developed by Australia in
### TABLE 2 Ten Steps to Better Prognostication*

<table>
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<th>10 Steps to Better Prognostication</th>
<th>Action Steps</th>
<th>Example</th>
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<tbody>
<tr>
<td><strong>Foresee</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease</td>
<td>1. Start with an anchor point</td>
<td>Obtain details of known survival statistics by current stage of disease, eg. Cancer SEER Web, etc; speak with expert about 1-, 5-, 10-year survival statistics</td>
<td>68 y male; ca RUL lung x4mos; multiple bone metastases; pall RT only 3 months ago; re-# left humerus; personality disorder; fever</td>
</tr>
<tr>
<td>Function</td>
<td>2. Assess changes in performance status (amount; rate of change)</td>
<td>Use a functional status tool that is part of prognosis (eg. PPS, KPS, ECOG) to assess illness trajectory</td>
<td>PPS 30% for several months But has declined to PPS 20% in past 2 days and rousable yet incoherent</td>
</tr>
<tr>
<td>Tests</td>
<td>3. Known physical and lab markers related to prognosis</td>
<td>For example, ↑WBC, ↓lymphocytes, ↑albumin For example, Delirium, dyspnea, anorexia, weight loss, dysphagia</td>
<td>Delirium, febrile, ? pain control, fluids only, restless, O2 satu-rated 85% room air</td>
</tr>
<tr>
<td>Tools</td>
<td>4. Utilize palliative or end-stage prognostic tools</td>
<td>PPS, PaP, PPI, SHFM, CCORT, CHESS, nomograms, etc</td>
<td>Life Table 7 day 9%-40%; 14 day &lt;%-4-23% Nomogram median ~7 days; 50% die 4-30 days</td>
</tr>
<tr>
<td><strong>Skill</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judgment</td>
<td>5. Clinician prediction of survival. Would I be surprised?</td>
<td>Use your clinical judgment to formulate See if it fits with the above prognostic factors &amp; adjust accordingly Remember common optimistic bias &amp; adjust further</td>
<td>Condition unstable Decline not good, but is still drinking May improve to PPS 30%, and if so, perhaps 1-4 weeks prognosis</td>
</tr>
<tr>
<td><strong>Center</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is important to my patient? To the family?</td>
<td>Who/what do they want to know/not know? Is it “how long?” or “what will happen?” What are their goals; what is hoped for?</td>
<td>Forensic past history; does not want needles and gets agitated; agree not to inves-tigate</td>
<td></td>
</tr>
<tr>
<td>Frame it</td>
<td>7. Use probabilistic planning &amp; discussion</td>
<td>Ball-park range; average survival; most will live X period of time; outliers; talk in time-blocks; etc</td>
<td>Not clear tonight; will know more in 1-2 days; 50:50 chance of improve if PO antibiotics on spec</td>
</tr>
<tr>
<td>Cautions</td>
<td>8. Share limitations of your prognosis</td>
<td>No one knows for sure; exceptions do occur Changes can occur at any time</td>
<td>Might respond to antibiotics, but if decline to PPS 20% or lower, will die Not known for sure</td>
</tr>
<tr>
<td>Changes</td>
<td>9. Review and reassess periodically</td>
<td>“What is” will change Especially if “triggers” arise</td>
<td>With his variable mental status, may require sedatives if becomes violent</td>
</tr>
<tr>
<td>Follow-up</td>
<td>10. Stay connected</td>
<td>Discuss advance care planning as things may change further Initiate effective symptom control Involve interprofessional &amp; home team</td>
<td>Available through night; regular Pall Phys. will see tomorrow; RNs monitor pain, etc [NB. Patient actual survival 2 weeks; died in Pall Unit]</td>
</tr>
</tbody>
</table>

*The processes of prognostication involve 2 overall aspects including foreseeing and foretelling. Each of these have 5 components that when utilized may assist in improving one's skills in sharing difficult news. An example is demonstrated on the right side of the table. Reprinted with permission from Downing.64

