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Proofreading the Final Chapter: Studies towards Improving Holistic End-Of-Life Care within
ArchCare at Terence Cardinal Cooke

Introduction:

The size, location, and composition of ArchCare at Terence Cardinal Cooke (TCC) present both opportunities for and challenges to the improvement of end-of-life (EOL) care unique from those of many other long-term care facilities. TCC consists of nine clinical programs split into four organizational units: the skilled nursing facility (SNF), consisting of geriatric, Alzheimer's and dementia, respiratory and tracheotomy, and end-stage dialysis residents; the special services division, consisting of sub-acute transitional care patients and Huntington's Disease residents; the discrete division, consisting of HIV/AIDS residents; and the Specialty Hospital, consisting of pediatric residents with developmental disabilities. TCC's large occupancy, at 729 beds—roughly 500 of which compose the SNF—makes administrative coordination and implementation of EOL care improvement a more complex operation than it would be at other long-term care facilities¹, which generally consist of 100-300 beds. Although EOL issues necessarily vary on a case-by-case basis, the great medical and social diversity of patients and residents at TCC—due to its location in New York City—further expands the scope of EOL matters that arise on a daily basis. TCC's unique makeup thus presents both an opportunity for exposure to EOL issues of all manners and a challenge to address them all sufficiently.

Laws and Policies Governing EOL Care at TCC

New York State Family Health Care Decisions Act

Effective June 1, 2010, the New York State Family Health Care Decisions Act (FHCDA) “establishes the authority of a patient's family member or close friend to make health care

¹ TCC's model for improving EOL care is based on those used at other skilled nursing facilities, most commonly nursing homes but also specialized EOL facilities, such as Calvary Hospital in Bronx, NY.

decisions for the patient in cases where the patient lacks decisional capacity and did not leave prior instructions or appoint a health care agent. This ‘surrogate’ decision maker would also be empowered to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.” (New York State Bar Association) The FHCDA put in place a protocol by which a “surrogate” decision maker could be chosen and contacted by TCC staff to make end-of-life treatment decisions and complete advance directives when the patient lost capacity to do so. There are similar acts in many other states.

New York State Palliative Care Information Act

Effective on February 9, 2011, the New York State Palliative Care Information Act states that “If a patient is diagnosed with a terminal illness or condition, the patient’s attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including … prognosis, risk and benefits of the various options; and the patient’s legal rights to comprehensive and symptom management” (NEJM). The act is intended to encourage physicians to have meaningful discussions about EOL care, and met much opposition among the medical professionals in New York. Many other states are predicted to pass similar laws in the near future.

ArchCare at TCC Policies and Protocols:

Copies of these policies can be found in the “Policies” section of the binder.

Treatment Decisions for Adult Patients who Lack Decision-Making Capacity, Policy No. 4033

This policy outlines the protocol for establishing a resident’s capacity to make medical decisions and deciding who has the authority to make treatment decisions for patients who lack decision-making capacity. It also outlines the types of treatment decisions that can be made by physicians, the health care agent, and/or the ethic committee.

Terminal Prognosis/End-Of-Life Care, Policy No. 7.2.1.26

This policy outlines the responsibility of each discipline in EOL care for a particular resident once they have been designated as “EOL” and also establishes a timeline for occurrence of those actions.

Medical Orders for Life-Sustaining Treatment (MOLST) Policy Draft, Effective September 1, 2010

This policy describes the purpose of the MOLST (Medical Orders for Life-Sustaining Treatment) protocol “To help ensure that ArchCare nursing home residents’ and ArchCare Senior Life participants’ wishes for life-sustaining treatment are honored and that these individuals have a meaningful opportunity to consider end-of-life and palliative care options.” The MOLST protocol includes eight steps for the IDT to gather information about a patient’s wishes and conduct meaningful discussions with a patient and their loved ones regarding end-of-life treatment wishes. The MOLST form documents comprehensive medical orders reflecting the current status of a patient’s wishes for life-sustaining treatment. It can be used to document a patient’s wishes regarding resuscitation, intubation, hospitalization, and artificial hydration and nutrition—or the patient’s desire not to withhold any of these life-sustaining treatments and remain a “full code.” It also serves as a record of the patient’s health care agent or surrogate and must be periodically reviewed. The policy outlines the timeline and responsibility of each discipline in regard to the completion of the MOLST discussion and form and sets up guidelines for the continuous review and renewal of MOLST.

Terminal Prognosis/Comfort Measures Care Protocol Checklist

This protocol serves as a step-by-step checklist for the IDT to ensure they have taken the appropriate actions to ensure patient comfort as outlined in the Terminal Prognosis/End-of-Life Care policy and as an informal place for documentation of advance directives.

End-of-Life

A TCC resident may be designated as “end-of-life” if his/her attending physician, in accordance with the best of medical knowledge and standards, determines that the resident has a terminal prognosis, regardless of the length of their life expectancy. TCC’s EOL designation is designed to alert staff members to the issues that may arise at the EOL with the resident and to encourage extra care towards those EOL needs; EOL patients are brought up at morning reports, have EOL Care Plans in SIGMA, and have EOL Care Plans in their paper charts. EOL residents do not receive the services of additional staff.

Hospice

A resident is considered for referral for in-house hospice services when a physician, in accordance with the best of medical knowledge and standards, determines that a resident has a terminal prognosis and a life expectancy of six months or less. A resident can then elect to receive services in addition to those he or she already receives from staff at TCC—a hospice aide to attend to the resident, in addition to TCC staff, for up to four hours a day, a hospice pastoral care counselor, and a hospice social worker. Calvary Hospice and Visiting Nurse Service provide TCC's in-house hospice services. These hospice staff members work in conjunction with TCC's IDT to ensure the best EOL care for the resident. A resident must also have a Do Not Resuscitate (DNR) order to be considered for hospice.

The principle of the “good death”

The principle of the “good death” guides TCC’s mission to make death as physically and emotionally painless as possible for the resident and his or her loved ones. Metrics of a “good death” are outlined in the End-Of-Life Care Protocol Checklist, and include measures such as effective pain management, family, friend, or volunteer accompaniment at the time of death, advance directive status, and emotional and psychological contentment.

The Interdisciplinary Team (IDT):

The IDT is both an organizational unit at TCC and a principle by which to implement EOL care. The IDT refers to the group of staff members from different disciplines that care for any particular resident or patient at TCC. Members of the IDT include the physician, nurse, and social worker, as well as the resident’s dietitian, recreational therapists, physical and occupational therapists, psychologists and psychiatrists, pastoral care members, and nursing assistants. Different members of the IDT may consult over any of the resident’s care decisions. Perhaps the clearest manifestation of the IDT appears during Comprehensive Care Plan Conferences (CCPs), during which specific members of the IDT are chosen, depending on the issues to be discussed, to meet with the resident and/or family members to deliver a periodic update or discuss rapid change. The principle of the IDT emphasizes TCC’s commitment to providing holistic care for all of a resident’s needs—medical and non-medical, physical and

emotional—and to the understanding that a patient or resident’s progress rests on a myriad of factors. The “team” approach that the IDT unit is designed to facilitate is crucial to improving EOL care, as achieving a “good death” rests upon the harmonious integration of medical and non-medical decisions: advance directives that reflect the patient’s last wishes, for example, often cannot be satisfactorily obtained without collaboration between medicine, social work, and pastoral care. Much of TCC’s efforts to improve EOL care focus on strengthening the communication and collaboration between members of the IDT to build a model for a “team approach to EOL care.”

Summer Project:

My partner Huili Zhu and I, Ashley Shaw, had the opportunity to complete an internship sponsored by Columbia University’s Earth Institute Center for the Study of Science and Religion (CSSR) to study palliative care at TCC under the supervision of Dr. Anthony Lechich, TCC Medical Director. Our ten-week internship coincided with the start-point of a new round of three-year projects at TCC, one of which is titled “Excellence in Holistic End-Of-Life Care.” While we began directing our internship efforts towards the improvement of EOL care before the official project was announced, all of our areas of study fall under those of the project and our summer efforts may be incorporated into its upcoming implementation. I assisted Dr. Lechich in drafting the proposal, attached as **Appendix 1**, for a sub-project whose mission was “To create an education program to facilitate a ‘team approach’ for end-of-life care, pain management, and spiritual and palliative care, including advance directives”. Huili assisted Dr. Lechich in drafting the proposal for the sub-project “MOLST Implementation and Education,” attached as **Appendix 2**. I believe that these two sub-projects aptly summarize the culmination of our summer internship efforts to improve education on end-of-life and palliative care, which was first suggested to us as an area to study by Father Patrick Bonner, director of pastoral care, and Sister Sheila Brosnan, ArchCare Vice-President of Mission Integration.

Assessing Barriers to Educating Families About EOL Care and Advance Directives:

Perhaps the most difficult—and arguably most important—task of the IDT in EOL care is to educate families about advance directives and palliative care. We began our initiative by conducting short one-on-one interviews with twenty-one staff members from administration,

medicine, nursing, nursing assistance, social work, and pastoral care to assess the societal, cultural, and institutional barriers that TCC staff encountered while discussing EOL issues, specifically advance directives, with involved family members. I brought a blank interview form with our scripted questions to each interview and took notes on the form during my conversation with the staff member. Immediately after the interview, I would return to a computer to translate my written notes and mental recollection of the interviewee's key concerns into a digital transcript. The blank interview forms and the interview transcripts are attached as **Appendix 3**. During the interview period, Huili and I also discussed certain sentiments the staff members had expressed with Dr. Lechich, who felt the interview transcripts gave him "insights into other's perceptions of their responsibilities and issues." After the interview period, Huili conducted an analysis of all the interview transcripts and generated a report that included summaries of key points by discipline and an analysis of the frequency (by percent) of certain sentiments; this analysis report is attached as **Appendix 4**. Frequently occurring statements centered on "feeling short on time and knowledge" and "feeling as if I had to do everything by myself".

While Huili and I did not conduct formal interviews with family members on difficulties they experienced during these discussions, we observed many of the previously identified and others in our daily interactions around the facility—speaking with family members, attending CCP meetings, listening in on morning reports, and following Dr. Lechich on his rounds. Huili and I wrote accounts of the cases "in play" during our internship, attached as **Appendix 5**, and noted the types of EOL issues they exemplified. We followed the progress of these patients and their families throughout the course of our internship, and doing so gave us the most invaluable source by which to assess barriers to EOL care education: the patients' and families' daily experiences at TCC.

We witnessed a multitude of cases in which language barriers and pre-disposition to cultural mores regarding death and dying played a large role in the process. TCC has a large population of Spanish-speaking-only residents and family members, and it is often difficult to find staff members who have both the language proficiency and training required to successfully discuss the intricacies of EOL care. While TCC does subscribe to a telephone translator service available 24 hours a day, TCC staff does not feel this is a good tool through which to conduct sensitive conversations. Currently, various staff members such as Linda Sarfo, Nurse Manager on 4H and 4C, Joan Dauhajre, Administrator of Special Services, and Spanish-speaking nursing

staff fill in whenever there is a need for translation services. It may benefit TCC to appoint a more consistent translator "team"—perhaps to hire a Spanish-speaking social worker who could be assigned to all of those residents who only spoke Spanish. We sat in on a CCP in which Ms. Sarfo pulled a Spanish-speaking nurse from the floor to translate between the resident, his mother, and the social worker. It was a highly emotional discussion, as many CCPs called to discuss sudden declines are, and we could sense that it was frustrating for both the resident and the social worker to have to wait while the translator fought to translate both quickly and accurately for three people. The oft-repeated motto on advance directives discussion is that "We want to make it as easy for the resident and family as possible." It seems to me that eliminating the frustration inherent in the translation lag, decreasing the time spent searching for an adequate translator, and making the resident and family more comfortable with a discussion conducted in their native language would all serve this motto. Furthermore, the language barrier does not exist only in person-to-person communication, but also in the educational materials distributed by TCC. Huili and I obtained a copy of the Social Work Admissions Packet given to residents within two days of their admission. This packet includes four documents regarding advance directives: two two-page ArchCare informational brochures titled "Health Care Proxy Guide" and "Do Not Resuscitate Orders: An Explanation and Overview of Your Right to Decide," a New York State Department of Health (NYDOH) packet labeled "Health Care Proxy: Appointing Your Health Care Agent in New York State," and a NYDOH packet titled "Deciding About Health Care: A Guide for Patients and Families." None of these documents are currently available in any other languages besides English, inhibiting the ability of TCC staff to prepare families for such discussions before they happen. Huili and I conducted an Internet search and found Health Care Proxy information and forms in Spanish on the MOLST website, Compassion and Support, and sent the links to those documents to Ann Carroll, Administrator of Geriatric Services. Additionally, TCC now has copies of the Advance Care Planning Booklet that are given to patients before MOLST discussions in Spanish. Having reliable, knowledgeable translators and materials in a resident's native language can only help to lessen those barriers to education.

Cultural beliefs about death and dying often act as a subtler barrier to education about advance directives. Hispanic families have been observed to, as Ms. Dauhajre remarked, "simply refuse to talk about death and dying." Families from other cultures, such as a Japanese family we

observed, may discuss these matters in private but seem reluctant to open up to the efforts of doctors and social workers to initiate such discussions. These cultural barriers are often harder to overcome, as they may be life-long, firmly engrained beliefs. We believe, however, that TCC has the strength of its multi-cultural staff, which automatically creates the environment of mutual respect and keen cultural awareness necessary to decrease the detrimental effects of this barrier.

The greatest barrier to educating families, however, is that it is undoubtedly a difficult, time-consuming, and sometimes thankless task for staff to perform. Families are all too often not ready or unwilling to accept that their loved ones may be approaching the end of their lives. Nonetheless, Huili and I have observed heroic and compassionate efforts to help families reach such acceptance from staff members of all disciplines and ranks, from CNAs and housekeepers to the administrators and Medical Director, and thus we believe that this "greatest" barrier may also be resolvable through innovative, compassionate, and persistent efforts to improve TCC's educational methodology.

Staff Education:

Many of the staff members we interviewed also remarked on the need for continuing staff education on EOL care, including topics such as advance directives, hospice, and palliative care. A previous CSSR-TCC summer intern and our predecessor, Raphael Rosen, implemented one such educational program for the staff on 6H in conjunction with Calvary Hospital to great success and positive feedback. One year later, Dr. Lechich's reflections on the program spoke to the effectiveness of thoughtfully planned, practical, unit-centered educational initiatives on this topic, but also revealed that such educational programs lost their efficacy without constant reinforcement. Huili and I sought out to investigate different educational models and materials that had been previously utilized in similar EOL education initiatives, and chose to work on finding educational solutions for different audiences. We also attended Dr. Lechich's meeting with the Social Work department to discuss the ideal working relationship between social workers and physicians within EOL care, and an IDT Case Conference centered around a particularly challenging palliative and EOL care case.

Physician-Social Worker End-of-Life Discussion Communication Skills Workshop:

I chose to focus on creating a joint educational workshop for physicians and social workers. At TCC, physicians and social workers are the leaders of the IDT effort in EOL care. The social worker is the first person to approach an incoming resident about their existing advance directives and wishes regarding their care; often, they are the ones who introduce the concept of advance directives to patients and families and become experts on the non-medical factors affecting a patient's medical decisions. However, only the physician can provide the medical information, prognosis, and diagnosis that must serve as the foundation for thoughtful consideration of advance directives and EOL wishes; in fact, the physician's discussion of the resident's medical condition can be a crucial turning point and a golden opportunity for the IDT to assist the resident and family in beginning what can be a cathartic period of healing and family togetherness in the face of the inevitable end.

The need for such an educational program was introduced to me through several sources, the most prominent of which was shadowing Dr. Lechich. A few times per day, Dr. Lechich would receive two types of calls: the first, when a doctor or nurse considered transferring a patient to the hospital due to a rapidly developing medical condition (fever, difficulty breathing, chest pain, etc.) and the second, when a displeased family member called Dr. Lechich with their concerns about their loved one's care. Observing these calls and Dr. Lechich's responses (which were almost always to "fly" to the bedside to see the resident and/or family members) exposed me to a pattern of breakdowns in communication that had possibly contributed to these acute crises. "Why was the family calling the medical director instead of the attending physician?" asked Dr. Lechich. During these calls, I overheard families expressing dissatisfaction with their conversations with the attending physician, usually citing the physician's unavailability, impatience, or unhelpfulness. Hospitalizations and rapid declines often stir staff, patient, and family to rush to complete advance directives and make decisions about EOL care that ideally would have been settled when the patient was stable. There is the example of GA, who developed aspiration pneumonia and whose daughters, counseled during "crisis mode" by Dr. Lechich, settled their familial disputes to sign a DNR and invoke hospice mere days before their mother's death. Many conversations with Dr. Lechich, observations of staff in daily interactions with patients, and staff interviews corroborate with our assertion that gaps in communication between members of the IDT ultimately result in errors in patient care.

In order to customize the workshop specifically for the physicians that would be participating, Huili and I conducted interviews with the physicians to discern difficulties they encountered while communicating with families. We asked them if there were any specific communication skills they felt they could improve on personally, and whether they had any challenging scenarios or tips for the other doctors. The responses we received were varied—one physician reported that he did not feel there were any communication skills that he needed to improve. One physician indicated that he wanted to sound less blunt when delivering an unexpected prognosis, and another described her nervousness at approaching an almost-complete stranger with such a sensitive conversation. Huili assisted me in recording these interviews, and her transcripts are attached as **Appendix 6**.

The goal of the workshop for the physicians is two-fold: one, to reinforce the communication skills that physicians need to conduct meaningful discussions about EOL care, and two, to re-emphasize the crucial role such physician-led discussions have in successful EOL care. The workshop centers around a 5-10 minute role-play based on a real-life, challenging scenario that has occurred at TCC. One doctor and one social worker will address the situation, and another doctor and social worker will play the challenging patient and/or family members. After each role-play comes a discussion in which doctors and social workers exchange suggestions and critique in a peer-enforced setting. I applied the role-play-and-feedback-based model used in the communication skills training Huili and I receive as Residential Advisors at Columbia University to this workshop. It is a model, we both believe, that tests your true comfort and knowledge with the application of practical skills and fosters an environment of open discussion and flow of ideas. In our experience, this model also has a long-term impact its students.

I designed a short packet of learning materials to be used along with this workshop; both the suggested workshop structure and learning materials are attached as **Appendix 7**. The first portion consists of tips and helpful language for conducting such conversations from the INTERACT II Advance Care Planning Tools. The second portion is a collection of quotes pulled from current events articles from both medical and popular publications filled with tips from palliative care experts around the country and compelling persuasion for physicians to conduct these conversations thoughtfully and meaningfully.

The impetus for including the social workers in the workshop was a social work conference organized by Jeanine Abruzzo, Director of Quality of Life. Dr. Lechich was asked to speak about the difficulties the physicians were experiencing in EOL care planning. The “small-medium-large approach” was brought up as an idea for a methodology to categorize patients nearing EOL and the magnitude of the challenges they represented. A “large” problem, for example, would be an unstable new admission to the sub-acute unit, seemingly days away from death. A “small problem” would be one of the many stable hospice and EOL patients at TCC. Such a categorization system would, it was suggested, make it easier for the IDT to focus their efforts on developing EOL challenges and facilitate the sense of mutual responsibility and urgency needed to efficiently respond to such challenges.

On Dr. Lechich’s suggestion, I spoke to Ms. Abruzzo about coordinating the workshop I had designed for the physicians with the Social Work Department to include the social workers . She agreed to collaborate on the workshop and added more educational goals: the discussion and solidification of each discipline’s role in EOL care planning between members on the same unit, and the establishment of a pledge to hold one another responsible for the expectations discussed. It is my hope that a pilot of this workshop will be implemented sometime in the near future, as part of the “Holistic Excellence in End-Of-Life Care” educational program sub-project.

Speaking with Dr. Aida Wen about the IMPRESS initiative in Honolulu, HI:

Dr. Lechich introduced us to an article in the American Medical Directors Association journal about an award-winning poster session featuring the IMPRESS initiative. The IMPRESS initiative, presented at the poster session by Dr. Muang Muang Tin under Principal Investigator Dr. Aida Wen, stands for “Improving Professional Education and Sustaining Support” and was aimed towards improving EOL care in long-term care facilities. It was a yearlong engagement between five nursing homes consisting of a series of collaborative sessions and in-services on EOL care, advance directives, and palliative care.

After reading the article and poster abstract, Dr. Lechich suggested that we consult Dr. Wen and Dr. Ting for their reflections on IMPRESS and advice for facilities undergoing similar quality improvement initiatives. We spoke to Dr. Wen over the telephone on Monday, July 25, 2011. The transcript of our conversation, prepared by Huili, is attached as **Appendix 8**.

