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DEMENTIA IN CARE TRANSITIONS

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I. INTRODUCTION

The forceful consequence of dementia was referred to as a “tidal wave” at the First World Health Organization (WHO) Ministerial Conference on Global Action Against Dementia in Geneva, Switzerland, where it was estimated that 47.5 million people world-wide have dementia, and that number is expected to double every 20 years.¹ Today in the United States there are 5 million people living with Alzheimer’s Disease (AD) alone, with the number projected to rise to some 14 million by 2050.² The estimated impact of the Baby Boomers over the next 35 years is that nearly 30 million will develop AD.³

Despite the massive impact of those currently counted as having a dementing illness, the actual incidence of cognitive impairment enumerated above may be only the tip of the dementia iceberg. It is estimated that 27%-81% of cognitive impairment is unacknowledged in primary care settings.^{4,5,6,7,8} American nursing facilities already provide a glimpse into the future of the population at large. There are 1.35 million individuals living in nursing homes in the U.S., and nearly half (48%) of nursing home residents have Alzheimer’s disease and related dementias (ARD) and 68% in 2009 had some degree of cognitive impairment.⁹

The challenges associated in those individuals who have dementia strain health and long-term care systems. This stress will only intensify for Medicare, Medicaid and other involved payers as the number of elders, and the resultant population of ARD, grows over the next decades. They utilize a disproportionate amount of health care resources. They are hospitalized 2-3 times as often as people the same age who do not have the disease.¹⁰ There is a significant association for Medicare beneficiary hospitalization in those with dementia across chronic disease comorbidities and disease pairings.¹¹ Those with dementia have an increased number of comorbidities along with and more serious comorbidity.^{12,13,14}

Healthcare costs for persons with dementia are more than 80% higher than those for people with heart disease or cancer in one study, with the costs over the last five years of life for patients with dementia of \$287,038.¹⁵ A likely source of enhanced costs in those with dementia is the higher incidence of transitions with the resultant hospitalizations, duplicative testing, adverse drug events, delirium and other eventualities due in part to deficient handoffs between care sites or due to unnecessary transitions in care site. Older adults with prevalent or incident dementia had higher Medicare and Medicaid nursing facility use, greater hospital and home health care utilization, more transitions per person-year and more mean total transitions than those never diagnosed with dementia. Additionally, of those with dementia with a re-hospitalization with 30 days, 45% had been discharged to nursing facilities from the index hospitalization.¹⁷ Another study also revealed similarly increased readmission incidence with dementia. Hospitalizations of beneficiaries with a dementia diagnosis were more likely to be followed by a readmission within 30 days, compared to hospitalizations of those of without dementia regardless of discharge site of care.¹⁸ Burdensome transitions are common in those with advanced cognitive and functional impairment, vary according to state, and are associated with markers of poor quality in end-of-life care.¹⁹

The National Plan to Address Alzheimer’s Disease: 2015 Update, under Goal 2: Enhance Care Quality and Efficiency, states that for the complex care needs of persons with Alzheimer’s Disease and Related Dementias (ADRD), high-quality and efficient care depends on smooth transitions between care settings, coordination among health care providers and long term services and supports (LTSS) along with dementia-capable health care and LTSS. Strategy 2.F in that same title is to specifically “ensure that people with Alzheimer’s disease experience safe and effective transitions between care settings and systems.” Nevertheless, a limited set of specific information, guidelines and quality measures on the subject of the impact of dementia on care transitions exists. This paper is envisioned to initiate an essential conversation regarding the special needs of dementia patients during transitions, and how dementia influences key transition decisions including a discussion of:

- Prevention of unnecessary transfers and unnecessary admissions to acute facilities for those with dementia;
 - Appropriate onsite interventions in nursing homes;
 - Partnering with the busy Emergency Department to better meet the unique needs presented by cognitive impairment without an unnecessary hospitalization or observation stay;
- Early end-of-life discussions, their documentation and regularly updating them;
- Regular assessment of decision-making capacity of appropriate residents, and respect for the person’s health care preferences;
- How dementia complicates the transition process, and the information exchange involved;
- Appropriate medication management in cognitive impairment which can cause inappropriate hospitalizations; and,
- Specialized nursing home “dementia units” which deliver more uniform, evidence-based care, promote appropriate on-site interventions and reduce unnecessary transitions.

The cognitively impaired person undergoing transitions must be viewed not with a singular focus, but dually. Quality clinical care for the special needs and risks of this population is the first pathway to their care. That approach will appear in the first three sections of this paper. The second, and perhaps more important, need is for intense search for the “person within the patient.” It is essential to elicit the wishes and instructions of the individual to guide the interdisciplinary team to craft a care plan that meets those desires, and maintains the dignity of that human being. The remaining portions of the work will address this perspective. Finally a number of recommendations will be proposed that are envisioned to improve the quality of appropriate transitions, and reduce unnecessary ones.

Nomenclature and Definition of the Problem

The AMDA Clinical Practice Guideline (CPG) on dementia (2012 update) defines “Dementia” as “a syndrome characterized by progressive decline in multiple areas of cognitive function, which eventually produces significant deficits in self-care and social,

occupational, and functional performance.” Dementia is not a specific disease but a syndrome comprising multiple etiologies and the nomenclature reflects this diversity. Terms currently utilized such as “Cognitive impairment,” Alzheimer’s disease and Related Dementias (ARD), “dementing disorders” and “Major Neurocognitive Disorder” will be utilized as synonymous with dementia. The broader term of “Mental Status” is defined in that same AMDA CPG as “an individual’s overall level of alertness, activation, and responsiveness to the outside world.” This paper will focus on dementia, reflecting permanent cognitive loss. It is anticipated that the principles here can be extrapolated to other disorders that affect cognition.

II. BARRIERS TO GOOD TRANSITIONS IN DEMENTIA

Although the perils of transfer from the hospital to a post-acute (PAC) care facility are increasingly recognized, this peril is not shared equally among all patients.¹⁹⁻²¹ Rather, patients with cognitive impairment may be most vulnerable during this time.²²⁻²⁵ The reasons for this likely stem from an interplay of patient risk factors (impaired cognitive and functional status)²⁵⁻²⁷ and hospital and skilled nursing processes of care, including invasive interventions such as feeding tubes,^{23,28} infrequent use of palliative care,²⁹ and unsafe transitional care.^{21,30-32}

Significant barriers to safe transitional care exist for cognitively impaired older adults. These barriers are important to identify for three reasons. First, cognitively impaired patients constitute a significant and increasing population of patients discharged to skilled nursing facilities (SNFs). In prior work, 61% of nursing home residents with advanced dementia were discharged to SNFs after hospitalization.³³ As the population ages and more elderly patients are discharged to post-acute care, this proportion can only be expected to increase.³⁴⁻³⁶ Second, there is strong evidence that transitional care is frequently inadequate in this population. For example, the Office of the Inspector General (OIG) found that 22% of patients transitioning from a hospital to SNF experienced an adverse event, and 59% of these were preventable with better care processes. The 30-day readmission rate from PAC facilities (26.0%) is higher than the rate of patients discharged from hospital to home (19.6%)³⁷ and is rising over time.²¹ Tools to promote safer transitions have shown significant benefit in some populations, illustrating proof of concept that transitions can be improved through better care processes.³³⁻³⁹ Third, clinicians, are called upon to protect the most vulnerable. Perhaps there is no more vulnerable patient than an older adult with impaired cognition transitioning to a PAC facility following acute hospitalization. Their health, prior level of function and way of life are being challenged on a fundamental level.⁴⁰

Patients with cognitive impairment face unique barriers in transitions of care. After an examination of those barriers, strategies will be proposed to prevent unnecessary transfers from the nursing home to the hospital, a key contributor to poor outcomes in this population.⁴¹ The Ideal Transitions of Care framework⁴² is utilized to systematically analyze barriers and identify strategies to decrease transfers back to acute care as it has been validated⁴³ and is derived from position statements in both medicine and geriatrics.^{20,44} This framework consists of 10 domains for general populations; seven of these are salient for cognitively impaired persons (Figure 1).

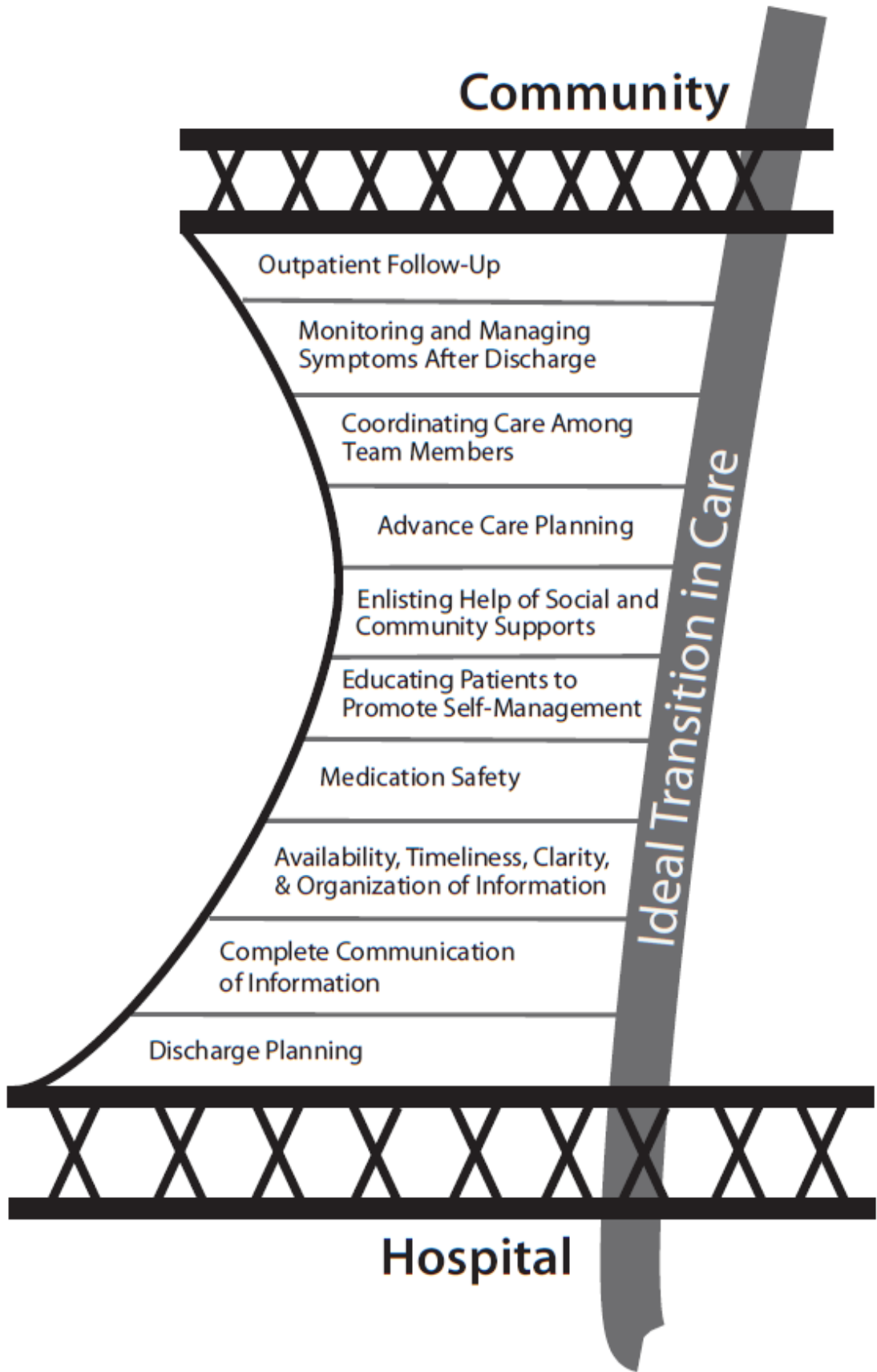


Figure 1

Barriers to safe transitions in the cognitively impaired

Domain 1: Discharge Planning

The first step in the safe transition a cognitively impaired older adult is correctly identifying their needs and matching them to an appropriate PAC facility. However, selection of patients most likely to benefit from SNF care is an inexact science.^{45,46} In fact, variability in the use of PAC facilities is responsible for most of the variability in Medicare spending nationwide.^{47,48} Evidence surrounding the efficacy of SNF care for patients with dementia is mixed,^{49,52} and likely reflects variability of the quality of care provided.^{33,53,54}

