



THE NEIL SAMUEL GHISO FOUNDATION  
FOR COMPASSIONATE MEDICAL CARE

**To cure sometimes, to relieve often, to comfort  
always - my experience as a Neil Samuel Ghiso  
Fellow for Compassionate Care**

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*Neil Samuel Ghiso Foundation Report 2003-2004*

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## *I. On being a Ghiso Fellow for Compassionate Care*

I first became familiar with the name Ghiso in late 2002 and early 2003, when I browsed through a thick red book, Harrison's Principle of Internal Medicine, in the TMEC HST Lounge. At that time, I was briefed by Patty Cunningham about the story of Neil. It was a story that really took me to heart.

I became interested in palliative medicine and end of life care during my first year in medical school, when I enrolled in a class, "Living with Life-threatening Illness", taught by two palliative care experts, Dr. Susan Block and Janet Abrahm. After that, I have exposed myself to several educational opportunities in palliative medicine, including working with terminal cancer patients, attending HMS Palliative Care Faculty Seminar, and participating American Medical Student Association (AMSA) End of Life Fellowship Program in summer of 2003.

When the Ghiso fellowship solicited application for academic year 2003-2004, I decided to take this opportunity to further enrich my educational experience in palliative medicine. At that time, I just decided to take HST 5-year research plan to extend my medical school studies. Therefore, I was able to spread my learning and research in the Ghiso program longitudinally throughout the academic year.

David Hwang and I were fortunately to be named the first Ghiso fellows at HMS. It was a great honor to carry the tradition of a fellow HMS student, who had fight through his illness and learned the essence of doctoring. More importantly, we were given the opportunities, financial support, and faculty mentor, to fulfill our long-standing interest in palliative medicine as well as learning what Neil Ghiso had stated in his commencement speech:

*"Caring for your patients, just caring, is the most important part of medicine"*

Throughout our fellowship year, we were fortunate to be supported by many people associated with Neil Ghiso, the foundation, and the HMS. All of whom had significantly contributed to our experience as Ghiso Fellows and we are grateful of them.

This report summarizes my fellowship activities during the year and hopefully, would provide a springboard for future fellows and fellowship program going forward.

## ***II. Year-long Fellowship Activities***

### **End of life and palliative care didactic sessions**

The educational component of the Ghiso Fellowship was organized around a format of monthly seminar/didactic session, which typically last one to one and half hours. David Hwang, Jean Hess, and I met with Dr. Buxbaum to go over different aspects of end of life and geriatric care, in particular issues important in the field of palliative medicine. Some selected areas of discussion are: principles of pain management, which reviewed basic pharmacology of clinical pain management; and terminal sedation, which examined the clinical practice of sedation and explored the controversial ethical and legal issue. In addition, we used that time to review the progress in our individual project and share related experience.

### **Ongoing research project formulation and evaluation**

This is really the bulk of my fellowship work, which involved many hours of literature search, project formulation, pre-test protocols, and mock interviews. The eventual project, which was carried out at the Sherrill House skilled nursing facilities in Jamaica Plain, MA, examined the use of a questionnaire-based screen to evaluate the need for long-term care residents to receive palliative care. The proposal of the study is attached (appendix pp.1 to pp.6).

My mentor, Dr. Buxbaum, played a critical role in this research project. Not only he helped shaped the overall structure of the project, he also spend a lot of time with me to review the progress, to steer the direction, and to evaluate the final results. I also received valuable inputs from Jean Hess and David Hwang, as well as some of my classmates and AMSA EOL fellows, whom I run my questionnaire through. Finally, the nursing staff at the Sherrill House, in particular Brenda Morgan and Lucy Sanders, has provided valuable help and suggestions to my project. This research project will be outline in detain in section III.

### **My experience with HMS Institutional Review Board (IRB)**

Because of the nature of my project, which involves in human subjects and interviews, led to our decision to submit the proposal for HMS IRB review. However, this experience proved to be time consuming, painful, as well as confusing. First of all, I underestimated how rigorous and time consuming the process is. Second of all, either Dr. Buxbaum or I have the expertise for formulating human research project to gain IRB approval. Last, the help we got from HMS IRB was minimal. Eventually, after four months of paperwork going back and forth, we were rejected by IRB, citing our inappropriateness in conducting this kind of research (the IRB letter is attached in the appendix pp.7 to pp.8).

However, we did learn valuable lessons from this experience. First, if future Ghiso fellowship maintains a research component, it would be helpful to keep these things in mind and start out the process early. Second, someone who has experience in human subject research should be actively recruited to help out the process.

### **2003 HMS Ebert Community Service Day Poster Presentation**

As requested by Jean Hess, I set up a poster at 2003 11<sup>th</sup> annual HMS Ebert Community Service Day on Oct. 30, 2003. The poster is attached in the appendix pp.9 to pp.12. The poster received warm responses from interested faculty and students.

### **2004 HMS Soma Weiss Research Day Poster Presentation**

A poster to reflect my year-long NSGF experience was displayed on April 15, 2004 during the 64<sup>th</sup> annual HMS Soma Weiss Research Day. It received enthusiastic support from two faculty members who were present. The abstract and poster were attached in appendix pp.13 to pp.14.

### **End of life care curriculum for BWH IM residents**

At the suggestion of Dr. Buxbaum, David and I met with Dr. Daniel Federman, former Dean of Medical Education at HMS, to discuss how we as Ghiso Fellows might be able to help develop the evolving curriculum regarding end-of-life care for BWH Internal Medicine residents. After meeting with Dr. Federman and several BWH physicians who are involved in resident education, we decided that it would be helpful to make self-directed PowerPoint presentations on various palliative care topics developed by The Education on Palliative and End-of-Life Care Project (EPEC) available for all medicine residents to access on their own. The CD-ROM is now on file and available at the BWH Medical Residency Office.

