Creating a Wellness Program/Safety Net for the Medically Complex and Frail Patient

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Abstract: There is a small subgroup of Medicare and Medicaid patients (2%–4%) who have complex illnesses, frailties, and often disabilities. The medical problems of these patients are characterized by multiple diagnoses, complex medication routines, frequent hospitalizations, many physicians and physician visits, impairment of activities of daily life (including cognitive disabilities), and reliance on a caregiver for support and keeping them in the community. The cost of their care increases year after year averaging $40,000 per year. Strongly associated with these multiple problems is isolation and often depression, which compounds their medical problems resulting in nonadherence to their prescribed medical regimes which might otherwise keep them out of the hospital. This article describes a new approach to providing both a wellness program and medical safety net for this unstable population. Key words: care management, community based, comorbid, medicaid, medically complex, medicare, wellness program

You know I always wanted to live a long life but I had no idea that I would not be able to do all the things I so wanted to do. Traveling, even on short trips, alone is so difficult, almost impossible. I need so much help. My old friends have all moved to Florida or Arizona, or one of those homes that promises you everything, or they have died. I still talk to those in Florida and Arizona but I am finding the phone harder to use despite the voice amplifier because I have trouble hearing. Yes I still have my driver’s license, but I am a little afraid to drive and just don’t feel as confident. What if I hurt someone? I really want to live in my own home. I love it, but it is not as easy as it used to be.

I am a senior, I am 86, and I have all those diseases that I thought only older people got—arthritis, a little heart failure, and I get really short of breath. I think my smoking of 30 years has caught up with me. I have some heart pain when I go up stairs and a lot of flutters in my chest along with breathlessness. And that is not the only pain. It seems like pain finds a new place every few days, and it is never really gone.

I would like to say I remember everything—my childhood, yes, but sometimes I can’t even remember whether I had my coffee this morning. My hearing is not quite bad enough for those expensive hearing aids, so I turn the TV up a little louder than my kids like [I smile at what I used to say to them].

My doctor says my cataracts will need surgery soon, but I have gotten some big print books and newspapers and I can read fine. I will do anything to stay out of that hospital. The last time I was there, they nearly killed me. I do not want to die in the hospital.

I wish doing the simple things I used to do so easily—making meals, taking a bath, making the bed, climbing the stairs, weren’t so hard and scary at times.

I never thought I would have to ask so many things of my kids but I am glad the 2 of them are near by. I am so appreciative but also a little guilty. I know they have busy chaotic lives and I am not much of a help.
I feel so vulnerable, so dependent, so lonely and isolated [and feeling a little sorry for myself, but I know all the other alternatives are worse]. There are days I just do not want to get out of bed. Not much to look forward to and yet I am so appreciative when someone comes to visit or I can go out to lunch with an old friend. Why bother taking those meds that just upset my stomach, mess up my regularity, and make me dizzy? And there are so many of them. I can’t keep them all straight—what they do and even worse what they do that they shouldn’t. It’s difficult enough just remembering when and how many to take. My daughter has tried to help with that little pill counter box.

And the money: that one heart drug is so expensive; I have to split it some days just so I have enough. And really, they are not going to make me better—I know I am not going to get better. It’s all downhill from now on. And my doctors: so many of them, and shouldn’t they at least talk to one another so they have a full picture of me? I can’t remember everything I need to tell them nor can I remember what they told me.

THE PHYSICIAN’S PERSPECTIVE

She is healthy and in pretty good shape for 86 despite the chronic illnesses and disabilities. She has been in the hospital only once when she was first diagnosed with congestive heart failure. But with the conditions and the inevitabilities of age and deterioration there will be more.

There are a lot of seniors like her and there will be a lot more in the next few years with many of them wanting much of what she has articulated. But they are also often sicker, with multiple hospitalizations, even more ills, medications, and disabilities.

About 1% of the Medicare population utilizes 27% of the resources, and 2% utilizes up to 38% (Berk & Monheit, 2001). This is a small, complex, and very costly group of people who often do not get the care they need and frequently slip through the cracks of our healthcare system. Some of the characteristics of this medically complex and frail 2% of the Medicare population include the following:

- Multiple diagnoses
- Many medications (prescribed and OTC)
- High use of medical resources [Average annual medical costs—$40,000 (Berk & Monheit, 2001)]
- Multiple physicians and physicians visits
- Most have deficits in activities of daily living (ADLs)
- Isolation and depression is endemic
- Most do not meet the standards for basic preventive screenings and treatment; that is, flu, pneumovax, HgA1c screens if diabetic, appropriate medications for heart disease, etc.

