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Suggestions for an Emotionally Centered Approach to End of Life Care at Terence Cardinal Cooke

In my ten weeks at Terence Cardinal Cooke I have grown to appreciate the supreme sense of care, compassion and dedication that goes into managing the overall health of people within the nursing home. In this immense facility that houses over 600 beds there is a huge variety in the people that come in and out of its doors. Some are short term patients in the sub-acute rehab units of the hospital and others are long term residents in units dedicated to Geriatrics, Huntington's Disease and patients with HIV. In some cases people come into TCC for short term care and later move into a different area of the building to stay in the facility until the time that they die. In these situations with long-term residents, TCC becomes the place where people spend their last months and days so that the kind of care given to these patients towards the end of their life becomes very important.

Currently there are several plans in place to address the needs of patients at TCC who are short on time to be alive in this world. These approaches include Hospice care, Palliative Care, and End of Life (EOL). While there are some distinctions in the methods of these different teams of care, there are many similarities amongst the goals of care in these various disciplines. I have seen that all are very concerned with easing the pain and hardships of death. I chose to work with the EOL protocol at TCC because it offered a very concrete action plan that includes many disciplines of the care team within the facility.

I. Possibilities for Altering the EOL Policy at TCC

At the thought of EOL care, many staff members within the facility automatically equate it with Hospice care. Hospice care has defined guidelines including government medical insurance and a terminal prognosis by at least two physicians with a less than six month life expectancy. EOL care concerns patients who are in an “active phase of decline and dying where their condition can no longer be treated or cured”¹. The examples that come to mind for most people in thinking when to put someone on EOL are very clear cut: when a person has stage IV cancer, severe late stage AIDS, or kidney failure and is no longer receiving hemodialysis to replace their kidney function. However the peculiarity of working in a nursing home with such a variety of patients is that many people defy the odds. Many residents have so many ailments and chronic diagnoses that their declining health is very slow, with intermittent periods of stabilization or even improvement.

An example of this difficulty in putting people onto EOL care is JJ. Ms. J is a 60 year old patient in the long term care unit of the Discrete unit which cares for patients with HIV. In addition to HIV she has a long list of medical conditions including heart disease, lung disease, osteoporosis, asthma and depression. According to her diagnoses she would be a prime candidate for End of Life care as her weak lungs make simple actions, like sitting up in bed to eat meals, very labor intensive. Yet because of her comprehensive support group of family and friends who meet at her bedside daily she looks to be in wonderful spirits and could continue living a satisfying life at TCC for years. JJ is a prime example of the many patients at TCC who have a multitude of

¹ Terminal Prognosis/End Of Life Care: Terence Cardinal Cooke Health Care Center Policy and Procedures

severe health concerns that could place their life expectancy at less than 6 months, but because their medical conditions have stabilized, they could be at TCC for years.

The Discrete unit faces particular challenges to putting people on EOL care. In talking to staff on the 6 Cohen unit, an area of the hospital for physical rehab of chronically ill patients with HIV, many patients come into TCC looking like they are “at death’s door”. This is mostly due to a lack of overall health for the patients including regular administration of HIV specific medication. Yet once a patient comes into TCC with a full staff of physicians, nurses, dietary, and therapy staff, a patient can make a miraculous recovery and be discharged into the community within weeks.

One difficulty in effectively executing EOL care is that it is inherently giving a different set of protocols for the care of certain patients that is not given to others. This sort of prioritization of care is not a foreign concept in the nursing home. Certain residents get additional nurse practitioners for skilled nursing care for a limited time when they are experiencing acute illnesses in the facility. This additional staff has its own limitations in terms of the insurance of the resident and how the hospital gets reimbursed for its services. Bringing up the comparison to skilled nursing care is only to show that without a surplus of funding, it is difficult for the staff members to give every patient the same amount of one on one attention.

Another possibility is that implementation of the EOL policy could be redundant in that many tools are already used to care for the individual needs of patients.

Government services from Medicaid and Medicare provide the Minimum Data Set (MDS) assessment tool that categorizes a list of medical issues a resident in the nursing home may be at risk for. These care plans can be very detailed, requiring one or more

actions from several members of the IDT. When each patient can have dozens of care plans with a multitude of goals and interventions necessary for each care plan, these detailed lists of things to do for each patient can compartmentalize and dehumanize the complex approach needed to care for the many residents of the facility. A practical and helpful EOL policy should be simple enough to easily address the needs of patients while also allowing for a more complete picture of the patient.

One of the biggest problems in trying to figure out an action plan for a patient is a lack of communication about the patient's current state. There can be huge complications in the means of transmitting information either verbally, hand written and recorded electronically. This communication can happen between the members of the care team or between the team and the patient. In many meetings of medical and nursing staff I have heard complaints that weigh the necessity of recorded information against the time taken away from care giving by continuous documentation. Even more difficulties arise when this information must be transmitted between the various members of the Inter-Disciplinary Team (IDT), including medicine, nursing, social services, psychology, pastoral care, dietary services, and recreation just to name a few.