Patients and hospital providers currently lack sufficient information to appropriately match patients to high quality PAC providers. Patients generally choose their PAC facility using proximity as a guide, rather than a formal assessment of needs of the patient and quality of care that can be delivered at that facility.⁵⁵ The problem of selection of a PAC facility is particularly relevant for patients with cognitive impairment, since they may require specialized care plans and staffing. However, even if patients and providers were trying to choose a PAC facility based on quality, tools such as Nursing Home Compare do not provide granular information distinguishing facilities with high-quality dementia care. Additionally, these ratings are not correlated with hospital readmissions from SNF, considered by many to reflect the quality of the care received during the transition.^{40, 56}

Current reimbursement systems also complicate effective discharge planning. A patient may develop delirium during a hospital stay which could subsequently clear during the PAC facility stay. However, there is not currently a mechanism to “delay” Medicare-supported rehabilitative care until mentation clears and allow for more focused participation in rehabilitation and therefore successful rehabilitation.⁵⁷ Rather the patient may “fail to progress” and be readmitted to the hospital or transitioned to long-term care before they can benefit from rehabilitation.⁵⁸ Innovative models targeting rehabilitation to the individual needs of patients with cognitive impairment are needed. In particular, recognizing the common occurrence of delirium in this population is necessary given 14-16% of patients meet gold-standard Confusion Assessment Measurement criteria on admission to PAC facilities and up to 50% have sub-syndromal delirium.^{59, 60}

A final emerging barrier to effective discharge planning is the rapidly growing number of older patients being cared for by hospitalists.⁶¹ Hospitalists may have little knowledge of PAC or its capabilities,⁶² leading to more discharges to PAC⁶³ but perhaps less knowledge of how to execute these safely.

Domains 2 & 3: Information Transfer (including completeness, accuracy, timeliness, and clarity of information)

Two significant barriers exist to adequate information transfer in the cognitively impaired patient. First, there is no uniform metric standardized in either the hospital or nursing home setting to measure and communicate the current cognitive and functional status. Second, in the absence of a knowledgeable historian of the patient, how can hospital staff ascertain a clinical and mental status baseline?

These issues are particularly salient for delirium, and in particular hypoactive delirium, which is under-recognized among elderly patients in the hospital and may only be discovered later in the PAC stay.^{59,60,64-68} This leaves PAC facility staff unsure if a change of mental status occurred, frequently leading to rehospitalization.^{24,25,31,52,69-74} However, even important information such as the presence of dementia is often missing. In retrospective record reviews, 70% of discharge summaries do not contain any mention of mental status in those discharged to SNFs; 67% of these patients had dementia.⁷⁵ The lack of assistive devices, such as glasses or hearing aids, which may contribute to the development of a delirium are rarely documented. In addition, capacity to consent to treatment is infrequently documented, leaving considerable ambiguity about who the decision-maker is when inevitable decisions about further treatment, re-hospitalization, and discharge arise.

Many hospital physicians struggle to identify a PAC provider whom they could contact during the transition.⁷⁶ Similarly, PAC providers can find it quite difficult to identify a provider in the hospital who is a point of contact to ask about the patient's baseline mental status, goals of care, caregiver support, and other issues especially relevant to the cognitively impaired population.⁷⁵ In the event that the discharging hospital has dictated discharge summaries, the 24-48 hour turn-around means the patient has been receiving care in a facility for days without accurate information about their medical conditions or trajectory. The poor ability of clinical trainees to complete adequate discharge summaries has been well-described.⁷⁷ Without a discharge summary or a patient who can convey details of the hospitalization, these barriers may cause disproportionately higher risk of incomplete care planning for cognitively impaired older adults.

Domain 4: Medication Safety

In the OIG report on adverse events in SNFs, medication-induced delirium or other change in mental status was the most common medication-related adverse event, responsible for 12% of all preventable adverse events reported. Medication effects leading to falls or other trauma was responsible for another 4% of events.

While the challenges of achieving high-quality medication reconciliation during transitions from hospital to home are well-known,⁴⁶ where medication errors are also the most common kind of preventable adverse event,⁷⁸ these errors rarely cause harm, and thus even large randomized controlled trials have failed to improve patient-level outcomes.⁷⁹ However, medication safety in nursing homes may be altogether different. While the barriers to achieving high-quality medication reconciliation may be similar, the harm may be disproportionately larger.⁸⁰⁻⁸³ In the transfer from hospital to PAC facility, there are two main medication-related barriers that are particularly important in cognitively impaired patients: poor quality medication reconciliation and inappropriate prescribing.

Compared to discharges home, where scant data exists on best practices,⁸⁴ there is even less data available about best practices for ensuring a reconciled, accurate medication list travels with the patient to the PAC facility.⁸⁵⁻⁸⁸ Well-intentioned electronic medical records often are set to populate the patient's outpatient medication list at time

of discharge, when the inpatient hospital list may be more appropriate. Hospital-based clinicians may assume that a pharmacist and physician will be reviewing the medications at the PAC facility, resulting in less oversight and patient education than for patients being discharged home. Medications are frequently listed without an indication or duration, and particularly for high-risk medications (pain medications or sedating medications) the reason for an “as needed” order may not be clear. This is particularly significant for cognitively impaired patients, who have limited ability to participate in medication reconciliation.

The second major issue is whether the prescribed medications are appropriate. Despite development of multiple lists of medications to be avoided in older adult populations (e.g., Beers, STOPP criteria), evidence indicates these medications are still frequently prescribed.^{71,89-92} Current quality measures for nursing homes may compound this difficulty.⁹³ For example, pain frequency and intensity of residents is a quality measure reported by Medicare on Nursing Home Compare which may lead to over prescribing of pain medications.⁶⁴

Domains 5 & 6: Educating Patients to Promote Self-Management/Enlisting Help of Social and Community Supports

While cognitively impaired patients are unlikely to respond to an educational intervention to promote self-management of disease, enlisting help of social supports may be particularly important in this population. Although little published work is available, anecdotally it appears that cognitively impaired patients who are accompanied by a caregiver in the hospital and PAC facility sustain less harm and have better outcomes than those who are not. An activated caregiver in this setting can help identify changes in patient status, encourage physical activity that may be infrequent otherwise, advocate against harmful interventions, and anticipate barriers to discharge. Further work is urgently needed to evaluate whether this anecdotal experience is valid more broadly, to understand which characteristics of caregivers may be most important, and identify how best to prepare or engage caregivers during most the transition to a PAC facility.

Domain 7: Advance Care Planning

Increasing evidence demonstrates that highly invasive care provided to cognitively impaired older adults can have substantial negative impact on health outcomes.^{23,28,29,94,95} Hospital and PAC facility characteristics contribute substantially to whether “do not hospitalize” or other advance orders are written,^{29,96} and how invasive care provision is for these individuals.^{53,54} Improved advance care planning is directly linked to increased utilization of hospice and decreased hospitalizations in cognitively impaired older adults.⁹⁷⁻¹⁰³ However, despite the predictable events that occur in dementia, timing of discussions about preferences in the event of serious illness vary and are often delayed until a crisis occurs.¹⁰⁴

Neither the hospital nor PAC facility may feel it is their primary responsibility to establish goals of care; alternatively, providers in each care setting may assume the other will complete these often difficult, time-consuming conversations.¹⁰⁵ Few providers may be aware of hospice criteria for advanced dementia or the availability of POLST

forms to document advanced care wishes.^{100,103,106} Clinicians may not know whom to approach to have advance care planning conversations when formal capacity evaluation has not been completed and a surrogate decision-maker is unavailable.

If goals of care are discussed, they are often not communicated across care settings and there is a lack of uniformity in documentation formats for communicating goals of care.¹⁰⁷ Do not hospitalize and do not resuscitate orders are poorly communicated to SNFs and wide variability in the presence of these orders across states suggest that regional practice variation is a powerful determinant of whether or not these orders are written.⁹⁶⁻¹⁰⁸ Physician Orders for Life Sustaining Treatment (POLST) and variations on these types of orders are improving uniformity across states but consistent use of this type of documentation and state registries has not yet been achieved.^{98,109-111}

Domain 8: Coordinating Care Among Team Members

The connection between the treating hospital clinician and the receiving clinician, or its absence, is a known pitfall to providing high-quality transitional across care settings and PAC facilities are no exception.⁷⁶ This is particularly relevant because this connection might provide the sole opportunity to discuss a cognitively impaired patient's baseline and current mental and functional status and for the receiving physician to provide feedback on the care plan prior to discharge to the PAC facility, including the current cognitive state. Currently, there is no mechanism for hospital-based providers to receive feedback on the outcomes on the patients they discharge to PAC facilities to create a "learning health care system."¹¹² However, it may be even more important for hospital nurses and therapists to be able to communicate directly with PAC facility nurses and therapists, particularly for the cognitively impaired older adult. These clinicians may have a sharper sense of the patient's physical and cognitive function, presence and involvement of caregivers, and effects of treatment given their consistent presence at the bedside. We are unaware of any programs to coordinate "sign-out" between these clinicians and clinicians at the PAC facility.

Domains 9 & 10: Monitoring and Managing Symptoms After Discharge/Outpatient Follow-Up

In the OIG report on adverse events in SNFs, failures of monitoring and managing symptoms were one of the three most common categories of preventable adverse events. This may be unsurprising as the patients being discharged from the hospital "quicker and sicker," and in higher volume than previously.^{17,113,114} In fact, PAC facility care could be substituting for a longer hospital stay in some cases³⁴ and nursing home staff may not feel equipped to know when transfer back to a hospital is indicated.^{88,115} The presence of more staff (which may be more prevalent in not-for-profit facilities) may improve monitoring and decrease hospitalization rates. However, staff turnover is a major issue and increased acuity stands in stark contrast to staffing at PAC facilities.¹¹⁶

Contrary to the views of many hospital-based providers and family members, there will often not be a provider at the PAC facility ready to assess the patient as they arrive or titrate medications on a daily basis. Though many states have more stringent requirements and a common community standard is a physician visit within 72 hours of PAC admission, Federal Medicare regulations simply describe that a physician visit is required within the first 30 days of admission to a nursing facility¹¹⁷ Hence, there is

commonly a large “voltage drop” in the intensity of care provided across this transition. In the hospital, these patients often have vital signs every four hours, hourly rounds by a nurse, and daily physician visits; in the PAC facility physician visits will be less frequent and the majority of the care will be provided by certified nursing assistants and licensed practice nurses.¹¹⁸⁻¹²⁰ These providers may not have clear directives on how to evaluate patient changes in status, when patients may require transfer to a nursing home, or whom to call when a change in status occurs.⁸⁸

Change of condition is particularly difficult to detect among cognitively impaired older adults, who are likely to develop the types of adverse events cited in the OIG report: including aspiration pneumonia, catheter-associated urinary tract infections, dehydration, falls with injury, and exacerbations of their medical conditions from omissions of care. While some accountable care organizations (ACOs) are establishing relationships between hospitals and SNFs, few hospitals are aware of outcomes associated with the SNFs their patients are most commonly referred to following hospital discharge.¹²¹ As ACOs are increasingly held accountable for the health of populations, collaboration with PAC providers will be a critical step in overcoming many of the barriers described in the ITC framework including the monitoring and management of symptoms throughout the discharge process.

Cognitively impaired older adults face significant barriers to safe transitions from the hospital to PAC facilities in multiple domains. These barriers often overlap, interact, and as a result are difficult to address individually. For example, a cognitively impaired older adult may receive an inappropriate medication, resulting in aspiration pneumonia and development of delirium, which is not discovered due to inadequate monitoring. Once finally discovered, the wishes of the patient for hospital or ICU –level care may not be known without caregiver involvement or advanced care planning. These barriers call for collaboration between hospitals and PAC providers to integrate care on behalf of this vulnerable population and improve outcomes.

