

NEIL S. GHISO FELLOWSHIP: REPORT 2007-2008  
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## **INTRODUCTION**

The Neil Samuel Ghiso Foundation (NSGF) was essential for my training in end of life elderly care and elderly chronic care healthcare delivery during my time at Harvard Medical School. It was encouraging to know that an organization was supporting me in my efforts to improve elderly care, especially at the end of life. During third and fourth year medical school, I have been focused on geriatric long-term care and therefore I spent my time completing four broad activities: (1) researching healthcare delivery solutions for older patients (2) creating a needs assessment of families that need care giving for their frail loved ones (3) advocating for greater public awareness in geriatric end of life care; (4) working on a paper that addresses dilemmas in American healthcare, especially older patient care. This organization is dedicated to fostering compassionate care for chronically and terminally ill patients and their families through medical education, research, and training, and I have attempted to work on projects with this mission statement in mind.

## **SUMMARY OF ACTIVITIES**

I spent a majority of my time working on research projects analyzing healthcare delivery systems for elderly with chronic illnesses and exploring the problems of healthcare delivery for chronically ill elderly patients. Many of these projects are currently still in progress, therefore I will discuss them and convey a few of the conclusions we have made thus far.

During my second year of medical school, I spent several months taking a course called “Living with a Life Threatening Illness” that was very interesting. We learned from speakers about the field of palliative and hospice, and each student teamed up with a patient who had an end-stage disease. After the course, we wrote a reflection paper about the experience. I decided to incorporate many of these concepts into my interaction with the terminally ill patients that I have encountered during my Geriatrics Rotation this year.

During the fall of 2008, I worked with Dr. Joseph Coughlin, Director of the Massachusetts Institute of Technology Age Lab, an organization that exists to enhance care for elderly people. The MIT Age Lab was created in 1999 to invent new ideas and creatively that would translate into practical solutions that improve people’s health and enable them to maintain independence throughout the lifespan. The AgeLab has assembled a multi-disciplinary and global team of researchers, business partners, universities, and the aging community to design, develop and deploy innovations to improve quality of life. Moreover, the existing stock of affordable housing is in dire need

of modification and renewal to meet the needs of an aging America. Citing these factors, combined with the convergence of available and affordable technologies, Coughlin stated that there is an opportunity to re-envision housing as a platform for services innovation – enabling public/private partnerships to creatively develop and efficiently deliver health, mobility, nutrition and social services to low-income and chronically ill older Americans.

The project that we are currently working on involves researching the desires of both providers and consumers of health care services, and it aims to promote informed choice, comfort, and compassionate care at the end-of-life. During my month with the organization, I became involved with a number of different initiatives, all of which were focused on achieving quality of life for older patients. During my months with the MIT Age Lab, I have worked with Dr. Coughlin to understand what older people desire at the end of life. On December 9, I attended a conference titled “Innovation Studio.” I met the leaders in various industries that are catering to the patients with chronic illnesses and helped develop a presentation that summarizes the needs of patients with chronic illnesses and their desires in life.

Currently, I am involved in efforts at residential homes for older patients to incorporate palliative care teams into their facilities. This concept is not widely accepted because families are very cautious of facilities that will choose not to attempt every medical treatment in order to honor the patient’s wish for palliative care and support measures only. However, we have found that many patients would rather accept palliative care than invasive procedures that prolong their life but have risks of debilitating the patient permanently. The current project involves incorporating family and patient support, improving provider team communication, increasing care continuity, and increasing documentation of these activities. The organization is planning to create documents made available for on its website soon that address particular areas in end-of-life care.

We have researched this because healthcare in the hospital is characterized by high-technology, institution-centered, aggressive treatment to extend life at all costs. In contrast, hospice care is a set of services provided by local agencies, which usually allow patients to die in their homes. Services offered include medications, equipment, nursing care, social workers, home health aides, chaplains, and volunteers. Palliative care is designed to reduce the suffering of patients. This institution is interested in studying, practicing, and furthering the goals of palliative care.