The current EOL policy, revised in 2008, is a very detailed explanation of the steps that can be taken by various members of the IDT to address the needs of EOL patients. However one drawback to the policy is its segmented allocation of responsibilities so that many aspects of care are only assigned to one department instead of being the responsibility of the entire team. I believe certain aspects of care like assessments of interventions to improve quality of life should be priorities for all members of the IDT to give a greater sense of the holistic approach to EOL patients

During this summer I have seen that there are many platforms of communication between the gamut of people on the IDT. Yet one of the most effective areas of communication I have witnessed occurs during continuing care plan (CCP) meetings. In these meetings members of the IDT discuss the status of patients and go on to make suggestions about how to care for them. After sitting in on a few of these meetings I was able to see that an effective intervention to improve the care for EOL patients could easily be implemented in CCP meetings to avoid taking time away from the packed schedules of the team.

In my recommendation for a possible template to be used during EOL care² I sought many different sources to improve the efficacy of care plan meetings. The first was a survey³ asked to members of the IDT throughout different units in the hospital. Others include checklists to be used after a resident has expired at TCC to check if anything that was possible was done for the patient.^{4, 5} The current policy is also very general in that many descriptions can be applied to all patients. In condensing the checklist of issues to be discussed for EOL patients into a single page, only things directly pertaining to the highest priority needs can be easily seen and addressed.

While some people are addressed monthly, quarterly and annually, EOL patients should be addressed on their condition weekly since these are the patients who could foreseeably die within a short period of time. Understanding the need for individualized goals of care is a must for these patients. I have seen EOL care to be more of a mindset than a direct protocol of what should happen: a mindset of caring in which the small

² Template of Checklist to be Addressed During CCP meetings of EOL patients

³ Interdisciplinary Team Survey on End-of-Life Care

⁴ TCC EOL Interdisciplinary assessment tool

⁵ End-of-life-checklist

things, like making sure your resident has a constant supply of ice because it calms her down, become a priority.

II. Possibilities for Addressing Care at TCC

“What we do depends not upon rules, or at least not wholly on rules -not upon a prior determination of what is fair or equitable- but upon a constellation of conditions that is viewed through both the eye of the one-caring and the eyes of the cared-for. By and large, we do not say with any conviction that a person cares if that person acts routinely according to some fixed rule.” Nel Noddings, *Caring*, p13

I believe it is my visit to Calvary hospital that gave me a greatest sense of direction in terms of how I could make contributions to TCC to come close to repaying all the knowledge, experience and perspective TCC has given me over this summer. Calvary Hospital is an outstanding facility caring mostly for patients in the end of life due to cancer. Among people familiar with medical facilities in NYC, Calvary is known as “the place where people go to die” since very few patients rehabilitate enough to leave the hospital. As ominous as this description sounds, the dedication of every member of the staff, (nursing, medical, kitchen,housekeeping) to maintaining comfort for the residents and their families showed an admirable embodiment of palliative care in the end of life.

Upon the visit to Calvary hospital, one important thing I noticed was the smell of the place. There was no odor of harsh cleaning supplies or the faint smell of urine that I usually associate with hospitals, especially with very sick patients. For the entire day I

tried to pinpoint exactly what this smell was. Finally I realized it didn't smell like a hospital at all, but just clean and welcoming like home. Other than the smells there was also something else very distinct in the air at Calvary hospital. By the end of my summer at TCC I was finally able to identify this key component in the Calvary atmosphere was a pervading and noticeable sense of care.

Care in itself can be a challenge to describe, but much easier to identify from examples. One of the greatest senses of care I saw this summer came from the patient SL. He was 58 when I met him, yet the wasting of cachexia in his late stage of AIDS made it so that his skin clung to his concave face like wet cloth on a shallow bowl. It was this sight of a 78 lb. man on hospice care and dying of AIDS that was so disturbing to me that I could only visit him at most every other day. However, after a few days of visiting SL, I became familiar with the smiling modest woman who sat at his bedside every morning. I watched as his hospice aide spoon-fed him until he said "No more of that" when he was tired of eating although he never said a word when I would visit on my own. Even though SL was receiving complete assistance with every activity of daily living, his aide was able to identify his personal preferences after months of daily attention. This understanding of him as an individual allowed her to give him exactly what he wanted into his last hours alive.

About 3 weeks after SL died the facility held a memorial service for him. Five residents came down from their rooms to hear the Rabbi lead the service to remember SL by his personality and his humanity. Although none of SL's family was present at the memorial service his hospice aide closed the service with a heartfelt memory that would make any mother proud. She recalled that in his last moments she saw a tear roll down

SL's face and she responded by telling him "Now is no time for crying. You are a fighter and have fought so well for so long" and then he died about 30 minutes later. It is this knowledge of SL, this intimacy and care that his hospice nurse provided that allowed me to see just how much of a difference love and care can make in the last months of life.