### ***III. Summary of Research***

#### **Delivery of Palliative Care in Nursing Homes - a pilot survey of Sherrill House residents using palliative performance score and direct interviews**

##### ***Introduction***

- 1.6 million people reside in nursing homes in the US and 20-25% of all US deaths (500,000 deaths) occur each year in the nursing homes
- Nursing home residents have limited access to palliative and hospice care
- Medicare reimburses hospice care provided in nursing homes
- Research has shown major problems in pain and symptom management, advance care planning, and psychosocial support

##### ***Case Vignette***

Mrs. PA, a 83 yr old white female with histories of CAD, CVA, HTN, Type II DM and PVD, has been a long term care resident of the Sherrill House since 11/27/02 following left lower leg amputation.

This is one of the typical long-term care residents at SH:

- Usually geriatric population
- Usually with multiple complex co-morbidities
- Usually with a broad spectrum of diseases ranging from medical, surgical, and neuro-psychiatric illness

##### ***Method and Approach***

###### **A three-step approach:**

- Identification of eligible candidates using a simplified palliative care screen and chart review
- Determination of palliative performance status (PPS) score (Figure 2) of eligible candidates by reviewing the minimal data set (MDS) section of the patient chart
- Resident interview using a palliative care questionnaire

###### **Exclusion Criteria:**

- Mental disorders or psychiatric illness such as schizophrenia or depression as major diagnosis
- Non-verbally communicative (AD, dementia, stroke etc.)
- Residents who are currently enrolled in hospice service

###### **Inclusion Criteria for Interview:**

- PPS score of 50% or less (generally considered hospice eligible)

- Evidence for progression of disease as indicated by multiple recent hospitalizations or ER visits
- Worsening functions in ADLs as indicated by floor nursing staff

**Categories of interview questions:**

- Living with terminal or chronic illness
- Symptom control and support care
- Advance care planning
- Death and dying; reality and future
- Knowledge of palliative/hospice care

**Palliative Performance Scale (PPSv2)**

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

**Figure 1.** Palliative Performance Scale (PPSv2). A PPS score of 50% or less usually indicates hospice eligibility.

**Results**

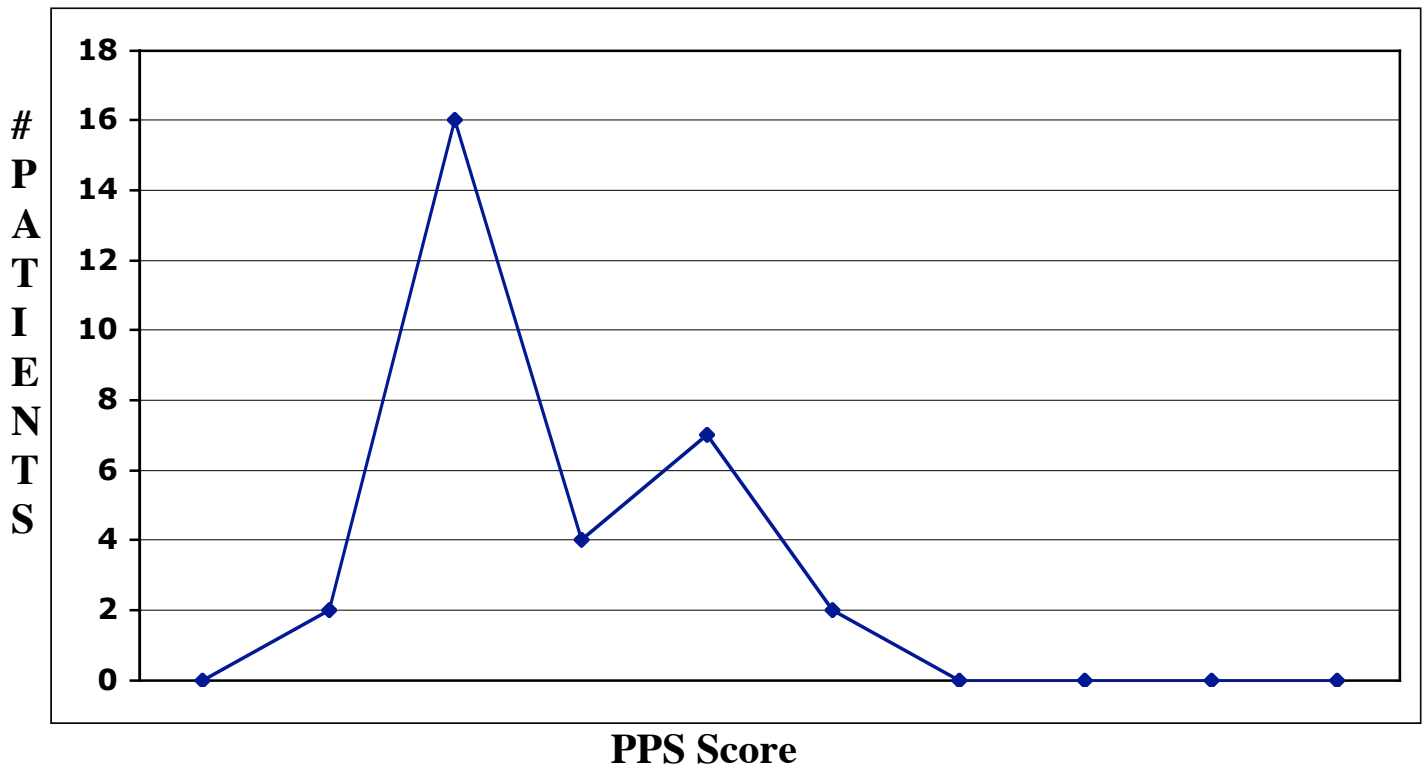
**Patient Selection:**

- There are currently 56 long term care residents on the first and second floors of Sherrill House
- The study population consists of 31 residents whose average PPS score is 38%. The distribution of PPS score is shown in Figure 2
- Of the 31 residents, 8 were selected based on the criteria for interview
- The spectrum of disease in the final study population is very broad (cancer, CAD, CVA, DM, MS, ALS etc.)
- The candidates were selected without consideration of their code status (70% DNR)