Abbreviations: CHESS, changes in health, end-stage disease and signs and symptoms; ECOG-PS, eastern cooperative oncology group (ECOG-PS) performance status; KPS, Karnofsky performance scale; PaP, palliative prognostic score; PIMOA, Prognostic index for 1-Year mortality in older adults; PPI, palliative prognostic index; PPS, palliative performance scale; SEER, surveillance epidemiology and end results; SHFM, seattle heart failure model.
There are multiple recommendations that are evidence-based and focused on a palliative approach and provision of palliative care services to this population. A major benefit of this approach to care is the rational and patient-centered approach to the use of pharmaceuticals. Many residents come into care with multiple medications aimed at prevention and there is a need to have a sensible approach to the use of these medications at this stage of life. Review and revision may reduce side effects and cause less adverse effects on function.

A palliative approach to care is also consistent with the prevention of suffering through education of the resident and family about what to expect as the disease progresses. Many families have trouble understanding how dementia ultimately affects mobility and activities of daily living such as eating. Gaining insight into the progression of the illness is essential for shared decision making particularly when it comes to issues of withdrawal or withholding of therapies that are not in the best interest of the resident.

Conflict within family or between the family and care team can occur. It is essential to have open communication about concerns and disagreements so as to avoid conflict and to utilize other resources if possible such as an ethics consultation when decision making is complex or disension exists. Consistency in messaging about the resident to the family from the health care team is needed to help the family understand what is happening and to support them in the anticipatory grief and other emotions that they may have in seeing their loved one decline.

**PROPOSED GOALS OF CARE FRAMEWORK FOR GUIDING PHYSIOTHERAPY CARE IN ADVANCING ILLNESS**

Resident access to services in residential care environments can vary greatly between institutions. Rehabilitation services by physiotherapists and occupational therapists (OT), if available, are often provided in a consultant-only model. In this model, specific interventions may be provided by rehabilitation assistants under the direction and supervision of the PT or OT. Moreover, this model typically requires the PT to prioritize assessment and treatment of residents based not only on evidence-informed best practice but also with preference of service provision for the residents who are most likely to achieve the best outcome. However, it is important that these factors not prevent the PT from performing a meaningful role with the chronically and terminally ill residents.

Figure 2 provides a proposed framework for the practice of the PT within a residential care setting for residents approaching the end of life due to advanced illness. The framework includes function, safety, and comfort and captures the required fluidity of the primary focus for the PT at any given time in the advancement of illness.

Figure 2 shows the FSC Goals of Care. In early/chronic illness, the primary goal is to maintain Function (F) as seen on the first circle on the far left. In the chronic/advanced phase, depicted in the middle diagram, is the primary goal is Safety (S). In late/terminal phase, illustrated on the right, the primary goal is Comfort (C). All 3 goals are important at each phase in the progression of illness but the most important focus is at the top of the triangle in each stages of illness. The triangle “rolls” clockwise with progression of the illness to reflect changing priorities.

**Phase 1 priority: Function**

The first phase depicted in Figure 2 addresses the earliest stage in the illness trajectory, prior to significant decline. In this phase the goals of the health care team concentrate on maximizing function. It is important to recognize, however, that for individuals living in residential care who have multiple comorbidities, dementia, and other terminal illnesses, there is always a degree of dependence for some or all of their future care.
activities of daily living. The family and resident may be unrealistically focused on returning to a previous level of functional mobility and independence. The level of dependency for residents in residential care will vary with the diagnosis, acuity of medical condition, and presence of comorbidities and dementia. Residents with congestive heart failure or chronic obstructive pulmonary disease may be much more mobile toward the end stages of disease than others with dementia, Parkinson disease or neurodegenerative conditions such as multiple sclerosis or amyotrophic lateral sclerosis. Residents with diagnoses such as cancer, frailty, and organ failure may not have a high degree of disability until the final few months of life if the Lunney model is used.3

The goal of maintaining function typically targets maintenance of lower extremity strength for transfers and ambulation as appropriate. A systematic review of physical rehabilitation in LTC concluded that physical rehabilitation programs had potential benefits for improvements in mobility, strength, and flexibility.75 These programs included activities directed at performance of functionally specific activities, and walking programs, which increase the mobility of residents within the LTC setting.21 Maintaining mobility in the later stages of life may contribute to improved quality of life by maximizing the resident’s participation in activities within the facility as well as outings with family and friends. The resident that is already dependent for transfers may benefit from upper and/or lower extremity and cardiovascular training that allows them to mobilize independently in their wheelchair.