A study conducted by Wennberg et al. (2004), utilizing data from some of the best hospitals in the United States, looked at care in the last 6 months of life. The variation in the care is a little scary.

1. Hospital days 9.4 → 27 [3-fold difference]
2. Intensive care unit (ICU) bed days 1.6 → 9.5 [6-fold]
3. Hospice
4. Die in the hospital 8.4 → 37 [4-fold]
5. % seeing > 10 doctors 17 → 58 [4-fold]

So why all this variation and inadequate care when there is Medicare, disease management, skilled nursing (SNF), long-term care facilities, and various other support services in the communities?

MEDICARE’S APPROACH

The problem is not just money. Medicare with a “wrap around” [and now Part D] pays for most of the care and reduces the potential financial burden immensely. However the Medicare enrollees have unlimited access to providers and this often means multiple providers who unfortunately don’t always talk with each other. Even if they do, there are significant differences between practitioners and their comfort and aggressiveness with treating the medically complex patient. Many physicians take the approach “do not disrupt the medical regime if it is working (‘the do no harm approach’).” The other very important missing link is the transfer of
information. There are numerous studies that have documented that the cognitive ability of the medically complex, unstable patient declines significantly (Kuo et al., 2005; Ska et al., 2006). Likewise, studies show that patients retain only about 20% of what a physician tells them (Anderson et al., 1979; Kessels, 2003). In addition, there are still real gaps in coordination of care, services, and medications. The complexity and difficulty in managing this small subset of very needy patients often leads to little or no management and coordination and resultant high costs and increased morbidity.

Coordination is better within a managed care setting but only a small portion is enrolled in the Advantage programs with most being enrolled in Fee For Service (FFS) plans (Kane, 1998). Wennberg’s studies of Medicare patients in the last 6 months of life show that the huge variation in the use of resources varies among geographic areas in the country. The communities with the highest use of resources and, subsequently, highest costs consistently had the most physicians, hospital, and ICU beds available. And higher costs did not necessarily yield higher quality. In fact, the quality started to decrease as both the costs and the number of provides and services increased (Wennberg, 2002).

CARE AND CASE MANAGEMENT APPROACHES

Most case management has attempted to focus on patients with acute problems who generally use a lot of resources, are moving from one place of care to another requiring mostly posthospital care and coordination. These interventions are episodic and usually withdrawn when the acute episode is stabilized (Wen et al., 2003). In contrast to this scenario are the Medicare patients, who are frail and have medical complexity, and don’t ever really get better. The challenge is to stabilize them and enable them to continue to live in the community while optimizing their capabilities so that their quality of life is better. The outcome of such care would be a reduction in the use of the ER, decreased hospitalizations, and decreased transfer to long-term care facilities.

Disease management has done a lot to help focus on chronic disease and high cost. However, it begins to falter with the patients who are complex, frail, and sicker.

Such patients often drop out of DSM programs, or are dropped, because they cannot meet some of the requirements [telephone communication, standing on a scale, “cooperating”].

The telephone becomes a more difficult tool for them while real face-to-face relationships become more important.

Even the Medicare Heath Support project, which targets the (FFS) population, is finding it very challenging to manage this population. The intensity of services required to effect patient behavior in this medically complex frail subset has proven to be beyond the scope of most disease management efforts and as yet a proven model of care for these people has eluded the health community. The challenge is this: They do not get better and they will not live longer; but they can live better. Therefore, a new model that addresses the unique needs of this population is needed.

A NEW MODEL

Over the last 6 years we have been working on a model that focuses uniquely on this small but needy population. Our goal was to put together the critical ingredients, to create a sustainable safety net around these patients.

Our fundamental principles as we developed the program included providing more care up front to prevent the need for costly high-risk care downstream, create interventions around the patient and within the healthcare system (Don’t reinvent the system), align the right tools with the right patient, relationships and information (data) drive behavioral change, employ a Health Advocacy Model—not a Control Model, true integration with the physician in his or her office, incorporate the caregiver as an active part of the patient care team, tailor exercise programs for the patient (movement is
critical to getting and staying well), combine care and case management around the patient.

