Canadian Hospice Palliative Care Nursing Competencies Case Examples

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Competencies Case Examples

INTRODUCTION

Many avenues of study are needed to prepare for and successfully write the Canadian Nurses Association (CNA) Hospice Palliative Care Nursing Certification Exam.

This dedicated group of certified hospice palliative care (HPC) nurses felt that having some practice case examples could be yet one more avenue to assist fellow HPC nurses to picture, apply and study for their HPC certification exam.

The case examples represent some situations that HPC nurses may encounter on a daily basis in practice and are designed to encourage thinking and studying around issues from a variety of the competency perspectives.

The cases are designed to complement the full program of study for a nurse who plans to write the HPC nursing certification exam. **All documents and references on the CNA HPC Certification Prep Exam Guide and Competency Bibliography are expected to be used when preparing to study for and write the exam.**

Each case illustrates some of the competencies within a particular competency category. However, some competencies, particularly around interprofessional practice and education, are illustrated in several of the cases as well as being the focus of a particular case. All the competencies form the basis of the CNA Hospice Palliative Care Nursing Certification Exam.

The 2009 HPC Nursing Competency Categories include:

1. **Care of the Person and Family**
2. **Pain Assessment and Management**
3. **Symptom Assessment and Management**
4. **Last Days/Hours/Imminent Death Care**
5. **Loss, Grief and Bereavement Support**
6. **Interprofessional/Collaborative Practice**
7. **Education**
8. **Ethics and Legal Issues**
9. **Professional Development Advocacy**

CITATION

The authors welcome the use of these cases in hospice palliative care nursing study in all care settings.

The recommended citation is:
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HPC Nursing Competency Category 1

Care of the Person and Family

HPC Nursing Competency Category 1 - Care of the Person and Family

INTRODUCTION

Competency 1 focuses on the many aspects to the care of the person and family faced with a life limiting illness. Effective communication skills are at the heart of developing a therapeutic relationship, assessing, and providing holistic care to the person and family.

Some basic principles of effective communication during each person and family encounter are helpful to guide discussions and decision-making. The HPC nurse should:

- Establish the right setting which includes privacy and removal of physical barriers (e.g. TV).
- Elicit what the person understands using active listening and open ended questions.
- Draw out what the person expects to obtain a clear understanding of person's goals.
- Discuss and provide information in keeping with the person's preferences regarding information. (Clinicians are ethically and legally obliged to provide the person with as much information as they desire about their illness and treatment - this allows them to understand and participate in the decision-making process. Informed consent requires that they be fully informed in order to understand the risk and benefits of interventions. Having accurate information allows them to prepare for the future.)
- Respond to emotions. Naming and acknowledging emotions helps the person and family know that the HPC nurse is striving to understand the situation and the unique experience.
- Identify the person's coping strategies. How the person dealt with difficult situations in the past helps to identify other sources of support and allows for all parties to be reaching for the same goals of care.
- Establish a plan that includes family conferences.
- Be prepared to deal with any conflicts that may arise among person, family and health care providers.
- Summarize the encounter and document ongoing discussions.
- Be flexible (This helps the person avoid feelings of abandonment and indicates that you will be there in the future for them).

The following five-step approach may also be useful in facilitating effective communication particularly around decision-making:

- **R**elate - Establish a therapeutic relationship and elicit concerns, ideas, feelings and expectations.
- **R**eview - Discuss the extent of diagnosis and hopes for future as described by person and family
- **R**eframe - Discuss the need to hope for the best (cure and care) while being prepared that the main focus may have to be care - when cure is not obtainable.
- **R**evise - If hope expectations change - discuss realistic hope in the face of worsening prognosis - share control of decisions
- **R**eflect - What are your own responses and reactions to discussing these issues with terminally ill persons and their families?

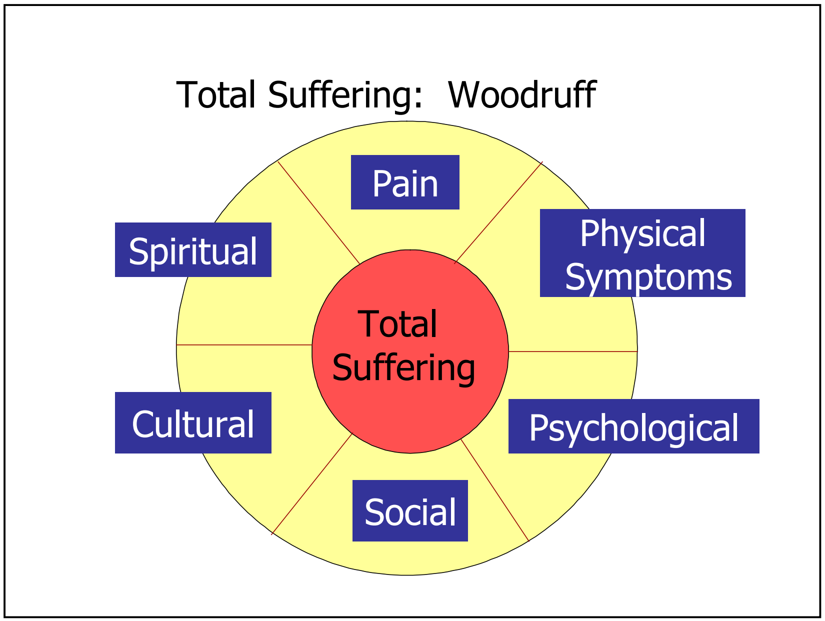
Effective communication around the many issues that relate to terminal illness will assist the HPC nurse to decrease the persons' and families' distress and total pain and suffering.

CASE

Mrs. Cook is a 50 year old Aboriginal women diagnosed with end-stage AIDS. She is admitted to a private room in an AIDS Hospice for pain management and meets with Cindy, the HPC nurse.

Cindy sits at Mrs. Cook's bedside and introduces herself. She asks Mrs. Cook to tell her a bit about herself and what brought her to the hospice. Mrs. Cook shares with Cindy that she was born on a First Nations Reserve, was sent from the reserve to attend residential school at the age of 5, and returned back to the reserve at age 16. Soon after her return she became pregnant, got married and had two children. The marriage ended shortly after the second child was born because of the abusive (physical and verbal) nature of her husband which added to her low self-concept and self-esteem. Mrs. Cook left the reserve when she was 20, and her children (then 4 and 2 years old) were left in the care of her parents with the plan to send for her children once she was settled in the city. According to Mrs. Cook this plan never happened because shortly after arriving in the city she felt so vulnerable, scared, and alone with no sense of control. Mrs. Cook felt this lead her into a self-destructive coping lifestyle of prostitution and drugs and to her diagnosis of HIV/AIDS 6 years ago. She feels this diagnosis is punishment for the mistakes she has made in her life. Mrs. Cook has deep regrets about many of the choices she has made and the lost opportunities with her children, now grown with children of their own. She has not had contact with her family for many years and they are not aware of her diagnosis. She has managed to stay off the streets and has been sober and drug-free for 4 years due to the additional support she was given following her diagnosis. She has come to the hospice now for management of poorly controlled pain due to a large fungating malignant pressure ulcer that consumes her entire coccyx area. It has several open areas with some bleeding and extensive tunneling. Daily wound dressing changes take over an hour to complete. Mrs. Cook tells Cindy she doesn't know what she should be doing and would just like for it all to be over and for all of the pain to go away.