Dr. Wen stressed the relationship between the number of in-services attended and measurable improvement. Staff who attended more than four of the six in-services were much more likely to feel empowered to improve EOL care than those who attended one to three of the six in-services. Dr. Wen was kind enough also to send us materials from the collaborative sessions among the leadership staff of the nursing homes. In addition, she sent us the “Quality of Life in Long-Term Care (QOD-LTC) forms that her team used to evaluate the success of the initiative and the compare the before-and-after qualities of EOL care. While long-term effects of the IMPRESS initiative are not yet measurable, Dr. Wen stressed that improving institutional EOL care workflows and structures and involving staff at all levels are the only ways to sustain the effects of such improvement.

I believe the materials forwarded to us by Dr. Wen can be used in the implementation of the “education program” sub-project of “Excellence in Holistic End-Of-Life Care.” Specifically, I think the QOD-LTC forms her team used to evaluate EOL care before and after IMPRESS can be adapted to create a quantifiable metric by which to measure the success of our own efforts. These forms and PowerPoint presentations from the first two IMPRESS collaborative sessions are attached as **Appendix 9**.

August 3, 2011 Case Conference: EOL Care Issues Confronting Interdisciplinary Teams:

On August 3, 2011, Dr. Lechich led a Case Conference to study the challenging case of BF, a patient on 4H, and to frame the need to strengthen the “team” approach to EOL care. Around 30-40 IDT members attended the conference to troubleshoot the difficulties staff encountered while trying to care for BF. BF was admitted to 4H, the sub-acute transitional care unit, with advanced prostate cancer with bony metastases. He had arrived from the hospital with a hospice referral, but had not signed on with hospice until a month after his arrival at TCC. Perhaps the biggest challenge BF presented to the staff was pain management—the development of his cancer worsened his pain until it affected his ability to perform daily tasks and, at times, his mental status. Emotionally, BF seemed internally discontent, unable to come to terms with his disease. His relations with his supportive family were strained as the cancer wore on. In short, BF’s case showcased almost all the challenges TCC staff face in the care of an EOL patient. Dr. Lechich asked BF’s social worker, Ms. Alicia Hansome, to reflect on BF’s first days at TCC. IDT members around the room then commented on the case and offered suggestions for

bringing about a better “team” approach to IDT care. Our observations of this EOL Case Conference and the feedback Dr. Lechich received revealed the willingness and commitment of staff members to work on improving the “team” approach and also the plethora of ideas available for such improvement. It was also at this Case Conference that Ann Carroll, Administrator of Geriatric Services, introduced MOLST and Dr. Lechich announced the start of a new round of EOL quality improvement.

Dr. Lechich asked us to present some of our summer project findings at the Case Conference. Huili presented the analysis report of our staff interviews, while I presented my work (described in a later section of this report) identifying gaps in internal IDT communication as evidenced in BF’s SIGMA and paper charts. I passed around printouts containing three of BF’s SIGMA Care Plans—Advanced Directives, Cancer Care, Pain Management, and Terminal Illness/End-Of-Life Care—which served, in my opinion, as evidence of the current fractionation of EOL care plans. I also passed around the SIGMA notes I had gathered on the conversations BF’s IDT had conducted with him and his family. I asked the staff to take note of the quality of this discussion documentation and also the discrepancies between the SIGMA chart, the paper chart, and what had occurred in actuality. My report on BF is attached as **Appendix 10**.

MOLST Implementation

Since 2010, ArchCare policy has dictated that ArchCare facilities must use the MOLST form to document advance care planning and residents’ EOL wishes. TCC is now in the process of implementing that policy, which necessitates a series of educational sessions about MOLST targeting all of TCC’s staff. The current timeline for MOLST implementation calls for TCC to start using the MOLST form on September 1, 2011 for all new admissions and then to convert in-house residents’ advance directives forms to the MOLST during their quarterly care plan conferences. Sarah Strum, ArchCare Vice President of Compliance and Regulatory Affairs, initiated the MOLST education program on August 10, 2011 with a global overview information session. Around 60 IDT staff members from social work, recreational therapy, medicine, and administration attended this large information session, which was followed by a Q&A session. Many of the logistical decisions—where to put the MOLST form in the paper charts, how to sync the MOLST paper form and SIGMA EOL Care Plans, etc.—are still up for discussion. Currently, Dr. Suja Sabastin and social worker Iona Mitchell are conducting a “pilot session” of

MOLST on 6H. Erlinda Girardo, Staff Development Director of In-Services, is designing in-services that will take place before September 1 for all staff. Huili and I had the opportunity to participate in many of the administrative meetings on MOLST implementation and assist Ms. Girardo and Ms. Carroll with selecting and assembling educational programs for both the global overview information session and the smaller in-services.

I attended Ms. Girardo's in-service for Dr. Sabastin and Ms. Mitchell along with Ms. Carroll and Gemma Lynch-Moore, Director of Nursing for Geriatric Services. Ms. Girardo stressed the importance of the information-gathering and patient and family education that must occur before completing the MOLST form; "Without this preparation and discussion," Ms. Girardo expressed, "the MOLST is useless." At this in-service, we established an ideal timeline for the MOLST discussion. The social worker would approach the patient with the Advance Care Planning Booklet provided by Compassion and Support, the organization that supplied the community with educational resources for MOLST, and prepare the patient for the conversation with the doctor. After a day or two, the doctor would engage in the MOLST discussion with the patient and complete the form. It was decided that Dr. Sabastin and Ms. Mitchell would first approach two alert and oriented patients on 6H, and also try to implement this timeline with a new admission coming to 6H. Another topic of importance that was debated was the usefulness of two different discussion documentation forms: the "MOLST/Advance Directive Discussion Documentation Form" and the "Advance Planning Assessment Form". Both forms can be used to document prior information (existing advance directives, living will, etc.) and what Dr. Sabastin called "anecdotal information"—observations on family dynamics, personality, etc.—that could also affect the discussion and aide staff. The merits and logistics of each form were debated, and it was decided that Dr. Sabastin and Ms. Mitchell would fill out both forms in their pilot efforts to determine which form was more useful. The in-service attendees all agreed, however, that a consistent form of documentation of the preparation and discussion leading up to MOLST was beneficial to the resident, the staff, and the facility. I asked to shadow Dr. Sabastin when she engaged her first patient with the MOLST discussion, which has not yet happened. However, I did approach the patient, on Dr. Lechich's advice, with the Advance Care Planning Booklet to ask him if he had any questions about the information. At this time, he had not yet received the booklet and told me he would read it over. My notes from this in-service and discussion are attached as **Appendix 11**. The in-service reflected both the promise that MOLST

shows to improve the quality of EOL care discussions and revealed all the logistical details that have yet to be worked out.

Audit on Documentation of IDT Communication:

As TCC prepares to transfer all of its medical information onto SIGMACare, the task of proper documentation of communication between the IDT, residents, and families becomes, more and more, an area requiring regulation and improvement. Huili and I noticed discrepancies between what we heard about the status of a particular case and the documentation we often encountered in SIGMA. For example, the Health Care Proxy was often not identified by name on SIGMA; if a doctor wanted to contact the HCP, they would have to retrieve the physical paper chart on the resident's floor. Huili and I found that doctor's notes on these discussions were often scanty and did not capture the full conversation that we might later hear, re-counted to Dr. Lechich during lightning rounds. Quality notes on discussion between IDT members, residents, and families are also an important tool for strengthening the "team" approach to EOL care that TCC so covets, since they are often the only evidence that such a conversation has occurred. Detailed notes highlighting the essence and progress of these important discussions are necessary for all the members of the IDT to be "on the same page" about EOL care for a resident. Quality documentation also helps staff to avoid repeating errors and conversations already had. To this end, I sought out to audit the quality of notes in both the paper charts and SIGMA charts of current EOL and hospice patients in the geriatric and sub-acute units.

SIGMA Audit and Observations on Paper Charts:

As of right now, physicians write their notes in SIGMA, while social workers write their notes in both the paper charts and on SIGMA. My audit of the paper charts show extensive social worker notes documenting the ongoing progress of EOL care discussions with families in the "Progress Notes" section. There was, however, a notable lack of any written notes that read "Will discuss with physician" or "Discussed with physician, and physician responded _____." While documentation of discussions between the social workers and families were plentiful and high quality, documentation of communication between the social workers and physicians were scant to non-existent.

I then prepared an audit report on the SIGMA notes written by social workers and physicians documenting IDT-to-resident/family discussion. I collected information such as unit, date of birth, advance directive status, and dates that Hospice or EOL Care Plans were entered on SIGMA. I also noted whether the Health Care Proxy of those residents who had such an advance directive were marked as such in the “Contacts” section of SIGMA. I then combed through the resident’s chart and copied quotations pertaining to discussions between the IDT and the resident/family members. Notes on advance directives discussions between the social worker and the residents and/or family members were entered in the “Details” section of the Advanced Directives Care Plan. Physicians often included notes on advance directive status and discussions mixed with clinical notes in the “Progress Notes” section of the SIGMA chart. Depending on the physician, these notes varied in length, detail, and quality. In one case, there existed documentation of such discussions among the progress notes entered since TCC started using SIGMA in late 2010. They did not, in my opinion, serve as adequate documentation of the subtle and important details of these discussions, or even match up with what I would hear when the physicians recounted their conversations to me or Dr. Lechich. Only in one case out of the 17 patient charts audited did the physician write the phrase, “Discussed with Social Worker.” I believe this lack of internal IDT communication documentation is less than ideal, and perhaps a product of the inefficiency of TCC’s current two-system documentation process (chart and online) as well as the lack of set standards on what should be included in the notes. This audit report is included as **Appendix 12**, along with an “End-Of-Life Checklist” that Huili and I used to both keep track of and analyze the status of EOL care planning for the patients we followed this summer.

EOL Care Portal:

I proposed to Dr. Lechich the creation of an electronic EOL Care Portal after having gathered complaints from physicians and social workers about the inefficiency and inherent fractionation the structure of the SIGMA system created in EOL care documentation. I spoke to Ms. Abruzzo, Director of Quality of Life, on this subject as well. She stressed the need for a “platform for shared communication” within the IDT—one place in which information pertaining to all the areas of EOL care could be kept and easily accessed. Inspired by the notebooks that serve as communication portals between the nurses and physicians, I drew up a

rough schematic of a screenshot of what such an EOL Care Portal could look like. It would contain an area for each EOL care issue: pain management, family involvement, pastoral care, recreational therapy, and advance directives/MOLST. Any member of the IDT could enter notes into any of the areas, and the latest note entered in each area would appear on the screen in that area. I have attached my schematic as **Appendix 13**. Although the creation of such a portal would ultimately be dictated by SIGMA's design, it is my belief, influenced by Dr. Lechich, that "having all the information on one page, to paint one picture" will serve to facilitate IDT communication and improve EOL care.

Calvary Hospital Visit:

Dr. Lechich arranged for Huili and I to visit Calvary Hospital in Bronx, NY. Calvary Hospital provides most of the in-house services for our patients on hospice. Calvary Hospital is a specialty hospital providing comprehensive care for end-stage cancer patients; therefore, its staff members are experts in EOL and palliative care. We attended a medical student information session at Calvary Hospital's Palliative Care Institute and then shadowed Dr. Gail Chrzanowski on her rounds around one of the hospital's units. Dr. Chrzanowski presented palliative care case studies as we watched her interact with patients and families on the unit. Through her interactions, Huili and I observed Calvary Hospital's fervent commitment and actualization of holistic end-of-life care. We saw her ask about the pain management of several residents and listened as she explained to an unrealistically hopeful family that she could not envision their mother, somnolent and non-verbal in the chair right next to them, making rapid progress and returning independently to her home. Even the organization of the units reflected this commitment to EOL care: the nursing stations are large and circular so that nurses can have a 360-degree view of the rooms around the unit. The rooms on the unit we visited are single-occupancy, large, and flooded with natural light during the day. The facility is spotlessly clean, and the color palette is warm and comforting. In environment as much as staff practice, Calvary Hospital is a leader in holistic EOL care. We returned to TCC the next day and heard Ms. Akea Blanden, Director of Nursing for Special Services, remark that she had never seen a facility that lived its mission as thoroughly as Calvary Hospital. Calvary Hospital does and should serve as a model of the excellence in EOL care for TCC to strive towards achieving in its own facility—

Calvary Hospital serves as a reminder that “good deaths” can be accomplished through institutional dedication.

Suggestions and Personal Reflections:

We aimed all of our summer efforts towards improving EOL care at TCC and were rewarded when the work we had completed was included in the TCC project proposals for achieving “Excellence in Holistic End-of-Life Care.” My hope is that our work will be used to reform TCC’s current EOL care structures into innovative, effective, and sustainable protocols that will facilitate “good deaths.”

Dr. Lechich, who has had countless years of experience in EOL care improvement efforts, asked us the “million-dollar-question” the day before we finished our internship: “How do you sustain all of this?” I was stumped, temporarily, despite all of my research into the subject and enthusiasm for the work Huili and I had completed. After a few minutes, a solution came to mind. I replied, “You need good institutional structures, protocols, and frameworks, and you need dedicated, innovative people to keep them up and running.” Dr. Lechich acknowledged my reply and pointed out that the previous “champion of EOL care” figure, a doctor that had been recruited years ago to start the EOL care revolution, had not succeeded in achieving long-term change.

I considered this problem of sustainability throughout the evening. I reflected on what I had seen in my ten weeks at TCC. Ms. Zelda Williams, a certified nursing assistant on 3H, made an extra effort to talk to all the family members who came on the floor, regardless of whether she took care of their loved one. Ms. Mabel, head nurse on 5H, told me about her decision to resuscitate a choking patient, who was DNR, because “just because the patient has a DNR does not mean she should die from choking.” The patient lived four more years in peace and her family told Ms. Mabel that she had made the right decision for them. Ms. Mabel spoke with pride about the nurse’s role as the “hub of the wheel” of patient care, and of her own deep commitment to end-of-life care. On her own leisure time, Ms. Hansome, a social worker, brought flowers to visit with a patient who had been transferred to Calvary Hospital over the weekend. Walking around the units, I could hear Reverend Steele singing in Spanish for patients in their rooms, and I could hear Dr. Barbara, a beloved psychologist, reading to her Huntington’s disease residents. I often saw family members hug the housekeepers that cared for their loved ones’

rooms and thank them for being “wonderful human-beings.” I saw top administrators rush down to patients’ bedsides and beg them to make decisions that would ease their pain. My studies on improving EOL care at TCC have taught me that you cannot just depend on a general to lead the effort. You need an army of compassionate souls that believe to provide excellent EOL care is to be a good fellow human being.

But, in order to enact change, this army must come together and work for the common good. At TCC, that common good is quality care of the patient. I see all the materials necessary for this revolution right under the surface of TCC’s daily hustle-and-bustle, as if it is hiding under a thin bed-sheet. The dedicated people, of all ranks and disciplines, are there everyday—caring for their patients in an all-too-thankless environment.

This willingness to commit oneself to excellent patient care I see in TCC’s staff every day needs to be mobilized if TCC’s efforts to improve are to be sustained. It needs to be recognized and perhaps rewarded. It needs to be seen as the standard and the mutual expectation, and not the exception. It needs constant encouragement from leadership staff, who must remind everyone constantly that when the forms seem too tedious and the hours too long, that there is a bigger picture, a higher calling, made up of all the cups of medication, the bags of dirty laundry, and the countless lab reports. The “team approach to EOL care” must be the mantra of every educational program, every presentation, and every meeting to field complaints until it is actualized. Leadership must justify the irritations of everyday work—speaking with an unaccepting family, signing multiple advance directives forms—as worth it for the progress they will bring about. New members to TCC must be selected on their potential to agree with this mission, to embrace this commitment.

It seems a gargantuan task, but it is a simple concept: an attitude adjustment. As Dr. Lechich says: “You have to love your patients” and recognize that “It’s not about you.” But, perhaps, in the end, it *is* about you. It is about sharing the experience of being human, of the ability to empathize with another human being who also fears pain, dying, and loss. It is about understanding what you have in common with the patient who kicks and bites you, who calls you names. It is about recognizing the distinction between the person and their disease. At the end of the day, this will be the fuel for keeping the commitment to patient care alive. Perhaps TCC must balance their expectations for staff to work for others with a commitment to helping staff cope with their own emotions in the midst of all this sickness and death.

I leave my ten-week internship at TCC armed with a deep appreciation of palliative care and the people behind it. TCC has helped me re-affirm my commitment to medicine and has given me a more defined vision of the kind of doctor I hope to become. My time here has given me new standards by which to evaluate medicine's role in the contemporary world—most notably higher standards for compassion. I want to thank Dr. Lechich for embodying the physician and mentor I hope I will someday become—a compelling, compassionate, and above, all, brave soul that embraces this exploration of death and dying with unparalleled vigor and vitality.

Project Proposal

Date Submitted:	July 27, 2011
Project Name:	Excellence in Holistic End-of-life Care
Champion:	Anthony Lechich, MD
Project Team Leader:	
Proposed Team Members:	

Implementation Schedule:

	Date(s)	Target
Project Start Date:		Establish workgroup; provide background material from years of effort
Other Phase-In Dates:		Map out a logistical plan for the education of broad base of staff; nursing; medicine; PT/OT therapies; social work; Pilot education sessions include staff competency measures against what is taught;
Other Phase-In Dates:		Assess gaps and barriers in staff behavior and care elements as relating to patient and families and their loved ones in need of palliative care (deliberately loosely defined)
Other Phase-In Dates:		Prepare educational materials appropriate to discipline; set up pilot tutorials to learn ideal size and composition of groups; Use Raphy's work here
Other Phase-In Dates:		Review pilot results; critique and modify as appropriate; continue with roll-out of the educational efforts
Completion Date:		Demonstrate (percentage) of staff that have been exposed to training with appreciable increase in their understanding and approach to care as death approaches.

Project Mission:

To create an education program to facilitate a "team approach" for end-of-life care, pain management, and spiritual and palliative care, including advance directives.

Project Scope:

Project Proposal

To create an educational program whose aim is to improve staff communication skills with residents and families to improve the quality and frequency of meaningful conversations between staff, residents, and families on the topic of end-of-life and palliative care.

To troubleshoot and reduce the communication barriers between different members of the interdisciplinary team.

To instill in all staff members a sense of internalized dedication and individualized empowerment in improving palliative care.

Action Plan:

Assess gaps in knowledge about palliative care, hospice, and EOL protocol at TCC

Assess gaps in communication skills

Assess difficulties in the sharing and communicating of information about residents' palliative care plans between members of the IDT

Create an educational program with informational sessions and hands-on exercises to address these gaps and difficulties

Create an avenue for ongoing discussion (follow-up sessions, feedback surveys)

Create a protocol by which to measure success of educational program

Create a methodology by which to perform EOL checklist

Expected Outcomes / Deliverables:

Each member of the IDT will internalize the responsibility to ensure that each resident at TCC may achieve their idea of a "good death."

Members of the IDT will feel more comfortable conducting end-of-life conversations with families and residents using communication resources and conversation protocol provided

Breakdowns in communication between different disciplines will be reduced significantly.

Creation of a sustainable environment of open discussion and interdisciplinary collaboration on palliative care at TCC.

Proposed Metrics:

Number of hospice referrals

Quality of IDT notes in charts/SIGMA about conversations

Quantity of notes

Staff surveys on understanding

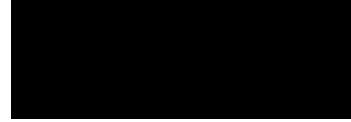
Potential Resources:

Staff Development-Educational Staff

Medical Records/SIGMA

Philanthropic support;

Project Proposal



Potential Obstacles / Barriers:

Difficulty of maintaining long-term efficacy of educational program
Difficulty in measuring qualitative improvement without direct observation methods
Difficulty in scheduling a time for all members of IDT to gather for educational program
Unrealistic self perceptions by professional staff in this area

Project Proposal

Date Submitted:	July 28, 2011
Project Name:	MOLST Education and Implementation
Champion:	
Project Team Leader:	
Proposed Team Members:	

Implementation Schedule:

	Date(s)	Target
Project Start Date:		
Other Phase-In Dates:		
Completion Date:		

Project Mission:

- *Address advance directives in diverse and complex populations by focusing on cultural sensitivity and health literacy
- *Educate and implement MOLST

Project Scope:

The goal of this project is to successfully teach all staff necessary information regarding MOLST. On the path to improving palliative care for all residents of TCC, MOLST education and implementation can serve as a crucial stepping stone. MOLST can also enable fluid and frequent communication between the TCC team and residents and their family members.

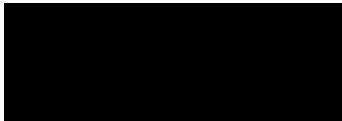
Action Plan:

- *MD's must have demonstrable understanding and performance competency in the MOLST program
- *Begin with small trial sessions of MOLST education with a specialized team of a few trained individuals, namely the physician and social worker.
- *Find an appropriate environment, quiet or with soft background music, where the MOLST team can have conversations with residents and their family members.
- *If trials prove to be satisfactory, they can be expanded to the rest of the facility, one team, one floor at a time.
- *Set target dates for each step along the way, to enforce punctual task completions.

