

The Alzheimer's Patient Experience

By: Ron Wince, President/CEO of Guidon Performance Solutions

Introduction

According to the Alzheimer's Association, approximately 5.2 million patients are afflicted with Alzheimer's disease today; a number that is expected to nearly triple or quadruple by the year 2050. While scientists have made extreme strides in unraveling the mysteries of the disease over the past 25 years, the Alzheimer's Association reports that more than 411,000 new cases are reported each year and the disease is the third leading cause of death of individuals over the age of 65.

Currently, no treatment is available to delay or stop the deterioration of brain cells in Alzheimer's disease. And while the U.S. Food and Drug Administration has so far approved five drugs that temporarily slow worsening of symptoms for about 6 to 12 months, on average, these treatments only work for about half of the individuals who take them.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for diagnosed individuals and their caregivers. Active management includes appropriate use and coordination of available treatment options, effective integration of coexisting conditions into treatment plans, and utilization of supportive services such as counseling, activity and support groups, and adult day programs throughout the cycle of care.

While active management of the disease is considered by many to be a primary driver for improved quality of life for both the patient and caregiver, the current state of care delivery today makes realization of active management virtually impossible. Lack of standardization, systemic gaps in reimbursement policies, the absence of common medical data and information sharing protocols and poor end-to-end care coordination all contribute complexity that cannot easily be overcome.

Because Alzheimer's disease progresses fairly slowly – the average care cycle for a patient is typically 2-10 years – many family members are forced to spend many difficult years in the caregiver role. Further, individuals with the disease often suffer from additional medical conditions such as heart disease and diabetes, requiring increased levels of supervision and personal care. Add in the high levels of stress and negative effects on the health, employment, income and financial security of the caregiver and it becomes evident that the true systemic cost of Alzheimer's Disease reaches far beyond the cost of care delivery and pharmaceutical expenses.

All of these challenges make Alzheimer's Disease one of the most significant threats to an already strained health care system.

Evaluating Alzheimer's Patient Care

In July 2008, Guidon Performance Solutions, in conjunction with the Banner Alzheimer Institute in Phoenix, Arizona, set out to evaluate and document the end-to-end Alzheimer patient health care process. The team, which was led by Dr. Pierre Tariot from Banner, sought to document and analyze the current care delivery system, identify gaps in continuum of active care, explore drivers of cost in acute, primary care and other settings and to look closely at how patients and their caregivers traveled through the system from pre-diagnosis to the end of life.

Using tools from Lean Six Sigma to document and analyze the process, the team was charged with tracing the flow of a patient and caregiver and examining the current quality, cost and outcome drivers of the existing care process. The group also closely examined local, state and federal policies for reimbursement for chronic illnesses, such as Alzheimer's Disease, and gaps where policies do not exist. And last, the team was to identify opportunities to reduce costs and improve the overall quality of care for Alzheimer's patients and their caregivers.

Finally, by comparing the current standards of care and protocols to the actual end-to-end process the team sought to create an action plan to address its findings and to hopefully achieve an agreed upon set of results for improving the system.