During this encounter Cindy uses gentle presence, reflective listening and empathy to encourage Mrs. Cook to tell her story. Cindy acknowledges the many losses that Mrs. Cook has experienced in her life-time as well at the losses she is facing with her illness. Mrs. Cook's suffering is palpable as she relates the story of her life. Cindy notes that the many issues that contribute to this suffering fit well with the Total Suffering Model:



(Source: Woodruff, R. (2004). Palliative Medicine, Oxford University Press)

Cindy reflects back to Mrs. Cook how many of the life experiences she has described are impacting on her current situation and experience with illness. Cindy empathizes with Mrs. Cook's current vulnerability, uncertainty, and hopelessness for the future. Over the next few days Cindy continues to meet with Mrs. Cook and deepens their therapeutic relationship. Cindy conducts further assessments and begins to develop a care plan using the components of the Total Suffering Model as a guide.

Pain and Physical Symptoms:

Mrs. Cook's main reason for coming to the hospice is her physical pain; therefore Cindy begins with a comprehensive pain assessment. Mrs. Cook identifies her primary physical suffering as the pain from the coccyx wound which prevents her from eating, sleeping, and doing anything she enjoys. Cindy works with the team to maximize pain control through regular assessments, continuous pain medications administration as well as obtaining orders for breakthrough doses and giving additional medications prior to dressing changes and movement. Cindy also makes a referral to the wound care nurse who visits regularly and suggests appropriate dressings to contain the odor, drainage and protect the surrounding skin.

Psychological:

Cindy asks Mrs. Cook to tell her more about her feelings about what is happening to her. Mrs. Cook admits she feels both depressed and anxious related to the disconnect from her family, fear of her impending death, what she perceives as a shameful diagnosis and the significant changes in her body image. Cindy commends Mrs. Cook for the strength of character she must possess in order for her to have survived life on the streets and to now be free of alcohol and drugs. She further explores the various recent healthy coping strategies Mrs. Cook has used and how they may also help her cope with what she is experiencing now. Cindy makes referrals to social work and psychology to help Mrs. Cook explore further the meaning of her diagnosis, prognosis, and body image changes.

Cultural, Spiritual, and Social:

Cindy realizes that Mrs. Cook's cultural, spiritual and social sufferings are intertwined. She asks Mrs. Cook about her connection to her First Nations' values, beliefs and traditions. Mrs. Cook relates some of her experiences at the residential school and how that had disconnected her from her cultural roots. She has tried over the last few years to learn more about her culture and still always felt too ashamed to really reach out to her First Nations Community. She feels that she has burned many bridges with people throughout her life and does not believe they would be willing to forgive all that she has done. She tells Cindy that she believes it is now too late and she will never get to enter the spirit world. Cindy asks Mrs. Cook if she could have one wish right now what that would be. Mrs. Cook reveals that her greatest wish would be to reconnect with her family and go home to the reserve to die within the circle of care of her community. She believes this will help her to heal some hurts, find inner healing, and enter the spirit world. Cindy explores these beliefs further with Mrs. Cook. Cindy then finishes her session for the day with Mrs. Cook. Before her work day ends, with previously received permission from Mrs. Cook, Cindy begins by making a connection with the community health nurse from the reserve where Mrs. Cook was born.

A few days later Cindy meets again with Mrs. Cook and uses some of the 5R's (Relate, Review, Reframe, Revise, Reflect) to assist Mrs. Cook to make some further decisions and develop a care plan.

- **R**elate **–** Cindy has successfully established a therapeutic relationship with Mrs. Cook.

- **R**eview **–** Cindy reviews with Mrs. Cook her diagnosis and prognosis (which is likely a couple of months). She highlights Mrs. Cooks hopes to reconnect with her family and First Nations Community. Cindy tells Mrs. Cook that she was able to speak with the community health nurse and with her help was able to connect with both of her children who are still living on the reserve. The children were wary at first and finally admit they secretly hoped they would hear from their mother some day. They would like their children to get to know their grandmother. Cindy relays all of this to Mrs. Cook who is overwhelmed.

- **R**eframe **–** Cindy discusses with Mrs. Cook the feasibility of going home to the reserve while also noting that her present care needs are quite high due to the large wound on her coccyx. Cindy works with Mrs. Cook to plan the things that she could do right now to reconnect with her family and community in case she is not able to actually be transferred to the reserve for her care. Cindy assists Mrs. Cook to speak further with the community health nurse who connects her with her children by telephone to initiate this step. The community health nurse also connects Mrs. Cook with an elder and medicine man from the reserve.

Over the next week Mrs. Cook speaks several times with her children and an elder. With Cindy's and the hospice team's assistance and participation they hold a healing circle at the hospice with Mrs. Cook's family, a few elders, and other community members. The healing circle is very powerful for all of them.

Cindy subsequently spends a great deal of time with Mrs. Cook and her children discussing her illness, prognosis, current treatments, and eventual death. The children believe that it is their responsibility to care for their mother, however are concerned about what this will entail. Cindy spends further time exploring these concerns with them. She also shares the booklet: "First Nations - Caring for the Terminally Ill: Honoring the Choices of the People (available at: http://www.chpca.net/interest_groups/aboriginal_issues_ig.html). She encourages them to read the booklet and talk further with their own families and community about what supports might be available for Mrs. Cook and for themselves. She advises them that providing care to a dying person, though often considered a stressful and exhausting experience, can also be a very meaningful and rewarding one. With the supports and team in place for Mrs. Cook at the hospice her pain and physical symptoms are well managed, she has made great progress in forgiving herself for mistakes in her life, and forgiving other people for the things that were done to her. She has actually improved to the point where she may have a bit longer to live than initially thought.

- **R**evise **–** Cindy relays the new prognostic information to Mrs. Cook and her children. She commends their support of each other in making this improvement happen. Together they decide that Mrs. Cook will go to the reserve, and can return to the hospice if her care becomes too burdensome for her family. Cindy arranges for the transfer and advises the family that although she will not be formally involved in their care unless they return to the hospice, she will keep in touch with them through the community health nurse. Mrs. Cook is transferred back to the reserve with the help of the reserve elders, community, family, and health care team who come together to rally round to set in motion her final healing journey.

Mrs. Cook dies peacefully four months later on the reserve with her children, extended family and community by her side.

- **R**eflect **-** Cindy looks back upon the rewarding experience of caring for Mrs. Cook, coming to understand better Mrs. Cook's cultural values, beliefs and traditions and feeling that she and the hospice plus community and reserve teams were able to help Mrs. Cook and her family have her final wishes respected and fulfilled.