Expected Outcomes / Deliverables:

- *All TCC providers become certified in MOLST program.
- *Transparent communication between staff and residents and family members.
- *Residents' wishes are upheld.
- *All staff embrace full responsibility so residents die with dignity and comfort.

Project Proposal



Proposed Metrics:

- *MOLST forms present in all resident/patient charts; proper forms and signature.
- *Documentation that MOLST/advance directive discussions occurred.
- *Compare DNR, DNI, DNH statuses before and after MOLST program.

Potential Resources:

- *Official educators and materials on MOLST usage
- *The INTERACT document on advance directives
- *Conversations with family members

Potential Obstacles / Barriers:

- *Language, education level, and communication
- *Medical issues: dementia, deafness, etc.
- *MOLST communications are time-consuming, nuanced, and complex
- *Document filing and updates critical to success are time-consuming

Background Research Interviews

Interviewee:

Interviewer:

Date:

Time:

Hello, my name is Ashley and I am working as a summer intern under Dr. Lechich. Dr. Lechich has asked us to explore the role and processes of family education about palliative care, EOL care, hospice care, and advance directives. We are currently gathering some background information and interviewing various staff members about their involvement in this family education process. Due to your close involvement with the residents and families on a day to day basis, you hold a unique position in this family education process and we have a few questions to ask you.

1. In general, especially when you know a particular resident and family well, do you feel that your opinion about the family's involvement is sought?
 2. Do you feel that there is good communication about family involvement between CNAs and other staff members?
 3. What are the difficulties you run into as a CNA in the context of being involved with family education?
 4. What are possible improvements to the CNA role that would benefit your involvement in this process?
 5. What are the biggest sources of conflict/gaps in understanding that families have about the situation of their loved one in regard to hospice or End of Life care?
 6. What do you see as current institutional barriers to improvement in family education?
 7. What role do you think a CNA should have in this family education process?
-
1. Please walk me through your role as a CNA in family education of palliative care. When a situation arises in which a resident may want to consider palliative care, at what point do you jump in? What is the extent of your involvement?
 2. What difficulties do you run into as a _____ in this education process? Possible improvements? What advantages do you have as a _____ in this process?

3. What elements of understanding do you feel a family should have when a resident enters the realm of palliative care/end of life and beyond?
4. How can care plan meetings be adapted to this purpose and these conversations about palliative care options?
5. What are current institutional barriers to improvements in family education?

Background Research Interviews

Interviewee:

Interviewer:

Date:

Time:

Hello, my name is Ashley and I am working as a summer intern under Dr. Lechich. Dr. Lechich has asked us to explore the role and processes of family education about palliative care, EOL care, hospice care, and advance directives. We are currently gathering some background information and interviewing various staff members about their involvement in this family education process.

1. Please walk me through your role as a _____ in family education of palliative care. What part of the education do you provide and how do you provide it? When a situation arises in which a resident may want to consider palliative care, at what point do you jump in? What is the extent of your involvement?

2. What difficulties do you run into as a _____ in this education process? Possible improvements? What advantages do you have as a _____ in this process?

3. What elements of understanding do you feel a family should have when a resident enters the realm of palliative care/end of life and beyond?

4. How can care plan meetings be adapted to this purpose and these conversations about palliative care options?

5. What are current institutional barriers to improvements in family education?

Appendix 4
Interview Summary Report

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Interview Summary Statistical Analysis

Task: Huili Zhu and Ashley Shaw, the two summer interns, interviewed a total of 17 staff in various disciplines on the topic of palliative care. Questions asked include: how events are run currently, what are some difficulties and possible improvements, what should be provided for family members, and what some institutional barriers are.

*Percentages represent the percent of interviewees who mentioned a particular statement. Statements are listed in order of percentages.

Recurrent statements:

1. In this facility, there are often heavy demands on one person, more like a one-man show as opposed to a team. There needs to be a sense of a team. (100%)
2. There are cultural barriers, especially in language and communication. (100%)
3. Open and frequent communication and adequate education are keys. (100%)
4. Institutional barriers include budgeted staff time and understaffing, for often times very labor-intensive work. (88%)
5. Care plan meetings should contain one member of each discipline involved in the patient's care, especially the certified nurse aide or registered nurse, social worker, physician therapist, occupational therapist, nutritionist, and physician. (35%).
6. Bereavement services or support groups should be made available for family members. (30%)
7. Pastoral care and social work services should be increased. (24%)
8. We should develop a skilled palliative care team. (24%)
9. We should develop a fact sheet or pamphlet with common palliative care facts and our facility's EOL/hospice services and frequently asked questions. (18%)
10. Palliative care should be introduced to residents and families after an important change occurs in their diseases. Only after a big decline will families consider advance directives. (18%)
11. Many people have misconceptions about the exact meanings of various advance directive terms. (9%)
12. Hospitalization should be treated as the last resort. (9%)
13. A patient's terminal prognosis is not addressed adequately in the hospital. Families have false hopes. (9%)

Physician #1

- It should be the doctors who speak with family members about palliative care, since doctors have all the information.
- Palliative care should be introduced to family members in baby steps.
- Acute hospitals give misconceptions about patients to their families, send them to TCC to “get stronger”, but really they are dying. They should be sent directly to Calvary Hospice.
- At the end of an episode that occurs in a resident’s disease, a doctor can introduce the idea of palliative care, as opposed to at the beginning stages or during stable time periods. Families will learn and accept better during those times.
- People have misconceptions about the true meaning of DNR. People think that getting a DNR form signed is equivalent to leaving their loved ones dying and uncared for.

Physician #2

- There are often heavy demands on one person to carry the rest of the people on their shoulders.
- This is an ongoing process of engendering trust, solace, and realization of imminent death of a family member.
- It is too much of a one-man show.
- Barriers include cultural, logistical, and legal.
- In terms of a resident’s care network, it can be likened to a chain with weak links.
- Possible improvements can be to mentor and train someone else to perform the same job with the same quality and quantity as me. The team can be greatly expanded.
- The trajectory of each resident’s disease prognosis should be individualized.
- Hospitalization is the absolute last resort and often it is unnecessary.
- Thoughtful preparation, respect for family schedules and receptivity, and inclusiveness (in terms of who are included in the meeting) are very important.
- The best, most skilled person, who can handle it, should lead meetings.
- The key is to instill comfort and trust. Support groups should be built.
- Meetings should be properly scripted and perhaps should use role-plays as a means to practice beforehand.
- Institutional commitments, budgeted staff time, cost, and labor-intensive work are all crucial barriers.
- Pastoral care and social work can be a bit more involved.

Social Worker #1

- We want to provide as many literature and resources as possible, be there as a support group for the family members as they go through this process.
- We want to provide emotional support, which is linked to the spiritual support provided by pastoral care.
- Possible improvements include installing bereavement (in thinking about the bigger picture) or support groups, make us available as a team, provide resources, and help families build upon their own support groups.

- The main thing families should understand is that here at TCC, our goal is for patients to be as comfortable as possible.
- We should have special palliative care team members come and speak with the patients.
- We need to fortify such meetings with a rich supply/reservoir of educational texts. Patient-family education literature on wellness can be a good start.

Social Worker #2

- A patient's terminal prognosis is usually not addressed in the hospital, and families are very unaware of what goes on.
- Within 24 hours of every admission, we will sit down with the resident and/or the family and go over advance directives information.
- We must wait some time to first build rapport with the residents before we try to break the news to them.
- The phone interpreter service that we have is really ineffective for these types of conversations about palliative care, which really should be face to face.
- Another difficulty is getting a team consensus about what is best for the patient, whether it is home health care or outpatient rehab.
- Encourage open communication to create a realistic opportunity for patient to say the things they want to say.
- Care plan meetings should have lengthy, intimate, and detailed conversations.
- I think we need staff more experienced specifically with palliative care issues.
- We could benefit from a pain management palliative care specialist.
- We should have a palliative care team and hopefully all the palliative care patients could be on one unit.

Social Worker #3

- The social worker's role here is to apply quality of life services—counseling, assessments, discharging, psychosocial assessments, behavioral counseling, assist psychologists in cognitive—behavioral therapy, a lot of family case management, MDS assessments, and most importantly, bereavement counseling.
- We start the education process within 24 hours of admission—the implementation may not and usually does not happen at that point, but at least the education is out there.
- Usually, only after a big decline will families consider a DNR.
- You have to be comfortable with yourself and about learning of the beginning, the middle, and the end of life.
- Improvements to the role of the social worker come with learning about the process.
- The social worker has to have the ability to not only become comfortable discussing these topics but to have the empathy that goes with accepting the mortality of life.
- For CCP meetings, the most important thing is to have the WHOLE team present: you need the doctor, you need the nurse, you need the CNA, you need the nutritionist, PT, OT, SW...
- What suffers here is when you don't have family that is involved...and when you do, all of them are not necessarily bilingual.
- Many families are illiterate (so giving them packets of information is of no help).

- It is no help when the psychiatrist who does the evaluation does not speak the language of the resident.
- Another barrier is adequate staffing—CNAs are a very important part of the process but they are really left out, and it probably impacts on their job performance, because when a professional is not treated like a professional, it just doesn't go well.

Nurse Practitioner

- Nurses often times do not know what their roles are and what should be done.
- There needs to be a sense of a team.
- There needs to be someone, with knowledge and experience, which can become a teacher or mentor for the rest of us.
- It is very important to be clear and select only one person as the main spokesperson for the family.
- It is very crucial for everyone to understand his or her roles and “DO IT”.

Registered Nurse #1

- The more explanation and the more times that families hear about advance directives, the more it will help.
- Upon admission, family members and residents should be given education on advance directives.
- The more information they get, the more accepting families become.
- The number one problem is understaffing, we don't have much time to spend with patients and families because we all do three jobs.
- This whole floor (floor 4) is Spanish speaking and we do not really have enough Spanish-speaking staff.

Registered Nurse #2

- As an R.N, you are really the hub of the team, and your timeliness, your communication, and your advocacy for the residents make all the difference.
- Families should really know the limitations of EOL/palliative/hospice care, the implications of such care, and most importantly their role as the family, managing last business, taking time to come see their family member more.
- This is why I love morning meetings, because it's like having an IDT meeting every morning.
- We should have short pamphlets with “Frequently Asked Questions” on EOL or hospice care.
- We should also have a document for residents and families about our EOL/hospice services.
- It is important to maintain a fluid flow of questions between the two parties.
- How does mom look today? Do you have any ideas for her care/anything we could improve on? What is your opinion?

Licensed Practicing Nurse

- As far as advance directives are concerned, we are responsible for being the liaison in the staff between the families and the doctors, so any information we get about those topics we are responsible for sharing with the whole team.
- From the very beginning, doctors should talk about realistic prognosis for residents with their families to set up realistic expectations.
- “Excellence in Customer Service” workshops can be very useful tools.
- I think the best strategy to improve this education is to think “This could be my mom or dad” in this very same situation—how would I want them to be treated?

Certified Nurse Aide #1

- Many times I do not know the technical answers to the questions families are asking me.
- CNAs should be considered part of the nursing staff, for uniformity, also because we do a lot of the care work and have important information to share with the families.
- In general, patients and families do not talk to us when they should.

Certified Nurse Aide #2

- Examples of questions that families ask: what is wrong with her eye? What kind of IV is she getting?
- As a CNA, if the questions get very technical, I tend to refer families to nurses or doctors.
- We don't really have any conversations about specific EOL or hospice care details.
- It's difficult for me to get help when I need it.
- We really need to be involved in Care Plan meetings—we have a lot to say, and we used to be included in those.

Nurse Manager

- As the nurse manager, I serve as an advocate for the family, the resident, and the facility.
- There is a higher rate of pay for therapy and a lower one for hospice/palliative care, but what the facility wants (therapy) is really not always best for the resident.
- Trying to reconcile the financial incentives with what's best for the resident is the biggest struggle.
- Teamwork is an integral component of improvement on this front.
- Questions that families should be provided answers for: What does comfort care mean? What do advance directives mean? For example, did they know about the pastoral services that come in addition to hospice care? What does home management entail?
- There should be education on how to deal with and discuss dying and death.
- There is no memorial service for staff to remember residents after a resident passes.

Administrators #1 and #2

- Conversations regarding palliative should typically initiate upon admittance.

- TCC staff may approach residents to talk about palliative care issues when something happens in their lives (such as: spouse passing away) to make them fully appreciate the importance of planning in advance.
- Every member of the team is important; a plan can only be made with their collaborative efforts.
- With non-verbal residents, it becomes especially important to speak with families as to what they would have wanted.
- Even within families, there may be disagreements over care options.
- Many families placed a shield between themselves and the ugly truth; as a result, they are not prepared in the face of an emergency.
- Families are not prepared in the event of an emergency.
- Within one family, there may be disagreements.
- Family dynamic depends heavily on their background and culture.
- The family should be realistic and learn to accept the current state of things.
- The culture of an acute hospital is very different from that of a nursing home. Acute hospital focuses on curing and discharging people.
- There should be an intermediate step between admission and care plan meetings, so the concept of terminal illnesses and possible options can be introduced to the residents first.
- Barrier: time is the number one issue. A better and more extensive pastoral care service would be great.
- Psychological services should be offered for family members as well.

Administrator #3

- We should have a palliative care committee that follows cases, follows progresses, and works together as a team to discuss care management issues.
- The staff themselves must first know a great deal about this area of study and not confuse hospice with palliative care.
- It would be wise to have a fact sheet of knowledge to know for palliative care (such as: what is, what is not, etc). This fact sheet can be given to all members of the staff and family who are involved in a resident's care.
- One barrier is the lack of knowledge and lack of teamwork, lack of agreement, and whose responsibility it should be to give this education.

Administrator #4

- Health care proxies often do not know what the patient wants and are struggling to make decisions.
- Patients are themselves in denial and refuse to see the whole picture.
- The understanding of timing is important, when to say and push certain issues.
- We want family members to know that we are focused on comfort, and we always want to maximize the quality of life.
- Hospitalizations and repeat hospitalizations are counter-productive.
- Involvement of the doctors is crucial, and everyone should act more like a team.
- People are often under-enrolled in the hospice program.

Pastoral Care

- Many residents enter hospice care without pastoral care's knowledge.
- Unit chaplains used to attend all care plan meetings, but this proved impossible to sustain due to pastoral care understaffing.
- Pastoral care has NO role in the clinical part of EOL/hospice education.
- The current ratio is 1 pastoral care member: 200 residents and that will probably go down to 1:150 soon.
- Another difficulty is that the staff don't always recognize role of pastoral care; we may benefit from staff education about the resources that pastoral has to offer
- A big difficulty is family conflict—and lack of awareness of the indignity of spending the end of your life in an emergency room.
- What needs to happen is perhaps education about “hopeless” cases—when hospitalization is futile and really unnecessary.
- We could use some more resources.
- A large part of the work is—and should be—done by Social Work.
- The idea is that staff will let the resident settle in and then follow up—but the problem is that the follow-up never occurs.
- Utilize the family council support system, the 1st Monday of every month.

Appendix 5

Case Studies

1. Katherine Becker has a HD patient who was on the verge of end-of-life. Every symptom and sign directed to the possibility of an impending demise. She spoke with the family members as well as the physician. However, the physician refused to place orders for advance directives saying that the patient was fine. After learning about the details, the family members took the matter into their own hands. They said to the doctor, you have two choices, either you refer him for hospice care or we switch doctors. The doctor complied and the HD patient was successfully put on hospice care. Two months later, he passed away peacefully and comfortably.

2. Katherine Becker had another HD patient whose health situation had always been fluctuating up and down. There were extreme highs and lows, and he would always float back to his baseline eventually. There was one week in which he lost seven pounds, was not eating or drinking regularly, had several infections, and looked very weak overall. She was afraid this patient was really nearing his end and telephoned his family. Katherine spoke with his mother about the current state of things and suggested hospice care. However, the mother refused to give up and suggested there must be other possibilities. She did not want to think about giving up on her son because of guilt. Katherine suggested that the mother speak with the physician. When the physician was asked how her son was doing, he answered: "He's just chugging along." He showed no concerns and worries for the patient's health. A few weeks later, this HD patient miraculously came back to his baseline norm again. His health greatly improved. As a result, the mother held a grudge against Katherine for being pessimistic and not believing in her son. Yet, for Katherine, she held no regrets. Because if she hadn't spoken with the mother and the patient indeed past away, then there wouldn't have been any chances for the family to prepare for such an outcome. Occasionally, an administrator's attempt of counseling the family about advance directives does in fact backfire.

3. GA

In word document titled CSSR BLOG NOTES (Appendix 10).

4. SV, LV

In word document titled CSSR BLOG NOTES (Appendix 10).

5. MJ

MJ is a 48-year-old resident with advanced cancer—as of 6/24/11, she was alert and talking, but as of 6/29/11, her status dramatically changed. She had constant seizure activity, had stopped eating, and an edema over her eye had swollen. Dr. Lechich was brought in by the sister and the niece to discuss her situation, and the family (sister, niece, mother, and daughter, and older brother) have all been involved in deciding her care. She was placed on hospice care on 6/28/11 but already had a DNR and a HCP (her mother) in place. The family recently decided to stop IVs, and her daughter Regina, who lives with her, has stayed with her all night.

6. MG

MG is 83 years old, with dementia and a hip fracture. She is mostly somnolent now, but when we visit she opens her eyes and will grab strongly to the hand of her son, to which we ask about her state that day. She does not look like she is in pain, but did have a sacral ulcer. She sometimes mouths words, but her son, who is her HCP, tells us that one can not always understand what she says. She was and is a very strong woman, says her son, who went through a lot and sacrificed for the family—things he didn't even know she did back in the 60's, raising them. He feels a sense of duty to be at her side every day, and even turns her when he feels the nurses should have done it but have not yet. Her niece and son come to visit her every day, and when told that it was a very nice thing he was doing, the son replied that he didn't see how he could do any differently and that she had been there for him when he had his operation, even though she had been weak. After having watched her friend's death, Ms. Gonzalez had written a living will, and is currently on hospice care with all applicable advance directives in place. Family is very content with her care (except that they feel sometimes they do not turn her enough) and accepting of her possible demise. However, she continues to be stable.

7. YMC

In CSSR Blog Notes (Appendix 10)

8. AY

AY is a 92-year old tiny, frail Chinese woman. She exemplifies the potential long-term patient who is admitted to the sub-acute unit, having come to our facility to recover from a hip replacement. We first encountered her sitting by the nurse's station, wondering why it was taking so long to get to physical therapy—which seemed to be the highlight of her day. Through speaking with her, we found out that she had moved to New York City a long time ago by herself from China and had worked as a bank teller in the city. Every few sentences she would interrupt us, look up, close her eyes, shake her head, and tell us "Please, God, Let me die!" and "I wish to die!" Naturally, this was rather alarming to us. Huili attempted to cheer her up, but her response was "Life is sad"—I tried to keep her talking. We asked about family in the city, and she told us all her siblings were gone. The only family she had left was a niece who lived in the city and came to visit her several times a week. She was a lucky patient among those in our facility, for she had enough means to hire a Mandarin-speaking aide who came in, diligently, every day. When approached with our concerns over her depression, the aide reported to us that saying such phrases just made her feel better and was an old habit. Dr. Lechich pointed out that the prognosis was often not good for patients with hip fractures who stayed in nursing homes for more than six months, and depression made that prognosis worse. AY was often irritated with us when we came to visit, and never remembered that she had spoken to us before. AY exemplifies the difficulty of prognostication in a nursing home setting, even though she defied the odds of her age, her apparent depression, and her fractured hip. As of 8/10/10, AY was discharged home.

9. RT

RT is an 80 year-old patient on hospice. During our time here, he has been remarkably stable—however, a few months before our arrival, he was what Dr. Lechich would call "in play," meaning that he had an acute situation that could perhaps lead to imminent death. RT had been refusing dialysis and non-compliant with all his medications, causing his end-stage renal disease

to become almost fatal. His HCP is his long-time significant other, who Dr. Lechich describes as an “Angel”—reasonable, accepting of his demise, involved, etc. When he started refusing dialysis, Dr. Lechich had called his HCP in to visit the patient at the bedside and warn him of the consequences of his actions. His HCP is recorded to have asked him, “Are you trying to leave us today?” Out of that conversation, RT had made it clear that he was done with hospital intervention and treatment, and so hospice care was put into place and advance directives were squared away. RT perhaps presents as a case with the “best death” possible, in which the resident could make his wishes known to the end, enjoyed the benefits of hospice for a sizable period, and have the most ideal HCP dedicated to his care and comfort in his final chapter.