Recreation, especially in the specialty unit, seems to have the greatest handle on the perspective it takes to care. For the staff that work with very medically vulnerable patients, cognitively and even visually impaired there is a parental desire for happiness that is hard to find anywhere else. These recreation therapists have the unique gift that allows them to be tuned in to the emotions of children completely immobile and nonverbal. By evaluating even the smallest responses of the children therapists can know whether Michael enjoyed the story just read based on how often he rolls in his chair or whether Alex is happy by how long she has her eyes open.

One of the strengths in the specialty unit is the very low turnover between staff, since most have chosen to stay there for over 10 years, some for over 20. This same sort of self-selected staff could be applied to EOL patients to have the skill-set needed to work in this type of environment: patience, nurturing, caring, listening skills. These certain qualities, while they should be present in all TCC patients, could be defining qualities in nurses and volunteers assigned to EOL patients.

An important aspect of EOL care could also be present in the volunteer program as I learned from my time spent with WW. In sitting with Mr. W, a 90 year old hospice patient, I found it difficult to assess whether my time spent with him was meaningful. WW was very far in his life to become affected by chronic kidney disease, dementia,

and issues with his vascular system that left his feet covered in large painful ulcers. Every time I saw him he was lying in bed with his eyes closed, fists balled and mouth puckered into a grimace. He hardly ever spoke due to the combination of his advanced dementia as well as his heavy dosage of pain medication to subdue the ulcers on his feet. I didn't know whether I should sit next to him changing the channel on the TV, or talk at him seemingly asleep.

In meeting with members from the volunteer and recreation department I learned that the challenges I faced while meeting non-verbal end of life patients were common to many other people unfamiliar with the unique challenges EOL patients face. One problem comes from the difficulty in "assigning" volunteers to patients as the compatibility in personality necessary to form a meaningful connection will most certainly not overlap with every volunteer and every patient. Another issue is that many of the college age volunteers may only be able to come to the hospital twice a week at most during the school year.

Knowing these difficulties in creating relationships with residents and the wide periods of time between volunteer visits I sought to create a template that could guide volunteers in their sessions with EOL patients.⁶ The role of specific volunteers assigned to EOL patients is integral. These volunteers could identify and address needs of EOL patients with a review compiled by the volunteer with additional input from the nursing staff where useful. This sheet could be contributed to CCP meetings as a way to represent EOL patients, their needs and the needs of their family at weekly meetings. It

⁶ Template of checklist to be filled out by EOL Volunteers

could also serve as a location for volunteers to reflect upon their thoughts about the meaning of their time spent with the patient.

Being at TCC I've learned a lot this summer. I've learned that it is very difficult to improve someone's health if you do not take care of them as people; people who have families, hobbies, beliefs, religion, and needs for autonomy and companionship. The many crucial members of the IDT have shown me the value of emotions in decision making. When anyone walks into a room and it feels sterile or lonely, those are not observations to be dismissed. In End of Life discussions there are times when it is important to hear facts, likely hoods and percentages of efficacy given a certain condition and other times when it's just good to sit and listen to music with a patient. I have learned that feelings really do matter in situations concerning quality of life and can be indispensable.

**FOOTNOTE 1: Terminal Prognosis/End Of Life Care: Terence Cardinal Cooke
Health Care Center Policy and Procedures**

TERENCE CARDINAL COOKE HEALTH CARE CENTER
POLICY AND PROCEDURES

TITLE: TERMINAL PROGNOSIS / END-OF-LIFE CARE

DATE REVISED: October 5, 2008

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POLICY NO.: 7. 2. 1. 26

DATE ISSUED: February 2002

DIVISION: MEDICAL SERVICES

SUBJECT: RESIDENT/PATIENT CARE

POLICY STATEMENT:

When it becomes clear that the resident is in a progressive state of decline where their condition can no longer be treated or cured and the physician documents a terminal prognosis, quality of life and pain management take precedence. To maximize the quality of life for the residents Terence Cardinal Cooke Health Care Center is dedicated to providing services that meet the needs of the residents and their families.

As the end of life (i.e. the active phase of decline and dying) approaches, the ultimate goal of care is to provide the dying resident with a “good death”. A good death may be thought of as: providing relief from distressing symptoms, addresses psychological and spiritual needs, provides a chance for patients and families to face the inevitable without additional fear or misinformation, and produces a sense of autonomy and reduced powerlessness in the face of death.

The tasks involved in providing optimal end-of-life care includes but not limited to: explicit recognition that an individual resident has a limited life expectancy with no reasonable expectation of a change in this prognosis, care planning that specifically includes end-of-life issues, implementation of the care plan with monitoring to ensure that the resident receives appropriate care, promotion or maintenance of the dignity of the resident.

Identification of the person authorized to make decisions:

In the case of a resident with capacity to make medical decisions, the orders for terminal prognosis /end-of-life care will be written after discussion with the resident.