HPC Nursing Competency Category 2

Pain Assessment and Management

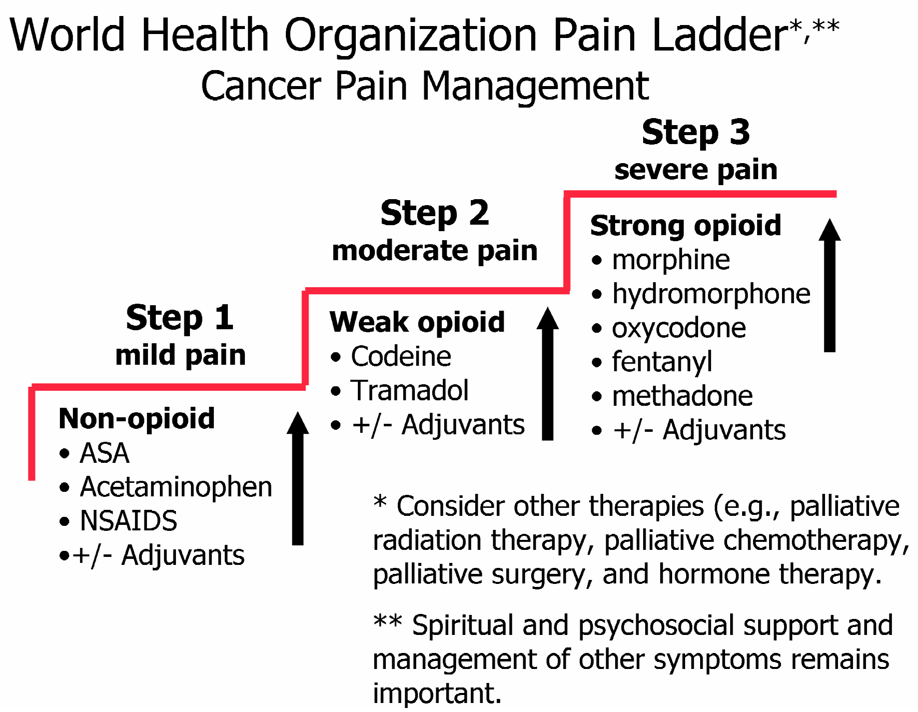
HPC Nursing Competency Category 2 - Pain Assessment and Management

INTRODUCTION

Competency Category 2 focuses on palliative pain assessment and management. The HPC nurse caring for a person who is experiencing physical pain must possess the knowledge and skill to conduct a comprehensive pain assessment (using evidence-based tools), understand the physiology of pain (transduction, transmission, modulation and perception), be able to identify and classify the types of pain (acute, chronic, malignant, non-malignant, neuropathic, nociceptive, somatic, visceral), while also demonstrating knowledge of special considerations with varying populations in various settings.

Pain has physical, psychological, emotional, social and spiritual components with suffering and issues around dying also affecting the meaning of pain. This accounts for the term "total pain" or "total suffering" model. The HPC nurse has an essential leading role to play in ensuring that total pain is regularly assessed and managed effectively.

Management of physical and total pain is based on comprehensive assessment. The HPC nurse must be familiar with the principles of pain management and be aware of the World Health Organization (WHO) Analgesic Ladder. The ladder is a 3-step model to guide analgesic choice depending on the severity of the person's pain.



* Consider other therapies (e.g., palliative radiation therapy, palliative chemotherapy, palliative surgery, and hormone therapy.

** Spiritual and psychosocial support and management of other symptoms remains important.

(Source: Pallium Palliative Pocketbook 2008 p.5-11)

The WHO Ladder

The WHO analgesic ladder is intended to be a guideline in structuring the use of analgesia in the pharmacological management of pain, and is not intended to be a rigid framework. The WHO approach to pain control may need to be combined with other treatment modalities.

The HPC nurse must evaluate the type and intensity of the pain, and then match the drug to the pain intensity and other characteristics.

The use of analgesia should start at the step of the analgesic ladder appropriate for the severity of pain. It is not necessary to initiate therapy at Step 1 if the person is experiencing moderate to severe pain as persons with severe pain usually need therapy initiated at Step 3.

The use of the ladder can be reversed in situations of acute pain, starting at Step 3 and moving to Step 1 analgesics as or if relief and/or recovery occurs.

The non-opioid analgesics that characterize Step 1 (Mild Pain) of the WHO ladder all have a ceiling effect to their analgesia and start with moderate to maximal doses to achieve optimal efficacy quickly. The Step 1 analgesics have the greatest risk of severe adverse effects so anticipating and monitoring of them is to be done carefully by the HPC nurse in conjunction with the physician and team.

Step 2 and 3 (Moderate to Severe Pain) opioid analgesics usually reach their peak effect and plasma concentration approximately 60 to 90 minutes after oral or rectal administration, 30 minutes after subcutaneous injection, and 6 minutes after intravenous injection.

The general rules to administer pain medications are:

- By the ladder (WHO Ladder)
- By the mouth (The oral route is effective and preferred.)
- By the clock (palliative persons often experience continuous pain or pain that recurs frequently. A regular analgesic regime that prevents pain is required.)
- Breakthrough orders
- Taking into account each unique individual and their total pain and suffering

Other important management principles include recognizing and responding to incident and breakthrough pain, barriers to pain management, alternative routes of administration, side effects, opioid toxicity, rotation and conversion of opioids, use of both pharmacological and non-pharmacological interventions, adjuvant medications, monitoring and documenting pain treatment effectiveness regularly and keeping the person, family and interdisciplinary team involved in the ongoing care plan.

CASE

Jayne is a nurse who works on a palliative care unit (PCU). Her assignment is to admit Mr. Smith a 75 year old man with end-stage Non-Small Cell Lung Cancer (diagnosed two years ago). Mr. Smith was initially seen by the outpatient palliative symptom management team at the Cancer Center for mild pain and was started on regular Acetaminophen which is an effective WHO step 1 analgesic for mild to moderate pain. He eventually developed more moderate pain and was started on WHO Step 2 regular Codeine 15 mg orally every four hours with a breakthrough dose of 15mg every hour if needed. This regime was working well with no need of breakthrough doses until the weekend when he developed a new acute pain which required an increase of his oral Codeine to 30 mg (with an hourly breakthrough of 15 mg) for 24 hours and then 45 mg q4h (a breakthrough dose of 30 mg). Mr. Smith took six breakthrough doses of 15 mg. in the first 24 hours and then 3 breakthroughs of 30 mg which was still not helping. He knew he had reached the limit of Codeine he could use and was fearful of switching to a stronger medication such as Morphine and of also having to take needles. His wife took him to the local Emergency Department (ED) as his pain was getting worse and he was now nauseated and unable to take the Codeine by mouth. After a series of tests, assessments and recommendations with Mr. Smith's refusal to take a new stronger opioid medication by needle (major fears for him) he asked the ED physician and nurse if they could please contact the palliative care symptom team to help him. This was done and Mr. Smith was transferred to the PCU for further symptom assessment and management.

Comprehensive Assessment of Pain

Because of Mr. Smith's acute severe pain situation, Jayne completes a stat plus ongoing comprehensive pain assessment on Mr. Smith by screening for his pain, ascertaining a full history, completing a physical examination and reviewing diagnostic investigations while throughout the process incorporating her pain and whole person assessment skills. She also identifies and documents Mr. Smith's present poor prognostic factors for pain control. She will work with the physician and the interprofessional team to develop an ongoing comprehensive care plan, which includes pain management that is consistent with Mr. and Mrs. Smith's goals of care.

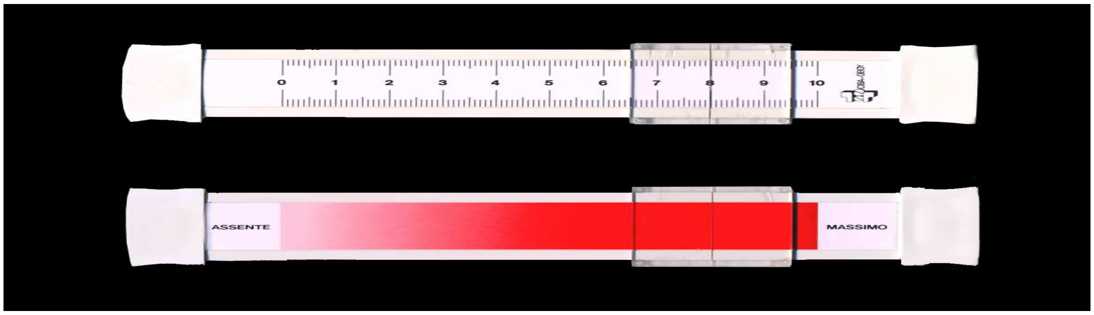
Screening:

Mr. Smith tells Jayne that he came to the ED because he developed severe back pain which was very different from the other pain he had been experiencing. He feels the new pain is not controlled on the present increased oral Codeine medication and is becoming worse. Jayne documents this in the chart, the kardex and notes that Mr. Smith's pain will continue to be screened as his condition changes and/or when his goals of care change. Her documentation will serve as a measure of ongoing pain assessment and treatment responses and guide the plan for further pain treatments and interventions.