I have also worked with Dr. Wolfgang Klietmann, a physician and Harvard Medical School Lecturer in Pathology, who is experienced in healthcare policy. He and I have had many didactic sessions on the American healthcare crisis as it relates to chronic care for the elderly. We selected subjects that we could discuss in a paper revolving around the cost of health care and the various players including hospitals, patients, physicians, and insurance companies. We were able to prepare a paper entitled “Diagnosis of the Healthcare Crisis” which touches upon issues relating to caring for chronic and terminal illnesses. I will summarize a few of the points below.

In November 2008, I spent a month working full-time in the Beth Israel Deaconess Medical Center where I enrolled in Clinical Geriatrics and learned about the end of life issues surrounding the elderly such as Alzheimer's disease, dementia, hospice care, rehabilitation, long-term care facilities, and the multiple issues surrounding end-of-life for the elderly. Two weeks were spent on the Geriatrics consult and inpatient service where we addressed issues of where the elderly would be discharged to: home, palliative care, hospice care, rehabilitation, or nursing home facilities. Two additional weeks were spent on the Geriatrics outpatient clinics where I worked to help patients with chronic degenerative diseases address end of life issues. I also visited many nursing homes and learned about the different types of living situations for patients at the end of their life.

In December 2008, I attended the 20th Annual National Forum on Quality Improvement in Health Care conference given by the Institute for Healthcare Improvement in Nashville, Tennessee. This conference taught me different models of care for patients, and I specifically attended workshops addressing palliative care. I also connected with many advocates in the palliative care movement, including the CEO of Partners in Care Foundation, W. June Simmons. They have developed Palliative Care At Home, a model of care apply concepts and findings to help with dying at home. End-of-Life care is currently very fragmented and 25% of Medicare revenue is spent on 5% who die each year, with the average cost of care in last year of life is being \$26,000 in 1996.

As a Ghiso Fellow this year, I placed a lot of emphasis on elderly care because the elderly population is growing into an ever-increasing list of chronic and terminal diseases. As end-of-life institutions determine how to best serve the diverse needs of Americans, they will be better prepared to provide appropriate care if they have analyzed the limitations and contradictions in the current practice. I feel very fortunate to have been able to conduct research in this area and to have some publishable material once these projects are complete. I am also thankful for Dr. Buxbaum's guidance as my fellowship advisor and for all the other mentors that have guided me. The opportunity to be involved with end-of-life elderly care advocacy work during third year clinical clerkships and fourth year research months was invaluable, an opportunity for which I am clearly indebted to the Ghiso Foundation for its vision and support.

## **RESEARCH OPINIONS**

### *The Healthcare Dilemma*

The healthcare system continues to worsen during this present financial crisis, as forty-five million Americans, many of them among the working poor, still lack health insurance. The problem is aggravated by the rapidly climbing unemployment rate, which reached 6.5% by October 2008 (United States Department of Labor, 2008). American healthcare spending in 2008 has climbed to an estimated \$2.4 trillion, an average of \$7,868 per person,<sup>1</sup> and an average of \$11,093 per Medicare enrollee. This is an increase of 96% in Medicare expenditures from 2000 to 2008, in part due to the enactment of the prescription drug coverage Part D.

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Governmental initiatives such as the federal Health Information Network and the introduction of a standardized electronic medical records (EMRs) system have remained in a rudimentary phase, despite the EMRs estimated savings of \$40 billion annually<sup>2</sup>. The study showed it could improve medical care delivery, reduce medical errors, reduce adverse drug reactions, reduce employee sick days, and lower death rates from chronic diseases. On average, medical errors amount to 300,000 deaths annually, unacceptable by any standards of business practices (Herzlinger, R 2007).

