

**Testimony Presented by
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Dr. Levy : Chairman Grassley, Senator Breaux, Members of the Committee, thank you for this opportunity to discuss the impact on family caregivers of our intensive case management program, which expressly focuses on the needs of the sickest, most medically complex patients. As you have heard, family caregivers are integral to the care of millions of aging and chronically ill individuals, yet often go unrecognized by the health care system, and seldom receive the education and individualized assistance necessary to support the multiple and essential roles they play.

My name is David Levy. I am a family physician and epidemiologist, and Chairman and CEO of Franklin Health, Inc. In 1987 I founded the company to assist employers and other payers in addressing two significant weaknesses in our system of health insurance:

- While health insurance provides adequate coverage for a majority of the population, a very small number of patients require intensive medical care and thus disproportionately drive expenditures. These individuals - who we call "complex care" patients - have: a significant primary diagnosis, such as metastasized cancer, that may be terminal; significant co-morbidities, which might include diabetes, congestive heart failure or pulmonary disease; multiple specialists and other providers of care; and a range of other concerns, including disruption of family relationships and fear of financial ruin. In the under-65 population we estimate that this sickest one percent account for approximately 30% of health care expenditures. As you know, the often-quoted figure in Medicare is that 10% of beneficiaries account for 70% of program costs.
- Benefit plans are not designed for these patients. In our experience no two complex care patients ever want to be treated in exactly the same way. Yet standard benefit packages, including that of Medicare, lack the flexibility to treat each case as unique and traditional cost management strategies, such as pre-certification activities, utilization review and limited provider panels, frequently leave patients and their families feeling not only ill-served but confused, frustrated and angry.

From the beginning our Complex Care case management program has been driven by certain core values:

- First, that the patient must be at the center of the care system. Faced with difficult choices among treatment options, including the weighing of risks and outcomes, the preferences and decisions of the patient, along with his/her family, must take precedence over the concerns of benefit managers or the convenience of physicians and other providers or even the "best" treatment plan devised by a case manager. Patients accept the realistic limitations of insurance coverage in a less than ideal world, and understand the consequences of their decisions; particularly for those facing multiple and complex illnesses, the right to choose the care they want must be fully respected.
- Every patient deserves information and education about his/her treatment options. This right to knowledge must be accompanied by a right to privacy and full respect for the patient's relationship with his/her physician(s). When Franklin Health was founded we were confident that given good information and individualized support, patients would make good decisions about their own care needs; today we have several years of outcomes data showing that patient-centered decision-making leads to genuine changes in treatment plans and better quality care, increased patient and family satisfaction with services, improvement in quality of life, and incidentally produces

significant savings when applied to appropriately targeted individuals with complex care needs.

The heart of our Complex Care case management lies in personal, face-to-face contact with patients and their families. Today I have asked Ms. Carol Weinrod, a registered nurse who is one of our full-time case managers, to talk about the impact of those interventions on the family caregivers of extremely sick, medically complex patients.

Ms. Weinrod: Let me begin by briefly describing the kinds of complicated and difficult situations that patients and their families face every day.

Case Example 1: Ruth, a widow in her 80s was hospitalized with the latest of several hip fractures when I was called into the case by her Medicare managed care plan. In the previous three months she had been hospitalized on two other occasions for problems relating to heart disease and a chronic pulmonary disorder. Physical examination and bloodwork during this inpatient stay suggested a probable cancerous mass on a kidney, but Ruth refused further and invasive procedures that would have confirmed this diagnosis. Having been in nursing homes on previous occasions, her Medicare skilled nursing facility (SNF) benefit days were nearly exhausted. With multiple doctors involved in her care and certain that she could not be safely maintained at home, the hospital was anxious to discharge Ruth to a nursing home. Her only family support was a stepdaughter who was very much committed to her, but could see no way to effect Ruth's fervent wish to return to her home of some 40 years. The stepdaughter lived 45 minutes from Ruth's home and worked full time. Though she had been through several years of her mother's declining health the stepdaughter had a very limited knowledge of the health care system and potential resources and felt overwhelmed by her mother's needs. As with most cases, multiple questions need to be answered: what were Ruth's medical needs and how could these be matched with her wish to return home?; what resources could the daughter access or bring to bear, given the limitations imposed by the demands of her own life?; what education, assistance, support, coordination could I provide to both Ruth and her stepdaughter?