History:

- A Mini Mental State Examination (MMSE) was conducted on Mr. Smith to ascertain his ability to cognitively give a good pain and other history. He scores 30/30 and therefore is deemed cognitively intact to give a thorough pain history.
- Mr. Smith tells Jayne that immediately after his diagnosis he received several cycles of chemotherapy and a course of radiotherapy to his lungs with the aim for cure. He was then informed 6 months ago that his cancer had returned. Two months after that he was told that tests indicated that he now had bone metastases and he received 5 palliative radiotherapy treatments which helped. He was then told that no more radiation or chemotherapy treatments could be offered. He has been using Codeine 15 mg by mouth every four hours with 15 mg by mouth every one hour for breakthrough as needed to manage his pain. This regimen worked well until the last few days when his oral Codeine had to be increased to 30mg one day and then 45 mg orally mg every four hours the next day and he was taking up to six oral 15m breakthroughs over one 24 hour period and then three 30mg breakthroughs in the next 24 hours with no relief. He only trusted taking the Codeine and was refusing to take any different pain medication or to have it by another route besides orally.
- Jayne notes that Mr. Smith has been suffering with a chronic malignant generalized pain. Yesterday he went to the ED because he had begun experiencing a different acute pain to his back.
- Mr. Smith quit smoking two months ago and his wife tells Jayne that he is still battling a lifelong addiction to alcohol.
- Mr. Smith took an early retirement because of his cancer diagnosis. He loved his work, so this was a huge financial and emotional loss for him. He has been married for 54 years and has a supportive wife but is estranged from his only son. Mrs. Smith feels that her husband has been depressed since his diagnosis and lately he has been telling her that he is fearful of dying in pain like his brother. His brother died of lung cancer several years ago with very poor pain and symptom management.
- Initial goals of care have been discussed and documented with Mr. and Mrs. Smith. They have requested a do not attempt resuscitation order and a strictly palliative/comfort care focus. They are informed that their wishes will be respected and that goals will be reviewed with them by the team on a regular basis.

As part of her overall history taking and assessment Jayne uses a standard pain Numeric Rating Scale (NRS) (0-10) assessment tool:



Jayne states "I need to know how much pain you have in order to help you with your pain control. It is you who knows, feels, and can explain your pain the best and I would like you to use this scale to let me understand how much pain you have right now. The numbers between 0 and 10 represent **all** the pain a person could have. 0 means no pain and 10 means pain as bad as it could be. Please use **any** number between 0 and 10 to let me know how much pain you have right now." Mr. Smith rates his new pain as 10 out of 10. He rated his previous pain when controlled by the Codeine as 2 out of 10.

Jayne goes on to ask Mr. Smith about his worst and best levels of pain, when those occur as well as the location, duration, radiation of pain, and aggravating and relieving factors. Mr. Smith describes the present pain as continuous even when he is still. When he moves, severe pain shoots shock-like waves across his torso. For the past two days he has had difficulty walking and spent most of his time in bed. He has also had difficulty eating, does little to no drinking and has trouble voiding. Jayne determines that he has sensory deficits and muscle weakness in his right leg.

Jane asks Mr. and Mrs. Smith if they have any fears about analgesics and hears from them they are indeed wary of needles and some pain medications as Mr. Smith says "especially that Morphine because that will make me throw up, knock me out, and kill me faster like it did to my brother."

Jayne also uses the CAGE alcohol assessment tool as part of her initial multidimensional assessment. The term "CAGE" is an acronym derived from these questions:
1) Have you ever felt you should cut down on your drinking? (**C**ut down)
2) Have people annoyed you by criticizing your drinking? (**A**nnoyed)
3) Have you ever felt bad or guilty about your drinking? (**G**uilty)
4) Have you ever had a drink first thing in the morning or (**E**ye-opener) to get rid of a hangover?
You score 1 point for each yes response. Two or more yes responses indicate a positive CAGE, i.e. "probable diagnosis of alcoholism."

Mr. Smith's CAGE score is 3 out of 4 and Jayne is aware that since Mr. Smith has not been able to drink any alcohol since this acute pain episode began he is a candidate to experience alcohol withdrawal and possible problems with anxiety and cognition. Jayne keeps in mind that this will influence the ongoing pain assessment and management if Mr. Smith is unable to do an accurate description and self-report of his pain. In that case Jayne and the team will revert to pain assessment for the cognitively impaired and consider use of an adult faces scale, surveillance of facial expression changes of varying degrees, plus team and/or family observation for increasing agitation, moaning, behavioral changes or pain on movement (incident pain). Jayne also keeps in mind that with Mr. Smith's history of substance abuse that he may also need higher analgesic doses to control his pain.

Physical Assessment:

A general examination is done and Jayne assesses Mr. Smith as being in an acute pain crisis in addition to the chronic pain he has been experiencing. He is in bed, distressed, agitated, and unable to settle in one position. She documents his appearance as pale, cachexic and dehydrated. He has not voided in over 24 hours and is uncomfortable so he allows Jayne to insert a foley catheter and it is noted that his urine is concentrated. Mr. Smith's eyes have a yellowish hue and on one level he perceives his disease, symptoms and pain as a punishment for his smoking and drinking all these years. Jayne assesses Mr. Smith's Palliative Performance Scale (PPS) functional score as 40%.

Diagnostic Investigations:

Jayne and the PCU physician review the investigations done on Mr. Smith. A recent CT scan revealed metastases to bones, liver and adrenals with a suspicious lesion in the brain. A stat MRI confirmed a tumor compressing the mid-thoracic level of the spine. Recent blood work reveals a high creatinine level, low albumin and rising calcium level. Jayne is cognizant that even though Mr. Smith initially scored 30/30 on his MMSE he will need ongoing MMSE assessment as he may begin to have some difficulty concentrating due to his disease process and alcohol withdrawal.

Poor prognostic factors identified for pain control of Mr. Smith:
Jayne discusses Mr. Smith's pain control issues with the team. The following risk factors for poor pain control are identified:

- a neuropathic pain component
- a bone pain component
- high risk of delirium because he is dehydrated, jaundiced, has a high creatinine level and rising calcium level, and likely to go into alcohol withdrawal
- PPS 40%
- history of smoking and alcohol abuse
- presence of incident pain
- no longer a candidate for chemotherapy, radiation and/or surgery
- psychological / spiritual / emotional distress: history of depression, anxiety and fear of analgesics, dying in pain, regrets about his lifestyle and strained relationship with his son

Jayne assesses and documents that Mr. Smith has both an acute pain crisis and a chronic persistent malignant pain syndrome plus elements of total pain and suffering. There is a neuropathic component to his pain and he also has incident pain. His pain is affecting his activities of daily living to eat, drink, walk and move while also making him feel more depressed, guilty for his lifetime of smoking and drinking, anxious about his final days, and concerned that time is running out to reconnect with his son.