**Summary of interviews:**



- One of the common themes from the interview was that all of them expressed a strong desire to “die in their home, with their family members, rather than in a nursing home”
- Residents are generally happy with staff management of their symptoms; one major concern was the timely delivery of narcotics
- Most residents lack knowledge of advance care planning and its benefit to them and their family
- Staff support for resident psychosocial issues are poor
- Most residents do not understand hospice or palliative care and the benefits they offer

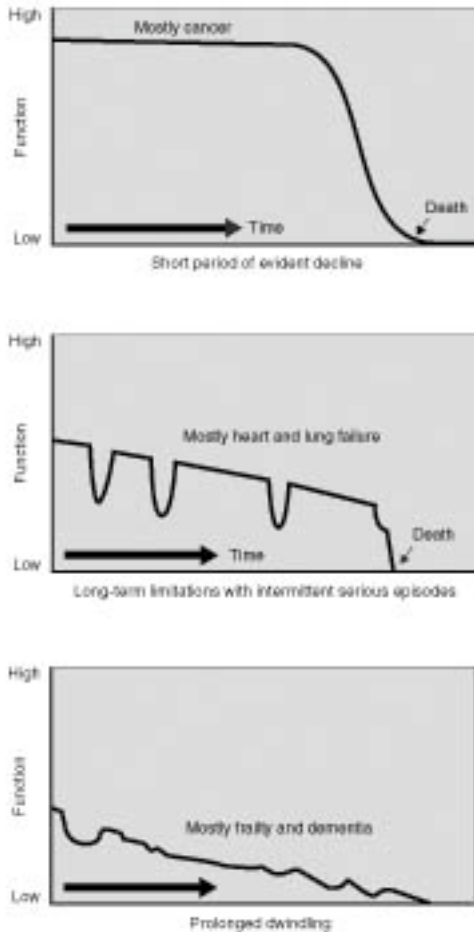


**Figure 2.** The distribution of PPS scores among the study population at the Sherrill House.

### Conclusions and Reflections

In the current study, we addressed the issue of palliative care delivery in the nursing home setting by conducting a survey-based palliative care screen on long term care residents at the Sherrill House. Review of their medical records indicted an end-of-life course consistent with the three predicted trajectories (Figure 3). Moreover, this study indicated deficiencies in education, support, and delivery of palliative care, particularly in the area of advance care planning, psychosocial support, and education on living with chronic illness and end-of-life care. Finally, the survey instrument used here has the potential to be used in another nursing home setting or applied to a study with a larger population of patients.

When I began medical school, I always wondered what the art of medicine means and how I can learn it. From my experience as a Ghiso Fellow, getting to know the remarkable story of Neil and his family fighting through cancer, and interacting with terminally ill patients, I started to understand that the art of medicine is at its best when there is no cure and when one is at the end of life. We, as future physicians, must then learn how to shift our focus from medical cure to quality of life, and to offer our compassion and companionship all the way through the end. **IF WE DELIVER QUALITY END-OF-LIFE CARE, IT IS LIKE THAT WE HAVE GIVEN THEM A FINAL GIFT OF LIFE.**



**Figure 3.** Chronic illness in the elderly usually follows three trajectories. RAND Health White Paper 2003 Publication 0-8330-3455-3

## *IV. Acknowledgement*

I would like to thank Alex Ghiso, the President of NSGF, for financial support and encouragement; Jeannie Hess of HMS Office of Enrichment Programs, for valuable inputs and administrative assistance; David Hwang, my co- Ghiso Fellow this year, for camaraderie and collaboration; and Dr. Buxbaum, who served not only as a valuable mentor for all of our fellowship activities, but also a good role model for our development as a physician.

In addition, my project would not have come to fruition without the assistance from the Staff of the Sherrill House, with whom I had the greatest pleasure of learning and working together throughout the year.

## *V. Appendix*

***Integration of Palliative and Hospice Care in Nursing Homes ----  
A Pilot Study of the Residents at the Sherrill House Using a  
Palliative Care Screen Based on Disease-Specific Karnofsky  
Score and a Support and Comfort Care Questionnaire***

**Introduction**

- 1.6 million people reside in nursing homes in the US
- 20-25% of all US deaths (500,000 deaths) occur each year in the nursing home
- Nursing home residents have limited access to palliative and hospice care
- Medicare reimburses hospice care provided in nursing home
- Research has shown major problems in pain management, advanced care planning, and psychosocial support

**Objectives**

- Evaluating the use of a palliative care screen based on Karnofsky score and a questionnaire to identify eligible residents at the Sherrill House
- Understand the preferences and goals of patient/family in dealing with a worsening and potentially terminal illness
- Observe the communication process between the ill patient/family and the health care team by rounding with Dr. Buxbaum
- Identify the key barriers to deliver a cohesive transition from curative treatment to palliative care

**Three-Step Approaches**

*I. Identification of residents who are likely candidates for palliative care*

**Diagnosis (As documented in Medical Record)**

Advanced Cancer

Type:

Lung

Breast

GI

Prostate

Other \_\_\_\_\_

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Terminal or End-Stage Illness