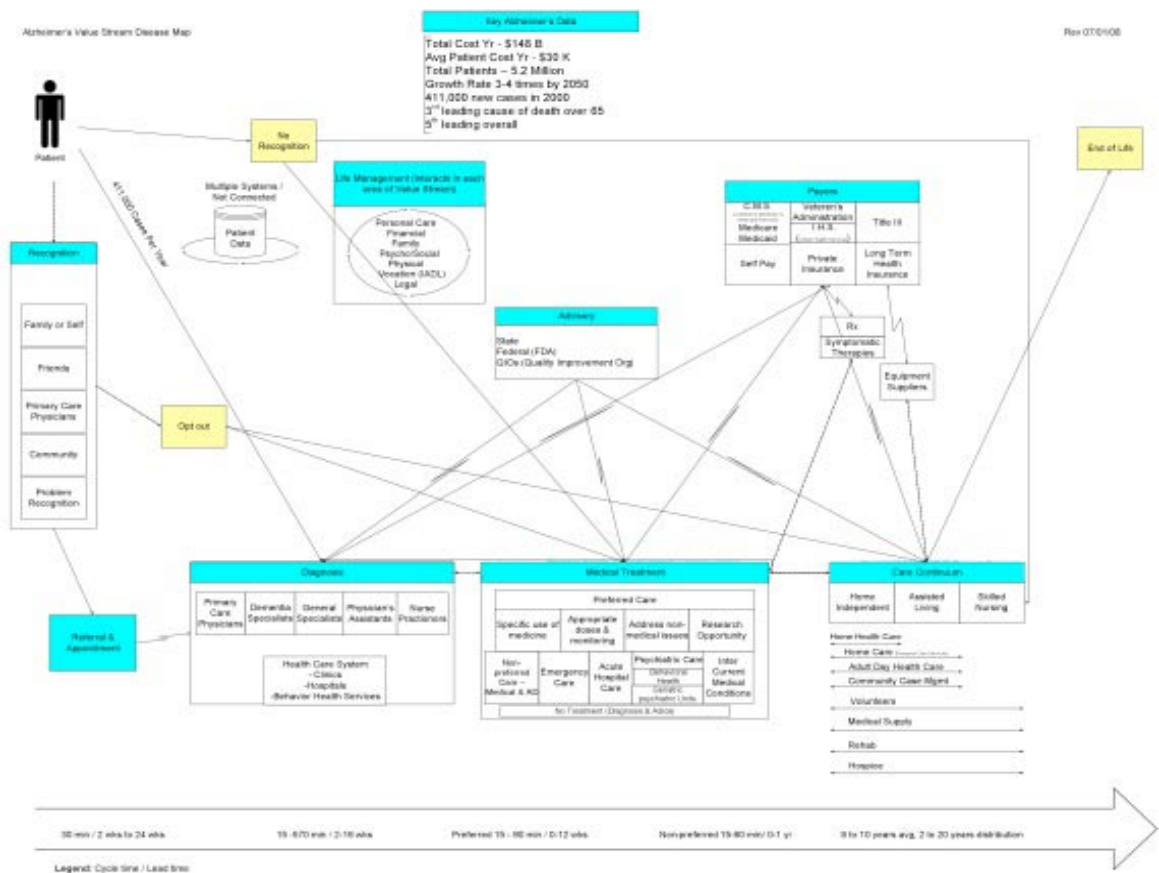
Mapping the Current State

Using Guidon's Patient Care Delivery Mapping process, the team set out to identify all of the actions and touch-points that a patient experiences from recognition of symptoms and diagnosis to end of life. The team mapped every action – both value-creating and wasteful – that is present or required to bring the patient through the entire care cycle. Utilizing key process and performance data about the existing system, the team reviewed two end-to-end “flows”:

- First, the information or requests that are customer driven, traveling “upstream” from the patient
- Second, the information/requests that are external of the customer and that travel “downstream” to the patient

This qualitative process helped create a visual representation of the care cycle well beyond a functional level. It helped the team examine more than just wasteful processes, but also helped identify the sources of waste and inefficiencies. Finally, the value stream map showed the relationship or links between information and the physical flow of information to identify breakdowns or inconsistencies.

Current Care Delivery System



Issues with the Current Care System – A Typical Patient Experience

As a result of the diagnostic process, a variety of issues were identified with the current state. The issues were grouped into four major themes:

1. The lack of awareness of the disease amongst the medical community and the general public;
2. The absence of standard procedures for diagnosing and referring the patient for long-term care and treatment;
3. The need to improve communications across the continuum of care, as well as between providers, payers and policy makers; and,
4. The need to address gaps that exist in the reimbursement policies at the federal, state and local level.

When the patient and/or family members begin to identify symptomatic signs of the disease, most patients seek out their primary care physician for treatment or diagnosis. But often, due to a lack of standard protocols for diagnosis, the physician is reluctant to offer a diagnosis and the physician refers the patient to a specialist for the final diagnosis. The inherent delay, typically from 2 – 16 weeks, to secure an appointment with the appropriate specialist, increases the emotional distress for the patient and family members and causes an unnecessary delay in the start of treatment.