The requirements of our intervention were that it had significant quantifiable impact on both clinical and economic outcomes, that the program be scalable, able to integrate into all communities, worked within the established system, and that it was economically sustainable as a stand-alone initiative.

THE CRITICAL INGREDIENTS

Stratification

This is distinct from predictive modeling that focuses on populations pre-event and tries to predict who will be unstable over the next period of time. In our model we identify those people already significantly impaired and unstable. We do this by using both administrative data and a phone-based Health Risk Assessment (HRA). We try to analyze up to 3 years of cost and diagnosis data on patients. We assign acuity points for costs, and for diagnosis. If patients have high cost and diagnosis acuity scores, we then do a phone-based HRA, which establishes a disability acuity. Our acuity scales have been derived by consensus of practicing physicians and by a thorough review of the literature relating clinical diagnosis to both future hospitalization and cost. In addition, we considered how our program impacts both the patient’s quality of life and the associated cost of their illnesses. Our system is iterative, as we gather more data on health outcomes in defined populations with defined profiles, we hope to be able to look back and further refine our scoring.

Relationship

Key to influencing this group of people is the need for relationship and, ultimately, trust. The relationship must entail a comprehensive understanding of the patient, their social, physical, financial, and cognitive issues. This relationship, to be effective, must extend to the patient’s caregivers as well as to their physician.

Hands-on care

Building these relationships requires an intensive 3-hour interview with the patient and their family. Within this evaluation using a tablet PC, we gather a detailed picture of the patient, which then drives our interventions. Within the intake we learn about and intervene on all aspects of care, from home safety, to fall and osteoporosis risk, depression, cognition ADLs, IADLs, SF12, get up and go test, hand grasp measures to name a few.

Physician integration

Getting the physician connected to our program was fundamental. In our program our nurse will go with the patient to the physician visit and participate. This visit is empowering in many ways: our nurses are able to grasp the full clinical picture and can alert the physician to what is actually going on with the patient at home, it allows us to dialogue with the physician around medication and exercise routines, and it allows us to discuss issues such as pain control, depression, and advanced care directives that are often not addressed.

Disease-specific exercise programs

Movement is often the missing link in the care of this population, and they become increasingly timid, afraid of falling and grow progressively weaker. There are numerous studies documenting the impact of exercise on patients’ quality of life. We have taken these from the literature and applied them with incentive programs to get people moving safely (Gill et al., 2002; Manini et al., 2006; Pang et al., 2005).

Nutritional assessments and interventions

Patients’ eating is assessed and recommendations are made.

Medications assessments

All medications, supplements, are vitamins are reviewed.

Advance medical planning

We try to get detailed advance planning as a discussion for the patient and family. We give
the patients scenarios to consider which ask the patients whether they would want to be intubated, have feeding tubes put in, or have dialysis to keep them alive.

**Biometrics**

Our nurses are equipped with an assortment of devices to leave with the patient, depending on their needs, tools include the Med-eMonitor, which allows us real monitoring of medication compliance, scales to monitor weights, pulse oximeters, blood pressure cuffs, and glucose meters. All of our devices are connected via the Internet to our nurses tablet PCs and to our call centers.

**Case management**

When a patient goes to the emergency department, hospital, or skilled nursing facility, our nurses stay involved taking on the role of case managers. They are uniquely suited to affect appropriate utilization, being able to leverage a deep relationship with the patient, family, physician, and the community resources available.

**Caregiver support program**

A 24/7 emotional phone support and referral service, the caregiver is assessed for their degree of stress and emotional stability and the appropriate referrals are made.

**SAM electronic health record**

Short for stratification, analysis and management, our electronic health record (EHR) is built within a comprehensive health record. SAM EHR was specifically built to manage this complicated patient population. Data collection is rapid, due to the “point & click” and hand-writing recognition built into the system. It connects the patients’ assessments, diagnosis, medications, and laboratory values with plans of care and clinical guidelines. SAM ehr is the engine that drives both our efficiency and accuracy (outcomes).