In the case of a resident without capacity but who has a health care proxy (HCP) agent, the orders will be written after discussion with the resident’s HCP agent. A resident’s advance directives, whenever available, and applicable will be followed/used as a guide.

In the case of a resident without capacity and who does not have a HCP the orders will be written after discussion with resident’s designated representative/family. In this case the discussion will

center around a determination (“clear and convincing evidence”) of what the resident’s wishes were regarding his/her health care except for decision regarding artificial nutrition (can only be made by resident, HCP or legal guardian). A resident’s advance directives, whenever available, and applicable will be followed.

In the case of a resident without capacity and without family/designated representative or HCP and without advance directives the physician will notify the Ethics Committee. The Ethics committee will review the need for guardianship and notify Administration as applicable. (DNR orders may be written as per NYS law by the attending physician and a concurring physician)

In cases where the resident lacks capacity to make medical decisions the physician will make all efforts, if applicable, to communicate the healthcare decisions and plans with the resident. If the resident disagrees with the HCP agent or designated representative the physician will order a psychiatric evaluation for determination of capacity for each specific advance directive. If disagreement is not settled then the case will be referred to the ethics committee for review.

Determining Incapacity

As per the “Health Care Proxy Law: A Guidebook for Health Care Professionals”:

The HCP agent's decision-making authority begins when the patient's attending physician determines that the patient lacks capacity to decide about health care.

The capacity to make health care decisions is defined in the Proxy Law as "the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision."

The patient must be promptly informed orally and in writing of an incapacity determination, if the patient can understand this information. The agent must also be promptly informed.

If the patient objects to the determination, or to a decision by the agent, health care professionals cannot honor the agent's decision or override the patient's wishes without obtaining a court order.

After the initial determination that the patient lacks capacity, the attending physician must confirm that the patient still lacks capacity before honoring new decisions by the health care agent. The confirmation must be written in the patient's medical record.

Before an agent decides to withdraw or withhold life-sustaining treatment, a second physician must confirm the incapacity determination and make chart entry.

There are often difficult or challenging decisions to make when a resident is determined to have a terminal prognosis. The staff is encouraged to consult with the ethics committee whenever there is a need for assistance or guidance to ensure that the resident’s choices and advance directives, if known, are followed.

Care givers must:

1. Assess and treat both somatic and psychologically induced pain.

2. Attempt to decrease pain and symptom burden to the lowest degree possible.
3. Ensure that medications are as few as possible and given by the simplest route.
4. Explore both pharmaceutical and non-pharmaceutical interventions for pain and symptom relief.

Terminal Prognosis/End-of-Life Care orders and/or Advance Directives can be revised or revoked in whole or in part if the resident improves unexpectedly and a longer period of survival is anticipated. Revoking of Terminal Prognosis/End-of-Life Care orders will be done in consultation with resident and/or HCP agent/designated represented/family. A progress note documenting the rationale for revocation of the orders will be written by a medical staff member and the Interdisciplinary team.

<u>RESPONSIBILITY</u>	<u>PROCEDURE</u>	<u>FORMS</u>
Interdisciplinary Team Members (IDT) /Admissions	1. Screen PRI documents & Acute care teams for possible EOL status 2. Notifies Attending Physician	P.R.I. Hospital Data
Medicine	3. Assesses resident/patient and documents terminal prognosis. 4. Determines capacity to make medical decisions or refers to psychiatrist as needed. 5. Psychiatrist (if consulted) may advise on end-of-life psychiatric needs. 6. Discusses/reviews terminal prognosis and Advance Directives including treatment plan/options (waiving weights, labs, invasive diagnostic tests etc.) with resident and/or Health Care Proxy (HCP) agent/designated representative. Once determined writes orders for each Advance Directive. 7. Conducts and documents clinical assessment of pain and symptoms. 8. Writes order for “terminal prognosis/end-of-life care.	History & Physical /Monthly Rewrites / Progress Note Physician Orders
Medicine	9. Reviews orders to determine if medication burden (including all prior medications) can be decreased. 10.Orders appropriate therapeutic interventions to ensure optimum comfort level. 11.Participates in the initial care plan meeting for end-of-life care. 12.Monitors resident/patient as necessary for improvement or decline and possible need for further treatments. 13.Consults with sub-specialists when pain or symptom relief is inadequate.	MD Orders
Nursing	14.Completes pain assessment form on admission, readmission, quarterly, annually and with significant change assessment. 15.Assesses pain daily and documents on pain flow	Pain Assessment Form Pain Flow Sheet