11. SF

SF is a 96-year-old woman who defies all odds. She remains on the sub-acute transitional care rehabilitation floor, where she has been for the length of our internship. Hers was among the first care plan conferences we attended, during which she was accompanied by what Dr. Lechich describes as her “barracuda” daughter. Her voice seemed frail during that meeting, but what moved us most was her daughter’s rallying of the staff sitting around the table to “encourage Mom as much as possible.” At this moving speech, in which the daughter described the setbacks her mother had experienced when she had been transferred to the hospital and how independent Mom had been before the hip fracture and how much she wanted to regain the hip fracture, SF burst into tears and managed to squeeze out, “I’m trying so hard...”. The whole room was silent for a minute with compassion for this 96-year old survivor who was, trying so hard—as we later witnessed in the therapy department, determinedly finishing the tasks assigned to her. SF must have had an unparalleled will to live, because at 96, wheelchair-bound, she had no advance directives except for a Health Care Proxy. Perhaps SF is a testament to the opposite sentiment the staff at TCC feels is best for most of its patients in the condition of SF—for she was discharged home on July 1, 2010, having been here for only two months.

12. MJ

MJ was a 48 year old with uterine cancer. When we became involved in her case, she was already in her last days—non-verbal, wracked with pain, having seizures, almost comatose in bed, lethargic, and snorting due to swelling of her palate. About a week before her death, she had been put on hospice as an emergency referral. We spoke to her hospice nurse, who was there watching over her four hours a day, as per hospice. Family members filtered in and out of the room on vigil—her sisters and brothers, her mother, and her daughter. We had the opportunity to solemnly enter the room, express our condolences, and speak to her older sister. We asked how she was doing, what she had been like. MJ had loved newspapers and magazines. She had been a tough and lovely woman. She had been speaking, conversing actively with staff and visitors only a week before. This recent decline had followed a stroke. We asked her how her family was coping with MJ’s decline—their mother, the older sister replied, was devastated, as this would be the first of her children to go. Her older brothers had already cracked, and the sisters were now holding down the fort. MJ had a daughter and an estranged son. Dr. Lechich had asked her daughter, “Don’t you think your brother should know?” and she hadn’t given us an answer. Then, her older sister said, “I don’t think I can be here when it happens, when she passes. I just don’t think I can handle it.” We stood in silence for a moment, thanked her for speaking to us,

and wished her family comfort and our condolences. Palliation had worked for MJ—during her final days, her family surrounded her while she slept peacefully through the days. We went back to see her a few days later and found out she had expired a few hours earlier. When asked whether the family was present at the bedside, the CNA replied that the nursing staff could not reach the family members. This, then, was a hole that could have been avoided in MJ’s “good death.” MJ’s case is an example of the kind of intervention for palliative care that should happen not a week before the end, but ideally a few months. But, in the end, she is also a success story, in a way—she died a “good death.”

13. BF

BF is a tiny, old man with prostate cancer and a host of other problems, dying what Dr. Lechich calls “a slow, painful death.” He had worked in the TCC hospital for 27 years in housekeeping, and knew the ins and outs of this building by heart. He totters around the sub-acute floor. His case is a bit heart-wrenching, and perhaps showcases TCC’s difficulties when it comes to dealing with hospice patients. Mr. Figueroa is on hospice, and Huili and I sat in on his care-plan meeting, in which our staff and the VNS hospice social worker and nurse were present, as well. The biggest topic of discussion was his pain management—BF has bony metastases and is constantly in a lot of pain—when I’ve passed his room, there are times when I have heard him whimpering like a small child. From the language that is tossed around about behavior and rules, regulations, and family involvement, in fact, an observer may not be able to distinguish this nursing home from a school, or even a juvenile correctional facility. The professional staff play the role of the administration here—the principal, and the residents are the children—to be watched, taken care of, disciplined, and regulated to TCC’s policies. What was discussed at BF’s meeting with his youngest daughter Lucy, whose care for her father was apparent to everyone by the tone of her soft Spanish voice, was BF’s ability to continue his daily life, and all that he had enjoyed doing for so long. He enjoyed watching movies and reading newspapers, something that he had not been able to do for some time now because the bony metastases had left him a medical term that meant his neck was misaligned; his neck no longer supports his upright head, and he perpetually looks down. He looks thin, bony, and small—helpless, in a way, his mouth perpetually in a grimace, his head always in his arms. We, and the staff, are hoping to be able to get a neck brace for him so he can at least look forward instead of down all the time—so he can read books and watch movies. His appetite was discussed—a poor appetite is often the harbinger of a sharp decline in health. He wanted his Spanish food, which his wife was providing every day to him, but as much as he wanted to eat it, his body had no appetite. The VNS social worker commented that “sometimes the body knows what’s good for it, even if the mind wants differently” A “victory tour” was also discussed—a tour around the nooks and crannies of the building he had worked in for so long. I noticed the phrases that were used in discussion of his care were much less “medical,”—nothing medical, really, besides the discussion of what medications BF had been prescribed, and much more normal, in a way. This could be a discussion at home, and I thought that was a lovely thing—hospice seemed to be working, to be working towards the end goal of making TCC a home, with a sense of home care, for BF. A couple days later, I poked my head into BF room again. His wife was sitting there, and again, he was whimpering out of pain. Dr. Lechich had been right: Figuring out a way to manage his pain was going to be a challenge for TCC, and no one was sure whether we really did have the resources to do it. He asked us what we wanted, and we said simply to say hello—the ordinary reaction to this is a smile. A

simple gesture produces a simple result: a smile, from someone who perhaps feels they have no other reason to smile. A few days later, the entire fourth floor was witness to his sudden change in mental status—he stood facing the wall near the nurse’s station, screaming in pain and wondering where his wife was. His daughter had been on the phone with him all morning, and they were coming in later that day. He would not take any pain medications or anti-anxiety medications. He must have been screaming for an hour at least, alarming all the residents and staff, who were left helpless, in a way. When we looked in his chart, we noticed that there had been a lot of disputes between him and his family; he felt “abandoned” by them and called his wife and step-daughter names. The family wanted him to move to Calvary Hospital, and after a dramatic exchange of him deciding whether he wanted to go there or not, he finally decided to go. And go he went—the report is that he is very happy at Calvary. We suggested that we say goodbye to him before he left, and we did. Reticent about his condition and his fears to the very end with us, he was an example of EOL challenges in almost every way—pain management, internal psychosocial contentment, familial relations, etc.

14. DD

DD is, in our opinion, perhaps the saddest case we have witnessed thus far at TCC. She is our age, 19 years old. She was born with HIV. Her mother passed away in 2004 and her father is not involved in her life. DD was a hard resident to have at TCC; she was physically and verbally abusive towards staff, who sustained bites, kicks, and hurtful racial slurs while trying to treat her. She has always been non-compliant with her medication. In our last week, DD declined sharply—the HIV had damaged her central nervous system to reveal her seizure disorder. She could no longer speak, and her left leg was paralyzed. She was seizing constantly. This is the end for her. Her case is fraught with emotional difficulties for the nursing staff—watching her die a gruesome, seizure-ridden death and having the courage to intervene to give her an intramuscular injection of anti-epileptic drug is more than most of us can bear thinking about. Another factor is her age; Dr. Abebe noted that it was difficult to watch a young woman go in an era in which HIV was treatable. “19 years”, Dr. Lechich remarked, “is a very long time to live with HIV.” There remained the question of whether TCC could successfully palliate her instead of sending her to Mt. Sinai. A debate over whether hospice would help the situation came up, much to Dr. Lechich’s dismay. He emphasized that palliation is a standard of care that TCC staff should enact regardless of hospice status or not, for every patient and every point. DD’s youth, disease track, behavioral patterns, influence on staff, and EOL issues speak to all the challenges a facility like TCC almost calls for, through its mission. Her death may be the best death that can be accomplished given her disease and non-compliance, but one might be pressed, I think, to call it a “good death.”

15. LW

The case of LW is an oft-repeated story in TCC, on 2H, where the renal patients are housed. There has been a high morbidity rate on that floor recently, and palliative care comes into particular focus on that floor, as patients refusing dialysis are often very quick to expire. When a patient starts refusing dialysis, it is almost a sure sign of decline and always raises quite the alarm. In our time here, there have been 3-4 patients who have gone down this pattern, despite the constant plea of nursing, social worker, and medical staff to get dialyzed. What usually happens, and did happen in the case of Mr. White, is that the resident will refuse dialysis for 3-4

shifts and then become lethargic. At that point, the patient either slips almost into a coma and prepares to pass away, or the patient suddenly agrees to dialysis and an emergency dialysis appointment is set up. Dr. Lechich came in one morning to see Mr. White and found him lethargic; he ordered him to be dialyzed immediately, to which the patient consented, and the patient ended up sitting in the hallway despite Dr. Lechich's immediate request, because the dialysis staff insisted on waiting for the nephrologist. When the nephrologist finally arrived, he overruled Dr. Lechich and sent him to the hospital. Dialysis is a tricky, painful, essential life-sustaining procedure, and thus it takes its place in the realm of EOL discussions.

A week later, it arose that LW was again refusing dialysis. We sat in on the conversation between the social worker and Dr. Lechich; the social worker reported that LW felt he did not need dialysis, which contradicted his medical diagnosis of "complete renal failure." He wanted a pass to go out into the park and see his girlfriend. Dr. Lechich said that the facility could not support LW, whose unrealistic expectations for his dialysis needs were not only affecting his own health but those of others whose dialysis schedules would have to be disrupted to accommodate his emergency dialysis sessions. LW was an example of that sizable constituency of those who just could not accept the medical danger they were in, and as a result, he did not stay at TCC.

16. EJ

EJ perhaps represents typical symptoms of TCC thrust upon an unlikely candidate—a young man, 50 years old, suffering from the worst of those diseases known to mankind. The worst of the worst was hepatic failure and infection of the stomach, both conditions that could not be treated outside our facility. Another TCC challenge that EJ embodies is a language, and perhaps cultural and educational barrier. We sat in on THE meeting in EJ's health—that meeting where he was to be told that he could not leave the facility, that he was too ill to do so and he would have to stay long-term. Huili and I sat with the dietician, the nurse manager, his social worker, and a nurse who acted as a translator. It started out calmly enough, and then the drama unfolded. EJ was bent, understandably, on going home. Breaking it to him that he was too sick to go home, that he would have to stay in this place he so disliked for such a long time, was heartbreaking. His desire to go home and go to dialysis in the community could never be fulfilled, as the other dialysis centers had rejected him. His mother told him she could no longer take care of him at home, and his anger rose. He spoke angrily at her, asking her not to visit him anymore, something I think that broke all of our hearts. He proclaimed that he would go live in another city, away from here—but we all knew that he was probably here to stay, unless he made a great escape. At the end of the conversation he repeated his query: "How much longer do I have to be here?" We stopped there for the day.

I had visited EJ with Dr. Lechich a day after he had arrived to our facility, when he was so ill he had to be re-hospitalized. He was lying down on his back, eyes closed, agonal breathing because his palate was swollen—looked so terrible Dr. Chanamolu and Dr. Lechich wasted no time in sending him back to be stabilized. His mom was there, then, looking over him with worried, tearful eyes, and I remember Dr. Lechich hugging her close, telling her it was going to be okay. The doctors' estimate for his life is 3 months or less, due to his non-compliance with his health regulations—the conversation about advanced directives has been brought up many times, and

he remains a full code. It seems to me that what little is left of his existence is pitiable, and most of all I pity him his defiance until the very end, which guarantees him a painful, sudden end.

17. AC

Today, Huili told me that during the geriatrics morning report, it was reported that “Ms. AC will be traveling; she will be traveling to heaven today.” It was likely, the staff thought, that she would pass away during the day. Her case was mentioned again during Dr. Lechich’s lightning rounds, and when asked if the family had been summoned, the answer was affirmative. Right around 1pm, Huili and I traveled up to 1C, said hello to the head nurse, who informed us that one family member was in with AC and that she was on contact isolation. We decided just to peek in—as, I, at least, am still uncomfortable with approaching a family and entering someone’s life on this precious time. AC was sleeping, it seemed, peacefully—a nasal cannula delivering oxygen. We saw a woman sitting across from her against the wall, and the sweetest, strangest sight—a toddler-sized baby doll sleeping in what looked like its own bed, right next to her. Ms. AC was dying from dementia, and the nurse confirmed what we guessed—with a smile, she told us that the doll was AC’s favorite thing, her greatest comfort. Writing it down reminds me of quite a few things—the beauty that even someone with advanced dementia can find peace in their mental world. Huili and I discussed later a sentiment reflected in an article on treating multicultural elders that we had read—that in those societies, dementia in elders had been seen as a special connection to the mystical, or the spiritual world. It was a beautiful sentiment, I thought, a more peaceful way of ushering in the end of life. Perhaps this was finally a story of a good death, or a death that was maybe as prepared for as it could have been.

18. CH

CH an 81-year old man with many chronic illnesses, was perhaps one of the most ambiguous cases of EOL care at TCC that we witnessed. CH was an old friend of Dr. Lechich’s. When we first met him, he was showing signs of rapid decline—his wounds were not healing, his voice was feeble, and he was lethargic. CH was dying before our eyes, with no one in the world to care about him—and the decision on whether to have a 2PC, or a Do Not Resuscitate Order signed by two physicians, was imminent. The administration decided to hold an ethics committee meeting on him, but before they could do so, CH passed away peacefully, alone. Dr. Lechich was rather bothered about whether there was anything that could have been done to make his death better, but what, exactly, could have been done? Some deaths, it seems, cannot be improved.

Appendix 6

Physician Interview Transcripts and Analysis

Questions:

What are some difficulties you face when speaking to families about advance directives?

How would you go about implementing MOLST into family education on palliative care?

What would you suggest as institutional improvements?

Transcript:

Physician #1

- Residents are transferred here from hospitals, and nobody from the hospital talks to them about what is ahead
- Many people are under the impression that they will get better here, that they are here for rehabilitation only (as this is the sub-acute unit), but these are misconceptions and not the whole picture
- Mount Sinai has a very extensive palliative care team; however, they do not do a great job. We get no notes, and we do not know what had been discussed with the patient. We do not know the prognosis.
- Often times, other hospitals should send residents straight to Calvary Hospice instead of to us. This also gives false hopes to patients.
- For MOLST, we need to talk to relatives, not in a matter-of-fact tone, but more of a sympathetic and understanding tone. You cannot be too business-like about it. You should try to sugar-coat it a little bit.
- The death certificate software can definitely be improved. It is costing me a lot of time and problems.
- Perhaps having a pain management specialist to help us would improve residents' morale

Physician #2

- I find no problems with the family members. Sometimes, they are not fully prepared, then I would tell them what is going to happen is going to happen someday.
- I use medium tone and sit next to the patient. I have no language problems.
- Most social workers do a good job.
- Perhaps TCC can have a little more structure. Nursing homes should receive patients with structured plans.
- I suggest installing more computers and more technology.

Physician #3 and #4

- Families cannot accept the truth. They think their family member is going to live forever, and they hold to their beliefs.
- Talking to a stranger about something so personal and emotional can be difficult. It is easy to gauge someone you have known for a while; however, how can you tell with a stranger?
- Private settings are a must. We try to talk to patients at a place most convenient to them, for example: by the bedside. Psychological services are definitely of big help to us.
- Sometimes, it is difficult to figure out whom to address, the son, the daughter, or the husband? Although this is indeed a family affair, it is crucial to focus on one person.

- The CNAs sometimes help us translate for the families.
- We think the physician-social-worker have good communication.
- A problem that can be fixed: we get 10 copies of the labs. This is not necessary.
- The death certificate software is difficult to use.
- I become discombobulated in trying to gather all the information on a particular resident, need to venture to four different places.

Analysis:

From these answers, for the most part, we can see that physicians feel there is room for improvement in terms of communication with family members. There are several recurring statements made. For example: conversations with residents should be held comfortably by their bedsides, acute hospitals do not provide adequate background knowledge for patients before transferring them to nursing homes, the facility can benefit from an easier-to-operate death certificate software, and the facility can also benefit from reducing redundancies like the 10 copies of lab reports. At the same time, from these responses, we also realize that there is a wide spectrum of sentiments amongst the physicians. Some feel one way about this area (advance directives conversation with residents and families) of their job, while some feel another way. Overall, these interview transcripts can provide insight into the structure of TCC and where improvements can be made.

Appendix 7-Physician-Social Worker Communication Skills Workshop

E-mail Transcript of Original Proposal Sent to Dr. Lechich by Ashley Shaw

From: miimiishaw@gmail.com [mailto:miimiishaw@gmail.com] **On Behalf Of** Ashley Shaw
Sent: Friday, July 15, 2011 2:04 PM **To:** Lechich, Anthony **Subject:** Project Update: Doctors' Training Module

Hi Dr. Lechich,

Just wanted to update you on what I've been working on:

I have a theory for the structure of the doctors' training module on communication skills, and I'd like to hear your thoughts on it. It is based on my own experience in RA training (which focuses extensively on communication and interpersonal skills), and Huili and I both think it is a rather effective model.

This training model is based on these assertions:

- Environments that facilitate ongoing discussion are constructive
- Positive and constructive feedback delivered by peers is generally well-received and considered valuable
- Every participant has a strength to contribute and areas they can improve in
- Equal opportunities/obligations to participate means no one feels singled out; no one feeling singled out leads to wider acceptance of the exercise
- Organized, succinct workshops that use time efficiently/effectively are appreciated
- Role plays based on actual past experiences are exceptionally useful and the most relatable

So, here are the logistics:

- Series of sessions—perhaps weekly or bi-weekly—to ensure continuity and ongoing improvement
- Each session is concise, focuses on one or two skills/subjects
- Built-in time for discussion, feedback, and sharing of thoughts/ideas at each session
- Here is a proposal of the organization of these sessions:

- o Session 1 (30 minutes): Doctors receive "syllabus"—small packet of quick communication tips gathered from different sources on palliative care.

§ Workshop series is introduced.

- § Two 5-10 minute role-plays—solicited from situations that doctors have actually encountered—focusing on the skills involved in “Starting the Conversation”.
 - § Three doctors in each role play: one doctor plays the doctor, one plays the resident, one plays the (perhaps difficult) family member.
 - § Doctors who play resident and family member act on what they have actually seen at TCC.
 - § All other doctors watch/take notes.
 - § After each roleplay, 2-3 minutes allowed for both positive and constructive feedback, troubleshooting, and suggestions.
 - § Doctors are encouraged to continue discussing with their colleagues, and to try new tips in their work
- o All remaining sessions would follow the same format, and each would focus on different parts of “The MOLST Conversation”, i.e. “Breaking Prognosis” or “Ending the Conversation”

I have already put together preliminary materials for a small packet of useful tips for these conversations from INTERACT II, University of Washington’s Robert Buckman’s Six Step Protocol, and the current events news articles we have been discussing. My hope is that when I have finished compiling it, I can submit it to you to edit/shorten.

Let me know if you think this type of training module would be infeasible, or not useful in this setting, or not amenable to the doctors’ personalities/work ethic. We never want to waste any valuable doctor-time that should go towards patient care.

Suggestions, thoughts, and general musings would be most appreciated!

Hope you are having a wonderful weekend, and see you Monday!

Ashley

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

Current Events: Snippets from Literature on Palliative Care in the News

Months to Live Series: At the End, Offering Not a Cure but Comfort

NY Times, August 20, 2009, authored by Anemona Hartocollis

"In March, [Mrs. Migliore] broke her arm while turning a mattress. While repairing the arm, doctors found more cancer, and Dr. O'Mahony was called in to talk about her uncertain future.

They met at Morningside House, the Bronx nursing home where she was recovering from surgery, joined by Mr. Migliore, social workers, nurses and a physical therapist. **For about an hour, Dr. O'Mahony asked open-ended questions, looking for clues as to how much she knew and how much she wanted to know.**

"What are your biggest concerns?" was his opening move.

"First of all, the food is terrible," Mrs. Migliore said. She was trying to fatten up with spaghetti — the thought of other food disgusted her, which is often a sign of deteriorating health. But the pasta was cold, she said.

One leg would not support her weight. Her back hurt; she would like a massage. "I get annoyed when things are not my way," she said. "And I cry too much."

"Well, it's hard for most of us not to have control over things," Dr. O'Mahony said.

"Aside from the food," he pressed, "what are the things that concern you?"

"I want to get better," Mrs. Migliore said.

"What's your understanding of the status of the tumor?" Dr. O'Mahony asked.

"The doctor that took it out, he was just amazed," she said. "He says, 'Oh, Debbie, I did a good job.' I said, 'Yes, you did.'

Dr. O'Mahony tried to remind her that she still had cancer. "One of the frustrating things about this illness is the way it can pop up in different parts of the body," he said.

Mr. Migliore joined in, asking whether there was a way to slow the growth of the cancer.

"The treatments that are available for it can provide some local control, and they can slow the progression of the illness," Dr. O'Mahony replied.

"But there is no way of knowing it, right?" Mrs. Migliore asked, astutely, apparently registering the equivocation in the doctor's tone.

Then Dr. O'Mahony fired his warning shot: "There are no established cures." And Mrs. Migliore fired back with her wish to be "alive again."