III. PREVENTION OF UNNECESSARY HOSPITALIZATIONS

Transfers from a nursing home or post-acute care (PAC) facility to the hospital are common,¹²²⁻¹²⁵ may frequently be preventable,¹²⁵⁻¹²⁹ and are associated with adverse outcomes.¹³⁰ The extent to which these general findings apply to the vulnerable subpopulation of cognitively impaired older adults is less well-understood.¹³¹ While nursing home residents with cognitive impairment may be less likely to be hospitalized,^{126,132,133} little evidence has evaluated whether these transfers to the hospital are more or less “appropriate” or their effect on patient outcomes. This is a difficult population to study, as large databases often are missing key information about cognitive impairment. For example, dementia is often not coded as the primary reason for a hospitalization (even if a comorbid condition), and delirium is frequently under-recognized. However, since initial evidence suggests that provider characteristics, rather than patient factors, play a large role in hospitalizations in this population,^{128,134, 135} there is an opportunity to establish standards of care for these vulnerable adults and reduce unnecessary transfers to the hospital for evaluation and treatment.

Risk factors for hospital transfer

“Potentially preventable” hospitalizations of nursing home residents have received significant attention, though the method for determining what may be preventable differs. One approach is to measure “ambulatory-care sensitive” conditions, though how these are defined varies.¹³⁶ Three studies using this methodology suggest: 1) hospitalizations due to these conditions have remained stable over time;¹²⁹ 2) injuries with falls may be the most common cause of these admissions,¹²⁷ and 3) nursing home characteristics are associated with hospitalization rates for these conditions. For example, the presence of nurse practitioners or physician assistants at facilities was associated with reduced rates of hospitalizations for ambulatory-care sensitive conditions.¹²⁸

Others have relied on retrospective chart review, using physician reviewers and a standardized template for determining how “preventable” a hospitalization was. Two studies have been completed using this strategy, and both found a majority of hospitalizations are preventable.^{137,138} The four processes of care found to be most commonly responsible for preventable hospitalizations included: 1) poor detection and communication of changes in resident status; 2) lack of prompt evaluation and treatment for a change in status; 3) preventable complications of resident treatment (such as medication side effects or catheter-associated urinary tract infections); and 4) lack of advance care planning.^{126,138}

A final approach is to label Emergency Department visits by nursing home residents that do not lead to hospital admission as “potentially preventable.” In a single study using this approach, ED visits by nursing home residents were quite common (1.8 per NH resident per year in the United States) but more than half did not require hospital admission. The most common potentially preventable diagnoses treated was injury.¹²⁵

None of these studies have evaluated preventable hospitalizations among patients with cognitive impairment specifically – a significant gap in the literature. There are plausible reasons to think reasons for hospitalization may differ in this population. For example,

changes in mental status or dementia-related behaviors may be more common reasons for hospitalization. Best practices for responding to these changes or behaviors are also not clear.

Preventing hospital transfers

Preliminary evidence suggests that improved processes for identifying a change in status early, communicating this clearly, and evaluating and treating in a safe and timely manner is key for reducing hospitalizations in nursing home populations.^{137,138} It also suggests prevention of catheter-related infections, medication side effects, and falls or injuries may be fruitful areas to target.^{125,127,138} Finally, advance care planning may be particularly important in this population.¹⁴⁰ However, prior systematic reviews of interventions to decrease hospitalizations from nursing homes have concluded that the evidence is poor and that no intervention has been replicated or tested in another setting beyond where it was originally published.¹³¹ In this context, it may be no surprise that cognitively impaired patients have been the primary intended recipients of very few interventions to reduce hospitalizations. Several strategies for preventing hospitalizations among cognitively impaired nursing facility residents are presented below.

Strategy 1: Proactively prevent potential complications

As patients are discharged from the hospital “quicker and sicker,” post-acute care facilities are admitting patients who are more disabled and actively ill than prior.¹⁴²⁻¹⁴⁴ In fact, nursing home care may be substituting for prolonged hospitalizations in some populations.¹⁴⁵ Older adults may be receiving more aggressive care once hospitalized,¹³ even if they are cognitively impaired.¹³⁵ Since these patients are more ill, may have more complex medication lists and levels of invasion, and are more often cared for by non-geriatricians in the hospital,^{146,147} more intensive monitoring and review of their care plan may be warranted.

This could be accomplished in several ways. One group found utility in a standardized admission template, so all providers were reminded to evaluate treatments that had potential to cause complications.¹⁴⁸ Others find that the presence of “physician extenders” as a daily presence in the nursing home decreased readmissions presumably through more regular visits and monitoring.^{139,149} Several large private hospitalist employers have begun sending hospitalists, referred to as SNFists, (confusing nomenclature as many specialists in skilled nursing facilities refer to themselves by the same descriptor), into post-acute care (PAC) facilities with the goal of improving outcomes, though evidence supporting this model is currently unavailable. In the ECHO-AGE project, geriatric psychiatrists tele-consulted on challenging cases of nursing home residents with psychiatric illness or dementia, and facilities who participated reported decreased hospitalizations as a result.¹⁵⁰

Strategy 2: Better identify, communicate, and evaluate changes in status

The main focus of the INTERACT program, created by Ouslander and colleagues, is to enable front-line staff to better identify, document, communicate, and evaluate changes in status of nursing home residents. This program includes education of all levels of staff, tools and order sets, and structured forms of communication with the

goal of reducing transfers to acute care.¹⁵¹ Initial evaluation indicated that engaged nursing homes were able to significantly reduce hospitalization rates.¹³⁷ An attempt to replicate this finding in New York resulted in non-significant trends toward decreased hospital admissions.¹⁵² This experience validates the anecdotal experience of many in the long-term care setting: that staff turnover and limited training are major barriers to implementing large-scale quality improvement efforts.¹⁵³

Strategy 3: establish robust advance care planning procedures

In a systematic review of interventions to decrease hospitalizations in the cognitively impaired, the only interventions that demonstrated success were those intended to improve advance care planning practices in the nursing home.¹⁴⁰ Of the three interventions identified in this category, two demonstrated reductions in readmissions.^{154,155} Another intervention that combined a structured admission template, automatic palliative care consultation for patients with more than 3 hospitalizations in the last six months, and monthly review of acute hospital transfers was also successful in reducing hospital admissions.¹⁴⁸ A final intervention that prospectively identified nursing home residents at high risk of death and implemented an advance care planning program for these residents demonstrated a massive reduction in death in the hospital - 48.9% of patients without the intervention died in the hospital compared to 8.9% who received the intervention.¹⁵⁶ These interventions suggest the most fruitful initial step in reducing hospital admissions for cognitively impaired older adults is to engage in robust advance care planning in the nursing home.

Promising future directions

The recurrent finding that falls with injury are a major source of potentially preventable hospitalizations calls for standardized practice guidelines for evaluation of these injuries. Providers at the nursing home may be concerned about liability if they do not send the patient to the ED after a fall¹⁵⁷ More than one-quarter of all nursing home residents sent to the ED receive a CT scan while there, and over 70% are CTs of the head.¹²⁵ Importantly, this rate does not differ between those admitted to the hospital and those discharged, suggesting they were obtained as a part of routine evaluation. This may be because, for example, four of the six clinical rules for evaluating potential head injury include age >65 as a criterion for imaging. Robust geriatric clinical rules for evaluating injury have the potential to significantly decrease ED utilization.

Caregivers and support people could be significant under-utilized assets in the care of older adults in nursing homes, particularly for post-acute care.¹⁵⁸ Anecdotally, frequently heard from nursing home staff is that family concerns may be a driver of potentially preventable hospitalizations, though no published research on this topic is identified. Conversely, these caregivers could also lead to earlier identification of changes in status and improved advance care planning if engaged and educated.

With the recent passage of the Affordable Care Act legislation, two major changes can be expected to impact this area. First, penalties for all-cause readmissions from post-acute care facilities will begin to be assessed.¹⁵⁵ Second, value-based purchasing will

begin to include post-acute care. Hospitals will be measured on their Medicare Spending Per Beneficiary (MSPB), including all costs from 3 days before hospitalization to 30 days afterwards.¹⁶⁰ These will combine to intensify focus on post-acute care and could serve to drive improvements in care, and increased resources invested in reducing unnecessary hospital admissions from facilities.

IV. MEDICATION RECONCILIATION AND MANAGEMENT IN DEMENTIA

Medication management in older adults is becoming increasingly complex. Older individuals take more medications than younger adults, and the rate is rising. Between 1988 and 2010, the number of adults aged 65 and older who reported taking five or more chronic medications rose from 12.8% to 39%.¹⁶¹ The increased number of medications leads to a variety of medication-related problems, including adverse drug events, many of which are preventable.^{162,163} Individuals 65 and older are two and a half-times more likely to be hospitalized for an adverse drug event than younger adults.¹⁶⁴ Almost one in four older adults discharged from the hospital to skilled nursing facilities for post-acute care experience an adverse event, many (59%) of which are deemed preventable. Eleven percent of the events are serious enough to cause harm, and 60% of these patients require hospitalization for management.¹⁶⁵ Older individuals, particularly those with dementia, transitioning into a nursing facility are at increased risk for medication-related errors due to acuity, comorbidity, polypharmacy and poor recall and insight into their own health history.

Polypharmacy, defined as medication use beyond a certain number of medications or use of more medication than clinically indicated or warranted, is a significant contributor to adverse drug events in older adults.^{162,163} It is also associated with increased use of potentially inappropriate drugs, as defined by Beers criteria and others, and increased rates of hospitalization in nursing home residents.¹⁶⁶ The number of medications an individual takes, therefore, is an important metric in assessing the risk of adverse drug events.

When older individuals transition between different health care settings medication discrepancies, such as omissions, duplications, and dosing errors are common, occurring at rates of 50% or higher in some studies.^{167,168} Other studies have shown that peer physicians often judge many of the discrepancies to be preventable and to have a high-potential to cause harm. These discrepancies can lead to adverse events, particularly in older adults and in those transferred between acute and long-term care facilities.¹⁶⁹ Such discrepancies increase the risk for hospitalizations and re-hospitalizations among older adults.¹⁷⁰

The patient medication list is a key part of the medical history of an individual, particularly during transfers between care sites. However, older adults often have difficulty recalling their medications. In a recent study of 99 older adult patients with no known cognitive impairment who presented to a primary care practice, only 22% correctly named their drugs from memory, and fewer than half (49%) were able to recall the number of drugs they were taking. In addition, only 34% correctly named the

medical conditions associated with their drugs.¹⁷¹ Individuals with dementia had poorer performance on these items of recall.¹⁷² Incomplete medication histories can lead to medication misadventures, with their consequent potential for avoidable care transitions.

The act of medication reconciliation, properly performed, remains the lynchpin of quality transitions. The most vulnerable, particularly those with impaired mental status, are the chief beneficiaries. The World Health Organization (WHO) uses the following definition: “Medication reconciliation is the formal process in which health care professionals partner with patients to ensure accurate and complete medication information transfer at interfaces of care.”¹⁷³ The process of medication reconciliation involves comparing a patient's new medication orders to all the medications that the patient has been taking, including non-prescription drugs and herbals, over the counter drugs, and those that may have been brought into the facility by family or others. The WHO High 5s Project developed several guiding principles that apply to medication reconciliation implementation. (Appendix D, Table 1). The process of medication reconciliation is depicted in Figure 1 in Appendix D. Medication reconciliation should be performed upon every facility discharge and admission, and upon significant clinical status change.

Medication reconciliation is a multidisciplinary process, requiring the engagement of the patient as well as family caregivers, physicians, pharmacists, case managers, and others to effectively reduce the risk of medication errors. In combination with other transitions of care interventions, hospitalizations and emergency department visits have been significantly reduced.¹⁷⁴ Pharmacist involvement in medication reconciliation in transitions between acute and long term care settings has had limited study, but shows promise for improving outcomes, including reducing medication discrepancy rates and hospitalizations.¹⁷⁵ Further pharmacist engagement in nursing homes will evolve with proposed regulatory changes, which include specific attention to pharmacist-conducted medication review of individuals undergoing transitions of care, and a periodic comprehensive medication review.¹⁷⁶ Under current regulations, the pharmacist mandated medication regimen review is often performed without consideration of transitions in care and absent of medication reconciliation principles.