<u>RESPONSIBILITY</u>	<u>PROCEDURE</u>	<u>FORMS</u>
	<p>sheet as per policy.</p> <p>16.Documents initial order for each Advance Directive and terminal prognosis /end-of-life care on 24 hr report and on protocol.</p> <p>17.Assesses the resident/patient weekly, documents findings in a progress note and revises care plan as needed.</p> <p>18.Notifies Chaplain when resident is close to death.</p>	<p>24-hour Report Terminal Prognosis/End-of-Life Protocol</p> <p>Progress Note</p>
Social Service	<p>19.Schedules a Care Conference meeting with the Interdisciplinary Team and resident and/or HCP/designated representative/family.</p> <p>20.Performs a psychosocial assessment of resident/patient and family situation related to end-of – life needs.</p> <p>21.Ensures appropriated Advance Directive forms are completed and treatment plan choices are documented in the care plan and “Terminal Prognosis/ End-of-Life Care Protocol”.</p> <p>22.Provides and documents counseling and emotional support to resident/patient and family as needed.</p> <p>23.Weekly 1:1 visits to provide support, assess resident and documents findings in progress note as well as revise care plan as needed.</p> <p>24.With permission from Administration, unlimited visitation will be granted to the family. SW to make arrangements for overnight stays as needed.</p>	<p>Psychosocial Assessment / Progress Note DNR/HCP/ Terminal Prognosis/ End-of-Life Care Protocol.</p>
Psychology	<p>25.Provides comprehensive psychological and mental status assessment if necessary.</p> <p>26.Provides and documents counseling and emotional support to resident/patient and family as needed.</p> <p>27.Recommends treatment for psychiatric symptoms and advises regarding use of psychotropic medications.</p>	<p>Consultation Request Form</p>
Pastoral Care	<p>28.Conducts and documents spiritual assessment and provides counseling and emotional support to resident/patient and families.</p> <p>29.Participates in bereavement process.</p> <p>30.Confers with volunteer department as to services provided by volunteers.</p>	<p>Progress Notes</p>
Dietary Services	<p>31.Assesses resident/patient’s nutrition and hydration status.</p> <p>32.Provides for resident/patient’s food preferences and individualizes plan based on assessment of resident/patients level of tolerance and clinical symptoms (i.e. meal size, supplements, pleasure feeding).</p>	<p>Nutritional Assessment / Progress Note</p>

<u>RESPONSIBILITY</u>	<u>PROCEDURE</u>	<u>FORMS</u>
Recreation	33.Assesses for possible recreation therapy based on resident/patient preference and tolerance. 34.Make arrangements for personal pets to visit.	Progress Note
Rehabilitation Services	35.Assess for modification of restorative treatment plan as applicable. 36.As needed assesses for positioning devices. 37.Provides therapy to improve comfort or decrease symptoms as per MD order and based on rehab evaluations.	Evaluation / Screen
Volunteer Dept	38.Provide support (Doula) as indicated.	
Interdisciplinary Team	39.Meets with resident and/or HCP agent/designated representative/family initially after terminal prognosis is established and monthly and/or episodically thereafter. 40.Develops individualized care plan to address all end-of-life care, reviews plan monthly and /or episodically to ensure quality of life and quality of care needs are met. 41.If resident is placed on hospice the IDT will review and ensure the hospice plan is integrated with the IDT'S plan for the resident and meet with hospice staff at least monthly.	Comprehensive Care Plan

FOOTNOTE 2: Template of Checklist to be Addressed During CCP meetings of EOL patients

Patient Name: _____ Room: _____ Date: _____

Advanced Directives

Current orders under the resident's MOLST form (bright pink sheets located within the resident's chart)

		Comments
DNR:	Yes___ No___	_____
Living Will:	Yes___ No___	_____
HC Proxy:	Yes___ No___	If yes, who is HCP: _____

Medicine

- Current assessment of patient pain/ pain management,
- Primary Symptoms/symptom Management,
- Communication with the patient/family about condition and treatment
- Assess possible need for hospice

Nursing

- Response to current patient needs/symptoms
- Monitoring of new patient needs/symptoms

Social Services

- Discussion with patient/family about
 - Advanced directives
 - Social service entitlements
 - Burial arrangements
 - Possible discharge

Any assessments or intervention resulting in better comfort

Spiritual

- Discussion of spiritual beliefs with patient/family

Psychological

- Assessment/counseling for patient and or family

Dietary

- Assessment or change to a more palatable diet

Rehabilitation

- Any interventions resulting in better comfort

Recreation

- Any interventions resulting in better comfort ex. sensory stimulation: aromatic (aroma therapy), auditory (music) , tactile (hand massages)

FOOTNOTE 3: Interdisciplinary Team Survey on End-of-Life Care

This series of questions was asked to various members of the Interdisciplinary Team that participates in Comprehensive Care- Plan (CCP) Meetings during a resident's stay at Terence Cardinal Cooke. The participating interviewees represent staff members that primarily work on the discrete and geriatric units of the facility. Some members of the team chose not to answer certain questions because they could not answer the question (ex. Constraint of time for the interview, not have sufficient experience with patients in End-of-Life care..). Questions asked in parenthesis are taken from an earlier version of the interview questionnaire.