Management of Mr. Smith's Pain

Plans for management of Mr. Smith's pain will continue to be guided by the WHO Analgesic Ladder. Jayne reviews the route guidelines when starting to give pain medications:

- Preferred route is oral
- When unable to swallow options are: subcutaneous (SC), intravenous (IV), or trandsdermal (TD)
- In special situations sub lingual (SL) may be used for breakthrough pain or incident pain and intraspinal (epidural or intrathecal) may be an option.
- Do NOT use intramuscular (IM)

Mr. Smith came from the ED on escalating doses of Codeine by mouth and it was now not controlling his acute or chronic pain. Since he is presently unable to take oral medications the option is to switch him to intermittent SC doses every four hours **OR** a continuous infusion IV or SC of opioid through a Patient Controlled Analgesia (PCA) pump. A one hourly breakthrough dose will be ordered as needed by the same route as his scheduled doses as well as medication to treat incident pain.

Jayne explores with Mr. and Mrs. Smith their fears and misapprehensions about opioids and routes. She explains that:

- ➢ opioids are started to relieve physical pain and when given in the right doses are very safe and are not initiated to shorten a life.
- ➢ when first started, opioids may cause some drowsiness and/or nausea but this usually resolves within a few days.
- ➢ since he is not able to take medications by mouth he will need to have his medication by needle.

Jayne and the team agree that the best practice is to use short-acting opioid formulations for opioid-naïve patients and those in pain crises such as Mr. Smith. Jayne reviews an equianalgesic conversion opioids table with the PCU physician as he writes and she transcribes plus double checks the opioid orders. Jayne takes into account that conversion ratios are base-line guidelines and considerable variation has been known to be found between individuals. Therefore Jayne and the team will use the conversion information as one part of their thorough clinical assessment in opioid dosing decision making. Along with useful guidelines Jayne, the physician and team will be doing ongoing close monitoring and documentation until Mr. Smith's pain is stable as he is switched from one opioid to another and one route to another.

Equianalgesic Doses:

Drug	**PO Dose**	**SC/IV Dose**
Morphine	10 mg	5 mg
Codeine	100 mg	50- 65 mg

Common conversion ratio is 2:1 for oral to parenteral, but in some persons the ratio may be 3:1
(Source: Adapted from Victoria Hospice Medical Care of the Dying, 2006, Page 195)

Because Mr. Smith has been on regular and breakthrough Codeine and is now in acute pain crisis he will be started on a Step 3 strong opioid for severe pain. Jayne has helped alleviate most of his fear of needles and taking Morphine so Morphine is the opioid that is first chosen. Since Mr. Smith is not presently able to eat or drink or take oral medication, Morphine will be given SC.

The PCU physician and Jayne begin by calculating the total amount of Codeine Mr. Smith has taken in the last 24 hour period: Codeine 45mg q4h (6 doses/24h x 45mg = 270mg) plus 3 breakthrough doses of 30 mg po q1h prn (3 doses x 30mg =90mg) for a total of **Codeine 360mg** in 24 hours. (Note: Ceiling dose for Codeine is 360mg/24h)

Using the table they calculate the Morphine equivalent: Codeine 100 mg po = Morphine 10 mg po therefore Codeine 360mg po = **Morphine 36 mg po**

The oral dose of Morphine is then converted to a parenteral SC dose using a 2:1 ratio. Therefore Morphine 36mg po = Morphine 18 mg SC. When converting from an oral to parenteral route, the dose is usually reduced by half, resulting in Morphine 9mg SC in 24 hours. The order would be: **Morphine 1.5 mg SC q4h**

Jayne and the physician then calculate the breakthrough dose, which can be done in two ways:

1. 10% of total daily morphine dose (10% x 9mg = 0.9mg) but can be rounded up to Morphine 1mg SC q1h prn
2. **OR** if the pain is severe, the dose can be 1/6 of the total daily morphine dose (1/6 x 9mg = 1.5mg) resulting in Morphine 1.5mg SC q1h prn

They chose to use the higher breakthrough dose so the order is Morphine 1.5 mg SC q4h with Morphine 1.5mg SC q1h prn for breakthrough pain. The physician also notes in the order to provide a breakthrough dose 10 to 15 minutes prior to activity that precipitates pain to preempt or decrease severity of incident pain.

Jayne, the PCU physician and the pharmacist note that because of Mr. Smith's previously identified risk factors they need to be alert to changes that may require altering his medications if he begins to show any signs of opioid neurotoxicity (sedation, confusion, agitation, myoclonus, hallucinations, hyperalgesia) or terminal delirium along with alcohol withdrawal. These changes need to be assessed for possible causes and may require a reduction in the opioid dose or a rotation of the opioid.

All steps of the WHO ladder include the possibility of adding an adjuvant medication. Now that Mr. Smith has bone and neuropathic components to his pain it is likely that adjuvant analgesics (or co-analgesics) will further improve his overall pain control. Mr. Smith is started on a steroid, anticonvulsant, and tricyclic antidepressant to help with these components of his pain. The PCU physician, at the request of Jayne and the PCU nurses, has also proactively written an order for an anti-anxiety and sedative to be given to Mr. Smith for control of symptoms if/when he goes into alcohol withdrawal.

Jayne discusses and provides information to Mr. and Mrs. Smith about:

- Addiction versus tolerance and dependent behavior with opioids and other adjuvant medications keeping in mind Mr. Smith's substance abuse history and the possibility of substituting opioids as a means of coping
- The use of complementary interventions such as meditation, relaxation, therapeutic touch to assist in controlling anxiety and symptoms
- Common opioid side effects (constipation, nausea, sedation, confusion, delirium, and myoclonus) and methods that will be used to help prevent and manage them.

Jayne teaches Mrs. and Mr. Smith to consider the use a pain diary that includes severity of pain (daily average, highest and lowest pain intensity during the day), use of breakthrough pain medications (severity of breakthrough pain, drug and dose taken, time taken, and effectiveness of breakthrough after 30 min and/or 1 hour) and incident pain medications. This ongoing record would empower Mr. and Mrs. Smith to maintain a central role in the pain management as well as assist Jayne and the team to monitor usage, determine and document if adjustments in the medication regime are needed.

Follow-up

Jayne and the team consistently evaluate and document Mr. Smith's pain outcomes. These outcomes include:

- Pain level.
- Adverse effects of medication.
- Patient and family ongoing knowledge of and participation in pain management.
- Development of other pains.
- Monitoring for progression of pain that may signal complications such as impending fracture or spinal cord compression.
- The care plan specifically stating a monitoring plan by the interdisciplinary team.
- Regularly evaluating pain management against set standards.

Since Mr. Smith was in severe physical pain crisis the focus is first on managing his physical pain and once that is better controlled, the interprofessional team will be more involved to address all aspects of his physical, psychological, social and spiritual components of total pain and suffering.

After 48 to 72 hours the team was able to get Mr. Smith's physical pain and symptoms under good control (1- 2 out of 10). He was assessed as still being in the final days to week(s) of living with a PPS score now at 30%. The physiotherapist and occupational therapist assisted him to be able to move better and to have physical aids to help him be more comfortable. The spiritual care provider worked with him to ease his sense of regrets, to seek understanding and forgiveness for his lifestyle and to ease his guilt associated with that. The social worker was able to assist Mr. Smith to reconnect with his son over several individual and family meetings. Mr. Smith remained alert up until the last day and he and his son were able to heal some of their differences. Mr. Smith died with good total pain control 2 weeks after admission with his family and some members of the PCU team by his side.