Case Example 2: In her mid-50s, Lynn had faced serious medical problems for a number of years. With a previous history of cancer, when I met her Lynn was hospitalized with pneumonia secondary to ALS (Lou Gehrig's disease). Although stabilized in the hospital, she required skilled nursing care including frequent suction and oxygen support. While her husband and two sons were devoted to her care, each worked full time and the family could not afford the daily nursing coverage necessary for Lynn to be discharged to home. The standard, employer-provided health plan specified maximum coverage of 4 hours per day of home health services. Lynn's husband could see no way to take her home with such limited medical support. While her disability would make her eligible for Medicare within a year, for a variety of reasons, including pride and a real belief in self-reliance, the family was extremely reluctant to seek additional assistance from the state Medicaid program in the meantime. Again, there were multiple questions: how should Lynn's complicated care needs and self-management training be provided and coordinated?; which family member would be the primary caregiver during this episode of care?- what would be the most cost-effective approach and could this be implemented?

Case Example 3: With family caregivers including his wife and daughter and several grandchildren, Angelo wanted to return home after a skilled nursing facility stay. Having been in and out of hospitals, he seemed to have made some peace with the cancer that would ultimately end his life but his family was extremely angry about what they saw as inconsistent and inadequate care. They were strongly opposed to hospice services, which they viewed as giving up on Angelo. During his stay in the nursing facility, Angelo developed a bedsore, a gaping wound, on his backside; because of strong feeling about Angelo's dignity and their own impending loss, none of the family members could perform the wound care that would be necessary to maintain him at home. Again, there were many questions: how could Angelo's medical needs be met in the home?; would the family reconsider hospice services?; how should

the family's emotional needs be addressed?

As these case examples begin to suggest, family caregivers are asked to assume multiple roles within an unfamiliar, seemingly impenetrable health care and social services system, in an emotionally charged atmosphere that often evokes fear and disorder. As each of us who has faced the serious illness of a parent or child or spouse knows, not infrequently family caregivers are asked to be:

- The interpreter or liaison, the one who connects the patient to the explanations, directions, decisions of physicians and other providers,
- The decision-maker who considers and helps choose among treatment and service options,
- A direct caregiver, who must learn and be responsible for providing nursing and other functions, and
- The coordinator of other caregivers, ranging from the scheduling of other family members to arranging needed transportation, nutrition, social, financial, and other services.

In most cases, family caregivers are asked to fulfill these roles even while maintaining full-time employment and attending to other important persons in their lives.

From my perspective, the varying roles of family caregivers can be matched by the varying functions of the case manager on an individualized basis. Case management might then include:

- Providing acknowledgement and support for the family caregiver as a integral member of the health care team;
- Offering information and assistance to the decision-maker, both in respect to identifying treatment options and resources, and by facilitating the process of identifying and respecting the patient's wishes, as well as the family caregiver's feelings about the choices the patient makes;
- Furnishing training and education regarding the patient's illness and in regard to specific caregiving skills;
- And establishing a trusting rapport that supports the caregiver while coordinating execution of the patient's treatment plan across all dimensions of care.

So, what do the family caregivers of the complex care patients with whom we work need? In every case they need someone who can track information across the continuum of care - from hospital to nursing facility to outpatient clinic and home health service, and around again - and work with them toward arranging the care system to meet the patient's needs and wishes. And at the outset each patient, along with his/her family, needs a face-to-face assessment to identify the appropriate, individualized goals of care. But how the case manager facilitates movement-toward those goals depends on the patient's needs and wishes and the circumstances of the family - there is no single answer.

Case I - With Ruth's stepdaughter I spent a great deal of time educating her about the differing capabilities of home health and hospice services, made sure that physical therapy was initiated before her mother's discharge from the hospital, and assisted in the interviewing of home health aides. I arranged a telephone case conference between the stepdaughter, the hospital discharge planner, the attending physician, and a nearby hospice agency that had a local hospital hospice bed should Ruth require re-hospitalization at some point. When Ruth was discharged from the hospital, I ensured that the people representing all the services she needed met her at home: the durable medical equipment supplier, a nurse from the hospice agency, the home health aide, and her stepdaughter. Ultimately, the hospice physician agreed to become Ruth's primary care doctor and followed her with home visits. I remained available for after-hours discussions with the stepdaughter to discuss her mother's care. Ruth, as the daughter gratefully reported to me several weeks later, got her wish and was able to die peacefully

at home.