Heart Disease (congestive heart failure, coronary artery disease)

Alzheimer's Disease/Dementia

COPD

CVA/stroke

Other disease \_\_\_\_\_

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## General Indicators

Multiple ER visits during the last 12 month \_\_\_\_\_

Multiple hospital visits during the last 12 month \_\_\_\_\_

**Patient/Family desire for supportive or comfort care** \_\_\_\_\_

*II. Further evaluation of patient eligibility using disease-specific Karnofsky score complemented by Activities of Daily Living (ADL) score*

### Karnofsky Score

Condition	%	Comments
Able to carry on normal activity and to work. No special care is needed.	100	Normal, no complaints or evidence of disease
	90	Able to perform normal activity; minor signs and symptoms of disease
	80	Able to perform normal activity with effort; some signs and symptoms of disease
Unable to work. Able to live at home, care for most personal needs. A varying degree of assistance is needed.	70	Cares for self, unable to perform normal activity or to do active work
	60	Requires occasional assistance but is able to care for most of own needs
	50	Requires considerable assistance and frequent medical care
Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	40	Requires special care and assistance; disabled
	30	Hospitalization indicated, although death not imminent; severely disabled
	20	Hospitalization necessary; active supportive treatment required, very sick
	10	Fatal processes progressing rapidly; moribund
	0	Dead

### Activities of Daily Living (ADL) Score

- **Bathing**
- 4. Independent
- 3. Uses a device (shower stool, etc.)

2. Needs personal assistance (in and out of bath tub)
1. Completely dependent (Bed bath)
  - **Dressing**
4. Independent
3. Uses a device (reacher, etc.)
2. Needs personal assistance (buttoning, choosing clothing)
1. Completely dependent
  - **Toileting: getting to toilet, on/off; opening appropriate clothing**
4. Independent
3. Uses a device (walker, cane)
2. Needs personal assistance
1. Completely dependent
  - **Transfer**
4. Independent
3. Uses a device
2. Needs personal assistance
1. Completely dependent
  - **Continence**
4. Independent
3. Uses a device (urinal, bedpan)
2. Needs personal assistance (to position urinal/bedpan)
1. Completely dependent (catheter or diapers)
  - **Feeding**
4. Independent
3. Uses a device
2. Needs personal assistance (fed by another)
1. Completely dependent (feeding tube or not eating)

### **Hospice and Palliative Care Admission Criteria**

- **End-Stage Alzheimer's Disease**

Bed bound or chair bound  
 Unable to effectively communicate with words  
 Markedly decreased appetite and/or intake  
 Karnofsky score of 5 or less  
 ADL score of 12 or less

- **End-Stage AIDS**

Patient is not receiving TPN  
 Patient is not receiving AZT or IV medications other than for pain relief  
 CD4 less than 50mm<sup>3</sup>  
 History of successive opportunistic infections  
 Karnofsky score of 5 or less  
 ADL score of 12 or less

- **End-Stage Cardiac Disease**

Dyspnea with minimal exertion  
 Azotemia as evidenced by elevated BUN

Multiple cardiac medications

Abnormal EKG or ejection fraction

If CHF or Cardiomyopathy: Evidence of fluid overload in spite of medications (peripheral edema, ascites, rales)

If CHF/ASHD/ASCVD/Ischemic heart disease; History or evidence of angina arrhythmias, previous myocardial infarctions

Karnofsky score of 6 or less

ADL score of 20 or less

- ***End-Stage Cerebral Vascular Disease***

Markedly decreased appetite and/or intake

Bed bound or chair bound

Karnofsky score of 4 or less

ADL score of 8 or less

- ***End-Stage Diabetes***

History of diabetes for more than 20 years

Severe vascular disease

Cardiac, MI, Angina, CHF

Cerebral: CVA

Peripheral: Amputation, Ulcers

Hypertension, Severe

Frequent infections

Karnofsky score of 5 or less

ADL score of 12 or less

- ***End-Stage Liver Disease***

Documentation of specific liver disease in history & physical

Abnormal liver enzymes:

Alkane Phosphatase, SGOT, and Bilirubin

Jaundiced

Ascites

Edema

Abnormal coagulation

Elevated Prothrombine Time

Karnofsky score of 6 or less

ADL score of 20 or less

- ***End-Stage Neurological Disease***

Bed bound or Chair bound

Patient has no ventilator support

Karnofsky score of 5 or less

ADL score of 8 or less

- ***End-Stage Pulmonary Disease***

COPD, Emphysema, Bronchitis, Cystic Fibrosis, Bronchiectasis, Pulmonary Fibrosis, Black Lung

No ventilator support

On multiple pulmonary medications

Oxygen dependent

Minimal activity results in severe dyspnea



Karnofsky score of 5 or less

ADL score of 18 or less

- ***End-Stage Renal Disease***

BUN greater than 75mg/dl

Creatinine greater than 5 U/L

Discontinuing or refusing dialysis

Chronic or acute illness that precipitated renal failure

Karnofsky score of 6 or less

ADL score of 20 or less

- ***Cancer/Malignancy***

Diagnosis confirmed through pathology or radiology

Patient is no longer receiving curative treatment\*

There is evidence of end stage disease and/or metastasis

Lab/diagnostic studies have been done recently to support disease progression

Karnofsky score of 5 or less

ADL score of 18 or less

### *III. Evaluation of the desire of patient/family for support and comfort care*

#### **Sample Interviewing Questions**

1. Living with a life-threatening illness – the development, diagnosis, seriousness, and prognosis of a disease told by the patient/family. This might also include life review to help build a strong relationship.
2. Are you given timely, accurate information and prognosis about your disease by your health care providers?
3. How are your medical decisions made? What are the factors you consider? Have you ever regret any decision you made throughout your illness?
4. What options of care were you given when you were first admitted? Have you heard comfort care/palliative care? What do you know about them?
5. What is your ideal care team? What do you think about your current team? How would you like your primary care physician involved in your current care?
6. In each phase of your illness (diagnosis, treatment, recurrence, or chronic symptoms), have you had difficulty in dealing with reality? If yes, how did you cope with it?
7. What do you see in yourself in three months, six months and a year? Have you thought about how your illness could affect your future?
8. Have you experienced great pain associated with your illness? If yes, was it properly managed?
9. Do you have other symptoms that you wish to have them better managed?