HPC Nursing Competency Category 3

Symptom Assessment and Management

HPC Nursing Competency Category 3 - Symptom Assessment and Management

INTRODUCTION

Competency Category 3 includes a multitude of symptoms that may be expected or are present in persons facing a life limiting illness that would require ongoing comprehensive assessment and management. The focus is on the required knowledge and ability of the HPC nurse to identify possible causes and anticipate, recognize, manage, respond to and evaluate the common, expected and unexpected symptoms when they occur. A key component is knowledge of individual life limiting disease processes in order to identify the symptoms, common emergencies and incidents that are most likely to take place as a result of the disease and/or its treatments. Assessment and management of symptoms must be based on the HPC nurse collaborating with the terminally ill person, family and interprofessional team to develop individualized goals of care.

In this particular case and, because of the large amount of components, only a small number of symptoms from the competency category are able to be covered. Our intent is to demonstrate the process of how to assess and manage symptoms. Comprehensive study for the exam should include the full variety of symptoms included in the category. Those studying for the exam are reminded to avail of all of the suggested bibliography in the CNA Study Guide in order to cover all of the material in this and all other competencies.

Symptom Assessment and Management

Based on a comprehensive assessment of symptoms, the HPC nurse must determine possible causes of any symptoms that are present (neurologic, cognitive changes, cardiovascular, respiratory, gastrointestinal, nutrition and metabolic, genitourinary, immune system, musculoskeletal, skin and mucous membranes, psychosocial and spiritual, plus others). Depending on the cause and the current goals of care, attempts will be made to reverse, correct and relieve the underlying cause(s) of the symptom(s). Some symptoms are a natural progression of a person's illness and when it is at the end stages it may not be possible to reverse or correct the cause. When that is the case the goal is to effectively communicate this to the person and family and work to relieve the physical, psychological, social, and spiritual burden of the symptoms to the best of the care team's knowledge and abilities.

CASE

Mrs. Jones is a rotund 72-year-old retired professor living alone and taking medications for hypertension, diabetes, congestive heart failure, and osteoporosis. Nine months ago, Mrs. Jones fell in her home and fractured her hip. When she was admitted to the hospital she was found to have physical symptoms of mild confusion, a stage IV pressure ulcer, pain (in her hip, feet and bones, and wound) as well as a cough, dyspnea, and fever. After hip replacement surgery and surgical debridement of her ulcer, her confusion and wound and hip pain resolved but she was still in pain from diabetic neuropathy in her feet and wide spread osteoporosis. Therefore, to participate fully in rehabilitation was challenging and this also caused her to become more depressed. She received post operative prophylactic anticoagulant therapy and also developed a number of complications including pneumonia necessitating a week's stay in the ICU, repeated courses of broad-spectrum antibiotics, and three further weeks in hospital. During her hospital stay she refused any offer of team interventions and support from the discharge planner, social worker and occupational therapist to help set up home supports.

Mrs. Jones has two married daughters who live in the same city and are busy with their own families and are discouraged from visiting by their mother. Mrs. Jones was always one to be very private, independent and some may say a "stubborn" lady and these characteristics have escalated especially in her senior years. She has refused to talk about advance planning especially around cardiopulmonary resuscitation decisions as she felt she would be fine and get better as she has so many times before.

Four months later, homebound, still refusing home help and unable to visit her doctor, Mrs. Jones became extremely short of breath on any exertion and was very anxious. She called 911 and was admitted to the hospital for treatment of dyspnea related to pneumonia, a pericardial effusion and her ongoing heart failure. Her stay was three weeks long including 10 days in the ICU. Mrs. Jones returned home again refusing any help and this time did not purchase all of her new medications because her drug plan did not cover all of them. Embarrassed, she did not want to burden her two daughters with her financial difficulties or to ask for their assistance in being cared for at home. She had difficulty moving around her home, and became incontinent when she was not able to get to the bathroom quickly. She tried to eat and drink less and cut back on taking her diuretics in order to decrease her trips to the bathroom.

Mrs. Jones returned to the hospital due to increased dyspnea, tiredness, insomnia, constipation, weight loss, depression, and was also found to be anemic, hypoglycemic and had electrolyte imbalances. Her anxiety and depression about the future escalated and she stated "I might as well be dead as to try to go on living like this".

On day 20 of her third hospitalization in 9 months, the medical unit team discussed future plans and goals of care with Mrs. Jones and offered a referral for symptom management and future planning with the palliative care team. Mrs. Jones and her daughters were surprised at the offer as they thought that a person had to have a cancer diagnosis to be consulted to this team. When it was explained to them that the palliative care team is available for consultation to persons dealing with any life limiting illness such as is now happening with Mrs. Jones they were open for a consultation. As Mrs. Jones cynically stated "I'll talk to anyone including God himself if it can help me relieve this gasping for air to get me more comfortable and get me home again."

Palliative Consult Team Referral Initiated

Emily is a HPC nurse who has been part of a palliative care consult team for two years. The team met with Mrs. Jones and her two daughters whom Mrs. Jones had previously designated as her health care proxies. It became clear that the daughters were unaware of the severity of their mother's multitude of complex disease processes and associated symptoms plus the ongoing decline in her general condition. The medical unit and the palliative care consult teams worked closely and had several family conferences with Mrs. Jones and her daughters to help them better understand Mrs. Jones' overall deteriorating illness and symptoms. Mrs. Jones still hoped to return home and in order to do that she was now open to accept advice and additional support. She now stated that she never wanted to ever again return to ICU even if she should have another episode of severe dyspnea or any other emergencies like pneumonia and said "I hope I have a heart attack and just die in my sleep."

An Advance Care Plan was developed with Mrs. Jones and an order to not attempt resuscitation or no ventilator support was agreed upon and placed on her health record. The new mutually agreed upon plan and goals of care were to primarily focus on maximizing overall comfort, relieving symptoms, and maintaining dignity and a sense of security for Mrs. Jones' in her final stage of life. This plan will be reviewed regularly with Mrs. Jones and her daughters.

Emily uses the Symptom Assessment Acronym of O, P, Q, R, S, T, U, and V (further information available at: http://www.fraserhealth.ca/media/SymptomAssesment.pdf) and the Edmonton Symptom Assessment Scale/System (ESAS) (further information at http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/esas.pdf). These tools further guide Emily's and the team's best practice assessment and documentation of Mrs. Jones' symptoms. Emily also taught this to Mrs. Jones and her family to follow through with and help document symptoms, especially if she returns home.

For each symptom Emily asked the questions:

- **O**nset - When does it begin? How often does it occur? How long does it last?
- **P**rovoking/**P**alliating - What brings it on? What makes it better? What makes it worse?
- **Q**uality - What does it feel like? Can you describe it?
- **R**egion/**R**adiation –Where is it? Does is spread anywhere?

- **S**everity - What is the intensity of this symptom (On a scale of 0-10 with 0 being none and 10 being the worst possible)? Right now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
- **T**reatment - What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past? What do you think will help your symptom?
- **U**nderstanding /Impact on you - What do you believe is causing this symptom or making it worse? How is this symptom affecting you and/or your family? How does it change what you are able to do for yourself?
- **V**alues - What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom? Are there any other views or feelings about this symptom that are important to you or your family?

Emily and the palliative consult team initiate the ESAS tool as one part of their holistic clinical assessment including physical pain and other symptoms. The severity of the symptom <u>at the time of assessment</u> on a 0 to 10 numerical scale is charted daily.