### *The Rising Costs of Healthcare*

American consumers are having a difficult time accepting the forecasted rising percentage of income growth devoted to healthcare, yet forced to do so by reducing overall non-healthcare spending. The average worker contribution per year for a family health insurance policy has increased 107% from 2000 to 2008, from \$1,619 to \$3,354, which is estimated to rise in the coming decade (Henry Kaiser Family Foundation Report, 2008).

While medical progress has increased costs, and some would argue that medical technology may account for at least half of real long-term care spending (Rand Corporation. Rand Health 2005), technology has also produced considerable benefits for the patient and society by extending life expectancy, improving outcomes and quality of life, and decreasing absence from work. Researchers have found that that in four conditions—heart attacks, low-birth weight infants, depression, and cataracts—the estimated benefit of technological change is much greater than the cost (Cutler DM, McClellan M. 2001). The prevalence of chronic diseases such as diabetes, asthma, and heart disease coupled with growing ability of the health system to treat the chronically ill contributes to the high spending, as 45% of Americans suffer from one or more chronic illnesses, which account for 75% of all health care spending (Ibid., 2007). Cutler and McClellan answer this question clearly, and point out that medical technology is only valuable if the benefits of medical advances exceed the cost. Further improvements can be expected with the advent of technological decision making models in complex situations such as chronic diseases and multi-morbidity.

### *American Access and Availability*

In the U.S., healthcare access disparities often result from demographic variations. These disparities are the result of the structure of the U.S. healthcare system, which is in reality a highly fragmented collection of public and private financing arrangements. In contrast to monolithic systems imposed by governments in other countries, the U.S. system reflects American entrepreneurialism, pilot projects, private interests, and grassroots trends mixed with some major governmental forces.

Corporate America seems to have reached an acceptable limit with healthcare costs. As a percentage of the GDP, healthcare spending has risen from 7.2% in 1970 to 16.6% in

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2008 and is expected to reach 17% of the GDP by 2011 (United States Department of Labor, 2008). What will be the consequences if healthcare spending continues to climb at this rate? In addition, reimbursements to physicians have been another concern. Is our specialist centered reimbursement model to providers too uneven? General practitioners can take care of 30% of complaints of patients at lower costs to contain, yet are paid one fifth less than radiologists on average (Health Affairs, September/October 2001). Is our nation too focused on high reimbursements for specialized care rather than preventative care? Although this may not be ideal for our society, this is clearly reflected in the reimbursement model to physicians.

Efficient healthcare depends on lifestyle, nutrition, the balance between work and recreation, and pleasant circumstances in professional and domestic spheres. Preventive healthcare measures are certainly neglected in this country and underfinanced. The spiraling cost of healthcare is a result of an explosive growth of chronic diseases like diabetes, cardiovascular conditions, and asthma; therefore the focus should be to create healthier Americans. The question our society will face is whether we will benefit the most from the advances of medical knowledge and technology to cure disease and maintain health and well-being? Shall resources for medicine fund scientific projects to slow the process of aging and support man's quest for the fountain of youth and immortality? Will this concept of hospice care emerge as patients realize their desire at the end of life, but also emerge as a result of the need to cut down costs?

#### *Financial Care at the End-of-Life*

The last two decades have brought an increased focus on how Americans die (DuPre Brodie & Powers, 2002). Despite this attention, our nation has made little progress in improving the dying experience for many terminally ill patients as well as reducing costs of care. New methods of shifting end-of-life care from an acute care inpatient hospital to focus on a chronic care home-based model have been widely successful but under-utilized.

In an examination of costs in the last year of life, Lubitz & Riley (1993) found that 10-12% of the total U.S. health care budget and 27% of the annual Medicare budget is spent on care at the end of life. Despite the changing demographics of our nation and increased use of hospice, this figure has remained constant over the past two decades (Hogan, Lunney, Gabel, & Lynn, 2001). The average per-person medical expenditures in the last year of life are estimated at \$28,000, with 50% of the expenditures attributed to hospital services (Emanuel et al., 2002).