#### **Final Evaluation**

The goal of step I is to identify target population of nursing home residents who are likely candidates for palliative care. This is mainly based on medical history and disease progression. No patient/family contact is made at this time.

The goal of step II is to systematically evaluate these patients for palliative care eligibility. The performance status is evaluated using a quantitative Karnofsky score and Activities of Daily Living (ADL) score. This would allow an objective, replicable model to be established at nursing home. Dr. Buxbaum, who has extensive experience using these evaluations, will help me to fulfill the goal. Patient contact will be initiated at this time.

The goal of step III is to establish extensive patient/family contact to probe their need and desire in medical care, to introduce the concept of support and comfort care, and to facilitate a transition from curative treatment to palliative care. Finally, key barriers that prevent a good transition at nursing home will be identified.

Overall, the project will be monitor closely by Dr. Buxbaum and staff at the Sherrill House to ensure its smooth progress and key findings will be reported.

5 February 2004

Richard Lin  
Division of Health and Sciences and Technology (HST)  
Harvard Medical School  
260 Longwood Ave., TMEC Rm. 213  
Boston, MA 02115

Re: ORSP Protocol # M11025-101  
*The Use of a Palliative Care Questionnaire on Nursing Home Residents*

Dear Dr. Lin:

I am writing to let you know that your protocol was reviewed by the HMS/HSDM Committee on Human Studies and has been deferred by the Committee with suggestions for clarification below. When these clarifications have been made, the Committee will re-review the protocol.

The proposed research addresses a critical issue in long-term care and has the potential to yield useful information. Below are some comments on specific concerns with the application reviews and/or issues that need to be described more clearly.

### **1. Recruitment**

- It was not clear from the application how potential subjects will be recruited. Section 10.e says approximately 15 to 20 patients, but no additional information about subject selection could be found. Please clarify subject selection procedures.
- The application states that only those who are competent and who have no mental illness will be interviewed. This is an appropriate restriction on the subjects to be recruited, but please clarify how such determinations will be made.

### **2. Rationale for Medical Record Review**

- The application does not have an adequate description and justification of the medical record review. Protocol says charts will be reviewed "to determine their illness." But no description is provided of why record information is being collected or how it will be analyzed or used for subject recruitment. Please clarify why a medical record review needs to be performed.

### **3. Study Goals**

- Please clarify what your intended goals are for the study. One goal apparently is to do content analysis of interviews to "identify common themes and trends." No mention is made of how medical record information will be used or why the palliative performance status (PPS) instrument will be used, or how data from the PPS would be used.

- In a letter to Dr. Connolly on November 2, the applicant states that it will “tell us whether it is practical to do screening based upon chart reviews and staff contact.” This goal is not referred to in the application and it is not obvious from the protocol description how this would be achieved. Please clarify.
- In section 17, the applicant says the study will “provide a valuable instrument to evaluate palliative care need in a long term care facility.” There is nothing in the project description to indicate how this would be done. Please describe how the instrument will be created

#### **4. Informed Consent**

- The informed consent form should be rewritten to include a description of the study procedures. It also needs to be revised to correct grammar mistakes etc. Also, some of the terminology should be changed as it may have an unnecessarily upsetting effect on the potential subjects. For example, it refers to “incurable, progressive illness,” but there is no reference to such a clinical state in the proposal or study goals, and such a statement could be surprising to the subject.

#### **5. Interview**

- The interview poses minimal risk but is too open-ended and unclear. Please clarify the interview questions

#### **6. Advice**

- You are raising potentially provocative questions that could find interesting answers; however, in its current form it does not constitute a research project. The Committee suggests that you seek the advice your mentor as well as possibly seeking the advice of a consultant who has expertise in this area of research. A suggested person to contact, who has expertise in the area of Gerontology and may be able to set you up with someone to help review the protocol, is Dr. Lewis Lipsitz, M.D. at Beth Israel Deaconess. His contact information is: 617-363-8318 and [lewis\\_lipsitz@hms.harvard.edu](mailto:lewis_lipsitz@hms.harvard.edu).

If you have any questions, please do not hesitate to contact me.

Sincerely,

Lucas Breen, M.S.  
IRB Coordinator  
Office of Research Subject Protection  
Harvard Medical School  
25 Shattuck St. Gordon Hall - 412  
Boston, MA 02115  
Phone: 617-432-4965  
Fax: 617-432-5175  
<http://www.hms.harvard.edu/orsp/>

# When There Is No Cure

## *A Medical Student's Reflection on Learning the Art of Medicine through the Neil Samuel Ghiso Fellowship on Palliative Care*



Harvard-MIT Division of  
Health Sciences and Technology

*Richard J. Lin  
HST Society Class of 2006*

*Robert C. Buxbaum, MD  
HMS Faculty Mentor*

### **THE NEIL SAMUEL GHISO FOUNDATION** *For Compassionate Medical Care*

Neil Ghiso was diagnosed with a brain tumor in the fall of 1997, while a HST student at Harvard Medical School. Neil underwent surgery, chemotherapy and radiation numerous times. Though fortunate to have had access to many of the brightest medical minds and most advanced technologies in the world, Neil discovered, through his unique journey as a student and a patient, that the most critical component of patient care is compassion. As Neil stated simply during his commencement speech at Harvard, "caring for your patients, *just caring*, is the most important part of medicine." Neil received his MD on June 7, 2001 and passed away on February 11, 2002.