Further, once a patient is accurately diagnosed, no system-wide standard exists for establishing treatment or for establishing a care cycle for the patient. Additionally, due to the terminal nature and lack of effective treatment for Alzheimer's, the team discussed that there exists a sense of treatment apathy; care providers making a diagnosis, yet not establishing effective options or referrals for proper care.

The group also recognized the overarching breakdown of communication at every patient touch-point. Often communications are left up to the individual parties involved in care to provide information to others involved in the case. In general, there is no one-point-of-service or patient advocate to steward the care process for the patient. While some patients may receive a case manager from their insurance company or other resource, these individuals aren't tasked with communicating with hospital-based case managers. And hospital-based case managers aren't tasked with communicating with other healthcare providers, who in turn aren't communicating with family members or care givers. Despite the exceptional expertise of case managers and care givers, the overall care for a patient is at risk due to poor information exchange across the spectrum of service providers as well as over the expanded time horizon associated with this type of illness.

In the end, the patient or the patient's family are left to be the drivers for their own diagnosis and treatment – a frustration that is only compounded by the level of intricacy and bureaucracy present in today's healthcare system. No central repository is present to track a patient's history of care, so the burden of facilitating information flow to the entire value stream becomes the responsibility of the patient and/or their caregivers.

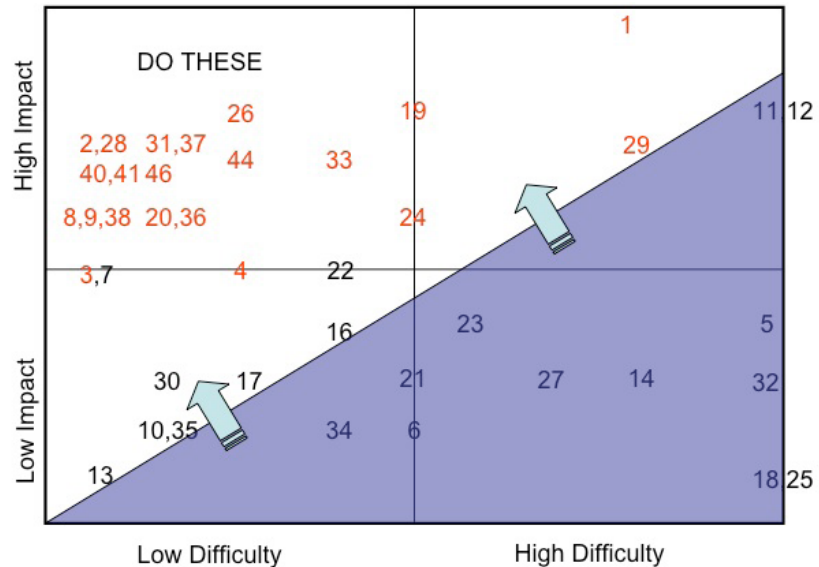
Finally, the team identified that there are several regulatory issues present at the local, state and federal levels further bogging down the system. For example, because regulations surrounding the continuum of care differ from state to state, standardization of the care process for Alzheimer's patients is nearly non-existent. On the federal level, the team cited the fact that there are a variety of existing care/medication options to treat the psychotic symptoms of the disease that are not yet recognized or approved by the FDA, causing further breakdown in the care cycle for the patient.

From a financial standpoint, the group identified the overall misalignment of financial incentives across the entire value stream and acknowledged a substantial breakdown of the Medicare system when it comes to treating Alzheimer's patients. Not only is the care extremely expensive for patients, but also for the federal government. According to The 2008 Alzheimer's Disease Facts and Figures Report, published by the Alzheimer's Association, Medicare beneficiaries age 65 and older, on average, paid for 37 percent of their nursing home care out-of-pocket in 2002. Further, because of the rising costs and the fact that most insurance companies will not cover social services such as in-home care (\$77,745/year*) or assisted living (\$35,628/year*), many eventually required support through governmental sources, primarily Medicaid. As a result, direct care for people with Alzheimer's disease cost the U.S. more than \$50 billion a year.