Identifying when the resident is in transition to a stage where maintenance of function is no longer possible is a challenge. Decreased nutritional intake is often associated with functional decline in nursing home residents77 and may be a factor in identifying transition toward end of life. A decrease in albumin levels have been identified in residents with declining mobility. With decreased nutritional intake there is a concomitant reduction in strength and increase in falls risk.

Phase 2 priority: Safety
The second phase identifies the need to shift the priority of care from function to safety as a resident’s illness progresses. Managing falls risk and potential injury is an important component of resident safety as illness progresses. All individuals are at risk for falls in institutional care but the risk magnifies for residents with dementia, with decreased nutritional intake and with acute illness or infection.76,79 The well documented sequelae of hip fracture and traumatic head injury secondary to falls, results in significant costs to the individual and the health care system.76,79 Both the PT and OT are integral members of the multidisciplinary team in mitigating falls risk.

Other aspects of safety for residents as function declines relate to fluctuations of ability. These fluctuations in ability can place both the resident and staff at risk for injury. Residents with dementia and Parkinson disease can have variability in functional mobility from day to day and within the same day. These fluctuations in mobility can be challenging for direct care staff. As a consequence, the safest option of assisted mobility must be promoted as best practice at all times. This increased dependence in care can result in conflicts between staff and residents and family members who are distressed with the increasing loss of ability. The PT is in a position to help explain to family the clinical reasons for the choice of transfer, to discuss fall prevention measures and to help the family to understand and adjust to transitions of care.

Phase 3 priority: Comfort
The last phase depicted in Figure 2 is the shift in focus from safety to comfort. Consultation or treatment will be directed primarily at both comfort and quality of life of the resident. This may involve providing recommendations, in conjunction with nursing and occupational therapy, for bed and wheelchair positioning to prevent secondary skin breakdown. At any stage of illness the OT and/or speech language pathologist will make recommendations for management of dysphagia. In conjunction with other team members the dietician, OT and/or speech language pathologist will discuss issues of nutritional intake and dysphagia with the resident and family members to assist them in making decisions about aspiration risk versus the advantages to quality of life that eating at risk may provide.

None of the earlier described 3 phases are exclusive of each other. Indeed, attention to comfort and pain management is important at all stages. Shifting the priority of care more clearly to comfort care generally acknowledges that the resident is now closer to the end of life. The functional decline and dysphagia often herald the trajectory of death. When function cannot be improved, and indeed is declining, then reassessment and discussion around prognosis is warranted. Advance care discussions, reviewing goals and decisions about future treatment if complications arise and the involvement of family can more readily occur when the clinician does not shy away from such discussion. If the clinician periodically asks his or her self “Would I be surprised if my patient died in the next 3 months (or 6 months)?” and the answer is “no,” this can provide opportunity to hold a family conference.80,81

SUMMARY
Living is complex; the end of life and dying is complex. Yet, although each patient’s illness journey is unique, there are somewhat predictable patterns. Identifying these patterns as “prognostic trajectories” can be helpful to guide decision making for end-of-life care. However, the limitations of this approach must be acknowledged. Functional decline is a common feature seen at end of life and prognostic tools, which incorporate this can, within limits, improve survival prediction. A 10-step approach that includes steps...
in formulating and discussing prognosis may enhance the clinician’s skill in sharing difficult news.

Although there are also challenges in identifying stages of advancing illness using outcome measures, the utilization of these measures can result in less dissonance between team members. Moreover, the incorporation of a framework that acknowledges changing priorities in care with advancing illness from a shift through function, safety, and ultimately comfort can provide the team and resident and family with a common foundation for discussion regarding decisions of care. Collectively, these tools can be used in synchrony with both clinician experience and resident values to provide symbiotic care decisions.

References
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