All terminally ill patients will have worsening conditions that will ultimately place them in hospitals at some point in their care. Hospitals bill under appropriate DRGs (Diagnosis Related Groups), fixed amounts paid to hospitals for a Medicare patient admission, priced by the diagnosis. Because hospitals are expected to pay for all aspects of care, the incentive under this funding scheme is to provide the least costly care and to discharge patients from the hospital as soon as possible, foregoing extra time spent working on the transition of the patient to the next facility.

While hospitals work under DRGs, physicians bill for their services under Medicare Part B and other health insurance policies. Another problem with finances for palliative care is that the physician care is typically only reimbursed for time spent with the patient and not for the coordination of care the end of life. The financing of the complicated team apparatus is very important but is often overlooked when implementing palliative care services. Fee for service reimbursement under Medicare is more profitable for procedures and less profitable for “counseling, planning, and continuity” services (Paul J. Feldstein, 1999). This reality pushes hospital-based palliative medicine towards procedural interventions to reduce symptoms, and away from more holistic approaches to care.

There has been much debate about the reality of cost savings at end of life using palliative care. In a review of studies examining savings from hospice care, Emanuel (1996) found inconsistent results between studies. Yet, all of the studies he examined are now more than a decade old and have dubious applicability to our current health care system. More recent investigations have supported the opinion that hospice may not result in significant savings. Hogan and colleagues (2000) found in their analysis of Medicare claims data from 1993 to 1998 that overall costs for hospice users were not significantly different from those of non-hospice users. However, this may be due in part to the high rate of late enrollment into hospice programs. Currently, the median length of stay on hospice is 22 days and 35% of hospice patients died within 7 days or less of enrollment (NHPCO, 2005).

### *A New Model at the End-of-Life*

My investigation in palliative care has shown that an integrated interdisciplinary team comprised of physical, medical, psychological, social & spiritual support for care provided in home could be a solution to the problem of end-of-life care. For example, the Partners in Care Foundation have developed a Palliative Care At Home model of care apply concepts and findings to help with dying at home.

In their model, the team is responsible for coordinating and managing care across all settings as well as providing assessment, conducting evaluation, planning, care delivery, follow-up, monitoring and continuous reassessment of care. Results of studies conducted within Kaiser Permanente found that this model of care is successful in reducing both emergency room visits and hospitalizations, resulting in cost savings that range from 37% to 45% less than terminally ill patients receiving traditional care (Brumley & Hillary, 2005; Brumley, Enguidanos, & Cherin, 2003; Brumley, Enguidanos, & Hillary, 2003).

Many new models of palliative treatment do not consider other factors important to the patient at the end of life such as family input, living in the luxury and privacy of one’s home, and acute treatment when necessary. Consistent with the Medicare Hospice benefit, the program emphasizes patient and family education with coordinated, patient-centered plans that do not prevent medical treatment and allow for comprehensive primary care to manage the underlying conditions. Also, patients do not have to forgoing

curative care in exchange for palliative care and they can continue to see their primary care physician. The clinical structure parallels the Medicare Hospice benefit with several important modifications. They also have aggressive treatment of acute exacerbations and 24 hour phone support, with visits by the medical staff if necessary. Volunteer & bereavement services allow for transfer to hospice if appropriate.

In addition, the palliative care physician coordinates all care to prevent service fragmentation. This is the first rigorous study to examine the effectiveness of an in-home, community-based palliative care program. This model provides strong clinical and financial evidence supporting the provision of palliative care in the home, with tremendous implications for improving end of life care for terminally ill. Currently, Kaiser Permanente has adopted this as standard care throughout Southern California and it is moving to national level. This model is worth exploring to start fundamental changes in the design of our health care system in order to bridge care between standard medical care and hospice care. First, it allows a modification of hospice benefit or development of a new “pre-hospice” benefit. Second, it creates the ability to be replicated within alternate funding structure via medical groups and health plans. Third, it demonstrates a program that can be tested.