Although the overarching goal of medication reconciliation is to create an accurate medication list, it is also an opportunity to identify medications that may be contributing to or complicating cognitive impairment and discontinuing them. The steps involved in the process of identification and removal of offending medications is often referred to as *de-prescribing*. Although this activity is beyond the scope of routine medication reconciliation, it is essential for individuals with dementia to minimize medication use.

Identifying Drugs Contributing To or Exacerbating Cognitive Impairment

Several classes of medications are known to cause cognitive impairment and complicate dementia management. The most notable of these are drugs with anticholinergic properties (see Appendix D, Table 2), which increase the risk of hospitalization for confusion, delirium, or dementia in older adults¹⁷⁷ It is important to keep in mind that while anticholinergic medications individually may have only mild side effects, multiple medications with anticholinergic properties can have additive or

synergistic effects detrimental to those with dementia. Benzodiazepines and sedative hypnotics with like properties have adverse central nervous system effects, including confusion and delirium, and can lead to falls resulting in hospitalization.¹⁷⁸ Practitioners also need to be aware of the potential of other, often obscure classes of medications, in causing incident delirium such as histamine receptor antagonists (e.g., cimetidine) and fluoroquinolone antibiotics.¹⁷⁹

Table 2 in Appendix D provides a list of these medications and alternatives to their use for individuals with dementia.^{180,181} While geriatric-trained clinicians would agree that fewer medications are the better course for older adults, the risk for an adverse drug withdrawal event needs to be considered when discontinuing selected medications and classes. However, studies have shown that oftentimes medications can be discontinued without negative consequences.¹⁸²

There are barriers to discontinuing medications. For the individual with dementia, the patient and/or family caregivers may feel that medications are a proxy for engagement, and that they are being abandoned by the healthcare system and providers with drug cessation.¹⁸³ Here the art of medicine comes into play. The clinician can reassure the patient and family that medication reduction is good patient-centered care, that fewer medications will reduce the opportunity of adverse drug events, and even potentially lower the chance for unnecessary hospitalizations and readmissions.

Drugs with Questionable Benefit in Dementia

Medications used to treat symptoms or prevent disease progression present several factors for consideration. The stage of dementia, life expectancy, time until benefit, the patients/caregivers goals of care, quality of life, and treatment targets are all considerations when planning for medication discontinuation.¹⁸⁴ Individuals with advanced dementia, such as those who need significant assistance with activities of daily living, have fecal or urinary incontinence, minimal verbal ability, and are unable to ambulate, require special consideration as palliation of symptoms is often the primary therapy goal. Table 3, Appendix D, provides a list of the medications rated as rarely or never appropriate for individuals with advanced dementia, due to questionable benefit and increased risk of adverse events.¹⁸⁵ Clinicians should use this as a guide to patient-centered care in these individuals, especially in light a recent study found that more than half of nursing home residents with advanced dementia were receiving at least 1 medication of questionable benefit.¹⁸⁶

Off-label Use of Antipsychotics

Behavioral and psychological symptoms of dementia (BPSD) can be expressed in repetitive speech, wandering, calling out and sleep disturbances. They are a core clinical feature of Alzheimer disease and related dementias. Left untreated, these behaviors can accelerate disease progression, worsen functional decline and quality of life of the person and produce significant caregiver distress.¹⁸⁷ Antipsychotic medications are not approved for use for behavioral and psychological symptoms of dementia. Despite this fact, it is not uncommon to observe their use for treating behavioral complications of dementia, even in the face of data showing these drugs are known to increase the risk of stroke and mortality in this population.¹⁸⁰ Despite these known risks and a “black box” warning from the U. S. Food and Drug Administration,

high levels of off-label antipsychotic use continues to occur in the LTC setting.^{188,189} Approximately one quarter to one-third of nursing home residents were prescribed antipsychotic therapy in 2011.¹⁹⁰ In one study, 22% of residents with dementia who were prescribed an antipsychotic for an off label use did not have behavioral symptoms and 29.5% had non-aggressive behavioral symptoms.¹⁹¹ While in some instances, there may have been appropriate clinical indications or a psychiatric diagnosis, in other situations these medications were used off-label to treat milder behaviors symptoms as wandering. In other instances it was instituted for non-approved uses such as “crying” or “resisting care” where its use constitutes a sedative or chemical restraint.¹⁹² Appropriate initial treatment for BPSD invokes non-pharmacological therapies before consideration of psychotropic drugs. A discussion of non-pharmacological treatments is available in the AMDA Dementia Clinical Practice Guidelines.

Educating Family and Caregivers

Family caregivers are typically responsible for medication management in the individual with dementia, particularly in the home care setting. They may feel unprepared and at times overwhelmed by post-discharge medication reconciliation and management.¹⁹³ There is often frustration and confusion about scheduling medications, reconciling new medications with old ones, and understanding the purpose of each medication. It is important for providers to recognize the burden of medication management and to provide or direct family caregivers to information and resources, such as pharmacist-conducted comprehensive medication reviews, to minimize the burden. Providers should assess the readiness of family caregivers to care for the individual with dementia through individualized discussion or using an assessment tool.¹⁹⁴

V. ELEMENTS OF A GOOD TRANSITION

The AMDA Clinical Practice Guideline, *Transitions of Care in the Long-Term Care Continuum* outlines the steps in transitioning patients in the long-term care continuum. These apply to all patients, including those with cognitive impairment. However, fastidious attention is imperative when dementia is an involved diagnosis, either as a primary or secondary disease process.

- **STEP 1:** *The patient has a recognized status change.*
Special issue(s) in dementia: in patients who have trouble communicating recognition of a health status change may be delayed.
- **STEP 2:** *Interdisciplinary team members communicate with each other and with the patient/family (unit of care) to determine the most appropriate care transition.*
Special issue(s) in dementia: patient may lack capacity and surrogate needs to be contacted; patient may have advance directive to not to transfer to hospital.
- **STEP 3:** *The sending facility or care entity communicates with the receiving entity. Patient information received by entity prior to patient arrival.*
Special issue in dementia: ensure accurate information about mental status and advance directives are communicated.
- **STEP 3A:** *The patient has an acute change of condition and transfer to an emergency department is appropriate.*
Special issues in dementia: ensure accurate information about mental status and advance directives are communicated;
- **STEP 3B:** *The patient is being transferred to another care site by emergency medical services.*
Special issues in dementia: ensure accurate information about mental status and advance directives are communicated
- **STEP 3C:** *Patient's condition has improved to the extent that transfer to his or her community home is appropriate.*
Special issue(s) in dementia: ensure patient's safety and care needs are met at home
- **STEP 3D:** *Patient is approaching the end of life and comfort care only is appropriate.*
Special issue(s) in dementia: confirm advance directives; educate on futile interventions including CPR and feeding tubes.
- **STEP 4:** *The patient is physically handed over to the receiving level or setting of care.*
Special issue(s) in dementia: uncooperativeness, agitation, and aggression are common in dementia patients at the time of transfer; investigate underlying etiologies such as medication induced delirium and physical discomfort (e.g., pain from movement).
- **STEP 4A:** *Patient is being discharged to his or her community home.*
Special issue(s) in dementia: ensure patient's safety and care needs are met at home.

- **STEP 5:** Both sending and receiving entities verify that the patient has been handed over and that essential patient information has been received.
Special issues in dementia: confirm accurate information about mental status and advance directives has been exchanged between sending and receiving facilities.
- **STEP 6:** Sending facility follows up to confirm that the patient has been successfully transitioned to the new level or setting of care.
Special issues in dementia: confirm accurate information about mental status and advance directives has been exchanged between sending and receiving facilities.
- **STEP 7:** Monitor the facility's performance in managing care transitions.
Evaluate the efficacy of the facility in transitions; view potential quality indicators at <http://www.amda.com/tools/clinical/toccpq.pdf>

Within the above steps it must be determined what specific actions within the transitional care process are integral to quality transitions. The National Transitions of Care Coalition has defined which actions denote appropriate care in all transfers, inclusive of patients with dementia, which confer quality into the transfer activity and may reduce thirty day readmissions.

The “Seven Essential Intervention Categories” of quality transitional care:

1. Medication Management
2. Transition Planning
3. Patient and Family Engagement / Education
4. Information Transfer
5. Follow-Up Care
6. Healthcare Providers Engagement
7. Shared Accountability across Providers and Organizations

In-depth discussion of these interventions may be reviewed at the NTOCC website at www.ntocc.org.

An especially concise process is warranted when the transitioning patient is cognitively impaired. The sending site of care must contact the receiving site to insure the patient was actually received and offer further data as needed. The receiving site is obligated to follow up on any uncertain areas of information, and then act on the intelligence. Several items informational areas must specifically be transmitted in the movement of the person with dementia:

1. Accurate mental status information. Such transmission should include at a minimum:
 - Mental status abnormality present or absent;
 - Features of cognition, including normal or abnormal alertness, orientation, attention, and/or thinking (psychosis);
 - Etiology of any present mental status abnormality or change, if known;
 - Time course of a mental status abnormality or change, if present, including onset, expected duration, and permanence.

2. Advanced directives information that is specific, updated and inclusive. Include:
Advance Directive information;
 - Physician Orders for Life Sustaining Treatment (POLST) paradigm or equivalent documentation;
 - Instructions regarding resuscitation and intensity of interventions to be performed;
 - Determination of patient capacity or incapacity; and, where the patient lacks capacity, the person legally entitled to speak for the patient with contact information.

VI. MEASURING THE QUALITY OF TRANSITIONS IN PATIENTS WITH DEMENTIA

Although NQF-certified measures and CMS quality indicators related to the care of nursing home patients with dementia exist, they do not address the care transition itself for patients diagnosed with dementia, delirium, or other cognitive disorders. There exists a need currently to determine the elements of what a “good” care transition looks like for cognitively impaired patients. Measures are required to evaluate the performance of individual medical providers and clinical organizations in transitions. While the medical community is lacking specific parameters to measure quality in the transitions of patients with dementia, several measurement domains deserve mention.

Presence of a reliable determination of the presence, degree and duration of dementia when patients change site of care should be scrutinized. Failure to accurately note acute changes in cognitive status or inaccurately label patients with cognitive impairment greatly complicates care. If the patient has dementia, staging that reflects the severity of the disease and its functional impact should be documented. Periodic reevaluation at least annually, and at the inception of a significant clinical status change, will provide the trajectory of the disease process. Understanding progression allows for communication with the family regarding prognosis, updating of advance directives and the appropriateness of aggressive interventions and allow precise transfer information.

Medication management in dementia care and transitions is a centerpiece of quality care. This subject is dealt with in depth in the “Medication Reconciliation and Management in Dementia” section of this paper. Facilities and clinicians will find numerous measurements in forthcoming federal initiatives. “Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities: A Proposed Rule by the Centers for Medicare & Medicaid Services” on 07/16/2015¹⁹⁵ invokes the Improving Medicare Post-Acute Transformation (IMPACT) Act of 2014 to propose requiring the hospital summary to include reconciliation of all discharge medications with pre-admission drugs (Section 483.21). Section 483.45 recommends specific, timed pharmacist reviews of the resident chart, focusing on psychotropic drugs and antibiotics and additional reporting requirements by the pharmacist.

A further prime area to measure quality is whether there is timely transfer of accurate, actionable information. Important data to transmit is that assessment for reversible

causes of dementia has already been accomplished. This avoids duplicate testing and allows a focus on the acute problems. It is critical to clearly identify the patient mental status baseline along with any deviation or progression. Transitional care documents should convey a core set of information on the cognitive status including:

- Mental status abnormality present or absent;
- Features of cognition, including normal or abnormal alertness, orientation, attention, and/or thinking (psychosis);
- Etiology of any present mental status abnormality or change, if known; and,
- Time course of a mental status abnormality or change, if present, including onset, expected duration, and permanence.

Few hospitals routinely perform standardized mental status assessments. This paper advocates that their use become the norm. Nursing homes do utilize the tools embedded in the MDS, the CAM and Brief Interview of Mental Status (BIMS), for mental status evaluation.