- 1) What characteristics have you seen make for a good “effective” care plan meeting? What characteristics have you seen make for a bad “ineffective” care plan meeting?**
- 2) Do you believe the policy holds an accurate description of your team’s responsibilities in EOL care? What, if any, changes would you make to the current description? Add anything, take out anything, make anything more specific...?**
- 3) What information is important for you to know about EOL patients specifically that comes from members of the IDT? (e.g. Medicine, Nursing, Social Services, Dietary, Recreation...)**
- 4) Do you believe volunteers have a role in EOL Care? If so how?**
- 5) Are there any needs for EOL patients that you have seen not being addressed?**

1) What characteristics have you seen make for a good “effective” care plan meeting? What characteristics have you seen make for a bad “ineffective” care plan meeting?

Pastoral Care 1

- When the whole team able to attend, which is rarely because of the small staff in pastoral care

Nursing 1

- IDT a great approach
- Sitting w/ family, patients, providers to create a group dynamic for problem solving helps residents feel “people have my back”
- Ineffective- letting patient or HCP get lost in their own thoughts so that a clear goal is not achieved

Nursing 2

- A good sense of whether the patient is improving or declining
- A sense of team effort
- Concrete goals and efficient use of time
- Knowing resident well helps contribute to effectiveness of goals
- Presence of many members of the team: MD, SW, psychologist, resident assessors to document and code for reimbursements
- Room to individualize care of patient to the extent of the patients capabilities.
- Ability to document good quality of life and review discharge possibilities

Hospice Nurse-

- Can't go because of demands from the patients which leads to a lack of feedback in whether actions of the aide is beneficial. Ex if a patient is on a new medication that changes output/color of urine but helps pain management it would be useful for hospice aid to know

Medicine 1

- Having everyone there, calling everyday or sending emails is time consuming
- Schedule meetings with patients and family to talk about trajectory of illness and use of hospitalization
- Prioritizing meetings for social/psychological refusal or drug abuse
- No real need for discussion of EOL patients in CCP meetings because those patients have a specific care plan already in place

Medicine 2

- multidisciplinary
- loose sketch of an agenda
- open mind and flexibility in goals ex. Covering the goals of the IDT but also allowing goals of the family to be addressed

SW 2

- Effective when family members attend
- Conference calls would be useful, sometimes NP or MD will call on their blackberry

Recreation 2

- Discussing what the situation is first before bringing in the resident
- Everybody acting as a whole, as team all people coming with different opinion, but working towards the same goals of care

Dietary

- family members present to represent needs of patient
- doctors present
- bad when family not notified

2) Do you believe the policy holds an accurate description of your team's responsibilities in EOL care? What, if any, changes would you make to the current description? Add anything, take out anything, make anything more specific...?

Pastoral Care 1

- Conduct unit based memorial service when required as grief counseling

Past Care 2

- Is there need for direct pastoral care interventions
- Do they have visitors

Nursing 1

- add- address family concerns and make appropriate referrals to CCP members
- communicate and coordinate IDT sessions as needed.
- Assess the resident/patient weekly/**daily** documents findings in a **weekly** progress note and revises care plan as needed.

Nursing 2

- Pain assessment different for nonverbal patients, and very difficult

- Add positioning regularly
- Hospice Aide
- No description for hospice/CNA
 - Have CNA more involved when hospice not there to communicate number of BM, urine...
 - Only way of gaining information is verbally asking nurse who can “brush off” aides for asking too many questions
- Medicine 2
- Medicine to be supportive towards patient goals in any way the patient needs. Ex. Social, clinical
 - The EOL list is very abstract in an effort to apply to everyone
- SW 1
- Ensures appropriate Advance Directive forms are completed and treatment plan choices are documented in the care plan and “terminal Prognosis/ End-of-life Care Protocol” can be done by administration of nights and weekends
 - Add- assess for possible discharge
- SW 2
- perform psychosocial assessment- should be amended to only upon admission and later only as needed
- Recreation 1
- Make environment relaxing, tailored towards individual
 - Contribute towards ambiance of room, colors, music
 - Look for interventions to increase comfort
 - Communicate w/ other subspecialties to stimulate senses- horticulture, art therapy
 - Not personal pets specifically as I’ve never seen it in the recreation department due to questionable health of animal or allergies within the hospital
- Recreation 2
- Add sensory stimulation: aromatic (aroma therapy), auditory (music) , tactile (hand massages)
 - 1:1 visits with residents, meditation, horticulture
- Dietary
- No changes, just give the patient whatever they like/can handle with less concern for long term balance of diet

3) What information is important for you to know about EOL patients specifically that comes from members of the IDT? (e.g. Medicine, Nursing, Social Services, Dietary, Recreation, Volunteers...)