Picking up on her cue, Dr. O'Mahony asked, "What gives you strength?" She liked to shop, she said. Perking up, she chided her husband for forgetting to bring the Victoria's Secret catalog.

"You sit home and watch 'I Love Lucy,'" Mr. Migliore said. "Do you think 'I Love Lucy' cares if you wear a \$400 outfit or a \$22.95?"

The meeting ended on a lighthearted note, and Dr. O'Mahony never returned to the prognosis that the nursing home staff thought Mrs. Migliore would want to know.

Beyond Mrs. Migliore's hearing, he said: "People giving very concrete estimates of survival can in essence cause as much harm as good. I think she was signaling to us quite a lot that it was important to her to be able to go home, to walk, to be able to promote her self-image, to shop for clothes."

He predicted that her disease would progress, perhaps rapidly, through a series of crippling events.

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

But he said he had learned from mistakes early in his career that it was not always helpful to presume to have answers, to mark a spot on the calendar. He said he would rather focus on things he really could help with, like making sure Mrs. Migliore was getting enough pain medication.

But before leaving, he made sure that she had a health care proxy — her husband — who would make decisions for her if she became incapacitated. He knew it would be harder to get one later.

[...]

Along the way, Dr. O'Mahony has picked up the wisdom of the trade. He has learned that older people tend to take bad news better than younger people.

That patients with advanced cancer generally go into a sharp decline three months before death, but those with dementia, heart disease or diabetes may have a bad month and then get better, making their prognosis trickier.

That people who do not have family or friends, or are alienated from them, are more likely to want to hasten death than those with more social support.

That patients who are agreeable by nature may not admit that they are in pain.

That people who blame their self-destructive behavior for their illness are less likely to ask for help, and that hard-charging professionals sometimes would rather not manage their own illness.

That people can know in their darker moments that the prognosis is grim, yet at other moments imagine they will go back to being their old selves.

And Dr. O'Mahony knows that the family is sometimes best at delivering bad news, as in the case of Eddie Ascanio.”

The Palliative Care Information Act in Real Life

The New England Journal of Medicine—May 19, 2011, authored by Alan B. Astrow, M.D., and Beth Popp, M.D.

“This case illustrates how fraught with uncertainty end-of-life decisions can be for doctor, patient, and family alike. No legal statute can capture their intricacy. **Death is not an event like a surgical procedure to which one consents; it is a process, sometimes protracted, and often painful to experience, witness, and accept. The straightforward provision of information is only the beginning of a complex process that requires communication skills, emotional engagement, and cultural awareness on the part of the physician.**

[...]

What is needed in such cases is not simply information, but **an appreciation for the profound anxiety everyone feels at the border between life and death.**

We all want physicians to speak about these matters with patient and their families openly, patiently, empathetically, and collaboratively. **That means physicians need to feel**

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

comfortable communicating their own values and experiences and providing non-authoritarian guidance and support while expressing interest in and respect for the experiences and values of patients and their families. These conversations must reflect both reasonable standards of good medical practice and goals that medicine can reasonably hope to achieve—all of which are subject to continuous revision in the light of new evidence.

Some physicians are naturally more comfortable than others in talking with patients about these issues, but there are specific skills that all can learn. Professional societies of many medical specialties, not just oncology and palliative care, need to recognize that skills for communicating about end-of-life care are as important as learning about the latest surgical technique or the newest pharmaceutical agent. They will need to expand opportunities for continuing medical education in physician-patient communication and take the lead in setting patient-centered guidelines for end-of-life treatment discussions. Institutions may need to review how they meet the palliative care needs of patients with advanced chronic illness and whether existing services ought to be augmented.

Delivering bad news well requires courage, patience, and empathy

Catholic Health World—September 15, 2009

“There are two things oncologist Robert Quadro never forgets when he is about to tell a patient bad news—Kleenex and his watch.

‘When I give bad news I try to say nothing for two to three minutes so the patient can process the information, and I just try to be present with them...I actually watch my watch because it’s going to seem like an eternity. So often a doctor will give bad news and instantly jump in and say: We can do this, we can do that. There’s just too much talking.’ “

[...]

“When it comes to delivering bad news, most doctors agree on a common sets of dos and don’ts: Do make enough time to answer a patient’s questions; don’t use technical jargon. Do find a private space to talk; don’t expect a patient to remember most of the conversation. Do prepare; don’t get flustered when those preparations unravel.”

“No matter how hard you try to set the time and place, sometimes the patient will take that out of your hands and ask you a question at the most inopportune moment, in the hallway, in the elevator,” said Quadro. “I’ve learned that patients will force your hand, and they do so on purpose. Many times I’ve had a patient say while leaving the room, “I’m going to beat this cancer, right, doc.? and what they are trying to do subconsciously is to get you to say everything is going to be fine. If that happens, I’ll say, “Let’s go back in the room and sit down and talk because this is too important a conversation to have in the hallway.”

[...]

Dr. P. Terrence O’Rourke, chief clinical officer at Trinity Health in Novi, Mich., agrees doctor should not presume to know what a diagnosis means to a patient...

“Never say, ‘There’s nothing we can do.’ There’s always something that can be done, like controlling pain for instance. We can almost always control pain. So clarifying what

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

is the greatest concern and what they really want to talk about is very important,” said O’Rourke. ‘It requires time and requires that you really stop and listen to what patients have to say. if you’re going to take care of these kinds of patients, you have to take time. It would be immoral to tell a woman she has breast cancer and not be prepared to talk an hour plus about what that means.”

[...]

“Patients and families will forever remember that moment when bad news is given,” said O’Neill, [vice president of mission and ministry at Maryhaven Center of Hope, a long-term care facility in Port Jefferson Station, NY], “They will remember where they were, and what was said, how the doctor said it. That can have a real impact on how the patient copes, and how a patient copes with an illness has an impact on the illness.

[...]

Castanares said it is an honor for a doctor to be able to care for a patient in the throes of terminal illness. **“It scares us, but it’s a privilege. When it comes to looking back at our professional lives, I think many of us will wish we engaged more. We’ll wish that we held that person’s hand, we’ll wish we hadn’t turned and walked out the door” after delivering a bad prognosis.”**

Serving Multicultural Elders: Recommendations for Helping Professionals

Care Management Journals: Volume 12, Number 2, 2011, authored by Hilary N. Weaver, DSW

“Indeed, not only professions such as social work have recognized cultural competence as an ethical imperative (National Association of Social Workers ([NASW], 1999), but also some helping professionals have stated **it is impossible to be clinically competent without being culturally competent (Coleman, 1998).**”

[...]

“Some elders who have migrated to the United States from other countries may expect a level of deference not common in the U.S. In cultures where status accompanies age, an elder may expect to be the first to speak, have the right to speak longer than others, and to have his or her viewpoint respected and deferred to. **An elder who perceives that he or she has not been treated with proper respect or deference may withdraw from services physically or disengage psychologically and, thus, be labeled as uncooperative or resistant”**

“The typical images of older people in American society are reflected in the thoughts of one older adult who struggled with his or her own internalized images about what it means to grow older. “Feeling alone and vulnerable, I feared becoming a geriatric case who follows the predictable pattern of retirement, painful physical diminishment, a rocking chair existence in a nursing home, and the eventual dark and inevitable end to my life” (Shacter-Shalomi as quoted in Paquette, 2002, p. 3). **This example clearly illustrates how societal images of aging can be internalized and affect how an individual sees himself or herself.** This example stands in stark contrast to the empowering image of aging noted previously. Given the predominantly negative images of aging common throughout American society, it is likely that even some elders from cultures where aging is traditionally associated with higher status may begin to internalize a negative self-image.”

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

“Letting Go: What should medicine do when it can’t save your life?”

The New Yorker, August 20, 2010, authored by Atul Gawande, MD

“I spoke to Dr. Susan Block, a palliative-care specialist at my hospital who has had thousands of these difficult conversations and is a nationally recognized pioneer in training doctors and others in managing end-of-life issues with patients and their families. **“You have to understand,” Block told me. “A family meeting is a procedure, and it requires no less skill than performing an operation.”**

One basic mistake is conceptual. For doctors, the primary purpose of a discussion about terminal illness is to determine what people want—whether they want chemo or not, whether they want to be resuscitated or not, whether they want hospice or not. They focus on laying out the facts and the options. But that’s a mistake, Block said.

“A large part of the task is helping people negotiate the overwhelming anxiety—anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances,” she explained. “There are many worries and real terrors.” No one conversation can address them all. Arriving at an acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany.

There is no single way to take people with terminal illness through the process, but, according to Block, **there are some rules. You sit down. You make time. You’re not determining whether they want treatment X versus Y. You’re trying to learn what’s most important to them under the circumstances—so that you can provide information and advice on the approach that gives them the best chance of achieving it. This requires as much listening as talking. If you are talking more than half of the time, Block says, you’re talking too much.**

The words you use matter. According to experts, you shouldn’t say, “I’m sorry things turned out this way,” for example. It can sound like pity. You should say, “I wish things were different.” You don’t ask, “What do you want when you are dying?” You ask, “If time becomes short, what is most important to you?”

Block has a **list of items that she aims to cover with terminal patients in the time before decisions have to be made: what they understand their prognosis to be; what their concerns are about what lies ahead; whom they want to make decisions when they can’t; how they want to spend their time as options become limited; what kinds of trade-offs they are willing to make.**

Discussing Treatment Preferences with Patients who Want “Everything”

Annals of Internal Medicine, September 1, 2009, authored by Timothy E. Quill, M.D.; Robert Arnold, M.D. and Anthony L. Back, M.D.

STEP 1: Understand What “Doing Everything” Means to the Patient

“Rather, the request [to “do everything” may reflect more nuanced wishes for how to balance the burdens and benefits of treatments and underlying affective, cognitive, spiritual, or family concerns.”

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

Table 1 provides examples of differences in the way patients may balance treatment burdens and benefits.

Table 1. Different Treatment Philosophies Underlying Requests for "Everything"	
Everything that might provide maximum relief of suffering, even if it might unintentionally shorten life.	
Everything that has a reasonable chance of prolonging life, but not if it would increase the patient's suffering.	
Everything that has a reasonable chance of prolonging life, even if it may cause a modest increase in suffering.	
Everything that has a reasonable chance of prolonging life even a small amount, regardless of its effect on the patient's suffering.	
Everything that has any possible potential to prolong life even a small amount, regardless of its effect on the patient's suffering.	

Table 2 outlines patient concerns that may underlie requests to “do everything” and gives examples of useful questions to ask.

Table 2. Potential Underlying Meanings of "Everything"			
Domain	Concept	What "Everything" Might Mean	Questions to Ask
Affective	Abandonment	"Don't give up on me."	"What worries you the most?"
	Fear	"Keep trying for me."	"What are you most afraid of?"
	Anxiety	"I don't want to leave my family."	"What does your doctor say about your prospects?"
	Depression	"I'm scared of dying."	"What is the hardest part for you?"
Cognitive	Incomplete understanding	"I would feel like I'm giving up."	"What are you hoping for?"
	Wanting reassurance that best medical care has been given	"I do not really understand how sick I am."	"What are your most important goals?"
	Wanting reassurance that all possible life-prolonging treatment is given	"Do everything you think as a doctor is worthwhile."	"What is your understanding of your condition/prognosis?"
Spiritual	Vitalism	"Don't leave any stone unturned."	"What have others told you about what is going on with your illness?"
	Faith in God's will	"I really want every possible treatment that has a chance of helping me live longer."	"What have they said the impact of these treatments would be?"
Family	Differing perceptions	"I will go through anything, regardless of how hard it is."	"Tell me more about what you mean by 'everything.'"
	Family conflict	"I value every moment of life, regardless of the pain and suffering (which has important meaning for me)."	"Does your religion (faith) provide any guidance in these matters?"
	Children or dependents	"I will leave my fate in God's hands; I am hoping for a miracle; only He can decide when it is time to stop."	"How might we know when God thinks it is your time?"
		"I cannot bear the thought of leaving my children (wife/husband)."	"How is your family handling this?"
		"My husband will never let me go."	"What do your children know?"
		"My family is only after my money."	"Have you made plans for your children (other dependents)?"
		"I don't want to bother my children with all this."	"Have you discussed who will make decisions for you if you cannot?"
			"Have you completed a will?"

APPENDIX 7: Current Events: Snippets from Literature on Palliative Care in the News

STEP 2: Propose a philosophy of Treatment

“Given what we know about your illness and what I have learned about your priorities, it sounds like you would prefer the following balance of burdens and benefits in your treatment...” Such statements help the patient and family know that any subsequent recommendations are based on knowledge of their values and priorities.”

STEP 3: Recommend a plan of treatment

“Once the physician and patient have agreed on a philosophy of treatment, the physician can make a more specific recommendation about what should (and should not) be done to support the patient’s treatment philosophy, given the patient’s medical condition and prognosis...” To avoid the patient feeling abandoned by the physician, clinicians should emphasize what will be done to achieve the patient’s goals before talking about what will not be done.”

STEP 4: Support Emotional Responses

Examples:

Acknowledgment: These are difficult discussions”

Legitimize them: “Anyone confronting these issues would feel somewhat frightened”

Explore their response: “Tell me what is the hardest part for you”

Empathize: “I can imagine that the future looks much less certain now that we have had this discussion.”

STEP 5: Negotiate Disagreements

“If differences between what the patient requests and what the physician recommends are substantial, the physician should begin by reviewing his or her understanding of the patient’s condition, values, and philosophy to ensure common understanding and reiterate his or her assessment of the patient’s condition and prognosis with or without treatment.”

STEP 6: Use harm-reduction strategy for continued requests for burdensome treatments that are very unlikely to work.

<i>Table 3. Harm-Reduction Strategy When Patients Request Treatments That Do More Harm Than Good</i>
Acknowledge and adhere to the patient’s treatment philosophy so that patient and family feel heard and respected.
Stop regularly discussing limitations on invasive treatments unless this issue is raised by the patient or family.
Address the medical team’s discomfort and disapproval by: Communicating the reasoning behind the treatment decision. Finding other patient-centered goals to work toward (symptom management, support, disease treatment).
Use clinical judgment to limit treatment that does not advance patient-defined goals.

APPENDIX 7: Doctor-Social Worker Workshop Proposal

Doctor-Social Worker Joint Program On Improving Inter-Team and Team-Family Communication Skills

Goals:

- 1) Physicians will gain hands-on simulated practice and resources to help them in conducting end-of-life conversations with residents and families**
- 2) Physicians and Social Workers will be aware of the other disciplines' roles, strengths, difficulties encountered, and possible areas of assistance. Past communication barriers between them will be voiced, assessed, and solutions to those barriers will be sought.**
- 3) A more friendly, peer-led environment of open discussion and consultation will be initiated and maintained.**

Educational Materials:

Brief outline of new roles of SW and Physician in MOLST protocol

Brief INTERACT guide for communication skills

Packet of current events excerpts highlighting palliative care skills

Real-life case studies to critique and discuss

Real-life role-plays

Educational program format:

***Note: Should each doctor pair up with the social worker they work with on a day-to-day basis? Unit-based education?**

Short informational sessions, focus mostly on role-plays and feedback sessions.

Perhaps a series of short sessions?

Order:

- 1) Informational Session: Packets, handouts, new roles in MOLST, communication solutions**
- 2) Discussion about efficacy of suggestions/improvements**
- 3) Role-plays, and after each role-play, a designated session for critique**
- 4) Conclusion**

Appendix 8

Field Research: Correspondence With Dr. Aida Wen

Questions: Huili Zhu, Ashley Shaw, and Dr. Lechich

Answers: Dr. Aida Wen, Hawaii Medical Center, Geriatrics M.D.

Q: Based on the educational structure of the program you use, how were the collaborative sessions and facility learning sessions implemented?

A: The nursing homes where we ran our program were small, around 150 beds, some 300 beds. The sessions contained anywhere between 10~20 attendees per group, with everyone (all nursing home staff, one shift, videotape it, other shifts could partake by watching); i.e. 11-7 shift. One of the things we learned from the IMPRESS project and about the learning session was that poster sessions have a benefit, made available/mandatory to other staff and the priest. We made the sessions very consistent with sign-in sheet. There were 6 sessions, 30 minutes each.

Q: For the family telephone interviews, were there EOL checklists?

A: We took scoring system, filled end-of-life checklists, looked up in the literature, and adapted the QOD-LTC protocol. Website has EOL checklist. We also used palliative care/long term care tool-kit and templates, but not specifically for every patient.

Q: How do you keep the efforts from going away/not let the efforts fade away?

A: It is indeed hard. We focus on in-services, need consistent reminders, and try to integrate our efforts into the fabric of how we run. We start from leadership downward and persistently question ourselves: Do they have their checklist? Are they evaluating their spiritual options? We need act like policeman and look after the structure to keep our efforts on the radar at all times. We implement in-services and follow-ups. Patient-satisfactory surveys (with questions regarding EOL/palliative care) are also given out.

Q: Does your facility have pain and symptom management in-house?

A: It is really a collaborative effort. We provide in services for five nursing homes. We have three main hospices and we have two in services per hospice. Yes, we do our own in services. Certified nurse's aides were involved in these in-services, and we have forms that the CNA and leadership teams fill out. We evaluate results using dose-response curve. The nurses need to be self-respective.

Q: What were some barriers in the process?

A: Barriers were listed as a question on our survey, along with knowledge, expertise, time, and quality. The intervention was implemented gradually. This is definitely a priority question. Knowledge was the most prevalent answer in these surveys. People all thought knowledge is lacking. After the teaching sessions and in-services, lack of knowledge was no longer a problem. The priority needed to be identified. Also, time is a huge barrier.

Q: Are there communication issues or difficult prognostications in your nursing homes?

A: We did talk about these during our collaborative sessions. There are check-boxes that people can use as ways to engage in the structure. They can fill out a template letter/form that contains questions such as: Would you like us to call palliative consult? Would you like us to...? These issues are often tricky. To prepare family for short/long course, we need to "hope for the best, plan for the worst". Still, some conditions/people are just not comfortable with this kind of conversation. So, we must focus on thinking "how can we make it easier for them?". We can focus on the things that can be done, given their conditions. We can prepare them so they are ready for what's to come.



COLLABORATIVE SESSION #1 IMPRESS Project Overview

Kokua Mau, Hawai'i Hospice and Palliative Care Organization
June 29, 2009

- “My own notion is that palliative care is a concept of care that should be given to all nursing home residents, regardless of their status as “terminally ill” or not...All residents need alleviation of symptoms, pain management, psychosocial intervention, and spiritual care...”

▪ Jacob Dimant



What is a good death?

- Provides relief from distressing symptoms
- Addresses psychosocial and spiritual needs
- Provides a chance for patients and families to face the inevitable without additional fear or misinformation
- Produces a sense of autonomy and reduced powerlessness in the face of death

Murtagh et al. Clin Med 2004; 4: 39-44.



The main tasks

- Explicit recognition that a resident has a limited life expectancy
- Identifying the surrogate/ Advanced Directives
- Care planning specifically for end-of-life needs
 - Physical Comfort
- Promotion of psychosocial support and dignity



Why does it matter?

- Improves patient care
- Improves family satisfaction
- It's about quality of life and respecting each individual
- Helps surveyors understand that a resident's decline is unavoidable.



The Project

- Kokua Mau received grants from the Chamber of Commerce and Hawaii Community Foundation.
- Front-line staff: a series of 6 educational "Learning Sessions" or in-services
- Facility Leadership: engagement of facility leadership to discuss how to create structures that facilitate the delivery of quality palliative care.
- Improvement will be driven by sharing of ideas, and feedback from family and staff.
- One year project



Expectations from us:

- SIX In-services
- Telephone interviews of decedent's families.
 - We will begin in July to call families regarding deaths that occurred up to 3 months ago (after April 15, 2009) for baseline data.
- Feedback from the staff and family interviews as we go along
- Final data and analysis.
- Resources as needed.
 - LTC Physician Information Tool Kit Series: Palliative Care in the LTC Setting (AMDA) (\$40)
 - Handouts
 - Accessibility to us



Expectations from each Facility:

- Advertise, encourage, remind your staff to attend LS.
- Try to videotape LS so other shifts can participate and benefit.
- Please provide and collect the Learning Sessions Feedback Form at every one of the six in-services.
- Complete demographic information on every resident who dies.
 - Provide at least three contacts with telephone numbers for their caregivers, so our staff can perform telephone interviews.

Expectations from each Facility:

- Please provide and collect the Learning Sessions Feedback Form at every one of the six in-services.
- Create a “storyboard” poster to show-off your program
 - This can also be prominently displayed at your facility to raise awareness, and demonstrate to families your commitment to quality comfort care.
- Do your own in-services regarding any changes in your own P & Ps.