Measuring compliance in accomplishing and respecting advance care planning is a crucial measure. These components must be in place to avoid cognitively impaired residents being inappropriately returned for hospital care when such transfers conflict with their best interests or previously expressed wishes.

Patient, family and caregiver satisfaction with the quality of the transition should also be assessed. Evaluation of patient-centered care in transitions includes the performance, with documentation, of patient and family education about dementia, its disease progression, prognosis and alternatives of care. Prior work has validated the assessment of patient and family preparation for post-hospital care as a quality measure.¹⁹⁶

Potential Quality Measures for Dementia Transitions

Improvements in the care of dementia persons will best occur by promoting and measuring actions felt likely to augment quality care. Examples of potential measurements to determine quality in the care of dementia patients, and their transitions are listed below. This consensus-based list is not validated, but is offered as a series of suggestions to evaluate dementia care.

- Each patient diagnosed with dementia is staged as to the severity of the disease during each assessment.
- Periodic assessment of dementia status with a consistent (for the facility), standardized tool is performed:
 - Upon admission
 - Annually, and
 - With significant change in condition (hospital transfer, clinical intervention on-site).

- There exists a permanent, specific site in the patient chart (or tab in the Electronic Medical Record) for advance care planning information. Measurable elements on this site could include the presence of:
 - Properly completed Advance Directive information;
 - Properly completed Physician Orders for Life Sustaining Treatment (POLST) paradigm or equivalent documentation (in states where available);
 - Properly completed Do Not Resuscitate (DNR) orders, or other instructions regarding intensity of interventions to be performed;
 - Determination of patient capacity or incapacity;
 - Incompetence declaration (when performed) paperwork on the chart;
 - Where the patient lacks capacity, the person legally entitled to speak for the patient, along with contact information is documented; and,
 - Advance Directives are updated annually, or when a significant change in status occurs (i.e., hospitalization, or diagnosis of major illnesses such as malignancy)
- Education of the patient and family is performed and documented on the chart at least once regarding
 - Dementia disease progression and prognosis and,
 - The potential impact of transitions on cognitively impaired patients.
- The facility transfer form transmits specific information on mental status that includes:
 - Mental status abnormality present or absent;
 - Features of cognition, including normal or abnormal alertness, orientation, attention, and/or thinking (psychosis);
 - Etiology of any present mental status abnormality or change, if known;
 - Time course of a mental status abnormality or change, if present, including onset, expected duration, and permanence.
- Documentation of the use of non-pharmacologic measures to address behavioral and psychological symptoms of dementia (BPSD) prior to any use of psychotropic medications.
- Annual staff education and training in recognition of, prevention of and non-pharmacologic interventions to address behavioral and psychological symptoms of dementia (BPSD).
- Annual staff education to address the special needs of dementia patients
 - Potential for increased BPSD with new providers and a new site of care
 - Need to provide in-depth information on mental status to a receiving clinical care site
 - Contact the new site of care to determine if questions exist as the patient will likely not be able to provide information.

VII. HEALTH INFORMATION TECHNOLOGY (HIT)

In 2009 Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act. (Pub. L. 111-5, Division A, Title XIII, & Division B, Title IV) The HITECH Act intention was to drive demand for the adoption and use of health IT with the Medicare and Medicaid EHR Incentive Programs (also known as Meaningful Use). These programs have already invested more than \$31 billion in incentive payments to health care professionals and hospitals that have, based upon whether usage is within the Medicare or the Medicaid program, attested to adopting, and/or “meaningfully” using electronic health records (EHRs) certified by the Office of the National Coordinator for Health Information Technology (ONC)¹⁹⁷

The majority of Americans’ health information is now stored in EHRs.¹⁹⁸ The value of an interactive, clinically viable EMR is tangible and inestimable as a repository for on-site clinical information regarding mental status. When functioning as envisioned by the ONC, it will benefit patients for its legible, accessible record of past interactions and efficiently transmit that information across sites of care. Clinicians would likewise value it as a resource for the nearly limitless availability of best practices and medical knowledge through the internet.

The promise, as opposed to the current value, is the potential to transmit patient-specific, concise clinical information anywhere in the world in a timely and actionable manner. Regarding dementia, such transmissions should include at a minimum:

- Mental status abnormality present or absent;
- Features of cognition, including normal or abnormal alertness, orientation, attention, and/or thinking (psychosis);
- Etiology of any present mental status abnormality or change, if known;
- Time course of a mental status abnormality or change, if present, including onset, expected duration, and permanence.

The keys to this potential of information sharing are the presence of interoperability, and use of structured data.

- Interoperability is defined as the ability of two or more systems to exchange information, and the ability of those systems to use the information that has been exchanged without special effort.¹⁹⁹
- Exchanging Structured Data encompasses two ideals. First, objective patient assessments are captured using standard measures and nomenclature. Secondly, and simultaneously, clinical observations which add context are incorporated so the individuality of the patient is preserved and communicated.

There are numerous, well documented barriers to interoperability. Some of the more prominent impediments and recommendations for resolution are noted in *Health IT Policy Committee Report to Congress: Challenges and Barriers to Interoperability (December 2015)*.²⁰⁰

Appropriate, accurate, timely data sharing to all members of the interdisciplinary team is the essence that drives the coordination of patient care, including safe care transitions. Simply stated, we are not there as a health care industry.

HIT in the Post-Acute/Care Long-Term (PA/LTC) Environment

If all EHR interoperability issues were solved, and EHRs were user friendly, hurdles would remain for effectively managing transitions of care between a Skilled Nursing Facility (SNF) and other sites of care. PA/LTC care is unique in the sense that multiple independent entities (i.e., medical groups, LTC providers, therapists and pharmacists) **concurrently** share care of the patient. However, none of the current models for Health Information Exchange address this concept.

Each of those service providers, must document care according independent regulatory expectations. Designers of a 'best practice' for the transition must consider how a complete picture of the patient's care, and total plan of care can be captured and transmitted. At present, the critical elements of that common patient are captured and stored in multiple, independent locations:

- The Facility EHR which has existing standards for the use of Structured Data, and contains information specific to the nursing care in a LTC setting (largely of low value to the receiving physician, but important for a Home Health Agency or other community based support services)
- The Attending Physician EHR, which is required to use Structured Data, and export in a specific format. This summary is important to the receiving physician, but requires active planning between the facility, attending physician, and community PCP to transmit.
- The Consulting Pharmacist – Nuances of medication management, and the rationale for many therapeutic choices in the PA/LTC setting are documented in interactions between the Consulting Pharmacist and the Attending Physician. There are no EHR/EMR standards for consulting pharmacists, and their notes are typically unavailable.

Even the most effective transition involving patients with dementia, and other chronic diseases, remains a high risk for adverse events. The use of EHR technology has great promise to improve this process. However, without a keen appreciation of the need to coordinate multiple documentations into a complete, pertinent summary of care and in a format effective to the PA/LTC setting, that promise remains elusive.

Beyond repository and conveyance of patient health information, Health Information Technology (HIT) offers promise in direct patient care and safety. One long-term care pharmacy automatically generated risk assessment reports and automated monitoring plans utilizing a clinical informatics tool with newly admitted nursing home residents at high risk with a reduction in potential delirium onset, hospitalization and mortality²⁰¹ Another study determined hypoglycemia can be detected through a clinical surveillance system utilizing a computer-generated alert in the nursing home setting.²⁰² Further promise arises with computer-based medication reconciliation tools to reduce

medication errors in the transition from the acute hospital.²⁰³ These tools are especially beneficial for cognitively impaired patients, at such high risk of adverse events due to the inability to often convey their symptoms.

While validation in the nursing home setting remains less than optimal, the potential for decision-support and alerts for inappropriate medication prescribing as well offers true promise.

VIII. COMMUNICATION IN DEMENTIA CARE

Research suggests specific barriers that might be targeted to improve transitions for nursing home residents with dementia. One study identified poor provider communication and unexpected transfers as frequent barriers to effective transfers.²⁰⁴ Incomplete transfer documents are a barrier, since such documents are often the only method of communication between hospital and nursing home for patients with dementia. In one study²⁰⁵ older-age, female gender, dementia, shorter duration of nursing home residence, and off-hours hospital transfer were associated with *less* complete NH-to-Hospital transfer documents. For older adults, especially those with cognitive impairment, mental status documentation and recognition of delirium are important features of transitional care.²⁰⁶⁻²¹⁰ Yet, in one study,²¹¹ mental status descriptions were present in only 69% of transfer documents, and 67% of patients missing a mental status description upon nursing home-to-hospital transfer *had dementia*. Even when present, mental status descriptions have no standard format and use abbreviated phrases, such as “alert and oriented,” with limited meaning. This is important because changes in mental status characteristic of delirium are associated with adverse outcomes,²¹²⁻²¹⁷ and require specific approaches to evaluation, prevention and/or treatment.²¹⁸⁻²²⁰

Healthcare providers lack a tool to quickly assess and document mental status and its changes. Mental status is best considered a “vital sign” akin to heart rate, temperature and blood pressure in providing a clinical baseline. Significantly, in ill older adults and those with dementia, changes in mental status may precede or supplant changes in traditional vital signs.²⁰⁹ There are important challenges to development and implementation of a mental status vital sign. First, mental status has multiple dimensions – e.g., consciousness, memory, executive function – that have varying significance depending on the patient’s baseline cognitive function. Second, cognitive assessment tools often require patient performance (e.g., digit span), and repeated performance (e.g., every day or every shift) may affect patient responses. Third, in most healthcare encounters vital signs are ascertained and documented by front-line nursing staff. Development of a mental status vital sign would need to be constructed with this use in mind.

Reducing barriers to transitional care for nursing home residents with dementia would require education and training of providers in a variety of settings and improving workflow to increase efficiency and completeness of transfer communication. This might include 1) flexibility in the technology providers use to communicate, 2) allowing providers to prioritize information in transfer communications according to the needs of

each patient and the circumstances of transfer, and 3) holding facilities and providers accountable when transfer communication breaks down. Given that sudden transfers are associated with greater barriers to communication, nursing homes and hospitals need to institute protocols to reduce sudden, night, or weekend transfers, and to increase communication consistency when unplanned transfers do occur so that they are as effective as planned ones. Aspects of patient safety culture that can hinder effective transfers include lack of feedback and communication about errors, punitive response to error, lack of organizational learning or continuous improvement, and low teamwork.²²¹⁻²²² Other studies²²³⁻²²⁴ have found that absence of specialized geriatrics care in the hospital is associated with worse inter-site communication and outcomes, including inconsistency of hospital care with end-of-life preferences, a crucial aspect of care for nursing home patients with dementia.

The potential benefits of a mental status vital sign that is effectively transmitted to the next site of care can be realized. However, it will require: 1) that barriers to reliable measurement, documentation, and widespread utilization are overcome; and, 2) research to understand organizational and cultural barriers be performed that may also help stakeholders predict whether systems-level interventions are likely to work. The rapid growth of the dementia population will demand that the barriers be overcome and the research be accomplished to efficiently and safely transition patients with dementia through their chronic illnesses and the existing health care maze.

IX. HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

Coordinating care, and effecting safe, efficient transitions may be stymied by incorrect understanding of the 2002 Health Insurance Portability and Accountability Act (HIPAA). The Privacy Rule specifically states that it is not intended to interrupt the flow of appropriate clinical information. However, overzealous or erroneous interpretations can impair communication. This lack of clinical data sharing becomes even more crucial in the transition of those unable to provide good personal health information due to cognitive issues. It is important that the clinician have an understanding of HIPAA and utilize it to support transitions in patients with cognitive impairment, and not allow it to be a barrier to that care.

Table 1 presents some examples of myths and facts about the HIPAA Privacy Rule. A number of web sites offer reliable information to clarify common misconceptions about compliance with the HIPAA Privacy Rule. See Resources for a non-comprehensive list of sites that facilities may wish to consult for guidance.