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best feeling of wellbeing	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of wellbeing
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
Other problem(s)	0 1 2 3 4 5 6 7 8 9 10	

Ideally Mrs. Jones would complete the ESAS form but if she is unable to do so a family or team member circles the most appropriate number to indicate where the symptom is between the two extremes. The circled numbers are transcribed onto a symptom assessment graph similar to a vital signs graph in order to provide an ongoing and comprehensive picture of Mrs. Jones symptoms. Mrs. Jones, the family and the team find this ESAS tool of great help to get an ongoing consistent picture of what is happening and helping with her symptoms.

Mrs. Jones rates her pains as 7/10, tiredness as 8/10 noting that it is variable depending on whether or not she is short of breath (SOB) and can get some sleep, nausea a 0/10, depression as 8/10, anxiety as between 2 to 9/10 again dependent on her SOB, drowsiness 5/10, appetite as 9/10, and well being as 8/10. Her most prevalent symptom is SOB which influences all of the other ESAS symptoms. Her SOB can be a 6/10 on average but 9/10 when she lies down or when getting out off bed, washed or dressed in the morning. Emily observes that when Mrs. Jones is quiet in her chair her breathing appears less labored and gets worse again when she talks. Mrs. Jones describes her breathlessness as heaviness where it feels like she has “no space” in her lungs for any air. In the past, Mrs. Jones had severe allergies which also affected her breathing and she would use inhalers before she got out off bed to help ease her symptoms, but now says they don’t even seem to help as much. She states that if she feels breathless she just stops what she is doing and sits still in her chair which does help her feel better.

When Mrs. Jones thinks about going home she still panics about how she will manage physically, financially and emotionally and this makes her breathlessness worse. Mrs. Jones is concerned that she will become so breathless that she will not be able to call for help and will die alone suffocating in agony.

Mrs. Jones would still like to go back home and feels she could do this if her feeling of breathlessness was at a 4/10 most of the time. On reviewing Mrs. Jones chart, Emily notes that her respiratory rate and blood gases have been within normal limits, but her hemoglobin level is still slightly below normal. Emily also understands that breathlessness is a subjective experience and that in advanced disease respiratory rate, oxygen levels and blood gases generally may not correlate with Mrs. Jones' feeling of breathlessness. The team talks to Mrs. Jones and her family about the benefits of starting opioids for her dyspnea; explaining that opioids such as Morphine are not just for pain but can also help decrease her feeling of breathlessness. Mrs. Jones, who is opioid naïve, agrees to start on a low oral dose of Morphine 2.5 mg every 4 hours and 2.5 mg every one hour as necessary (prn). She is also started on medications to alleviate constipation and on a therapeutic trial of oxygen therapy. She continues on her heart failure medications.

Emily works with the team to identify potential causes for Mrs. Jones's dyspnea including:
- Underlying pulmonary and cardiac disease (recurrent pneumonia, congestive heart failure)
- Pericardial effusion
- Anemia
- Anxiety and fear
- Family / financial / emotional / practical issues

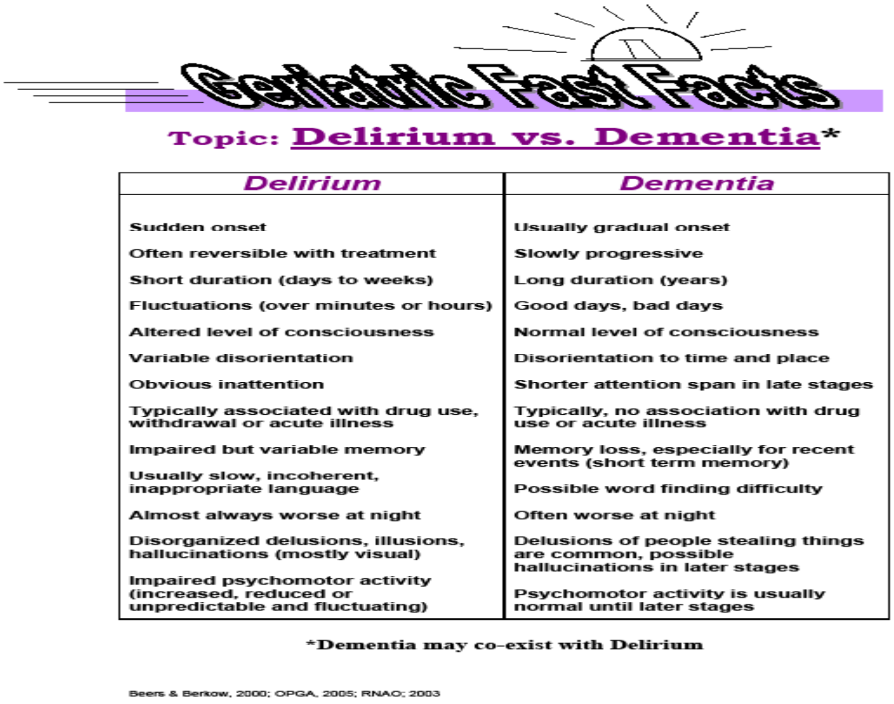
Emily and the team work with Mrs. Jones and her daughters to develop a plan to address some of the underlying causes and factors that may be contributing to her symptoms:
- All of her medications are reviewed. The doses of her diuretics are adjusted to better manage her congestive heart failure which is a major contributor to her breathlessness. Oral antibiotics to treat her pneumonia are continued as needed. Regular aerosol therapies are initiated along with a trail run of opioids and oxygen therapy. The team works closely with the cardiologist to ensure the medical treatments and medications have been optimized to address her present symptoms.
- The dietician meets with Mrs. Jones and her daughters to review and plan her diet to manage, where realistically possible at this stage, her anemia, diabetes and change in appetite. Good discussion is held on adjusting, understanding and not forcing food in the final stages but simply providing what Mrs. Jones is able and wants to eat or drink.
- The social worker meets with Mrs. Jones to address social, family, and financial concerns and discuss practical and realistic issues related to her desire to continue living on her own.
- The occupational therapist does a home assessment to identify ways to increase Mrs. Jones' mobility and safety at home.
- The spiritual care person meets with Mrs. Jones to assist in addressing some of her fears and the meaning to her illness, life and her final stages. A meeting with her daughters also takes place.
- Hospice volunteers begin working with the family to provide Mrs. Jones some companionship and support.

Emily works with Mrs. Jones and her daughters to develop a plan to treat further symptom episodes. Emily again reviews the ESAS and other tools to assess the intensity of symptoms and teaches how to document and report any changes on a regular basis when at home. She also reviews various medications (opioids, diuretics, steroids, anxiolytics, heart medications) that have been ordered to treat the symptoms and teaches Mrs. Jones and her daughters when and how to use them.

Emily introduces a number of non pharmacological ways for consideration to manage Mrs. Jones' breathlessness by:
- Eliminating environmental irritants
- Learning simple breathing exercises
- Sitting or lying in a different position
- Using a humidifier or fan or open window
- Playing appropriate music
- Keeping a larger space and a line of sight clear to outside
- Reducing the room temperature while avoiding chilling the person
- Considering massage and relaxation techniques
- Using prayer and meditation
- Providing a calming presence

Mrs. Jones is finally able to return home on her own with daily visits by home care, volunteer support, increased involvement of her daughters, weekly assessments by Emily and a “lifeline” pager system set up to press a button to call for help. Mrs. Jones had also relayed to her daughters that if a time came when she “didn’t know what she was doing” or “where she was” she didn’t want to stay at home or have anyone living with her in her home. She let them know she had already filled out an application for the nursing home of her choice “just in case”.