### **THE NEIL SAMUEL GHISO FOUNDATION** *For Compassionate Medical Care*

#### **Mission**

The Neil Samuel Ghiso Foundation is dedicated to fostering compassionate care for chronically and terminally ill patients and their families through medical education and training.

#### **Activities**

This year NSGF initiated its first program, the Neil Ghiso Fellowship, awarding grants to two Harvard medical students to work with palliative care teams in the treatment of chronically and terminally ill patients. In addition to caring for patients, the fellows will conduct research relating to compassionate care and, at the conclusion of the project, will submit papers reflecting on their experiences and sharing their findings. Over time NSGF plans to expand this program to other medical schools.

### **THE NEIL SAMUEL GHISO FOUNDATION** *For Compassionate Medical Care*

#### **Neil Ghiso Fellows**

Richard Lin (richard\_lin@student.hms.harvard.edu)  
David Hwang (david\_hwang@student.hms.harvard.edu)

#### **HMS Faculty Mentor**

Robert C. Buxbaum, MD (robert\_buxbaum@hms.harvard.edu)

#### **HMS Program Manager**

Jeannie Hess, Community Service (jean\_hess@hms.harvard.edu)

### **THE NEIL SAMUEL GHISO FOUNDATION** *For Compassionate Medical Care*

#### **Current Fellowship Activities**

- Monthly Seminar Meeting
- Nursing Home Visit and Rounds with Dr. Buxbaum
- Participation in the Massachusetts Coalition for Compassionate Care (MCCC) Activities
- Individual Research/Community Service Project  
*Richard Lin - Longitudinal Project at Sherrill House*  
*David Hwang - Intensive Month Long Rotation*
- Other Potential Projects Available

[www.nsgf.org](http://www.nsgf.org)

# The Use of a Palliative Care Questionnaire on Long Term Care Residents at Sherrill House

Richard J. Lin (HMS student investigator)  
 Robert C. Buxbaum, MD (HMS faculty advisor)  
 Sherrill House, Inc., Jamaica Plain, MA

## Introduction

- 1.6 million people reside in nursing homes in the US
- 20-25% of all US deaths (500,000 deaths) occur each year in the nursing home
- Nursing home residents have limited access to palliative and hospice care
- Medicare reimburses hospice care provided in nursing home
- Research has shown major problems in pain and symptom management, advanced care planning, and psychosocial support

## Goals and Objectives

- Evaluating the prognostic use of a palliative care screen based on Palliative Performance Status (PPS) score and a questionnaire on long term care nursing home residents
- Understand the wishes and goals of the patient/family in dealing with a worsening and potentially terminal illness
- Observe the communication process between the ill patient/family and the health care team
- Identify the key barriers to deliver a cohesive transition from curative treatment to palliative care

## A Three-step Approach

- Identification of likely candidates using a simplified palliative care screen
- Chart reviewing and determination of palliative performance status (PPS) score
- Resident interview using a palliative care questionnaire

## A Simple Palliative Care Screen

Diagnosis (As documented in Medical Record)

Advanced Cancer  
 Type: \_\_\_\_\_  
 Lung \_\_\_\_\_  
 Breast \_\_\_\_\_  
 GI \_\_\_\_\_  
 Prostate \_\_\_\_\_  
 Other \_\_\_\_\_

Terminal or End-Stage Illness  
 Heart Disease (congestive heart failure, coronary artery disease) \_\_\_\_\_  
 Alzheimer's Disease/Dementia \_\_\_\_\_  
 COPD \_\_\_\_\_  
 CVA/stroke \_\_\_\_\_  
 Other disease \_\_\_\_\_

General Indicators

Multiple ER visits during the last 12 month \_\_\_\_\_  
 Multiple hospital visits during the last 12 month \_\_\_\_\_

## Revised PPS Score (PPSv2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work. No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work. Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort. Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work. Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house Work. Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work. Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly Sit/Lie	Unable to do most activity. Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity. Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity. Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity. Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death				

The consensus is that PPS of 70% for cancer patients and PPS of 50% for non-cancer patients generally indicate hospice appropriateness.

## A Palliative Care Questionnaire

- Evaluate the need of Sherrill House residents for palliative care
- Questionnaire designed to probe quality of life; end of life decision making; symptom management; psychosocial/spiritual issues related to chronic illness
- An informed consent will be presented to the residents who qualify after first two steps of screen
- 20 to 30 residents will be each interviewed in two sessions and the process will be audio-taped
- Content analysis will be performed to identify common trends and themes

## Sample Interview Questions

- How long have you been at this nursing facility?
- Why did you come/stay here?
- How do you like it here?
- Were you given timely and accurate information explanation of your illness?
- How do you make medical decisions? Have you ever regretted any medical decision you made?
- When you think about illness, what worries you the most?
- How does your cultural tradition approach a serious illness like yours?

## Sample Interview Questions

- How do you cope with the physical limitations and challenges of your illness? Who is your primary caregiver? Do you have a health care proxy?
- What roles or responsibilities have you had to give up because of your illness? What relationships do you wish to maintain?
- What has been the hardest issue for you and your family during your illness? How did you and your family cope with it?
- Have you experienced physical or emotional distress or pain associated with your illness? How is it managed and by whom?
- Do you have other symptoms (fatigue, dyspnea, N/V, constipation etc.)? How are they treated?