TABLE 1 Examples of Myths and Facts about the HIPAA Privacy Rule

| Myth | Fact |
|---|---|
| Practitioners may not e-mail colleagues about patients. | The privacy rule does not forbid communication about patients by e-mail. |
| Practitioners must refer to patients by their medical record number, not by name, in e-mail messages. | The privacy rule does not forbid the use of patient names in e-mail messages. |
| A provider or hospital must have a release signed by the patient in order to provide test results to another provider or hospital that is treating the patient. | Providers involved in a patient's care are permitted to freely share information for treatment purposes without a signed patient authorization. |
| Prescriptions or insurance authorization forms may not be sent by fax. | The privacy rule does not forbid the faxing of prescription or insurance information. |
| Practitioners cannot provide any patient information to a patient's family. | As long as a patient does not object, the privacy rule permits practitioners to share needed information with anyone the patient identifies as involved in his or her care. |

Sources: Lo et al, JAMA 2005; Fast Facts for Covered Entities, Fast facts for Covered Entities, <http://.gov/ocr/privacy/hipaa/understanding/coveridentities/cefastfacts.html>

X. COMPETENCE AND CAPACITY

Every person, even with a diagnosis of cognitive impairment, is their own decision-maker until otherwise appropriately determined. This section addresses those occasions when the patient is declared as not able to make decisions in his/her own best interests. It is not created as a legal document, but as a guide to assist the clinician in how to generally proceed in decisions in regards to advance directives, transitions and clinical interventions for those with cognitive impairment. State statutes vary so the clinician should have some familiarity with their individual state laws concerning competence and capacity to function effectively in nursing home practice'

Competence

This is a legal designation, devoid of medical diagnosis. At the age of majority, which varies by state, all persons are inherently competent to make personal decisions. If that ability is challenged, a hearing is conducted by the court. Medical opinion may be sought by the court in the decision, but removal of competence is a court decision. Only a court of law may reinstate that competence. Once lack of competence is determined, decisions for that person are through a court-appointed proxy, although it is expected that the proxy will consult with the resident to the extent possible. Court documents will be available confirming this status along with the court-appointed proxy to speak for the patient. There may be more than one proxy, as the court may have one for healthcare decisions, another for financial matters, and even other proxies as it deems necessary to protect the interests of the person lacking competence. Facilities should have a copy of all related documents permanently installed on the clinical chart.

When told by the facility staff that the resident is “Incompetent,” ask to see the court documents as this term is not infrequently utilized interchangeably with “dementia” and “lacking capacity.” The difference is vital to appropriate determination of attempting or declining interventions, including transition to another site of care.

Capacity

In contradistinction to “competence,” this status is a clinical one. Every adult is considered to have decision-making capacity until properly evaluated and determined to lack it. The presence of capacity, or its lack, is a conclusion by the examining clinician(s) of a person’s ability to comprehend the decision – or decisions - at hand. There is no standardized instrument upon which a threshold score indicates decisional capacity or incapacity. It is independent of legal pronouncements and clinical tests. This clinical determination dependent on several factors: the specific decisions being contemplated, the judgment of the clinician, and the recognition that capacity may fluctuate both temporally and in relation to the subject under discussion. There are excellent tools available for clinicians to utilize (such as the U-CARE method based on the work of Grisso and Appelbaum) that may assist in the judgment. In general, if a patient is able to understand the options before him or her, appreciate the significance of the decisions being considered, use reasoning to weigh the differences between them, and express the choice—preferably on a consistent basis over time—then the patient will be considered to have capacity for that set of decisions. In complex cases, a formal mental health evaluation may be helpful. Since capacity may fluctuate over time, or be related to the subject under discussion, supportive documentation regarding

decision-making ability should be part of the clinical record when significant interventions such as hospital transfers are being contemplated. States may have a standard format or document for the declaration of the presence or lack of capacity.

Which licensures may determine capacity, and the number of clinicians needed to do so will vary between states. Generally speaking the nursing home attending physician or medical director should be able to determine the presence or absence of medical decision-making capacity without having to invoke any mental health professional consultation. Determine the applicable statutes in your state.

Key Concepts:

- A person can have cognitive impairment and have capacity
- A person can have cognitive impairment and be competent
- A person can be incompetent but not be demented
- A person can lack capacity but not be demented
- A physician can diagnose dementia, and can determine a resident to lack capacity, but cannot judge competence
- The court can declare incompetency, but not diagnose dementia or determine capacity
- People retain the right to make what the interdisciplinary team (IDT) considers “bad decisions.” Choices made with which the IDT disagrees are not, in and of themselves, evidence for a lack of capacity.

XI. ADVANCE CARE PLANNING IN DEMENTIA

Advance Care Planning (ACP) is a keystone of the care plan for those with cognitive impairment. Patients with dementia have lost, or over time will lose the ability to meaningfully participate in decisions about their medical care. Optimal ACP will determine the personal goals of care, attitudes toward medical interventions, and factors impacting quality of life while decision-making capacity still exists and memorialize those determinations. This should be done as soon as practical as all too often there has been no advance directive formulated for a dementia patient by the time they are suffering from a more advanced stage of dementia. This can leave family members—and health care providers—in a difficult situation.

Family members should be invited to participate in the discussions if the patient permits. If not, they should at least be notified of the results of the conversation with patient consent. It should never be a surprise when a family member discovers during a crisis that their loved one has decided to opt for no resuscitation or no aggressive interventions including not to be hospitalized. If a family member were to disagree with the patient decisions, or suggest that the patient did not understand due to the dementia, confrontational and potentially litigious situations may arise. Even more catastrophic, such disputes decrease the chances of honoring patient wishes. (Note: Additional information on evaluating capacity is available in the “COMPETENCE AND CAPACITY” section of this paper)

Having clear advance directives or appropriately executed Physician Orders for Life Sustaining Treatment (POLST) paradigm orders in place that firmly document treatment wishes of the dementia patient is essential. If the patient has made the decision to forgo aggressive interventions, unnecessary emergency department visits, hospitalizations and re-hospitalizations can be averted and allow onsite care in the nursing facility. A discussion with the resident and family before a crisis arises is the best timing to discuss these issues, including the benefits, risks and burdens of a trip to the hospital. Honest conversation can include that for vulnerable elders, particularly with cognitive impairment, any trip to the hospital can have very negative consequences including delirium, physical and chemical restraints, skin breakdown from prolonged time on a gurney, intrusive exams by strangers, and other unfortunate, bewildering events. If further hospital care is not consistent with the goals of care, appropriate documentation and orders can be initiated.

State laws vary in the handling of the patient lacking capacity when healthcare decisions are required. Some will allow a surrogate to make healthcare decisions on behalf of an incapacitated resident, even in the absence of a valid Advance Healthcare Directive or Durable Power of Attorney for Health Care. Additional states have a specific hierarchy for proxy choices (i.e., spouse, then child, then sibling and so forth), while others allow the person who best knows the patient’s wishes (substituted judgment) to serve as decision-maker. Additional states allow the interdisciplinary team to make decisions based on the patient’s best interest (with an Ethics Committee type format), while still others may require action of the court system to provide the

necessary declarations. Thus, being familiar with the laws regulating the identification of a proxy for patients lacking capacity is an essential tool in patient-centered care to honor patient wishes in the dementia population.

To allay confusion, and protect the rights of self-determination of the patient, this paper recommends a permanent, specific site in the patient chart or distinct tab in the facility Electronic Medical Record (EMR) for documentation on patient wishes regarding end-of-life care issues. The presence and location should be part of facility staff in-services. It should be updated at least annually, and in the event of significant clinical changes.

Clinicians who care for dementia patients should gain the skills to navigate such discussions. There are very useful educational tools available, including the Decision Guides from the Coalition for Compassionate Care of California (www.coalitionccc.org), the advance care planning section on the Interact website (www.interact.fau.edu), Five Wishes at www.fivewishes.org, and Vital Talk at www.vitaltalk.org to name a few examples. More generic advance care planning sites like prepareforyourcare.org and theconversationproject.org can help in acquisition of the necessary skills. If the physician feels uncomfortable in this sphere, consider alternative options. Perhaps the nursing facility has an exceptional member of the interdisciplinary team who is skilled in these discussions or local availability of a palliative or hospice team to involve.

One barrier to be surmounted is the confusing language utilized in advance directive conversations. Loaded words as “selective” or “limited” treatment, “no heroics,” “comfort care,” palliative care, hospice care, and many others build walls to understanding. Assisting the patient and family through this vocabulary using simple, clear language and being able to interpret it for the patient and family members making decisions on behalf of a loved one with dementia, is the clinician’s goal.

Low-health-literacy, neutrally written informational materials can be invaluable in helping families digest the complex material. Video tools can also be a highly effective adjunct. They can be relatively brief, available in several languages and can be shown on a mobile device. One such set of products can be viewed through Advance Care Planning (ACP) Decisions at www.acpdecisions.org.

Make it a priority to discuss goals of care and advance care planning with every dementia patient and family—as early as possible, and as often as necessary. Convene “Expectation conversations” with patients and families soon after the diagnosis of dementia is made. Those frank discussions can explore the likely clinical course of dementia, progression and decisions which can be expected to arise. Issues critical to discuss include: 1) What to do when pneumonia develops; 2) How to handle problems with nutrition and hydration, and 3) Whether or not to hospitalize for worsening conditions.²²⁶

XII. THE IMPORTANCE OF HOSPICE CARE AND PALLIATIVE CARE IN DEMENTIA PATIENT TRANSITIONS

Elders with dementia not infrequently fare poorly after a hospitalization for acute illness or trauma, with subsequent compromise in cognition and function. There is an increased rate, in this population, for institutionalization in the long-term care space, worsening comorbidity and mortality. Once begun, this functional decline often persists, and may even accelerate with a higher risk of delirium, pressure ulcers, falls, untreated pain, agitation or adverse behaviors, and incontinence, among others. Often, these events are rapid and surprising to the patient and family. Without a plan of care to guide in subsequent management, clinical management can become piecemeal and reactive, poorly serving especially the cognitively impaired patient. Ideally, the goal is to have a plan of care in place to support goals and potentially other treatment opportunities before an acute event occurs. Avoiding care based primarily on reactivity, provider teams can utilize acute changes to initiate, or further critical conversations. Convene “Expectation conversations” with patients and families as soon after the diagnosis of dementia is made, and with acute changes in clinical status. Those frank discussions can explore the likely clinical course of dementia, progression and decisions which can be expected to arise.²²⁷ Seeking patient wishes with these dialogues allows that desired patient-centered approach to care that may materially affect unnecessary transitions.

Palliative care, as defined by the Center to Advance Palliative Care (CAPC) is medical care lead by a specially trained, multidisciplinary team that works together with provider teams, at any point in the continuum of care, to establish an “extra layer” of support for patients with serious illnesses, even during curative treatments. It focuses on establishing goals of care, providing patients with relief from the symptoms and stress of a serious illness, and improving the quality of life for both the patient and the family. It is a holistic and systemic approach to care. Palliative care can help establish advance directives (i.e., the Health Care Proxy and other key decisions) and can work with patients and families on generating and supporting goals for life-sustaining treatment, including Physician Orders for Life Sustaining Treatment (POLST) paradigm forms.

A key point is the distinction between palliative care and hospice care. Hospice is a specific, defined Medicare benefit that provides multifaceted supportive multidisciplinary care for terminally ill patients who have been assessed by physicians, and certified to have less than 6 months of life if their terminal illness progresses at its expected pace. Patients who receive hospice care have a focus on symptom relief and quality of life rather than receiving curative treatment for their underlying disease. Hospice is end-of-life care, where the focus is on quality of life and symptom control rather than longevity. Residents on the hospice benefit are less likely to return to the acute care setting as shown in a randomized controlled trial showing that offering hospice in the NH setting reduced hospital transfers.²²⁸ Additionally, hospice in the nursing home is associated with decreased hospitalization, reduced intensive care unit utilization and fewer feeding tubes although no cost savings.²²⁹

There are specific guidelines as to who can qualify for the Hospice benefit regarding patients with cancer, COPD, congestive heart failure, etc. The Hospice eligibility recommendations for dementia include:

1. Stage 7C or beyond according to the FAST Scale (ability to speak is severely limited and ambulatory ability is lost without personal assistance), **and**
2. One or more of the following conditions in the past 12 months:
 - Aspiration pneumonia
 - Pyelonephritis
 - Septicemia
 - Multiple pressure ulcers (stage 3-4)
 - Recurrent Fever
 - Other significant condition(s) that suggests a limited prognosis
 - Inability to maintain sufficient fluid and calorie intake in the past 6 months

However, a patient with dementia, who has a life expectancy of less than six months, may satisfy other specific, hospice guidelines and merit the benefit as well.