Ground Rules



- **#1 Non-solicitation:** All speakers and project leaders should be representing Kokua Mau. During the six month LS sessions, they are asked to adhere to a **policy of non-solicitation** (i.e. they cannot use this as an opportunity to negotiate or sign new hospice contracts with facilities participating in this program). Of course, they may continue in the usual provision of their services.
- **#2 Sharing:** In order to maximize learning and facilitate implementation of strategies, we encourage facilities to share best practices, strategies, ideas and lessons learned with the other participants. There will be opportunities to share during discussions at CS as well as through your storyboard poster.

Data Collection Forms

- Collaborative Session Feedback Forms
- Learning Session Feedback Forms
- Demographics Form
- Telephone Interview (QOD-LTC)



Timeline for Learning Sessions

- Monthly from August 2009 – January 2010.
- Each session will begin with staff completing the LS form regarding provision of palliative care to their patients in the past month.
- Each LS will be about 30 min. long.
- Staff who sign up to attend are expected to come to EVERY monthly session, as we will be following their progress.



Learning Sessions

- The Topics to be covered include:
 - A good death
 - Pain Assessment and Management
 - Managing Distressing Symptoms
 - Life prolonging treatment, futility care and Advanced Directives, POLST
 - Cultural beliefs in death and dying
 - Grief and Bereavement



Timeline for Collaborative Sessions

- Collaborative Sessions will occur quarterly. Our staff will be available to support and assist facilities as needed in between sessions:
- CS #1 JUNE (Advance Care Planning)
 - Overview
 - Evaluating ways to identify residents who have limited life expectancy
 - Evaluating strategies for effective Advance Directive Discussions



Timeline for Collaborative Sessions

- CS#2 SEPT 28 (Pain and Symptom Management)
 - Review Policies and Procedures relevant to end-of-life care
 - Review Forms, Tools, and Care plans relevant to end-of-life care
 - Discuss strategies that enhance effective communication between physicians and nurses
 - Storyboard Poster Presentations for Facilities 1 and 2



Timeline for Collaborative Sessions

- CS#3 DEC 14 (Promotion of Psychosocial support and dignity)
 - Discuss strategies that allow better emotional support to patients and families
 - Discuss structures that facilitate the provision of "respectful death"- attention to culture, dignity
 - Storyboard Poster Presentations for Facilities 3 and 4



Timeline for Collaborative Sessions

- CS#4 MARCH 29 (Solidifying your gains)
 - Review contracts and expectations for collaboration and communication with hospice and palliative care providers.
 - Incorporate questions regarding end-of-life care into your facility satisfaction surveys, QA
 - Storyboard Poster Presentations for Facilities 5 and 6
 - Summary



First Steps...

- Assign Facility ID#s
- Complete CS#1 Feedback Form
 - Baseline data



Let's get started on our journey!





PRESENTATION #1 IMPRESS Project

Evaluating ways to Identify residents with limited life expectancy

Aida Wen, MD
June 29, 2009

Prognosis

At the time of Nursing Home admission:

- PERCEPTION: Only 1.1% of residents with advanced dementia were perceived to have a life expectancy of < 6 months
- REALITY: 71% died within a year of admission.
- HOWEVER: non-palliative treatment common within days of death.
 - Full code, Tube feeding, IV's, restraint use

Mitchell SL, et al. Arch Intern Med, 2004; 164: 321-326.

Prognostication Tools

MDS

1. Flacker Mortality Score
 - (AMDA Toolkit p. 10-12)
2. Mitchell Mortality Risk Index
 - (AMDA Toolkit p.14)
3. Wallace, Prevost
 - (CS #1 Appendix. handout)

Other

1. Disease-specific Hospice Criteria
 - 6-mo
 - Excludes many
2. Palliative Prognosis Score
 - 30-d
 - subjective

Flacker Mortality Score (1-year)

Flacker and Keily, JAGS 1998

Residents Characteristics	Information Location	Scoring Chart	Score
Functional Ability Score*	MDS G1	If >4, score 2.50	
Weight Loss	Weight sheet	If lost > 5lb in past 30d, >10lb in 180 days, score 2.26	
SOB	MDS J1i	Yes, score 2.08	
Swallowing problems	MDS K1b, K5c, diet order	Yes, score 1.81	
Male	MDS AA2	Male, score 1.76	
BMI	MDS K2	BMI <22, score 1.75	
CHF	MDS I1i	Yes, score 1.57	
Age >88	DOB AA3	Yes, score 1.48	
		TOTAL SCORE:	

ADL Scale

7 functional activities

	5 levels of dependence
Bed mobility	0 independent
Dressing	1 supervision
Toileting	2 limited assistance
Transfers	3 extensive assistance
Eating	4 total dependence
Grooming	
Locomotion	

ADL Scale= the sum of performance in each of the activities.

A total score of 28= total dependence

Mitchell JAMA 2004

Mitchell: Mortality Risk Index (6-month mortality)

MDS Risk Factor	Points	Score
ADL Scale =28	1.9	
Male	1.9	
Cancer	1.7	
CHF	1.6	
O2 dependent past 14d	1.6	
SOB	1.5	
<25% eaten	1.5	
Unstable medical condition	1.5	
Bowel incontinence	1.5	
Bedfast	1.5	
Age>83 years	1.4	
Not awake most of the day	1.4	
TOTAL SCORE (0-19)		

Mitchell: Mortality Risk Index

Calculate total score, rounded to the nearest integer

If total risk score is...	6-month mortality
0	8.9%
1 or 2	10.8%
3, 4, or 5	23.2%
6, 7, or 8	40.4%
9, 10, or 11	57.0%
> or = 12	70.0%

Wallace J Nurs Schol 2006

Wallace: Summative Index Scores (6-month)

MDS item	Bowel Incontinence	Summative Score	Died within 6 months
Short-term memory loss	Urinary catheter	1+	29%
Poor decision-making	Fell in past 6-months	2+	40%
Periods of lethargy	Unstable condition	3+	47%
Sad facial expression	Terminal diagnosis	4+	55%
Resists care	Recent weight loss	5+	65%
Unable to walk in corridor	Pressure ulcers- #	6+	71%
Unable to walk on unit	PU- higher stage	7+	76%
Unable to feed self	Stasis ulcers-higher stage	8+	75%
Unable to perform personal hygiene	Limited time in activities	9+	70%
Unable to get OOB	Overall decline in condition	10+	75%

Your Turn...

TEAM WORK PLAN #1



30 min

Presentation #2

Evaluating Strategies for Effective Advance Directives



KOKUA MAU
"Continuous Care"

Aida Wen, MD
June 29, 2009

Comprehensive Advanced Care Planning

- Nursing Home Options for Life-sustaining Treatment (NHOaLoT) www.uchsc.edu/palliativecare
 - Explains in simple language and pictures: CPR, Mechanical Ventilation, Hospitalization, Tube Feeding, Hospice Care
 - See appendix



KOKUA MAU
"Continuous Care"

Comprehensive Advanced Care Planning

- Physician Orders for Life-Sustaining Treatment (POLST, MOLST)
 - Comprehensive orders www.ohsu.edu/ethics/polst/



Comprehensive Advanced Care Planning

- Five Wishes
 - <http://www.agingwithdignity.org/forms/5wishes.pdf>
 - Need to go online to view and order forms for use.
- Hawaii State Advance Directive –
 - www.kokuamau.org - download free forms
- Let Me Decide
 - Molloy, et al. Systematic Implementation of Advance Directives in Nursing Homes. JAMA 2000;283:1437-1444



KOKUA MAU
"Continuous Care"

Goal-based

Advanced Care Planning

- FIRST understand the “Big Picture” Goal
 - Longevity
 - Function
 - Comfort
- NEXT determine the appropriate sites of care and limits of care
 - “Pathways of Care” Muriel Gillick; JAMDA 2001; 2: 305-309.
 - Intensive, Basic, Palliative, Comfort
 - “Let Me Decide” William Molloy; JAMA 2000
 - Intensive, Surgical, Limited, Palliative



Communication Techniques

REALITY: Medical decision-making is primarily based on non-medical issues (social, emotional and relational)

- Staff also need to understand the “big picture” and goals.
This provides more person-centered care, AND
This will help them:
 - Understand why things are done
 - Understand how to advocate for resident better
 - Understand how to support the resident and family better
 - Prepare the family for discussions with physicians

Communication Techniques

- Train Nursing and Social Work Staff
 - Communication skills can be learned and practiced
 - Improve listening skills
 - What NOT to say
 - Borrow “words that work” until you can find your own
 - Can ask local experts to assist staff in providing tips.
 - Review Palliative Care in LTC AMDA Toolkit, Chapter 3 for suggestions and strategies



Support Families with Literature

- Psychosocial support
 - “Hard Choices for Loving People” by Hank Dunn
 - www.hardchoices.com
- Quick Facts www.getpalliativecare.org
 - Handouts for patients and families of FAQ on topics such as Artificial Hydration and Nutrition, Fatigue, Depression, Delirium, Questions to ask your doctor, etc.

Be culturally sensitive

- Translated Advanced Directives:
 - Chinese, Spanish, Vietnamese:
 - <http://www.ih4health.org/> then click on Advanced Directives
 - Tagalog
 - <http://www.unr.edu/ncehp/ADs.html>
 - Korean, Russian
 - <http://www.swedish.org/body.cfm?id=77>



Your Turn...

TEAM WORK PLAN #2



30 min

SIGMA Audit on Inter-Disciplinary Care Team Communication re: EOL issues and collaboration

Standard Patient 1:

Date on Hospice:

No Hospice Care Plan on SIGMA

Date on EOL:

7/13/2011 (Date that Terminal Prognosis/End-Of-Life Care Plan entered on SIGMA)

Advanced Directives:

HCP named but not marked as HCP in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)

Comments under SIGMA Advanced Directives Care Plan:

No monitoring/evaluation notes added to Advanced Directives Care Plan.

Comments on SIGMA containing notes on discussions with families, inter-disciplinary care team communication, pain management, psycho-social EOL issues, and other potential triggers for EOL concerns from physician:

5/12/11: Physician Admission: has had difficulty with pain control...ADVANCE DIRECTIVES; DNR/DNI

5/25/11: Interim Progress Note: Prostate cancer - with mets, d/wpt's daughter, aware of his prognosis.

5/26/11: Interim Progress Note: Prostate cancer with mets - per daughter pt to go for chemo in 2-3 weeks, will give us the date later.

6/2/11: Interim Progress Note: c/o pain not well controlled. chronic metastatic pain, worse at night...Prostate cancer - with mets; Lung nodule - on CXR, f/u with oncology (daughter to make appt)

7/05/11: Monthly Progress Note: Assessment of active medical problems: Started on hospice. Seen in the interm for cough and by urology. No Cough, no chills, no sweating , no vomiting, no diarrhea, no pain in extremities. Indicates some pain in lateral sides Plan of Care (by problem):

On Hopice care

Metastatic Prostatic CA

HTN, tachycardia monitor

Anxiety on alprazolam

Constipation continue current laxatives. Resident on narcotics for pain. Currently moving his bowel

GERD's decrease reflux

anemia Hg 9.2. Monitor periodically

Hyperlipidemia on simvastatin

Insomnia on ambien as needed

On hopice care/ comfort care. Monitor for pain

Continue current meds
Monitor for Constipation/diarrhea

Prognosis: poor

7/15/11: Interim Progress Note: ref by hospice nurse re: need for steroid use. D/W Dr.Al Hartmann (Hospice) - stated steroids are indicated for bony metastatic pain control and has had success with his other similar pts...states has had bm the other day, no n/v, appears anxious and in pain

7/20/11: Interim Progress Note: f/u pain.

still sub-optimal pain control, no n/v/abd discomfort Chronic pain; Prostate cancer with bone mets

P: incr oxycontin 40 q8 --> 60 q8, cont prn dilaudid, cont decadron, incr xanax to 0.25mg tid

7/25/11: Interim Progress Note:

Ref for abn behaviour, standing in the corridor, insistent he needs to see his wife right away; initially denied significant pain, later stated yes...A: altered mental status—most likely decadron role, prostate cancer, anxiety.

P: check cbc, bmp, u/a, decr decadron 4 → 2mg qhs, taper off next few days, refused additional xanax, insistent that he sees his wife ASAP, Re-order psych consult

7/29/11: Interim Progress Note: pt refused to go to calvary today, transportation sent back.; stated " I had a cousin there and he died, I want to stay here or go home"; denied being in too much pain , stated he does not need more meds as of now.; family members at bedside, per daughter he cursed everyone and she requests a psych consult...consult psych re: capacity for d/c planning

8/1/11: Psychiatry Note: Reason for consult: capacity to make medical decisions, engage in discharge planningHPI: 68 yo man with h/o metastatic prostate cancer, DM, GERD, chronic pain, anxiety d/o cognitive d/o seen today for capacity. D/w SW, states pt was scheduled to go to Calvary hospital(hospice care) last week, and he refused to go. Family member reportedly wants pt to go to this facility. Pt seen this afternoon. He expressed depressed mood b/c they(referring to his family) "stabbed me in the back," but did not elaborate, except stating that "they put me here like an animal." Spoke to patient re:discharge to Calvary. States he did not go b/c he "didn't want to" and that he wanted to stay at TCC b/c he worked here for many years. Unable to tell me what kind of facility Calvary is. He is unable to tell me about his other medical issues except that he has cancer, does not know what kind, and does not know what kind of treatment he received or what has been recommended here. States his only medication is pain pills, denies taking other medications. Psych meds: Xanax 0.25 mg tidRemeron 22.5 mg qhsAmbien 5 mg qhsMSE: 68 yo man with irritable edge, oriented to person and place, limited historian. Mood is depressed with constricted affect. No AH/VH, +PI, no SI/HI. I/J poor. **DIAGNOSIS:** Anxiety DO NOS, Cognitive DO NOS(per prior note), r/o DeliriumRecommendations:1. At the time of this evaluation, this patient does not demonstrate capacity to make medical decisions or engage in discharge planning. 2. Pt reportedly with

change in baseline mental status, he is expressing paranoid thoughts. Recommend delirium w/up. 3. F/u 1-2 weeks.

8/1/11: Interim Progress Note: states pain is allright.

8/2/11: Physician Discharge Note:

68 yo m with metastatic prostate cancer (Prostate cancer diag 3 yrs ago, had chemo and radiation - per urology and oncology, poor prognosis)

h/o DM (not on meds now), GERD (Barrett's esophagus) Anxiety transferred to TCC from Mt.sinai in may 2011. during his stay here he was treated for uti, was able to have foley d/ced. his major issues would be pain control, anxiety and constipation. has no active complaints today.

109/73, 106, 18, 98.1

cvs- rrr, no m/r

lungs-ctab, no w/r

abd-s/nt, bs+

A/P:

Chronic Pain - pt currently comfortable on oxycontin 60 q8hr, decadron 1mg (had psychotic behaviour on 4mg of decadron)

dilaudid 8mg q3 hrs prn, tramadol 50 mg tid and icy hot patch to low back area.

seen by pain management yesterday and recs fentanyl patch but since pt is being discharged today would defer further changes to Calvary.

Attached is a copy of her consult sheet.

Anxiety - Xanax 0.25 mg tid.

Constipation - on colace 300, senna plus 2, miralax bid, lactulose and milk of mag daily

GERD - Prilosec.

Poor Appetite - on remeron and cyproheptadine.

Appendix 11

MOLST Implementation Trial Session

Notes on MOLST Implementation Crash Course for 6H Pilot:

Participants: Iona Mitchell, SW, Ann Carroll, Administrator for Geriatrics, Gemma Lynch-Moore, Director of Nursing Services Geriatrics, Erlinda Girardo, Director of In-Services, Dr. Suja Sabastin, MD for 6H (and me!)

- Discussed that this pilot will be started on 2 alert, oriented gentlemen on 6H
- Dr. Sabastin to not complete MOLST form by Wednesday, but to try to introduce the topic and start the process. Introduces the Advance Care Planning Booklet given out by Compassion and Support.
- Discussion between participants about whether we should and whether we can realistically complete MOLST for our subacute patients. ArchCare policy says yes, a MOLST should be completed for all residents upon admission.
- Discussion about the two forms documenting discussion and pre-MOLST planning, and whether they are necessary or are just extra paperwork. I noted that the Advance Care Planning Assessment Form is an inter-disciplinary form, with fields to be filled out by Nursing/SW and Physician, so it could be a vehicle for IDT communication, in a way. The MOLST/Advance Directive Discussion Documentatino Form is to be filled out by the physician.
- Erlinda remarks that she likes the idea of the forms because they necessitate pre-MOLST discussion and preparation, and are therefore in line with the 8-step MOLST protocol.
- Ann makes the point that with these two cases we are already fairly confident (i.e. have the information) of the answers to the questions on the form for these patients.
- Erlinda asked where these answers are documented, and Ann comments that they are in various places of documentation (SW notes, nursing notes, SIGMA, etc.)
- Dr. Sabastin asks, "Okay, so where should all this anecdotal information that I've never heard about be documented? We should really aim for one uniform place for all this information. One of these forms has a whole page for notes--that could be a good place."
- Discussion about ACP Booklet: Ann suggests that the SW should give out the ACP booklet at the care plan, so that the resident is already prepared for discussion when the doctor comes around.
- Dr. Sabastin notes that the timeline is weird, in a way, since SW must get information about advanced directives before the doctor sees the patient, so the patient in some way doesn't have the information about their medical condition that they need to know. It should be that the SW gives the information, then the doctor talks to patient, and then the patient decides about Advanced Directives.
- All participants go over the MOLST form, and each section. Clarifications about the form are made--all DNR forms regarding surrogates/health care proxies are still valid, but the "withdrawal of life sustaining medical treatment" is no longer needed. Doctors still have to put in orders for DNR so that the binders can be changed.
- The plan is then established: SW will give the pt. the ACP booklet today, and Dr. Sabastin will go in (for her monthly renewal) and tell the pt. to go over it on the weekend, and then to prepare for a discussion on Monday.

-It is decided that both discussion documentation forms should be tried out and troubleshooted, because Erlinda points out it would be very useful if the State wanted to inspect documentation to just have one form documenting the discussion.

-It is discussed that unit clerks must be part of the process even though they are not attending Sarah's MOLST information session.

-It is discussed that simply piloting MOLST with two alert/oriented patients is not exactly the greatest reflection, and that we shoudl also pilot it on a new admission and an involved family case, but we are short on time.

-It is discussed that all of this will be brought up at the next Family and Friends Council and the next Resident Council.