This is one method that has been explored which encourages patients, family members and professional caregivers to exchange knowledge and facilitates communication on treatment preferences. In addition, the biopsychosocial interdisciplinary approach ensures that the psychosocial issues are addressed as well as the medical problems. The social worker plays a pivotal role in addressing issues of depression, stress, and coping (Claiborne & Vandenburg, 2001), issues that are often present at end of life and are critical in improving self-efficacy for disease and symptom control.

Through restructuring health care delivery and reimbursement streams paired with realignment of financial incentives to provide comprehensive services in the home, end of life care experiences can be improved while simultaneously resulting in a significant reduction in costs, especially in light of the current American healthcare crisis.

## **PERSONAL REFLECTIONS**

In the life sciences, we cannot describe outcomes with certainty and in a predictable way. Medicine as part of the life sciences consists of a large number of concatenated interacting components of unpredictable behavior. This complex system clashes with the limitations of the human brain that tries to understand its dynamics. The art of Medicine and the Art of Healing have roots in folk medicine, religious and cultural tenets dating back by millennia. When we take a comprehensive and historical understanding of medicine, we see that the discipline stretches across the natural Sciences – Social Sciences- and Humanities. Therefore the problem of medicine can only be resolved through a pluralistic and interdisciplinary dialogue. This dialogue must bridge cultures, and extend our academic inquiry into the areas of morality and religion. We see that this is especially the case with pressing questions around euthanasia, abortion, and stem cell research.

What motivates us to move beyond these and other scientific, economic, social, and political obstacles we face is the exhilaration that we feel, when we sense, with vigilance, the extent of the complexity of this scientific system called Life. This experience emboldens us to innovate, not only in new technologies and new scientific breakthroughs, but also in new ways of understanding the human condition and framing the problem we face.

Therefore, as we near the end of life, the scientific knowledge of medicine fades to the background and the grasp of life seems to be the concern of many terminally ill patients. After hundreds of hours of dialogue with patients terminally ill or at the end of life, I have collected a few sobering and enlightening thoughts that I'd like to share. These words are from patients whom I developed strong relationships with, and I asked them what they would like to share as what they learned after living with chronic illnesses and sometimes terminal illnesses. Their response was:

“I know my body refuses to listen to me. But I am prepared. My doc has prepared me for a long time so I am ready. Whenever I wake up and I can't move my legs or have pain in my back, I think this is too much, but I am mentally ready... Others need to be ready.”  
~BM, 81 male with terminal prostate cancer

“My mind is cloudy sometimes, and I can't move as fast. But I know that I have other things, my heart, my mind when it is clear ... so my body is only a part of me, not all of me.”  
~SL, 83 female with mixed type dementia

“I couldn't stand not having privacy before. I was a very private woman. Living here has taught me to be tolerant of others. When my privacy is invaded by other people, I try to maintain my inner self. I just try to stay relaxed.”  
~PK, 89 female with breast cancer

“When I am sad that I am dying, I go to my happy place. It is in my childhood when I walked into a candy store. I don't stay there long because it makes me sad, but I go there just to get myself away some times.”  
~CK, 76 male with cholangiocarcinoma

“I used to hate friends visiting because I didn't want people to pity me, or to see me here, but I am okay now. I don't mind because I know they care. I try to be open to everyone I meet now...even the nurses. Someone who is open will be happier.”  
~DO, 78 male living in nursing home

“I am finally okay with getting help. You know, I was very smart when I was young. Now, I need someone to help me bathe, and that is okay with me.”  
~RP, 84 male with end-stage renal disease

Beyond an endeavor to serve scientific progress, we shall be guided by our professional values to serve humanity and society. Medicine is the art of healing and there is an obligation to protect it. Medicine is more than the test tube and the stethoscope, it is more than the clinical routine or the pursuit of excellence; rather it confronts the enigmas of human existence in birth, wellness, disease, and death with great courage and authority. This all encompassing responsibility will continue to challenge our attempts at reform together as a society.

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