Currently, the most rapid growth in hospice participants is in long-term care facilities, with dementia the most common diagnosis for entering hospice in long-term care. Entering the hospice program requires patient and/or family/health care proxy embrace of the concept, as cure no longer remains the goal. All end-of-life care in the nursing home is not within the Medicare hospice benefit, although the tenets of reducing end-of-life suffering remain the same.

Palliative care, similarly to the hospice goals, is designed to relieve the physical and mental symptoms of a disease process. While hospice is specifically enacted for the final stage of life, palliative care symptom alleviation can be implemented at any point in a chronic illness trajectory, and may continue in operation for prolonged periods of time. Patients receiving palliation may still pursue curative or more aggressive treatment of the underlying disease process. Embrace of this concept also requires an understanding of what palliation encompasses.

The dementia patient and the family should be apprised of the concepts of hospice and palliation as soon as they are ready for that discussion. There does not need to have been a specific, precursor event or medical issue to drive the discussion, although that typically is the case. Initiation of the discussion is in itself a heralding event. Typically this is not a single discussion, but a series of conversations that may require weeks, months, or even longer. There should be no aversion to initiating the conversation. A randomized controlled trial of systematic implementation of a program to increase use

of advance directives in a nursing home setting has been found to reduce health care services utilization without affecting satisfaction of mortality.²³⁰

XIII. SUMMARY & CONCLUSIONS

It is the conclusion of this paper that we, as a medical community, have a long journey ahead to enhance the quality of dementia care, particularly during transitions. The basic clinical lexicon appears perversely backwards for those involved in dementia care. Typically, transfer information declares the primary and secondary medical diagnoses of the transitioned patient. Meanwhile, cognitive impairment, often imprecisely or incompletely described, is relegated far down on the diagnosis list as an incidental comorbidity, if at all. The dementia patient is then shoehorned into the general population guidelines for Coronary Artery Disease (CAD), diabetes and/or Chronic Obstructive Pulmonary Disease (COPD) which are inappropriate to adequately address the core needs of the dementia patient. Post-transfer care plans often fail to address key problems; i.e., the bewilderment involved in being transferred to a new site of care with new caregivers who may not know of the presence of dementia and do not know the patient's personality, behavior triggers, likes, dislikes and habits; and, may introduce new, potentially inappropriate, medications and interventions. Fundamental issues of dementia care often go unaddressed: decision-making capacity, who speaks for the patient, advance directive decisions about degree of interventions desired, appropriate medication management, avoiding delirium and instituting non-pharmacological approaches to the distressed behaviors that regularly erupt during transfers.

We advocate for a clinical paradigm where: 1) Dementia is not overlooked in clinical documentation, for example, "Dementia, with acute exacerbation of COPD" for the transfer; and, 2) Unnecessary transitions, particularly to the acute setting are averted by appropriate interventions on site.

As the international struggle to improve transitions - particularly with the metric around 30-day readmissions to the hospital - continues, this paper suggests the issue of dementia in transitions is particularly timely.

Impetus is needed to cause dementia and related cognition impairments to emerge from the medical history backroom. Regular screening in high risk clinical sites, particularly in the LTC care arena, for dementia should be part of every care plan. When discovered it should be documented and monitored sequentially over time. Appropriate interventions should be instituted for this relentless, progressive and often fatal disease. These may include pharmacotherapy, but more pointedly include education for patient, family and interdisciplinary team of the dementing process, future decisions that will be required and embedding patient wishes into the care plan.

As a medical community, as multidisciplinary patient care teams, and as a society much is needed to insure quality in dementia care, and the frequent transitions that result. It is our fervent hope that this paper will both add to that discussion, and trigger additional conversations around safer, more efficient transitions when they are found necessary.

XIV. NEXT STEPS:

1. Seek out and appropriately document dementia and other cognitive impairment in patients in the long-term care continuum, both upon admission and at appropriate intervals thereafter.
2. Advocate for improving transitions for those with dementia across care settings that will allow providers to measure and improve care, including but not limited to
 - High-quality guidelines to guide the transition, and
 - Bi-directional measures to evaluate transitions.
3. Provide care planning for the patient with dementia that is individualized, consistent, and based on an appropriate assessment [AMDA Clinical Practice Guideline (CPG) on dementia (2012 update)]
4. Transmit mental status information consistently as part of the core data set when a patient is transitioned from one site of care to another. Such transmission should include at a minimum:
 - Mental status abnormality present or absent;
 - Features of cognition, including normal or abnormal alertness, orientation, attention, and/or thinking (psychosis);
 - Etiology of any present mental status abnormality or change, if known;
 - Time course of a mental status abnormality or change, if present, including onset, expected duration, and permanence.
5. Utilize tools from AMDA and other appropriate entities to optimize dementia care for on-site treatment whenever possible and in transitions when they become necessary. (See Appendix A for a list of AMDA resources)
6. Advocate for the widespread establishment of “geriatric friendly” emergency departments to appropriately evaluate the cognitively impaired in order to reduce iatrogenic harm and reduce unnecessary hospital admissions and readmissions.
7. Establish a permanent, specific, prominent site in the patient chart, and/or tab in the Electronic Medical Record for advance care planning information. This site would include, but is not limited to:
 - Advance Directive information;
 - Physician Orders for Life Sustaining Treatment (POLST) paradigm or equivalent documentation (in states where available);
 - Do Not Resuscitate (DNR) orders, or other instructions regarding resuscitation and intensity of interventions to be performed;
 - Determination of patient capacity or incapacity;
 - Incompetence declarations when performed;
 - Where the patient lacks capacity, the person legally entitled to speak for the patient, along with contact information; and,

- Update all information at least annually, or when a significant change in status occurs (i.e., hospitalization, or diagnosis of major illnesses such as malignancy)
8. Enhance awareness of the imperative to recognize the common occurrence of delirium in this population, its diagnostic differentiation from dementia, its negative prognostic implications, and the need to promptly address it,
 9. Create a feedback mechanism for hospital-based providers to receive outcomes of specific patients transitioned to post-acute and long-term care facilities. Lack of access to such information inhibits quality improvement activities.
 10. Establish Health Information Technology (HIT) platforms and standards for appropriate, interoperable and timely information exchange for all patients.
 11. Support appropriate and judicious medication usage for cognitively impaired patients, especially psychotherapeutic medications, to reduce harm and unnecessary transfers to the acute facility.
 - Regular medication reviews, gradual dose reductions (GDR) when appropriate and withdrawal of any medications without specific indications for their use.
 - Antibiotic stewardship to prevent their unnecessary use and adverse consequences.
 12. Activate and engage families in the caregiving process
 - Convene “Expectation conversations” (Levy C. Expectation conversations about the very predictable events in advanced dementia. JAMDA 16 (2015)²²⁷ with patients and families soon after the diagnosis of dementia is made. Issues critical to discuss include:
 - What to do when a pneumonia develops
 - How to handle problems with nutrition and hydration
 - Whether or not to hospitalize for worsening conditions
 - Educate providers and families of the importance of implementing a non-pharmacologic response to behavioral and psychiatric symptoms of dementia (BPSD).
 - Seek out and address caregiver burden of care, both in the family and in facility staff delivering care.
 - Educate and activate the social supports of those with dementia to be actively involved in transitions for the dementia population; i.e.,
 - Accompany them, whenever possible, to a different site of care
 - Provide crucial medical, social and advance directive information to new/different practitioners

- Act as an advocate in providing substituted judgment and communicating the patient's known wishes or, if wishes are not known, make decisions in the best interest of the patient.

13. Embed risk adjustment for dementia, with its significant mortality, morbidity and transitions into current value-based payment programs, and into subsequently developed ones.

XV. RECOMMENDATIONS

We recommend the suggested next steps to be put before the AMDA Board of Directors.

XVI. APPENDICES

APPENDIX A: AMDA RESOURCES FOR CARE TRANSITIONS IMPROVEMENT

- Palliative Care in the LTC Setting Clinical Practice Guidelines
- Dehydration and Fluid Maintenance in the Long-Term Care Setting Clinical Practice Guidelines
- Delirium and Acute Problematic Behavior Clinical Practice Guidelines
- Dementia Clinical Practice Guidelines
- Falls and Fall Risk Clinical Practice Guidelines
- Pain Management Clinical Practice Guidelines
- Acute Change of Condition in the Long Term Care Setting Clinical Practice Guidelines
- Know-it-All Before You Call®
- Know-It-All When You're Called®
- Multidisciplinary Medication Management Manual
- *Transitions in the Long-Term Care Continuum* Clinical Practice Guidelines

AMDA's NQF endorsed dementia measures to define and measure dementia in LTC

- *Persistent Indicators of Dementia without a Diagnosis—Long Stay*
 - <http://www.qualityforum.org/QPS/2091>
- *Persistent Indicators of Dementia without a Diagnosis—Short Stay*
 - <http://www.qualityforum.org/QPS/2092>

Transitions of Care:

AMDA White Paper: *Improving Care Transitions between the Nursing Facility and the Acute Care Hospital Settings* (2010)

AMDA White Paper: *Improving Care Transitions from the Nursing Facility to a Community-Based Setting* (AMDA White Paper, March 2009)

Improving Transitions of Care: The Vision of the National Transitions of Care Coalition (May 2008)

Cultural Competence: Essential Ingredient for Successful Transitions of Care (NTOCC White Paper)

Improving Transitions of Care with Health Information Technology (NTOCC White Paper, December 2010)

Dementia:

<http://www.prolibraries.com/amda/?select=session&sessionID=1073>

www.prolibraries.com/amda/?select=session&sessionID=1067

<https://www.amda.com/advocacy/demaddendum.cfm>

www.amda.com/governance/whitepapers/A12.cfm

http://www.amda.com/news/releases/2013/pr_121613.pdf

<http://www.amdafoundation.org/.../58-2013-amda-foundation-pfizer-qi-award-presentation-enhancing-the-implementation-of-a-new-advance-direc...>

http://www.amda.com/members/managementtools/amda_talking_points.pdf

<http://www.amda.com/consumers/CultureChangeMar10.pdf>

<http://www.amdafoundation.org/index.php/foundation-library/.../file>

First Diagnosis and Management of Incontinence in Older People with and without Dementia in Primary Care: A Cohort Study Using The Health Improvement Network Primary Care Database (Robert L. Grant, Vari M. Drennan, Greta Rait, Irene Petersen, Steve Iliffe, PLOS Med, August 2013)

Antipsychotics:

http://www.amda.com/advocacy/AMDA_Antipsychotics_Tlkg_Pts.pdf

http://www.amda.com/advocacy/amda_education_plan_antipsychotics.pdf

<https://www.amda.com/consumers/antipsychotics.cfm>

http://www.amda.com/news/.../AMDA_statement_on_ProPublica_Report.pdf

<https://www.amda.com/advocacy/demaddendum.cfm>

https://www.amda.com/advocacy/AP_package_070513.pdf

<http://www.prolibraries.com/amda/?select=session&sessionID=>

https://www.amda.com/tools/clinical/.../DementiaCPG_excerpt.pdf

<http://www.amda.com/advocacy/legal/.../Summary%20for%20web.pdf>

cpgnews.org/DE/MeasureTool-Dementia.pdf

APPENDIX B: HEALTH AND HUMAN SERVICES/CENTERS FOR MEDICARE AND MEDICAID SERVICES TOOLS

Focused Dementia Care Survey Tools

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-16-04.pdf>

CMS Dementia Tool:

www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/Survey-and-Cert-Letter-16-04.html?DLPage=1&DLEntries=10&DLSort=2&DLSortDir=descending
www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/Survey-and-Cert-Letter-16-04.html?DLPage=1&DLEntries=10&DLSort=2&DLSortDir=descending

Hospital Guide to Reducing Medicaid Readmissions

<http://www.ahrq.gov/professionals/systems/hospital/medicaidreadmitguide/index.html>
Publication # 14-0050-EF