** 2007 costs for long-term care according to Alzheimer's Association.*

Identifying Solutions

Reviewing the existing value stream, the team set out to brainstorm ideas to effectively improve the process for the patient and to establish a standard of care across the entire value stream. Using an impact/difficulty assessment, solutions were prioritized to identify those that fell within the high-impact, low-difficulty quadrant.



Creating Universal Awareness

Recognizing the lack of consistent information exchange and communication flow, one of the first recommended strategies the team identified was to create a public awareness program to educate stakeholders, address the inconsistency of care and hopefully remove the stigma of the disease. By creating universal awareness of the disease and by establishing a communications plan to bring the disease and the patient care process to the forefront, everything from the diagnosis, to the patient's ability to navigate they system could be improved.

As part of this awareness program, the team identified the inherent need to establish a comprehensive online presence – one centralized site which could be a repository and resource for everyone from patients to caregivers to medical professionals. Again, this pivotal, online presence will help establish a consistency with the information that is available about the disease and can establish a focal point for compiling information about the disease and options for care.

Patient Advocate

Second, and perhaps one of the most crucial solutions identified was to establish a patient “advocate” or care partner to help shepherd the patient and their family through the care process following diagnosis and achieve active care management. This individual would be assigned to act as a single-point of service for the patient, assisting with everything from family education to determining long-term care options. Further, this individual would help the patient navigate everything associated with their overall healthcare, beyond just the treatment of Alzheimer’s or dementia.