Appendix 12-SIGMA Audit on IDT Communication and EOL Checklist

NAME	ROOM	Hospice Date	Date on EOL	Advanced Directives (SIGMA)	Comments on SIGMA (SW)	Comments on SIGMA (Physician)
		10/4/10	8/29/2010	HCP not named nor marked in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)/DNH/DNI/NO BLOOD TRANSFUSION IN PLACE.	Care Plan: Advanced Directives: 4/13/2011: RESIDENT IS STABLE AND IN HOSPICE CARE AT THIS TIME. HER ADVANCED DIRECTIVES OF DNR/DNH/DNI/NO BLOOD-TRANSFUSIONS REMAIN IN EFFECT PER RESIDENTS WISHES. HER HCP IS HER DAUGHTER WHO IS VERY MINIMALLY INVOLVED. RESIDENT REPORTS INTERPERSONAL PROBLEMS WITH HER DAUGHTER WHO IS YET TO VISIT RESIDENT AT TCC.. RESIDENT HAS AN INVOLVED CLOSE FRIEND MS. D. NESMITH, WHO VISITS RESIDENT ON WEEK-END AND AS NEEDED. ADVANCED DIRECTIVES REVIEWED WITH RESIDENT. RESIDENT DID NOT MAKE ANY CHANGES TO HER ADVANCED DIRECTIVES OF DNR/DNH/DNI / AND NO BLOOD-TRANSFUSIONS WHICH ARE CURRENTLY IN EFFECT.	(Attending-10/12/2010): "Monthly Progress Note: Assessment of active medical problems: 90 yo woman with hypothyroidism, COPD, Anemia, insomnia, HLD, s/p R THR. Resident with mass in the lung and pelvis , refused further work up, because she doesn't want to be treated for cancer per her age. Daughter is in agreement. Also refuses iron supplements for anemia, was put on EOL protocol, pt completed her own advance directives including DNR/DNI/DNH/no feeding tube and no blood transfusions. now on hospice" (Attending-11/12/2010): "Monthly Progress note: Assessment of active medical problems: 90 yo woman with hypothyroidism, COPD, Anemia, insomnia, HLD, s/p R THR. Resident with mass in the lung and pelvis , refused further work up, because she doesn't want to be treated for cancer per her age. Daughter is in agreement. Also was going for IV iron transfusions, now refusing, was put on EOL protocol, pt completed her own advance directives including DNR/DNI/DNH/no feeding tube and no blood transfusions. now on hospice care per pt/family wishes" (6/1/11 Medical Note: 91 y/o female on hospice care for mass in lung and abdomen, presumed to be cancerous, pt refused further work up per her age. Also refused any further IV iron transfusions, is on EOL protocol with advance directives for DNR/DNI/DNH/no feeding tube and no blood transfusions, per pt and family wishes. Labs have not been monitored 2o above. -Cont present management and plan of care. Resident on hospice care with goal of comfort and maximizing quality of life. Recommendations by internist and psychiatrist were not implemented.
		No Hospice Care Plan on SIGMA	7/13/2011 (Date that Terminal Prognosis/End-Of-Life Care Plan entered on SIGMA)	HCP not named or marked in SIGMA contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)	No details added to Advanced Directives Care Plan.	5/12/11: Physician Admission: has had difficulty with pain control..ADVANCE DIRECTIVES; DNR/DNI 5/25/11: Interim Progress Note: Prostate cancer with mets - with mets, d/wpt's daughter, aware of his prognosis. 5/26/11: Interim Progress Note: Prostate cancer with mets - per daughter pt to go for chemo in 2-3 weeks, will give us the date later. 6/2/11: Interim Progress Note: c/o pain not well controlled. chronic metastatic pain, worse at night..Prostate cancer - with mets; Lung nodule - on CXR, f/u with oncology (daughter to make apt) 7/05/11: Monthly Progress Note: Assessment of active medical problems: Started on hospice. Seen in the interim for cough and by urology. No Cough, no chills, no sweating , no vomiting, no diarrhea, no pain in extremities. Indicates some pain in lateral sides Plan of Care (by problem): On Hospice care Metastatic Prostatic CA HTN, tachycardia monitor Anxiety on alprazolam Constipation continue current laxatives. Resident on narcotics for pain. Currently moving his bowel GERD's decrease reflux anemia Hg 9.2. Monitor periodically Hyperlipidemia on simvastatin Insomnia on ambien as needed On hospice care/ comfort care. Monitor for pain Continue current meds Monitor for Constipation/diarrhea Prognosis: ____ poor 7/15/11: Interim Progress Note: ref by hospice nurse re: need for steroid use. D/W Dr.Al Hartmann (Hospice) - stated steroids are indicated for bony metastatic pain control and has had success with his other similar pts...states has had bm the other day, no n/v, appears anxious and in pain 7/20/11: Interim Progress Note: f/u pain. still sub-optimal pain control, no n/v/abd discomfort Chronic pain Prostate cancer with bone mets P: incr oxycontin 40 q8 --> 60 q8 cont prn dilaudid cont decadron incr xanax to 0.25mg tid 7/25/11: Interim Progress Note: ref for abn behaviour. standing in the corridor, insistent he needs to see his wife right away.
		4/25/11		HCP not named nor marked in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR), DNH, DNI	Care Plan: Advanced Directives: 3/16/11: SW: Resident admitted to TCC with a copy of living will incuding advanced directives options. This writer was able to reach resident's son Mr. Anthony González,today, who is the HCP and POWER OF ATTORNEY for resident;(since resident is unable to make healthcare decisions at this time). HCP wants DNR/DNI/AND NO TUBE-FEEDING DIRECTIVES TO CONTINUE. However, he wants antibiotics to be given. Unit physician has been made aware of this IDT to review advanced directives quarterly and as needed. 5/18/2011: SW: ADVANCED DIRECTIVES RE-VISITED WITH RESIDENT'S FAMILY. NO CHANGES MADE TO THE ADVANCED DIRECTIVES IN PLACE. RESIDENT HAS A HCP AND A POA. ALSO DIRECTIVES OF DNR/DNI/DNH/NO TUBE-FEEDING IN PLACE. 6/13/2011: SW: Advanced directives had been revisited with resident's family HCP/POA. No changes made at this time. Resident remains stable in Hospice care. She has advanced directives of DNR/DNI/DNH/NO TUB E-FEEDING IN PLACE. Advanced directives to be reviewed with resident's family HCP quarterly.	3/15/2011: Physician holding note: 3. Advanced Directives= Living will instructions entered into Sigma computer. Granddaughter asked to explain the No antibiotics instruction and it is noted that she will give written clarifications/rider/codice that antibiotics may be given -parenteral or orally if for routine infections. No antibiotics are to be given to "sustain life". DW granddaughter implications of parameters of end stage dementia a) unresolved fever and b) weight loss 4/15/2011: Medical Note:advanced directives discussed with daughter who requests that the resident be DNH, the resident has a terminal prognosis. 5/11/11: Physician Monthly Progress Note: Pt has remained non-verbal on each exam since place on Hospice. Son and granddaughter reproto she is weak but is able talk with them during their visits. Remains on thin, cachectic, with muscle wasting. Has had significant weight loss #20 lbs since admission in Mar 2011. Stage 3 on left buttock has not healed but worsened and she has developed Stage 3 on her sacrum despite poor oral intake. Breakdown in skin integrity is unavoidable due to he end stage dementia and poor oral intake Appears comfortable. Son and granddaughter report they feel she is comfortable and does not need stronger analgesic regimen at this point. Family is invoking her directions regarding advanced directives DNR/DNI no tube feedings. 5/24/11: Medical note: MD late note for visit on 5/1/11. the pt's HCP has requested that the pt be DNR/DNH/DNI due to terminal prognosis stemming from dementia with poor PO intake and living will stipulating no artificial nutrition. M.Taitt 7/21/11: "Medical note: spoke with daughter who feels b/c mom is moaning when she visits in the evening, wants the analgesia medication increased. Options explored and will increase patch first.No change in treatment at this time. -Terminal diagnosis due to dementia= Remains on Hospice. Goal is to keep her comfortable., and will increase analgesic regimen as noted above. Chronic Pain=increase fentanyl from 12 to 25 mcg/hour every 3 days as first option as per daughter's request.. Will add oral po for breakthrough when daughter feels it is needed.
		2/1/2011		HCP not named nor marked in SIGMA contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)	1/25/2011: Care Plan: Advanced Directives: Resident was placed on Hospice Care 2/1/11 as per wife's request. 2/2/11: Resident was placed on Hospice Care 2/1/11 as per wife's request.	2/10/2011: Interim Progress Note: "cont hospice care" 2/22/2011: Monthly Progress Note: "lived with family, wife involved with care...hospice care in place" 2/25/2011: Interim Progress Note: "will cont comfort care, hospice care; spent more than 20 min with wife on phone yesterday about the plan of care. "This resident on hospice care , seen today, yesterday, no new complaints from the hospice care giver by the bed side . This was reported to wife." 3/3/2011: Interim Progress Note: "cont hospice care" 3/30/2011: Interim Progress Note: "will cont hospice care for now, cont supportive care and make him comfortable" 4/7/2011: Interim Progress Note: PLAN - vomiting may be due Bp fluctuation and electrolytes imbalance, will monitor clinically . he is on pm chlorpromazine for hiccup; This case was d/w wife on telephone today." 4/16/2011: Monthly Progress Note: "cont hospice care..."cont hospice care / DNR/DNI" 5/25/2011: Interim Progress Note: He is on EOL , Hospice care...cont EOL/ hospice care" 6/13/2011: Monthly Progress Note: "ON hospice care; cont hospice care (Decline ADL, NPH) / DNR/DNI" 6/24/2011: RENAL/DIALYSIS: after discussion with patient's wife, and prior outside nephrologist, plan to send patient to NYU Tisch for admission and PC exchange. 6/28/2011: Readmission: "FAMILY/SOCIAL HISTORY: wife involved with care; ADVANCE DIRECTIVES; DNR, DNR, Hospice care" 7/25/2011: Interim Progress Note: "ON hospice care, cont hospice care (Decline ADL, NPH) / DNR/DNI"

		3/29/11	Resident has an advance directive of DO NOT RESUSCITATE (DNR) order.	<p>Care Plan: Advanced Directives: 3/29/2011: Advance directives education provided to family due to resident cognitive impairment. family wishes to have DNR and end-of-life care. 4/01/2011: There is no change in advance directives.4/14/2011: Resident's advance directives protocol reviewed, DNR, & end-of-life care is in place.7/07/2011:There are no changes in advance directives.</p>	<p>11/11/2010: Monthly Progress Note: Met with daughter to discuss advance directives, wants more time to think about it. 11/15/2010: Interim Progress Note: Likely 2o advancing dementia, daughter came in to discuss advance directives, would like some more time to think about it and discuss with her uncle who will be in town towards the end of the week. 11/18/2010: Medical Director Entry: Patient was attended by daughter Donna Jones. 11/19/2010: Interim Progress Note: Weight loss - add megace, continue supplements, dietary on board, on low fat, puree diet; advance directives were discussed earlier in the week with daughter Donna Jones, called again today to f/u, message left. 12/10/2010: Monthly Progress Note: Met with daughter to discuss advance directives, wants more time to think about it 12/28/2010: Interim Progress Note: Echymosis of unknown origin in 83 y/o female with advanced dementia, on EOL protocol, d/c asa, no treatment, monitor 1/6/2011: Monthly Progress Note: Met with daughter to discuss advance directives, pt is DNR, no tube feeding, no blood transfusion 2/02/2011: Monthly Progress Note: Met with daughter to discuss advance directives; pt is DNR, no tube feeding, no blood transfusion 3/02/2011: Monthly Progress Note: advance directives: pt is DNR, no tube feeding, no blood transfusion 4/26/2011: Monthly Progress Note: advance directives: pt is DNR, no tube feeding, no blood transfusion 5/23/2011: Monthly Progress Note: advance directives: pt is DNR, no tube feeding, no blood transfusion 6/23/2011: Monthly Progress Note: advance directives: pt is DNR, no tube feeding, no blood transfusion 7/21/2011: Monthly Progress Note: As per instructions in Advanced Directives- pt is DNR, no tube feeding, no blood transfusion</p>	
		12/17/10	5/3/11	HCP named and marked on SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)	<p>Care Plan: Advanced Directives: 2/11/2010: Resident's ID bracelet placed on ankle, because bracelet on wrist keeps coming loose, probably due to resident's chorea. Resident does not object to alternative ID placement at this time.3/16/2010: HCP and DNR remain implemented and charted per resident's wishes and on her behalf by her HCP. HCP and family are clear that resident wanted and wants no artificial hydration and nutrition.7/02/2010: SWer continues to provide family and HCP with education about AD options. HCP and DNR remain in effect and charted per resident's wishes and on her behalf by her HCP. HCP is in effect due to resident's severe cognitive impairment. 9/30/2010: Resident continues to have HCP charted per her wishes and DNR implemented on her behalf by HCP. Resident made her wishes known when she still had capacity regarding artificial hydration and nutrition to the HCP, and she does not want a feeding tube.12/17/2010: Resident's HCP implemented EOL protocol on resident's behalf on 12/15/10, including DNH, DNI, no dialysis, no blood transfusions or blood products, and no invasive diagnostic procedures. HCP agreed to hospice on 12/16/10, which was implemented today. 1/03/2011: EOL protocol continues to be in effect per HCP. Resident's family aware of and in agreement with same. Hospice services in place as well. 3/2/2011: Resident continues to have same AD's in place per her wishes and by HCP's implementation on her behalf (and per her wishes as stated to him). Hospice services continue, as does feeding per HCP directions with full understanding of risks of aspiration from same. Resident has been treated for pneumonia in the past quarter, but has also gained 13 pounds since means of feeding which resident prefers was resumed. SWer to continue to provide education and counseling to family and HCP as appropriate. 6/16/2011: IDT met yesterday for CCP on resident, and HCP was teleconferenced into meeting to review AD's and EOL protocol already in place and to discuss resident's condition at this time. HCP (Ed Sahagian) indicated that all AD's should remain implemented as before; SWer and MD updated paperwork to reflect same. Care Plan: Hospice care/Terminal illness: 5/1/2011: Resident will be free from any discomfort or pain within 90 days. 6/07/2011: Hospice care continues, no discomfort noted within 90 days.</p>	<p>12/16/2010: Interim Progress Note: at care planing meeting, the resident's healthcare proxy was advised that the resident is unable to meet her nutrition requirements due to high risk for aspiration on the diet that she prefers. The HCP has stated that he agrees with a hospice evaluation and several end of life protocol directives. he wants to discuss the matter with the resident's daughter (alternate HCP) before making a final decision on feeding the resident an unsafe diet. he does not want a feeding tube. 12/23/2010: Interim Progress Note: the resident's HCP was contacted today and he confirmed his that the resident be fed with meals mixed with ice in a cup. the resident is s/p recent URI thought to be caused by aspiration of feeds. The HCP has been advised of the dangers of feeding the resident with food which is not thick enough for her to manage safely. he has accepted the risk of pneumonia associated with mixing her food with ice. HCP has directed that the resident be fed in the manner that she wishes. continue PO feeds. 1/09/2011: Interim Progress Note: the resident was started on meals mixed with ice which was contraindicated by speech. the resident's HCP has authorized this type of feeding today, staff reports that the resident is eating well. no coughing or vomiting. resident now eating meals with ice with HCP. continue to monitor. 1/12/2011: Interim Progress Note: Advance directives in place for no tube feeding, DNR, EOL protocol. 1/13/2011: Interim Progress Note: Resident is on EOL protocol / Hospice care. Advance directives for DNR/DNI/DNH/no invasive diagnostic procedures or blood transfusions. 1/18/2011: Interim Progress Note: Resident with dysphagia 2o huntington disease, on EOL protocol, receives meals mixed with ice per primary MDS notes, family prefers that she be fed this way even tho it is likely to lead to aspiration, advance directives for no feeding tube. On hospice care. 1/19/2011: Medical Director Note: Patient has been reviewed for swallowing and assessed as risk for aspiration. Her HCP has agreed to accept the risk for aspiration in light of the fact that she is not a candidate for a gastrostomy tube and that she is able to manage to swallow feeding that is blended with an ice slurry. She has recovered from her recent infection and appears stable at this time. 2/07/2011: Interim Progress Note: HCP has authorized this diet for the resident's comfort. 2/08/2011: Monthly Progress Note: no weights due to end of life protocol.2/14/2011: Interim Progress Note: the resident is on end of life protocol. 3/09/2011: Monthly Progress Note: the resident is on end of life care and further w/u is not indicated 3/10/2011: Interim Progress Note: the resident is on hospice, continue hospice care 3/18/2011: Interim Progress Note: she has had 2 episodes of PNA thought to be caused by aspiration since then. HCP is aware of the risk and accepts it. WEIGHT GAIN: likely from increased PO intake with upgraded diet. continue present diet as per HCP wishes. 3/20/2011: Interim Progress Note: Resident is on EOL protocol, hospice care with advance directives for do not hospitalize, DNR, DNI, no tube feeding, no dialysis, no invasive diagnostic procedures, no blood transfusions. 5/08/2011: Monthly Progress Note: the resident is on end of life protocol and labs are not drawn. 7/20/2011: Interim Progress Note: hospice nurse reports that the resident is severely agitated. staff reports that her appetite has declined. no invasive procedures as per end of life protocol. HCP has agreed to lab draws if necessary. no report of vomiting or diarrhea.</p>
		(No EOL Care Plan on SIGMA)	Resident has DNR and DNH.	<p>Care Plan: Advanced Directives: 5/04/2010: DNR is active. 11/08/2010: Family continues to want a DNR order. 4/05/2011: Family does not want to change A.D. 5/16/2011: Advance directives is in place</p>	<p>1/13/2011: Interim Progress Note: ACP: DNR, DNH, End of Life. Family Communication: Nevarez, Victoria (wife) (212) 831-3776 2/17/2011: Monthly Progress Note: code status: dnr/dni/dnh 3/01/11: Interim Progress Note: On End of life protocol 3/17/2011: Monthly Progress Note: 4/14/11 Interim Progress Note: code status: DNR/D.N.I./D.N.H.4/28/11: Interim Progress Note: On EOL protocol 5/06/11, 6/27/11: Archcare Monthly Progress Note: Continues On End of life protocol. ACP: DNR, DNH, End of Life 5/10/11, 6/09/11: Monthly Progress Note: resolved on EOL protocol 6/03/2011: Interim Proges Note: Resident has colon CA and is EOL. Continue with current pain management. 7/11/11: Monthly Progress Note: Patient is on End of Life Protocol.</p>	