- Pastoral Care 1
- “Are there visits from family,
 - Pastoral care visits EOL patients a minimum of 2/week

- Medicine- AD's
- SW- funeral plans and respective money for arrangements
- Most information on Sigma for medical needs

Pastoral care 2

- Latest info from morning report
- most coming from on the unit and nursing staff

Nursing 1-

- Medicine- be very clear on meaning and consequences of procedures on MOLST form
- SW- burial arrangements, financial allocation of resident's property
- Dietary- proper caloric need, no skin sores, constant sips to avoid dry mouth
- Recreation-sitting with re, watching TV, playing bingo, other activities to occupy resident and personalize every interaction

Nursing 2

- Wishes of the patients- ex, some left alone, some like being with others. Some prefer visits from priest/rabbi

Hospice Aide

- From SW- who are family members when visiting, what information to give to whom
- From Nursing- Medications prescribed to patient

Medicine 1

- Not much information required from others since most people ask doctor for information
- MD has most authority in prognosis
- Less pertinent information can be sent through email

Medicine 2

- From everyone- new symptoms, declining symptoms and the extent of care
- SW- life outside of community and family history
- Nursing- details of the day reported to the physician

SW 2

- Increase communication to social work of when hospitalizations occur
- Increase communication with family members. Not enough to have MD/RN try once and then document family not able to be contacted

(What would you like to see contributed by other members of the IDT?)

SW1

- Increase communication with hospice
- Everyone looking earlier to add residents to hospice
- More effective CCP meetings
- Doctors present at CCP
- Facility- add a unit for EOL patients specifically with special staffing and separate funding similar to Calvary hospital

Recreation 2

- Most things on sigma ex. Diagnosis, diet. But can ask doctor/nurse for specific things
- Much of the information about the patient can be gathered from individual research
- Necessary to be able to report observations to staff ex. A resident who has trouble reading the newspaper could have vision loss

- Important to have relationship with patient and to “know” them

(What would you like to see contributed by other members of the IDT?)

Recreation 1

- Dietary- stop weighing resident
- Offer whatever food the patient wants
- Hospice aide – maintain contact during the day
- Social Work-funding for funeral arrangements
- Volunteers- increase presence
- Medicine/nursing-pain management

4) Do you believe volunteers have a role in EOL Care? If so how?

Pastoral Care1

- yes, especially residents who are non-verbal
- many people give up on a person if they are non-responsive and keep going
- It is important to train volunteers w/ EOL patients

Pastoral Care 2

- yes, in every aspect of EOL care
- not every volunteer good for every patient

Nursing 1

- Absolutely, sitting with patients for minutes, hours
- Volunteers can observe small changes that others don't have time for ex. See relaxation in body, facial expression for non verbal patients
- volunteers help patients know they are not dying alone
- can observe and help in feeding for residents w/o aspiration issues

Nursing 2

- Yes, to sit with resident
- Volunteers specific to EOL care must have lots of patience. And the ability to approach with an open welcoming attitude. You have to care even when they[the patients] don't
- Not so much help in feeding because it requires time to get to know the patient, their habits.

Hospice Aide

- Yes, reading, talking , listening to patients who are alert enough to talk/reminisce

Medicine 1

- Yes, volunteers can call family, discuss w/ doctor and family the illness of the patient
- Volunteers could help explain terminal prognosis to patient

Medicine 2

- Yes, comfort, engaging patients, feeding, recreation

SW2

- HIPPA an issue in having volunteers at CCP meetings

Recreation 1

- volunteers can shape 1:1 relationship
- Even dementia patients remember certain things after forming a connection
- Volunteers could read newspaper during meals

Dietary

- Not necessary for volunteers to be involved, but would be nice

- They could record their observations of resident likes in absence of resident ant meeting
- Note any changes in condition

5) Are there any needs for EOL patients that you have seen not being addressed?

Past. Care 1

- proper burial – TCC as institution should take care of people until the very end, Not just death but into the ground
- Environment fixed up, even silk flowers for beauty

Medicine 1

- EOL very good once patient is in hospice and palliative care program
- Only issue is preventing patients from going to the hospital

SW2

- Funeral arrangements and saving money for after death.

Recreation 2

- Good because of Calvary aids that come in. Just having 1 extra person helps a lot for needs of the patient

Hospice Aide

- Everyone is already trying their best to deal with this difficult situation
- Some well trained volunteers that could help with feeding.

Nursing 2

- Every day make sure not to neglect patients
- Treat with same respect even when and when not EOL
- Someone by their bedside to make them feel not alone.

(What needs have you seen arise for patients who are nearing death?)

Recreation 1

- 1:1 comfort b/c facility very taxed
- Pull all resources b/w volunteers, interns, hospice to increase patient happiness, perception of illness, improvement
- Loneliness in residents

(What needs have you seen arise for patients who are nearing death?)