Care Coordination for People with Alzheimer's Disease and Related Dementias: Literature Review

<https://aspe.hhs.gov/care-coordination-people-alzheimers-disease-and-related-dementias-literature-review>

APPENDIX C: OTHER RESOURCES

The National Plan to Address Alzheimer's Disease: 2015 Update:

<https://aspe.hhs.gov/national-plan-address-alzheimer%E2%80%99s-disease-2015-update>

References for use of HIT in transitions and in nursing homes:

- Culley CM, Perera S, Marcum ZA, Kane-Gill SL, Handler SM. Using a Clinical Surveillance System to Detect Drug-Associated Hypoglycemia in Nursing Home Residents. *J Am Geriatr Soc.* 2015 Oct;63(10):2125-9. doi: 10.1111/jgs.13648. Epub 2015 Oct 12. PubMed PMID: 26456318.
- Lapane KL, Hughes CM, Daiello LA, Cameron KA, Feinberg J. Effect of a pharmacist-led multicomponent intervention focusing on the medication monitoring phase to prevent potential adverse drug events in nursing homes. *J Am Geriatr Soc.* 2011 Jul;59(7):1238-45. doi: 10.1111/j.1532-5415.2011.03418.x. Epub 2011 Jun 7. PubMed PMID: 21649623; PubMed Central PMCID: PMC3157676.
- Smith KJ, Handler SM, Kapoor WN, Martich GD, Reddy VK, Clark S. Automated Communication Tools and Computer-Based Medication Reconciliation to Decrease Hospital Discharge Medication Errors. *Am J Med Qual.* 2015 Mar 9. pii: 1062860615574327. [Epub ahead of print] PubMed PMID: 25753453.
- Bayoumi I, Al Balas M, Handler SM, Dolovich L, Hutchison B, Holbrook A. The effectiveness of computerized drug-lab alerts: a systematic review and meta-analysis. *Int J Med Inform.* 2014 Jun;83(6):406-15. doi: 10.1016/j.ijmedinf.2014.03.003. Epub 2014 Mar 29. Review. PubMed PMID: 24793784.

Act on Alzheimer's

Tools, videos and resources
Actonalzheimers.org

American College of Emergency Physicians Geriatric Emergency Department Guidelines:

<http://www.acep.org/geriEDguidelines>

Alzheimer's Association

www.alz.org

Society of Hospital Medicine

www.hospitalmedicine.org

Dr. Eric Coleman Website

www.caretransitions.org

National Transitions of Care Website

www.ntocc.org

Colorado Quality Improvement Organization Website

www.cfmc.org

Intervention to Reduce Acute Care Transfers (INTERACT)

<http://interact.fau.edu>

Physician Orders for Life Sustaining Treatment (POLST)

<https://wmsa.org/POLST>

Assessing Care of Vulnerable Elders (ACOVE) Measures

www.rand.org/health/projects/acove/about.html

Agency for Healthcare Research & Quality (AHRQ)

Care Coordination Measures Atlas

Available at the Institute for Healthcare Improvement:

www.IHI.org

Herndon L, Vones C, Bradke P, Rutherford P. How-to Guide: Improving Transitions from the Hospital to Skilled Nursing Facilities to Reduce Avoidable Rehospitalizations. Cambridge, MA: Institute for Healthcare Improvement; June 2013.

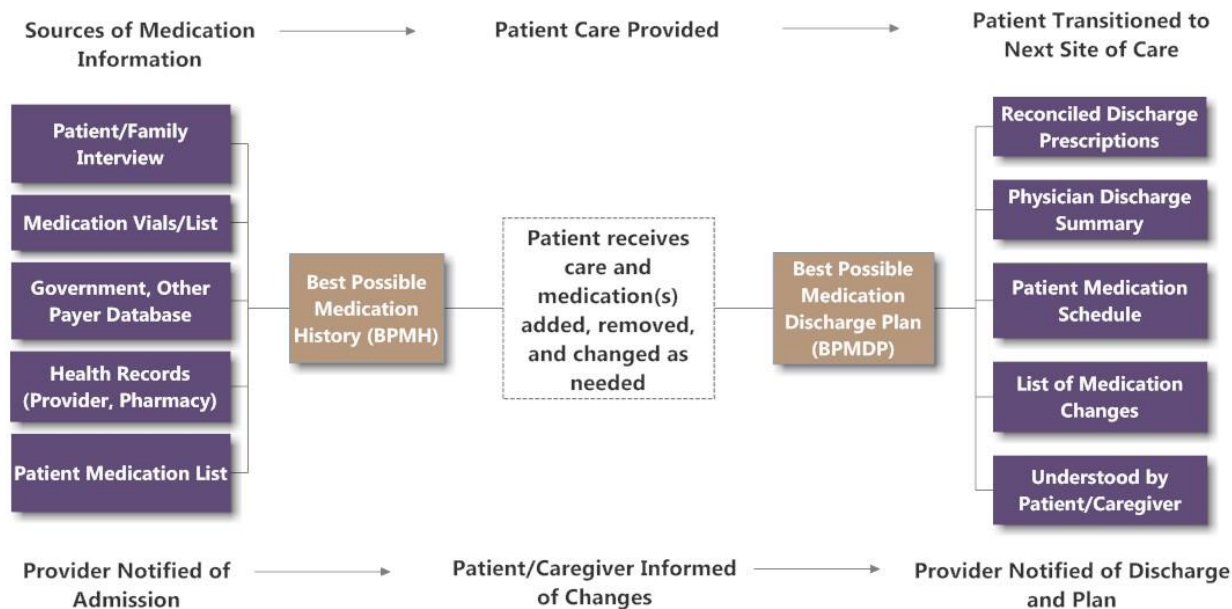
The High 5s Project Implementation Guide. Assuring Medication Accuracy at Transitions in Care: Medication Reconciliation. World Health Organization. Version 4; October 2014. Available at <http://www.who.int/patientsafety/implementation/solutions/high5s/h5s-guide.pdf?ua=1>

The Family Caregiver Activation in Transitions Tool © Eric A. Coleman, MD, MPH

<http://caretransitions.org/fcat-tool-download/>.

APPENDIX D: MEDICATION RECONCILIATION AND MANAGEMENT IN DEMENTIA

Figure 1. The Medication Reconciliation Process



Sources: The High 5s Project Implementation Guide. Assuring Medication Accuracy at Transitions in Care: Medication Reconciliation. World Health Organization. Version 4; October 2014.

Kwan JL, Lo L, Sampson M, Shojania KG. Medication reconciliation during transitions of care as a patient safety strategy; a systematic review. *Ann Intern Med* 2013;158:397-403.

Table 1. World Health Organization Guiding Principles for Medication Reconciliation

| | |
|--------------|--|
| Principle 1. | An up-to-date and accurate patient medication list is essential to ensure safe prescribing in any setting. |
| Principle 2. | A formal structured process for reconciling medication operates at all interfaces of care. |
| Principle 3. | Medication reconciliation on admission is the foundation for reconciliation throughout the episode of care. |
| Principle 4. | The process of medication reconciliation is one of shared accountability with staff aware of their roles and responsibilities. |
| Principle 5. | Medication reconciliation is integrated into existing processes for medication management and patient flow. |
| Principle 6. | Patients and families are involved in the medication reconciliation. |
| Principle 7. | Staff responsible for reconciling medications are trained to take a best possible medication history and reconcile. |

Source: The High 5s Project Implementation Guide. Assuring Medication Accuracy at Transitions in Care: Medication Reconciliation. World Health Organization. Version 4; October 2014.

Table 2. Potentially Harmful Medications in Individuals with Dementia and Alternatives

| Class | Drugs | Alternatives |
|---------------------------|--|--|
| Anticholinergics | | |
| Tricyclic antidepressants | Amitriptyline Amoxapine Clomipramine Desipramine Doxepin (> 6mg) Imipramine Nortriptyline Paroxetine Protriptyline Trimipramine | For depression – SSRI, SNRI, bupropion For neuropathic pain – SNRI, capsaicin topical, gabapentin, pregabalin, lidocaine patch Taper, time permitting, in the absence of delirium |
| Antihistamines | Brompheniramine Carbinoxamine Chlorpheniramine Clemastine Cyproheptadine Dexbrompheniramine Dexchlorpheniramine Dimenhydrinate Diphenhydramine Doxylamine Hydroxyzine Meclizine Triprolidine | Intranasal normal saline Second-generation antihistamine (e.g., cetirizine, fexofenadine, loratadine) Intranasal steroid (e.g., beclomethasone, fluticasone, over the counter) |
| Antiparkinsonian agents | Benzotropine Trihexyphenidyl | Levodopa with carbidopa |
| Skeletal muscle relaxants | Cyclobenzaprine Orphenadrine | For acute mild or moderate pain – acetaminophen, salsalate. Alternatively, ibuprofen or naproxen If no heart failure or if eGFR > 30 ml/min and given with PPI for gastroprotection if used for > 7 days. |
| Antipsychotics | Aripiprazole Asenapine Brexipiprazole Chlorpromazine Clozapine Fluphenazine Haloperidol Iloperidone Loxapine Lurasidone Mesoridazine Olanzapine | For behavioral complications of dementia – if nonpharmacological approaches have failed, and psychosis and danger to self or others, low dose nonanticholinergic agents (e.g., risperidone, quetiapine) for shortest duration possible may be acceptable Taper gradually as tolerated |

| | | |
|---------------------------------|---|--|
| | Paliperidone Perphenazine Quetiapine Risperidone Thioridazine Trifluoperazine Ziprasidone | |
| Benzodiazepines | <u>Short- and intermediate-acting</u> Alprazolam Estazolam Lorazepam Oxazepam Temazepam Triazolam <u>Long-acting</u> Clorazepate Chlordiazepoxide (alone or in combination) Clonazepam Diazepam Flurazepam Quazepam | For anxiety – Buspirone, SSRI, SNRI For sleep – non-pharmacologic approaches, including cognitive behavioral therapy, sleep hygiene, sleep restriction, stimulus control, and relaxation techniques (see Ref Ann Long Term Care 2010) Taper, time permitting, in the absence of delirium |
| Nonbenzodiazepine hypnotics | Eszopiclone, zaleplon, zolpidem | As above, for sleep Taper, time permitting, in the absence of delirium |
| Histamine-2 receptor antagonist | Cimetidine Famotidine Nizatidine Ranitidine | Proton pump inhibitor |

Sources: The American Geriatrics Society 2015 Beers Criteria Update Expert Panel. American Geriatrics Society 2015 updated Beers criteria for potentially inappropriate medication use in older adults. J Am Geriatr Soc 2015;63:2227-46.

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Abbreviations: eGFR = estimated glomerular filtration rate, PPI = proton pump inhibitor, SNRI = serotonin norepinephrine reuptake inhibitor, SSRI = selective serotonin reuptake inhibitor

Table 3. Medications Rarely or Never Appropriate for Individuals with Advanced Dementia

| Rarely appropriate | Never appropriate |
|---|---|
| Alpha blockers (e.g., doxazosin, terazosin) | Acetylcholinesterase inhibitors |
| Antiandrogens (e.g., flutamide, finasteride) | Antiestrogens (e.g., tamoxifen) |
| Antiarrhythmics (e.g., amiodarone, quinidine) | Antiplatelet agents, excluding aspirin (e.g., clopidogrel, prasugrel) |
| Antispasmodics | Cytotoxic chemotherapy (e.g., cyclophosphamide, methotrexate) |
| Appetite stimulants | Hormone antagonists |
| Bisphosphonates | Immunomodulators |
| Bladder relaxants | Leukotriene receptor antagonists (e.g., montelukast, zafirlukast) |
| Clonidine | Lipid lowering medications (e.g., statins) |
| Digoxin | Memantine |
| Heparin and low molecular-weight heparin | Sex hormones |
| Hydralazine | |
| Mineralocorticoids | |
| Tamsulosin | |
| Warfarin | |

Source: Holmes HM, Hayley DC, Alexander GC, Sachs GA. Reconsidering medication appropriateness for patients late in life. Arch Intern Med 2006;27:605-9.

XVII FOOTNOTES:

I. INTRODUCTION

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