**Community center meetings**

In each community we enter, we establish our community center-based program. Weekly we meet with our patients in groups. This allows us to efficiently evaluate and monitor a large group of people. The program consists of entertainment (Bingo, music, etc), exercises led by an athletic trainer, and education. While the program is in progress, our nurses can do individual evaluations of the patients. The community program is attended by up to 70% of our patients and helps address the depression and isolation endemic to this population.

**Patient selection**

Ours is not a predictive modeling tool. We use a complex algorithm based on 3 premises to find patients who are expensive and sick and will continue to be expensive. This is not the same as predictive modeling where the efforts are directed to patients who are not expensive or particularly ill at the current time who will become ill and costly in the near future.

Our algorithm is clinically and practically based. We define patients by 3 parameters: cost, diagnosis, and disability. Prior costs are an important parameter. We typically get 2 or 3 years of prior costs from administrative data. Each year costs are scored and a minimal score is required to enter the program. The minimal score varies by the number of years of data we have on the individual patient. The minimal cost for a patient with 1 year of data is $10,000.
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Figure 1. Average yearly cost of 539 health maintenance organization patients (Data are shown + 1 SD). *2005 data are annualized from period January to April.

The ICD 9 codes are used to drive diagnosis acuity. To be considered for our program, a minimal cost and diagnosis acuity score needs to be met. This then triggers a phone-based HRA, which allows us to derive a disability score. The patients with acuity scores above minimal cost, diagnosis, and disability are accepted into the program.

Figures 1 and 2 show populations chosen by this method. Each year this population gets sicker and more costly. The average cost of patients in this program is $40,000 per year. The average number of active diagnosis is more than 7. Medicare patients’ average age is 73 and in the Medicaid populations it is 53.

Figure 3 describes the typical diseases seen in this population. Since this program is truly a wellness program geared to the unstable person with disability, it is not for all costly sick patients. We therefore exclude patients with diseases we can’t impact. This includes aggressive cancers, multiple sclerosis, amyotrophic lateral sclerosis, Lupus, etc. Patients entering our program must have high cost, diagnosis, and disability. This represents the antithesis of cherry picking, it is bad apple picking.

Figure 2. No regression to the mean—these patients get more expensive each year. Year 2003 contains only 9 months extrapolated to 12 months’ data.
Intensity of services

This program is very high touch. In the first 3 months of the program in one setting where we enrolled 291 patients, there were more than 1750 touches. Touches are defined as voice to voice, home visits, physician office visits, and community group visits. More than 20% of these interactions were face to face. This included our initial visit, which requires about 2.5 hours to complete. Initially as the program is integrated into the community, most of the visits are home and telephonic, which gradually shifts to MD office and community centers.

Impact on costs

Figure 4 shows hospital cost data on the first application of our program in 1999. The data represent the impact of the program on 60 patients tracked for 3 years. The red bar represents in-hospital costs, the yellow bar represents outpatient hospital costs, and the brown bar represents total hospital costs. This initial program was a hospital-based program, and the actual costs numbers are internal to the institution. The program decreased total hospital-based costs by 75% after the first 13 months of operation after which the program was discontinued. One of our authors then went to Hartford hospital and participated in the development of a similar program that demonstrated a 44% decrease in total healthcare costs (Hanbury et al., 2002).

Currently the program has been implemented in the commercial Medicare Advantage programs and Medicaid programs. Figure 5 shows the impact of the program in a Medicare advantage population. The data tract 130 patients for whom cost data were available for 3 years, 2 years before the intervention and 1 year after. The median time of actual intervention was 8 months. The total cost savings for the program was 26% from historic without factoring in a healthcare inflation index. As anticipated, the major impact was on hospitalizations with a 44% decrease in costs. We have had a more difficult time gathering laboratory data and clinical measures.

SUMMARY

A community-based wellness program that focuses on the medically frail can significantly
Figure 4. Success: Marked decrease in hospital expenditures. Reprinted with permission from Bridgeport, CT Hospital Pilot Data, January 2000.

Figure 5. Health maintenance organization savings—first 8 months over 26% savings.
improve the health and cost profiles of this population. As managed care assumes an increasing number of these patients with the encouragement of Medicare Specialty Needs Programs, interventions to help manage this population will be required.

We believe that the critical elements of this program must contain an intense community-based hands-on presence, a true connection to the MD, exercise programs, monitoring capabilities, and informatics to drive reliable, reproducible outcomes in the community.

REFERENCES