SW 1

- None for hospice patients
- Family usually has more needs not being addressed
- Not a lot of financial planning or being realistic with expectations during death
- A need for in depth consequences of procedures
- Always consider hospice as an option from admission

FOOTNOTE 4: TCC EOL Interdisciplinary Assessment Tool

TERENCE CARDINAL COOKE HEALTH CARE CENTER

End of Life Care Interdisciplinary Assessment Tool

Resident's Name: _____ Unit: _____ MR#: _____ Date: _____
Discipline: _____ Date of Death: _____

Please indicate your response based on the following numerical scale. Note that the response of N/A will indicate that services were not applicable, not available or not answerable due to lack of information.

0 – Poor 1 – Fair 2 – Good 3 – Very Good 4 – Excellent

Statement

Response

1. If the patient experienced pain, management of the pain was: _____
2. If the patient experienced other symptoms, control of them was: _____
3. Medical communication with the family of the patient's condition and treatment options was: _____
4. Nursing response to the patient's needs and symptoms was: _____
5. Timeliness of receiving medications, especially for pain, was: _____
6. Nursing monitoring for new symptoms and needs was: _____
7. Discussions with the patient and/or family regarding advance directives were: _____
8. Discussions with patient and/or family regarding social service entitlements were: _____
9. Family counseling services were: _____
10. Discussions of spiritual belief issues with patient and/or family were: _____
11. Bereavement and spiritual support services for the family were: _____
12. Any psychiatric and/or psychological assessments or counseling for patient and/or family were: _____
13. Dietary assessment and any change to a more palatable diet regimen were: _____
14. Any rehabilitation assessments and interventions resulting in better comfort were: _____
15. Any recreation assessments or interventions resulting in better comfort were: _____
16. Considering the responses to the above statements, your overall assessment of the quality of the patient's end of life care is: _____

FOOTNOTE 5: End-of-life checklist

END-OF-LIFE CHECKLIST

Patient Name: _____ MRN: _____ Pl. ID: _____
Identified as EOL: Yes _____ No _____

Advance Directives:

DNR: Yes _____ No _____
Living Will: Yes _____ No _____
HC Proxy: Yes _____ No _____

Assessments:

Comments

Pain : Yes _____ No _____

Rx: _____

Symptoms: Yes: _____ No: _____

Dx/Rx: _____

Psychological: Yes: _____ No: _____

Social: Yes: _____ No: _____

Spiritual: Yes: _____ No: _____

Family Counseling: Yes: _____ No: _____

Bereavement: Yes: _____ No: _____

Rehabilitation: Yes: _____ No: _____

Dietary: Yes: _____ No: _____

Consultants: Yes: _____ No: _____

Outcome

Death at TCC: _____ Death at hospital: _____ Home hospice: _____

FOOTNOTE 6: Template of checklist to be filled out by EOL Volunteers

Patient Name: _____ Room: _____ Date _____

Name of current CNA: _____

Name of current RN: _____

What health concerns/symptoms are being experienced by the patient? How are they being addressed?

Is the patient experiencing pain? If so, how is it being managed?

Primary concerns of patient/CNA during this session (social, spiritual...)

Observations of patient and surroundings during this meeting (affect, mood, appearance, grimacing, hygiene...)

Volunteer assessment of the session, and patient's condition

Future plans and goals for patient (visitation from family, scheduled recreation activities...)

ADDITIONAL RESOURCE: S.O.A.P. Progress Note Checklist

S.O.A.P. Progress Note Checklist

	Check if Addressed
S Subjective <i>Client statement capturing the theme of the session</i>	
1. Subjective data about the client—what are the client's observations, thoughts, direct quotes? <i>N</i>	
2. Does the client's direct quote summarize the theme of the session?	
O Objective <i>Objective, often observable data or information supporting the subjective statement</i>	
3. Objective data about the client—what does the counselor observe during the session (affect, mood, appearance)?	
4. Does objective data or information match the theme expressed in the subjective statement?	
A Assessment <i>Counselor's assessment of the situation, the session, and the client's condition or prognosis Client's response to intervention and progress made in achieving treatment goals / objectives</i>	
5. What is the counselor's understanding about the problem?	
6. What are the counselors' working hypotheses?	
7. What was the general content and process of the session?	
8. Was homework reviewed (e.g., journal, reading assignments – if any)?	<i>N/A</i>
9. What goals, objectives, interventions were addressed this session?	
10. What is the client's current response to the treatment plan?	
P Plan <i>Document what is going to happen next</i>	
11. What in the treatment plan needs revision?	
12. What is the counselor going to do next?	
13. When is the next session date?	
General Checklist	
14. Does this note connect to the client's individualized treatment plan?	
15. Are client strengths/limitations in achieving goals noted and considered?	
16. Is this note dated, signed, and legible?	
17. Is the client name and identifier included on each page?	
18. Has referral information been documented?	
19. Does note reflect changes in client status (e.g., GAF Scale, measures of functioning)?	
20. Are any abbreviations used standardized and consistent?	
21. Would someone not familiar with this case be able to read this note and understand exactly what has occurred in treatment?	
22. Are any non-routine calls, missed sessions, or professional consultations regarding this case documented?	
22. Did counselor/supervisor sign note?	