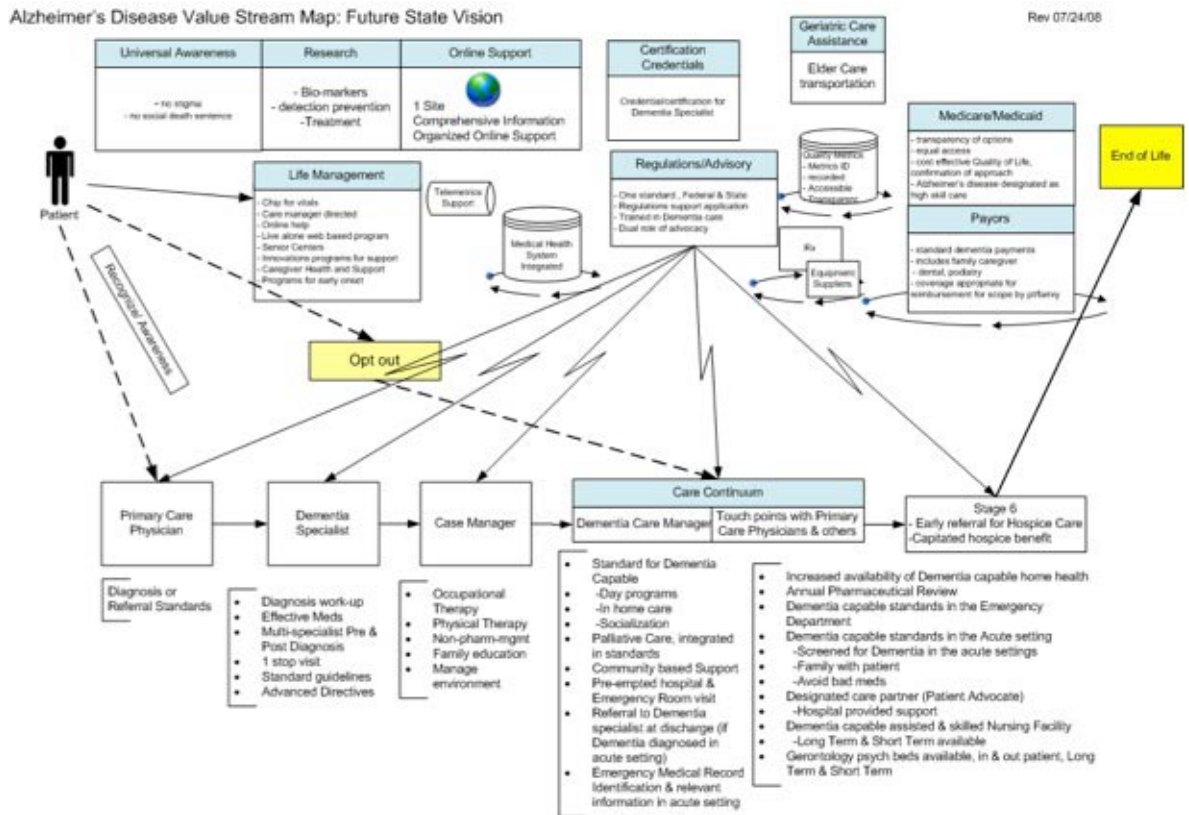
Standards and Metrics

Thirdly, the team identified the significant need to establish a national set of standards and metrics for the entire patient care value stream. From diagnosis to referral to continuum of care, the team recommended establishing a set of industry-wide standards to ensure the proper care and transition of the patient through the value stream. Further, the team recommended regulations be established from a federal standpoint to measure the effectiveness of newly instituted standards and protocols to ensure the system is continually seeking efficiencies and identifying improvements.

These solutions, in conjunction with a myriad of other high-impact recommendations were then used to establish a new, proposed patient value stream that was more patient-centered and addressed the breakdown of communication across the various patient-touch points. This new value stream was

created as an ideal scenario, giving the team, the industry, and all those involved in the patient care process with a base line goal and blueprint to work towards for improving the system.

Future State



A Vision for the Future

Even as this report is being completed, scientific and medical breakthroughs continue to advance rapidly in addressing the devastating effects of Alzheimer's disease. However, as we acknowledge these medical and scientific successes, it is important that we remember the purpose of health and healthcare – the wellness and well being of the person.

The Banner Alzheimer's Institute, led by Dr. Tariot, has set out to raise awareness of the breakdown in the current system and to generate mindshare in the need to move towards a more patient-centered process of care for Alzheimer's patients. Additionally, organizations like the Alzheimer's Association and Center for Health Transformation (CHT) are engaging thought-leaders in conversations about how we create a healthcare system that works for the patient.

To advance this mission, CHT is coordinating and facilitating the work of the Alzheimer's Study Group (ASG) co-chaired by Newt Gingrich and Bob Kerrey. The ASG was launched in July 2007 with strong bipartisan congressional support as well as the support of the Alzheimer's Association and other key stakeholders.

The Study Group's core mission is to create an Alzheimer's National Strategic Plan to overcome the mounting Alzheimer's crisis. It will assess the adequacy of the country's current efforts to combat Alzheimer's and recommend strategies to accelerate progress toward defeating this terrible disease. One of the primary missions of the group will be to accelerate the creation and use of new detection and diagnostic tools. These tools will allow better tracking and assessment of Alzheimer's growing impact on the nation and support the exploration of new models for care of those with Alzheimer's disease, under a range of care settings – from the home, to residential long-term care, hospital and hospice settings.

Dr. Tariot notes: “Knowing the improved quality of life that can be achieved by empowering the patient, it is critical that we establish a system that allows patients and their caregivers to actively manage their treatment so that an improved process can be experienced at all stages of the disease.”

About Guidon Performance Solutions

Guidon is a global management consulting organization that helps clients achieve rapid, sustainable improvements in operational performance and growth. Guidon pioneered the combined application of Lean and Six Sigma in the service sector and has a proven track record working with clients in financial services, insurance, healthcare, government, retail, technology and other service organizations. With a full-spectrum of capabilities focused on people, process, and technology, Guidon provides strategic direction and hands-on implementation to guide cultural and organizational transformation. Guidon’s approach, aligned with client leadership, generates measurable results including revenue growth, cost reduction, productivity improvement, increased customer satisfaction and innovation.



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