		4/11/11	HCP named and marked on SIGMA Contacts. Resident has Advance Directives of Health Care Proxy (HCP), Do Not Resuscitate (DNR), Do Not Intubate (DNR) and Do Not Hospitalize (DNH). Also EOL protocol per HCP.	<p>Care Plan: Advanced Directives: 3/23/2010: No changes in Advance Directives this quarter. HCP remains charted per resident's wishes. SWer to discuss DNR with HCP; resident is non-verbal and can not make his wishes known at this time. 3/25/2010: Spouse (HCP) implemented DNR on resident's behalf by verbal consent to MD yesterday. SWer and RN witnessed same. 7/02/2010: SWer continues to educate resident's family regarding AD options. HCP and DNR remain in effect per resident's wishes and on his behalf by HCP (spouse).</p> <p>9/30/2010: No changes in AD's for resident this quarter. Education to resident's family regarding AD options is on-going. 12/07/2010: Resident continues to have HCP implemented and charted per his wishes and DNR in effect on his behalf by HCP. SWer continues to provide education regarding long-term health care options to family as appropriate and necessary.</p> <p>4/08/2011: Resident's spouse implemented EOL protocol on resident's behalf at CCP on 4/6/11. Resident now has orders for DNI, DNH, Do Not Dialyze, No Blood Transfusions or Products, and No Invasive Procedures, in addition to previous HCP and DNR. Spouse also requested hospice eval for further comfort care if resident qualifies for same. 5/17/2011: Resident's primary HCP is too ill and elderly to perform HCP function any longer. Secondary HCP (spouse) should be contacted regarding all health care decisions on resident's behalf. 7/13/2011: No changes in AD's this quarter. SWer continues to provide resident's spouse (HCP) with education regarding AD options as appropriate. Care Plan: EOL/Hospice Care: 7/14/2011: continue to observe resident last wishes.</p>	<p>1/30/2011: Interim Progress Note: -pt is DNR 2/9/2011: Monthly Progress Note: the resident is not weighed due to end of life protocol. 2/24/2011: Interim Progress Note: the resident does not have capacity and was made DNR by his wife 2 years ago. today, she is clear that she wants him to be transferred to MSinai or to St Lukes in the event of an emergency. the resident is presently stable. staff reports that he is tolerating GT feeds without incident. 4/06/2011: Monthly Progress Note: the resident's wife has agreed at CCP for several end of life provisions including do not hospitalize, do not dialyze and do not transfuse. she has also agreed to a hospice eval. the resident has a relapse of a back rash along with left buttock induration. the resident is demented and unable to give a history.</p>	
		5/18/11	5/23/11	<p>HCP not named nor marked on SIGMA Contacts. Resident has an advance directive of DO NOT RESUSCITATE (DNR) order. RESIDENTS NIECE EDUCATED IN ADVANCE DIRECTIVES STATES THAT THIS RESIDENT BE DNR, DNH,DNI-RESIDENT DOES NOT HAVE CAPACITY</p>	<p>Care Plan: Advanced Directives: 4/08/2011: RESIDENT DOES NOT UNDERSTAND ADVANCE DIRECTIVES AS NIECE SPOKE TO HER IN HER PRIMARY LANGUAGE IN SPANISH SO THERE IS NO H C PROXY-NIECE IS THE SURROGATE STATES THAT SHE WANTS THIS RESIDENT AS A DNR,DNH/DNI AS HER ADVANCE DIRECTIVES -MA LMSW 4/8/11 NEXT UPDATE WITHIN 90 DAYS. 5/19/2011: WRITER REVIEWED ADVANCE DIRECTIVES OPTIONS TODAY DNR,DNH ,DNI, CALVARY HOSPICE REFERRAL,EOL PROTOCOL,RESIDENT NIECE INVOLVED AND IN AGREEMENT TO TX OBJECTIVES MA LMSW 5/18/11 NEXT UPDATE WITHIN 90 DAYS</p>	<p>4/8/2011: Physician Admission note: DNR/DNI - per niece, 7/7/2011: Monthly Progress Note: On Hospice care/ Failure to thrive</p>
		12/22/10		<p>Contacts: HCP named and marked as Health Care Proxy. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR); Resident has a Do Not Hospitalize order in place unless there is a fracture or hemorrhage.</p>	<p>Care Plan: Advanced Directives: 7/26/2010: Mr. Point's HCP and DNR remain on file in chart. HCP continues to agree to intent of DNR. 10/21/2010: Mr. Williams continues to be Mr. Point's HCP. Mr. Williams remains in agreement with DNR which remains in effect. Both HCP and DNR forms are filed in the chart. 11/29/2010: Mr. Williams returned from the hospital 12/26. SWr spoke to HCP today and reviewed advanced directive options. HCP and DNR remain in place. No further advanced directives are desired at this time. 12/09/2010: IDT members met with Mr. Williams who decided that PEG placement should not be attempted. Mr. Williams would like more time to think about withdrawal of hydration, medications, and putting hospice care in place. 12/15/2010: IDT members met with Mr. Williams to discuss continuing care. Mr. Williams continues to not want GT placement. He understands that IV hydration was discontinued. Mr. Williams would like Mr. Point transferred to the hospital in case of acute changes such running a temperature or sudden mental status change. 12/16/2010: During conversion 12/15 with Mr. Williams and Robert Middleton, LCSW, present, when asked if he wanted GT placement, Mr. Point clearly indicated that he did not want to have that procedure done. SW described the procedure to him and he understood what he was being told. Mr. Williams continues to direct staff to not have GT inserted due to knowing that Mr. Point does not want the procedure done. 12/21/2010: Calvary Hospice SWr, Mr. Williams, HCP and TCC SWr met to discuss hospice care. Mr. Williams decided to initiate hospice care and asked that the matter be discussed with Mr. Point. Mr. Point was brought into the room and he also agreed to hospice care. Mr. Williams signed forms to start hospice care. Hospice care will begin tomorrow, 12/22. DNR remains in place. The decision for no GT and no artificial hydration remain in place. Decision for DNH has not been made. 6/07/2011: Resident continues to lack capacity to implement advanced directives. Resident's health care proxy continues to be his friend Mr. Williams. Resident's do not resuscitate order remains in effect despite resident's health care proxy receiving education from social worker. Care Plan: Hospice Care: 3/10/2011: Social worker invited resident's health care proxy Julian Williams to the 3-15-11 care plan meeting to discuss the resident's declining appetite per Dr. Sternin's request. Mr. Williams stated he would attend and asked that dietian review menu with</p>	<p>12/08/2010: Interim Progress Note: MEETING WITH MR JULIAN WILLIAMS HCP/ SOCIAL WORKER ROBERT MIDDLETON REGARDING THE FACT THAT PATIENT IS NOT EATING, NOT TAKING IS MEDS FOR THE PAST 6-7 DAYS. PATIENT HAS BEEN ON D5 1/2 NS SINCE LAST FRIDAY. ISSUES DISCUSSED WITH HCP: CONSIDER DNH/ HOSPICE / PEG INSERTION / MR WILLIAMS WAS UNABLE TO MAKE A FINAL DECISION LAST NIGHT, HE WILL MEET WITH THE TEAM AGAIN ON FRIDAY. 12/10/2010: Interim Progress Note: ON 12/09 DR THOMAS RINALDI ,NURSE MANAGER LYDIA CUMMINGS, SOCIAL WORKER ROBERT MIDDLETON, AND HCP MR WILLIAMS MET A SECOND TIME FOR A FOLLOW UP REGARDING DECISIONS ABOUT PATIENT'S END OF LIFE ISSUES. THE HCP DECLINES PEG INSERTION, STILL REQUESTS DNR/DNI /IVF/ HOSPITALIZATION.</p> <p>12/14/2010: Interim Progress Note: HCP TO MEET W/ IDT TOMORROW TO FINALIZE DNH/HOSPICE CARE.</p> <p>12/15/2010: Progress Note: HISTORY OF PRESENT ILLNESS: MET THIS AFTERNOON AT 3:30 PM WITH MR WILLIAMS, IN THE PRESENCE OF DR ABEBE, R. MIDDLETON SOCIAL WORKER, NURSE MGR MS. CUMMINGS.. HIS WISHES REMAIN THE SAME : PATIENT TO BE HOSPITALIZED IN CASE OF ACUTE CHANGES, NO HOSPICE CARE. 4/4/2011: Progress Note: D/W SOCIAL WORKER ROB MIDDLETON TO CONTACT HCP TO ATTEND IDT MEETING TOMORROW .PATIENT IS DNR, ON HOSPICE . HCP AS WELL AS PATIENT HAD REFUSED PEG IN THE PAST. 4/20/2010: Monthly Progress Notes: IDT MET W/ HCP +PT, DECLINING PEG INSERTION SW/TO CONTACT HCP TO DISCUSS POSSIBILITY OF DNT TO HOSPITAL / SW ROB MIDDLETON EMAILED TO F/U WITH HCP.</p> <p>4/21/2011: Progress Note: Meeting with Mr Williams (health care proxy)- who expressed his wishes not to hospitalize, nor any GT feeding. 4/28/2011: Interim Progress Note: MD Note: A/P 59 YO W/ ADVANCED AIDS, POORLY EATING/ DRINKING, DNR/DNI /HOSPICE . CONTINUE SUPPORTIVE CARE. 5/20/2011: Progress Note: PATIENT W/ ADVANCED HIV DISEASE / DNR / DNI / FAILURE TO THRIVE/ POORLY EATING REQUIRING HOSPICE CARE. 6/15/2011: Interim Progress Note: 59 YO W/ HIV DISEASE / FAILURE TO THRIVE / POORLY EATING / DM / NEPHROLITHIASIS / CVA W/ LT HEMIPARESIS ON HOSPICE CARE , FOR F/U. 7/13/2011: Interim Progress Note: 59 YO W/ HIV DISEASE / FTT / POORLY EATING (REPORTED TO DRINK MOSTLY ENSURE) / DM / NEPHROLITHIASIS / CVA W/ LT HEMIPARESIS , ON HOSPICE CARE FOR F/U.</p>
		7/22/11 (Not marked as Hospice on SIGMA)		<p>HCP named, relationship to resident described, marked as "Power of Attorney" but not HCP in SIGMA Contacts. Resident has an advance directive of DO NOT RESUSCITATE (DNR) order. HCP-Steve Tellie</p>	<p>Care Plan: Advanced Directives: 7/08/2010: Advance Directives education given son still wants his mother to have DNR order. 3/15/2011: Son does not want any changes made to Advance Directives. 6/24/11: Patient remains DNR,DNI, HCP.</p>	<p>1/01/2011: Transfer Note: Advance directives: DNR. Attempted to contact son Steven Tellie, multiple phone numbers disconnected, cell phone turned off. 7/08/2011: Interim Progress Note: Asked by son (Steven Tellie, health proxy) to see patient for weight loss. A/P: After discussion with Mr. Tellie- he does not wish to add/alter appetite stimulants and would merely like to increase Ensure supplements available to his mother throughout the day. He does not wish to make her eat if she does not want to eat. T/C hospice if continued decline. 7/14/2011: Interim Progress Note: spoke with son, Steven Tellie to inform him of pt's status- all questions answered. 7/20/11: Interim Progress Note: A/P Dehydration/FTT - discussed plan of care with son, Steven Tellie. He agrees to Hospice consult. He would like to continue IVF for now. I explained this would not be the long term plan. He expressed understanding. Consult hospice. 7/22/11: Interim Progress Note: Seen by Hospice today. Discussed oliguria with son. Agrees to supportive measures only. Will d/c fluids and monitor. 7/25/11: Interim Progress Note: Patient enrolled in Hospice care. Still has poor intake. IVF stopped. Small amount of urine produced. She denies pain. No needs at this time. A/P FTT- patient persists in not eating; Hospice on board.</p>

		3/24/11	HCP named, relationship to resident described, marked as "Power of Attorney" but not HCP in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR) Resident's family (daughter-HCP), "has requested for end-of-life protocol over the week-end of 3/19/11). Resident now has DNH/DNI/ NO INVASIVE DIAGNOSTIC PROCEDURE/NO TUBE-FEEDING/ARTIFICIAL NUTRITION, INCLUDING DNR order IN EFFECT AS OF 3/18/11.	Care Plan: Advanced Directives: 3/18/2011: This writer spoke to resident's daughter on 3/17/11 regarding advanced directives options, and the need to discuss as a team. Ms. C. Sirriani HCP plans to meet with IDT on Tuesday 3/23/11 at 10:30 a.m. TO DISCUSS HER MOTHER'S CURRENT MEDICAL STATUS AND TREATMENT OPTIONS. Also HCP informed that she has consented for DNR; but "SHE DOES NOT WANT A FEEDING-TUBE" AS PER HER MOTHER'S WISHES. This writer communicated this to unit N.P. AND UNIT NURSE-MANAGER. 3/23/2011: RESIDENT'S DAUGHTER HAD VISITED RESIDENT OVER THE WEEK-END OF 3/19/11 DISCUSSED WITH UNIT N.P./PHYSICIAN "AND HAD REPORTEDLY DECIDED FOR ADVANCED DIRECTIVES OF DNH (EXCEPT FOR FRACTURE/HAMORRAGE; DNI; NO TUBE-FEEDING/ARTIFICIAL NUTRITION;NO INVASIVE DIAGNOSTIC PROCEDURES, INCLUDING DNR ORDER WHICH WAS PUT-IN PLACE AS OF 3/18/11 AS PER DAUGHTER'S REQUEST PER HER MOTHER (RESIDENT'S) WISHES. TO BE REVIEWED WITH FAMILY QUARTERLY. 3/23/2011: RESIDENT IS ON "END-OF-LIFE PROTOCOL AS OF 3/19/11" DNR IS IN EFFECT IN ADDITION TO OTHER ADVANCED DIRECTIVES MENTIONED EARLIER. 6/13/2011: Resident remains in end-of-life protocol at this time per family request. resident has DNR/DNI/DNH/NO TUBE-FEEDING/NO IV HYDRATION/NO IV ANTIBIOTICS/NO PO ANTIBIOTICS/NO BLOOD-TRANSFUSION/NO LAB TESTS EXCEPT INTR MONITORING/DO NOT WEIGH/AND NO INVASIVE DIAGNOSTIC PROCEDURES. ADVANCED DIRECTIVES WILL BE REVIEWED WITH RESIDENT/HCP QUARTERLY BY IDT. 6/13/2011: Advanced directives reviewed with Resident's family. End of life care is in place. No changes made except "family wants blood-transfusion when needed". Advanced directives will be reviewed quarterly by IDT	3/15/2011: Interim Progress Note: Called and spoke with daughter Christina Sirriani (HCP/POA) to inform her of mothers overall declining condition, spoke with social worker who will arrange team meeting with daughter to put advance directives in place. 3/17/2011: Interim Progress Note: called and discussed overall declining condition and advance directives with Daughter Christina Sirriani, she does not want tube feeding or hospitalization except for serious injury, she is in agreement with a DNR order. Paperwork was faxed to her, signed and faxed back. She plans to attend care plan meeting on tuesday. 3/18/11: Interim Progress Note: called and spoke with daughter Christina Sirriani, she is aware of condition and would like patient to remain at TCC. She will try to come visit her this weekend. Resident is DNR. Close monitoring. 3/19/2011: Interim Progress Note: Daughter Christina Sirriani and Son-in-law Fred present, they express their wishes for palliative care and no hospital transfer. EOL put in place, advance directives for DNR, DNI, DNH, no tube feeding, no dialysis, no invasive diagnostic procedures. They would like the IVF and IV rocephin to continue. Repeat CBC was drawn today. Meds reviewed, MVI, psych meds, and vit D d/c'd. Statin and ASA put on hold. Morphine 10mg rectal suppository Q4H PRN ordered. Tylenol Q4H for fever. Goal of palliative care. 3/20/11: Interim Progress Note: On EOL protocol, palliative care, do not hospitalize per family wishes. Family does want IVF and IV abx as needed. DNR/DNI, family aware of condition. 3/21/11: Interim Progress Note: On EOL protocol, family does not want hospitalization. Spoke this morning with daughter Christina Sirriani she is aware of condition, resident remains DNR, DNI, DNH, no invasive diagnostic procedures 3/22/11: Interim Progress Note: Remains DNR/DNI/DNH, daughter Christina Sirriani called this morning, given update on condition, she will not be attending care plan meeting today, will attempt to visit thursday 3/25/11: Interim Progress Note: Family wishes for comfort care and no hospitalization. Resident is DNR/DNI/DNH/ no tube feeding. 3/29/11: Monthly Progress Note: Was put on EOL protocol and advance directives for DNR/DNI/no feeding tube, no hospitalization, no dialysis, and no invasive diagnostic procedures were put in place per daughters wishes. 3/31/11: Interim Progress Note: If above neg, consider for abd CT scan, to be d/w daughter first, resident is on conservative care plan with advance directives for no invasive diagnostic procedures 4/1/11: Interim Progress Note: If above neg, consider for abd CT scan, to be d/w daughter first, resident is on conservative care plan with advance directives for no invasive diagnostic procedures. Will endorse to on-call coverage for the weekend to fu on labs. Remains DNR/DNI/DNH 4/08/11: Interim Progress Note: Spoke with daughter Christina Sirriani yesterday evening, she expressed her wishes to continue with conservative care plan and palliative care. She is considering stopping antibiotics given her mothers GMC and severe dementia, to be further discussed on monday after lab work available. Resident to remain DNR/DNI/DNH 4/11/11: Interim Progress Note: called and d/w daughter Christina Sirriani, she does not want any further antibiotics or w/u at this time, given mothers alzheimers dementia and GMC, she wants conservative, palliative care. Hospice referral was discussed, she will contact social worker to discuss financial concerns re: hospice. Goal of comfort care. 4/14/11: Interim Progress Note: Family has made their wishes clear re: no tube feedings and palliative care. Pt is receiving prostat and boost pudding supplements. Daughter and son-in-law were here today at bedside and plan of care was reviewed with her, resident is to remain on EOL protocol DNR/DNI/DNH/no tube feeding/no antibiotics/no invasive diagnostic procedures. They declined
		7/1/11	Contacts: HCP named and marked as Health Care Proxy. HCP's relationship to resident also indicated. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)	Care Plan: Advanced Directives: 5/28/2010: Advance directives is in place.	
		2/28/11	HCP named and relationship to patient described but not marked as HCP in Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and Do Not Resuscitate (DNR)	Care Plan: Advanced Directives: 2/11/2011: Resident returned from the hospital DNR remain active on file. 4/05/2011: Resident is receiving hospice care services. 6/28/2011: Resident is on End Of Life protocol. Resident continues to receive four hour HHA/companion through Calvary Hospice.	10/01/2010: Interim Note: Informed of resident who was unconscious yesterday for about 10 min. Afterward was supposed to be transferred to hospital but declined in the presence of HCP..Resident refused admission to hospital in the presence of HCP, who is supportive of his decision. Again I had an extensive discussion with HCP about the consequences of refusing hospitalisation for further evaluation which may include death. She understood and will not like to go against the wish of the resident. 10/02/2010: Interim Progress Note: Pt with esrd on dialysis with ever refused for hospital transfer seen as referred by floor MD no fevers reported but pt has chills and feels tired pts brother gavin at bedside explained the risks does not want hospital transfer , no chest pain or cough or sob. Resident currentl do not want to go to hospital ; staff endorsed if pt spikes fever will need complete blood work and blood cultures; family explained of above; 1/7/2011: Interim Progress Note: Advanced directive : HCP and DNR 1/14/2011: Physician History and Physical (Readmission): HCP; ADVANCE DIRECTIVES; DNR, 2/14/2011: Medical Director Entry: Called to see patient for refusal to take medication; tachycardia; and not being accepted into dialysis b/c of cardiovascular instability. I spoke to his friend and HCP Rosalee Farrington and to his brother Gavin via phone regarding his poor prognosis in general and possible imminent demise should the cardiac condition not improve with medication. I also tried to communicate directly with Mr. Todman and found him to be withdrawn and unable to answer other than to say "no" to his medication. When Rosalee tried she was wave off with a feeble dismissive gesture. He was asked by Ms. Farrington if "Are you trying to leave us?" He did not say "no" but when asked about going to the hospital he shook his head "no". After further discussion with Mr. Todman (brother) it was decided that he would not benefit from further hospitalization right now. The brother will try to come in tonight to see him. I gave Ms. Farrington my cell phone number for him to reach me with questions.On PE; patient is breathing shallowly at 20/min; P 130/min BP 152/116; JVD to mandibles Cor rapid reg Chest; no rales; abd soft; Assessment; Predialysis; cardiovascular instability; hypertension 2o to refusal of meds and fluid; appears approaching death from renal and cardiac failure ; Decision for comfort care now going into effect pending brother and friends re-confirmation; Plan: comfort care; prognosis grave 2/15/2011: Interim Progress Note: He has not been taking po well, but has categorically decline PEG. HCP and his bro could not persuade him; Explained to the resident and the HCP, as was in the past , taht refusal of available care carries grave prognosis . This is well understood by the HCP. 2/24/2011: Interim Progress Note: Resident has not been compliant with his meds and meals since readmission from hospital . Family conference was held recently and the consequences of his non compliance with meal advice were discussed including possibility of death . HCP verbalised understanding...Resident has not been taking meds and food regularly. He had refused GT feed. HCP is aware of this. 3/01/2011: Interim Progress Note: accepted to hospice care , started today. HCP involved in care. 3/03/2011: Interim Progress Note: cont hospice care . 3/07/2011: Interim Progress Note: Currently on Hospice care - Failure to thrive due poor oral intake; still refusing PEG . HCP is aware of this decision including possibility of demise; cont Hospice care. 3/09/2011: Interim Progress Note: Currently on hospice care.

		12/8/10	HCP not named nor marked in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP) and DNR, DNI, DNH.	<p>Care Plan: Advanced Directives: 11/29/2010: During CCP meeting today s/p hospitalization, resident's HCP implemented DNR, DNI and DNH on resident's behalf in consideration of resident's prognosis and wishes as stated to her. She also confirmed that resident does not want any artificial hydration and nutrition. 2/18/2011: Resident continues to have HCP, DNR, DNI and DNH implemented per his wishes and on his behalf by his HCP. SWer continues to provide education regarding AD options to resident's HCP as appropriate. 5/27/2011: No changes in AD's this quarter. SWer continues to provide spouse (HCP) with counseling and education regarding AD options as appropriate. Care Plan: Hospice Care: 4/25/2011: Continues to be kept comfortable and pain free. 6/17/2011: Resident continues to remain comfortable and pain free.</p>	<p>11/26/2010: Monthly Progress Note: ADVANCE DIRECTIVES; FULL CODE 11/27/2010: Interim Progress Note: medical director has convinced the resident's wife that the resident should be transferred to Mount Sinai for w/l of fever. 12/08/2010: Interim Progress Note: hospice has been requested as per his wife. no PEG as per wife. hospice requested. 12/10/2010: Interim Progress Note: Hospice care was requested by his wife accd. to a previous note. 1/10/2011: Interim Progress Note: the resident's wife is refusing a feeding tube. she now is agreeing to hospice care. ANOREXIA: persistent. the resident has been refusing puree diet. hospice has been requested. 1/10/2011: Monthly Progress Note: 59 y/o male with huntingtons disease, dysphagia, s/p hospitalization for aspiration PNA, refused GT per team notes, on hospice care. 2/28/2011: NEURO: on hospice care. MSIR added as advised by hospice nurse for comfort. continue present care. 3/10/2011: Monthly Progress Note: the resident is on hospice care and was recently started on roxanol RTC which has been effective. 4/11/2011: Monthly Progress Note: the resident's appetite has increased. his weight has been stable since last review. the resident is on hospice care. he has been more calm since roxanol was added. seen by psych this month. no changes in meds recommended. 5/11/2011: Monthly Progress Note: PFSH: 59 y/o male with huntingtons disease, dysphagia, s/p hospitalization for aspiration PNA, refused GT per team notes, on hospice care. 6/7/2011: Monthly Progress Note: 59 y/o male with huntingtons disease, dysphagia, s/p hospitalization for aspiration PNA, refused GT per team notes, on hospice care. 6/22/2011: Interim Progress Note: seen for CCP eval. staff reports that the resident is calm during routine care. wife reports that the resident tolerated an hour in the park and seemed to enjoy it. pain is controlled with roxanol RTC. his weight is stable over the past 30 days. the resident does not respond to questions. he is in no apparent distress. 7/9/2011: Monthly Progress Note: hospice reorts that the resident will likely be taken off of the program in 8/11 sue the stability of his conditition. his wife is in agreement with the plan.</p>
		1/15/10	HCP not named or marked in SIGMA Contacts. Resident has an Advance Directive of Health Care Proxy (HCP), Do Not Resuscitate (DNR) and DNI	<p>Care Plan: Advanced Directives: 9/20/2010: Family reeducated on Advance Directives they have requested to keep DNR but also added DNI. 3/24/2011: Family does not want to make any changes to the Advance Directives.Care Plan: Hospice Care: 5/31/2011: Resident remains on Hospice care secondary to advanced dementia and weight loss. Care coordinated with hospice and TCC staff as needed monitoring continues</p>	<p>7/14/2011: Physician Monthly Progress Note: Assessment of active medical problems: Pt seen for bloody drainage from left ear- treated for otitis externa. No other complaints or new issues. Denies pain, shortness of breath. Followed by Hospice</p> <p>PFSH: PMhx HTN Osteoporosis Alzheimer Dementia Glaucoma, on EOL protocol/Hospice for advanced dementia and progressive weight loss.</p>

EOL Care Portal	
PAIN MANAGEMENT	Advance Directives/MOLST
SW: 8/12, 7pm: Pt. complained of pain Dr.: 8/11, 5pm: Increased pain med.	
Medicine	Spiritual/Emotional
Recreation and Family Involvement	Individual Needs/Miscellaneous