Case 2: With Lynn's family my tasks were quite different. First, I advocated with the insurer to flex the standard benefit package, allowing an increase in home health services and the coverage of durable medical equipment in return for clear savings over the costs of a predictable future hospitalization or nursing home placement. Because her husband was deeply in denial about her ALS, over time I needed to identify the family caregiver who could be realistic and of greatest help to Lynn - this turned out to be one of her sons who, along with his mother-in-law, became the central contact person. The son was able to pursue supports I arranged that his father could not, including an attorney and a legal aid organization to explore Medicaid assistance, as well as the local ALS foundation chapter which provided great emotional and educational support to both Lynn and the family. In this case, as in many others, one of my most important roles was to serve as a liaison, and sometimes mediator, between the family caregivers and the home health agency. An important observation to make here is that families, especially at the outset, are often intensely ambivalent about the need for home health services - angry and reluctant about giving over the care of their loved one to a "stranger" but aware that they cannot possibly meet all of the patient's needs and aware, too, that their own lives have to continue. Given her deteriorating course, Lynn's family was deeply pleased (as was I) that she was able to remain out of the hospital for the entire eight months that I worked with the family.

Case 3: Anger was in some ways the predominant emotion among Angelo's family caregivers. Given their own emotional incapacity to perform Angelo's wound care, they were angry that the health care system did not offer the package of services they needed: traditional home health coverage plus daily nursing care. Over time what we were able to put in place was a kind of simulated home hospice, including arranging a primary care doctor who would act as a hospice physician, prescribing stand-by medications and following Angelo at home. The anger and neediness of Angelo's family could be overwhelming at times and, again, I frequently had to mediate between the family caregivers and the home health personnel to prevent total alienation between the two. Arranging pastoral care was important for this patient and his caregivers, as were extra social work visits. While the family never entirely conquered their anger, they were very pleased about being able to allow him to die at home, as he wished. In a moment his daughter described to me as "sacred," Angelo died with his family around him, his dignity intact.

When it comes to putting the patient's needs and wishes appropriately at the center of the care system, perhaps nothing is as frustrating to family caregivers - and case managers as the rigid application of coverage limitations or 'allowable' treatment protocols or, at worst, the active avoidance of costs on the part of an insurer or health plan. (In fact, it is the insistence on forcing the square pegs of patients with complex needs into the round holes of standard benefit packages that at least in part, has fueled a significant public backlash against the perceived excesses of managed care.) But utilization or cost monitoring or benefit reduction is not the same as real care management and the barriers to cost-effective care erected not only by private insurers but also by the Medicare program are terribly shortsighted. We all know of the example that until recently Medicare would pay for an amputation secondary to diabetes but did not cover diabetes self-management education or supplies. The answer, however, cannot be simply to expand benefit packages, and thereby explode costs - we must implement a care management system that ensures that appropriate services can be provided to patients, and their families, whose care needs are complex, costly and can be only partially met by even the most committed family caregivers.

Let me give an example of the case manager's role in devising a cost-effective treatment plan that actually fits the case. As you know, skilled homecare is a covered Medicare benefit, while custodial care is not covered unless attached to a skilled visit under supervision of a homecare professional. In reality, many patients fall somewhere in the middle of this neat distinction and there is considerable room for

interpretation as to the "medical necessity" of the service. Often, the coverage decision is made by a distant reviewer who has no first-hand knowledge of the person's needs. (In our experience, a Medicare risk contractor may tend to cut off services quickly, labeling such care custodial, while a homecare agency may stretch the service past the time of needed skilled care.) Having taken the time to assess the patient face-to-face, having identified his/her needs and wishes and the family caregivers' abilities and concerns, our case managers help make such judgments. Our job is to put the patient at the center of the health care system: a system which should, and - in our experience - can if given reasonable flexibility, meet the needs of patients and their families with a range of services that are necessary, appropriate, cost-effective and, perhaps most importantly, well-coordinated.

Thank you. Dr. Levy and I will be pleased to answer any questions.