## Sample Interview Questions

- Are you comfortable getting treated here? If you were to have an acute episode, do you want to go back to hospital?
- What do you know about advanced directive/living will? Do you have one? What do you know about DNR?
- From what sources do you draw your strength? What has been your hardest loss?
- How do you see yourself in six months? A year?
- Some patients with this condition tell me that they think about the possibility of dying. Do you? What is your image of death and dying?

## Progress Report

- A list of Long Term Care Residents at the Sherrill House have been compiled and their charts are being reviewed and passed through the palliative care screen
- The project has been approved by Sherrill House Ethics Committee and Medical Committee
- The project is under review at HMS IRB

## Reflection

When I begun medical school, I always wondered what the art of medicine means and how I can learn it. From my experience as a Ghiso Fellow, getting to know the remarkable story of Neil and his family fighting through cancer and interacting with terminally ill patients, I started to understand that the art of medicine is at its best when there is no cure and when one is at the end of life. We, as future physicians, must then learn how to shift our focus from medical cure to quality of life, and to offer our compassion and companionship all the way through the end.

*IF WE DELIVER QUALITY END-OF-LIFE CARE, IT IS LIKE THAT WE HAVE GIVEN OUR PATIENTS A FINAL GIFT OF THEIR LIFE.*

*To Cure Sometimes*

*To Relieve Often*

*To Comfort Always*

## Acknowledgement

- Neil Samuel Ghiso Foundation for financial support
- Dr. Robert Buxbaum for mentorship
- David Hwang for camaraderie and collaboration
- Jeannie Hess for valuable input and administrative assistance

## For More Info

- For more info on the fellowship program, please refer to the foundation's website ([www.nsgf.org](http://www.nsgf.org)) and Jean Hess at the Office for Enrichment Programs
- For more info on other potential projects and future fellowship activities, please refer to David Hwang ([david\\_hwang@student.hms.harvard.edu](mailto:david_hwang@student.hms.harvard.edu))



**To cure sometimes, to relieve often, to comfort always -  
my experience as a Neil Samuel Ghiso Fellow for Compassionate Care**

**Richard J. Lin  
Harvard Medical School, HST Society, Class of 2006**

**Robert C. Buxbaum, MD  
Harvard Medical School and Neil Samuel Ghiso Foundation**

Neil Samuel Ghiso Foundation was established in 2002 in honor of Neil Ghiso, MD., HMS02, who battled brain cancer during his medical school and passed away in early 2002. It is dedicated to fostering compassionate care for chronically and terminally ill patients and their families through medical education and training. I was fortunate to become one of the first two Ghiso Fellows at HMS and I would like to share my experience with fellow students.

Since this is the inaugural year for the fellowship, David Hwang, I, and our mentor Dr. Robert Buxbaum have set out to test different educational ideas, learning opportunities, and research/community service projects. Some examples from this year's program are monthly meetings of educational seminar on palliative care and end of life issues; visits to long term care skilled nursing facilities; resident teaching in end of life care; and involvement in activities of the Massachusetts Coalition for Compassionate Care (MCCC).

For my research project, I have chosen to study the use of a questionnaire-based palliative care screen on the long-term care residents at the Sherrill House in Jamaica Plain, MA. The rationale for this study is based on the facts that about 25% of US death occurs in the nursing home and that research has shown that severe deficiency exists in palliative care and end of life issues in nursing homes.

My study is designed to examine the eligibility of long-term care residents for palliative care service. This screening tool is consisted of three parts. First, medical charts of long-term care residents will be reviewed and their illness and hospitalization records will be documented. Second, their functions in activities of daily living (ADL) will be determined using a palliative performance status (PPS) score. Finally, a questionnaire-based interview will be conducted to probe the need of these residents for palliative/comfort care service.

We choose Sherrill House because of its large population of long-term care residents. So far, I have reviewed 82 charts and identified 10 residents who might be eligible to receive palliative care service. They suffer from a variety of illness, from multiple sclerosis to congestive heart failure to stroke. The average PPS score is 38%, below the general standard of 50% for hospice admission. The questionnaire-based interviews are ongoing but several common themes are emerging. There are universal complaints of food and lack of attention from staff. They all expressed a lack of knowledge on their illness and on what palliative/comfort care is. Most residents do not have a clear idea of what future holds and the death and dying process. In addition, the use of advanced care planning was poor in the general long-term care population at Sherrill House.

In summary, this program so far has taught me some important lessons in medicine. When there is no cure, we, as physicians, must be able to offer our compassion and to focus on the quality of life of dying patients to make sure they die in grace and dignity. This comprehensive approach to patient care is the art of medicine at its best.



# To cure sometimes, to relieve often, to comfort always - my experience as a Neil Samuel Ghiso Fellow for Compassionate Care

Richard J. Lin and Robert C. Buxbaum

HST Class of 2006, Harvard Medical School and Harvard Vanguard Medical Associate



Harvard-MIT Division of Health Sciences and Technology

## Neil Samuel Ghiso Foundation

Neil Ghiso was diagnosed with a brain tumor in the fall of 1997, while a HST student at Harvard Medical School. Neil underwent surgery, chemotherapy and radiation numerous times. Though fortunate to have had access to many of the brightest medical minds and most advanced technologies in the world, Neil discovered, through his unique journey as a student and a patient, that the most critical component of patient care is compassion. As Neil stated simply during his commencement speech at Harvard, "caring for your patients, just caring, is the most important part of medicine." Neil received his MD on June 7, 2001 and passed away on February 11, 2002.



Figure 1. Neil in the 2001 HMS graduation commencement speech. Courtesy of the Neil Samuel Ghiso Foundation.

The mission of the Neil Samuel Ghiso Foundation is dedicated to fostering compassionate care for chronically and terminally ill patients and their families through medical education and training. For the first year of the program, two HMS students had been selected to participate in a variety of activities and potential projects:

- Bimonthly education seminar on EOL care and project progress meeting
- Visits to sub-acute and long-term care facilities and rounding with Dr. Robert Buxbaum
- Longitudinal research/service project and month-long intensive rotation
- Participation of Massachusetts Coalition of Compassionate Care (MCCC) activities

For more information, please refer to the Foundation's website: [www.nsgf.org](http://www.nsgf.org) or contact Jean Hess at HMS ([jean-hess@hms.harvard.edu](mailto:jean-hess@hms.harvard.edu)).

## Delivery of Palliative Care in Nursing Homes - a pilot survey of Sherrill House residents using palliative performance score and direct interviews

### Introduction

- 1.6 million people reside in nursing homes in the US and 20-25% of all US deaths (500,000 deaths) occur each year in the nursing homes
- Nursing home residents have limited access to palliative and hospice care
- Medicare reimburses hospice care provided in nursing homes
- Research has shown major problems in pain and symptom management, advance care planning, and psychosocial support

### Case Vignette

Mrs. PA, a 83 yr old white female with histories of CAD, CVA, HTN, Type II DM and PVD, has been a long term care resident of the Sherrill House since 11/27/02 following left lower leg amputation.

This is one of the typical long term care residents at SH:

- Usually geriatric population
- Usually with multiple complex co-morbidities
- Usually with a broad spectrum of diseases ranging from medical, surgical, and neuro-psychiatric illness

### Method and Approach

#### A three-step approach:

- Identification of eligible candidates using a simplified palliative care screen and chart review
- Determination of palliative performance status (PPS) score (Figure 2) of eligible candidates by reviewing the minimal data set (MDS) section of the patient chart
- Resident interview using a palliative care questionnaire

#### Exclusion Criteria:

- Mental disorders or psychiatric illness such as schizophrenia or depression as major diagnosis
- Non-verbally communicative (AD, dementia, stroke etc.)
- Residents who are currently enrolled in hospice service

#### Inclusion Criteria for Interview:

- PPS score of 50% or less (generally considered hospice eligible)
- Evidence for progression of disease as indicated by multiple recent hospitalizations or ER visits
- Worsening functions in ADLs as indicated by floor nursing staff

### Palliative Performance Scale (PPSv2)

PPS Level	Activities	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Short Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to perform work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly in Bed	Unable to do any work Extensive disease	Consistent assistance required	Normal or reduced	Full or Drowsy or Confusion
40%	Mainly in Bed	Unable to do any activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy or Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy or Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to Nil	Full or Drowsy or Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma or Confusion
0%	Death	-	-	-	-

Figure 2. Palliative Performance Scale (PPSv2). A PPS score of 50% or less usually indicates hospice eligibility.

### Categories of interview questions:

- Living with terminal or chronic illness
- Symptom control and support care
- Advance care planning
- Death and dying; reality and future
- Knowledge of palliative/hospice care

## Results

### Patient Selection:

- There are currently 56 long term care residents on the first and second floors of Sherrill House
- The study population consists of 31 residents whose average PPS score is 38%. The distribution of PPS score is shown in Figure 3
- Of the 31 residents, 8 were selected based on the criteria for interview
- The spectrum of disease in the final study population is very broad (cancer, CAD, CVA, DM, MS, ALS etc.)
- The candidates were selected without consideration of their code status (70% DNR)

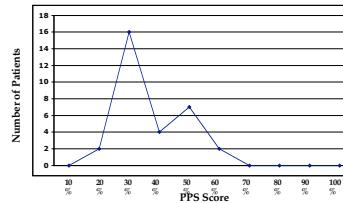


Figure 3. The distribution of PPS scores among the study population at the Sherrill House.

### Summary of interviews:

- One of the common themes from the interview was that all of them expressed a desire to "die in their home, with their family members, rather than in a nursing home"
- Residents are generally happy with staff management of their symptoms; one major concern was the timely delivery of narcotics

### Summary of interviews (continued):

- Most residents lack knowledge of advance care planning and its benefit to them and their family
- Staff support for resident psychosocial issues are poor
- Most residents do not understand hospice or palliative care and the benefits they offer

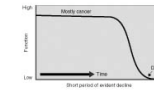
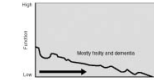


Figure 4. Chronic illness in the elderly usually follows three trajectories. RAND Health White Paper 2003 Publication 0-8330-3455-3



## Conclusions and Reflections

In the current study, we addressed the issue of palliative care delivery in the nursing home setting by conducting a survey-based palliative care screen on long term care residents at the Sherrill House. Review of their medical records indicated an end-of-life course consistent with the three predicted trajectories (Figure 4). Moreover, this study indicated deficiencies in education, support, and delivery of palliative care, particularly in the area of advance care planning, psychosocial support, and education on living with chronic illness and end-of-life care. Finally, the survey instrument used here has the potential to be used in another nursing home setting or applied to a study with a larger population of patients.

When I began medical school, I always wondered what the art of medicine means and how I can learn it. From my experience as a Ghiso Fellow, getting to know the remarkable story of Neil and his family fighting through cancer, and interacting with terminally ill patients, I started to understand that the art of medicine is at its best when there is no cure and when one is at the end of life. We, as future physicians, must then learn how to shift our focus from medical cure to quality of life, and to offer our compassion and companionship all the way through the end. IF WE DELIVER QUALITY END-OF-LIFE CARE, IT IS LIKE THAT WE HAVE GIVEN OUR PATIENTS A FINAL GIFT OF THEIR LIFE.

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