Mrs. Jones condition continues to slowly deteriorate and after several quality weeks at home Emily arrives to find Mrs. Jones showing symptoms of cognitive impairment. Emily discovers that certain medications are missing out of Mrs. Jones’ prepackaged daily and weekly pill blister packs. It seems Mrs. Jones has been slightly confused the last week and has likely taken too much of her diabetic, anti-anxiety and opioid medications. Since Mrs. Jones had also been showing and trying to hide previous signs of cognitive difficulties Emily reviews her fast fact card she carries on delirium and dementia to get a better assessment of the situation.



Geriatric Fast Facts

Topic: Delirium vs. Dementia*

Delirium	*Dementia*
Sudden onset	Usually gradual onset
Often reversible with treatment	Slowly progressive
Short duration (days to weeks)	Long duration (years)
Fluctuations (over minutes or hours)	Good days, bad days
Altered level of consciousness	Normal level of consciousness
Variable disorientation	Disorientation to time and place
Obvious inattention	Shorter attention span in late stages
Typically associated with drug use, withdrawal or acute illness	Typically, no association with drug use or acute illness
Impaired but variable memory	Memory loss, especially for recent events (short term memory)
Usually slow, incoherent, inappropriate language	Possible word finding difficulty
Almost always worse at night	Often worse at night
Disorganized delusions, illusions, hallucinations (mostly visual)	Delusions of people stealing things are common, possible hallucinations in later stages
Impaired psychomotor activity (increased, reduced or unpredictable and fluctuating)	Psychomotor activity is usually normal until later stages

*Dementia may co-exist with Delirium

Beers & Berkow, 2000; OPGA, 2005; RNAO; 2003

After further consultation with the team, it is determined that Mrs. Jones has early signs of dementia along with a sudden onset of delirium due to taking too many of her medications. Her early dementia possibly led to her to taking too much medication. The team was able to reverse the delirium by managing her medication doses. However, the subsequent Mini Mental State Examination (MMSE) that was conducted a week later had a score result of 10/30 indicating her dementia was escalating. Emily involved the social worker in a meeting with Mrs. Jones and her daughters to help put a plan into place for her eventual admission to her preferred long term care facility.

Mrs. Jones was admitted to the nursing home and after a month she developed pedal edema and exhibited consistent increased shortness of breath with minimal relief form previous interventions. She now has been complaining of some constant chest pain and wanted no tests or interventions done or transfer to the hospital. After reassessment by the long term care palliative care team and a family/team conference, it is determined that Mrs. Jones heart failure is worsening and she is likely nearing the final days/hours of her life. Regular doses of morphine are increased to treat Mrs. Jones chest pain and shortness of breath along with other complementary measures. All other medications are reviewed for efficacy, appropriateness and/or discontinuation at this stage.

Some staff in the nursing home are concerned about how to manage Mrs. Jones' diabetes now that she not eating or able to take her oral medications. Emily reinforces that once the person is in the terminal phase, when oral intake is minimal to nil, then issues such as hypoglycemic medications and blood sugar monitoring is usually decreased or stopped as the probability of reversing and stabilizing the blood sugar and the overall diabetes is not an anticipated realistic outcome. A blood glucose level may be checked if unresolved symptoms occur. The same would go for many other aggressive interventions and medications at this final stage of the illness.

Mrs. Jones comfortably dies a day later with her family by her bedside.

HPC Nursing Competency Category 4

Last Days/Hours / Imminent Death Care

HPC Nursing Competency Category 4 - Last Days/Hours / Imminent Death Care

Competency Category 4 focuses on preparation for the important final phase of a person's life, to help the family understand the signs and symptoms of imminent death while developing a consistent collaborative plan to deal with observed changes, signs and symptoms, anticipatory grief, comfort measures and the death event.

INTRODUCTION

Virginia is a home care nurse with 10 years nursing experience on acute care general medicine units and started work in the community 2 years ago. She has an interest in enhancing her knowledge and skills in the area of palliative and end of life care, as there is an increase in her terminally ill clients that wish to stay and die at home.

Virginia's comfort level with using her knowledge and psychosocial skills for guiding and coaching family members and caregivers to explore ways they can be involved in the care, if they wish, will help them to feel more confident, hopefully allowing for a more rewarding experience in caring for their loved one at home to the end.

The home care program uses the Palliative Performance Scale version 2 (PPS) -*(for full version and guidelines go to* http://palliative.info/resource_material/PPSv2.pdf) which, with consistent decreases in score, often indicate a progressive declining condition. The PPS is an excellent communication tool for quickly describing a person's current functional level that, along with good clinical judgment, can guide the care team in planning for appropriate care supports.

Palliative Care Performance Scale Version 2 (PPSv2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity and Work No Evidence of Disease	Full	Normal	Full
90%	Full	Normal Activity and Work Some Evidence of Disease	Full	Normal	Full
80%	Full	Normal Activity *with* Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job/Work Significant Disease	Full	Normal or Reduced	Full
60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any Work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most Activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma +/- Confusion
0%	Death	--	--	--	--

(Victoria Hospice Society, Medical Care of the Dying, 2006, page 121. Used with permission)

CASE

Mr. Thompson is a 68-year-old man with end stage pancreatic cancer. He lives with his 60 year old wife in a 2-bedroom house with a basement apartment. They have 2 children, a son and a daughter. The son is single, has no children and lives in Europe. Their daughter, her husband and children (ages 3, 7, and 14 years) have been living in the basement apartment for the last 6 months. Mr. and Mrs. Thompson have enjoyed the opportunity to now get to know their grandchildren better. Mr. Thompson was self-employed and his wife took early compassionate leave from her job when her husband was diagnosed. The home care program nurses had their first visit when his PPS was 60% and now that it is a consistent 30% Virginia visits at least twice a week.

Mr. Thompson and his wife have been open about the illness and prognosis and have talked with Virginia and their family doctor on their home visits. Mr. Thompson has indicated that he has an advanced directive, does not wish to be resuscitated and that he would like to be supported to die at home. They have been seen by the palliative care team and have agreed to be admitted to the PCU if they are unable to manage at home.

Now that Mr. Thompson is getting weaker and is in bed more, Virginia works with the Occupational Therapist to guide the family in adapting their home to meet their practical and physical needs as well as preparing for the dying event.

When Mr. and Mrs. Thompson completed their advanced directives and updated their wills a few years ago they also completed pre-funeral planning with their pastor and made burial arrangements with their local funeral home. Their daughter is aware of all of their arrangements. Virginia documents contact numbers for the pastor and funeral home in the chart.

Virginia provides a copy of *A Caregiver's Guide* (available to purchase from the Canadian Hospice Palliative Care Association at www.chpca.net) that gives medical and nursing information for family and informal caregivers in a language that is easily understood. She reviews the sections that are most relevant to them now and leaves it for them to keep and look at further as they wish.

Preparing for the Final Stage

Areas that Virginia covered and provided guidance to Mr. Thompson and the family over a few weeks included:

<u>Practical issues to consider:</u>

- Home aids and equipment (e.g. bed, mattress, bedpan, urinal, "baby monitor"/bell, side table etc.)
- Location and room where they want to be in the house (if he becomes bed bound)
- Availability of family doctor and community health nurse after hours
- Home support workers
- Having a list of contact numbers visible (on the fridge or next to the phone)
- An Occupational Therapist visit

<u>Physical issues</u>:

- Practicing universal precautions
- Bathing
- Mouth and skin care
- Proper Positioning, Body mechanics
- Feeding issues – dealing with decreased or no eating and drinking
- Toileting, dealing with bladder and bowel issues (e.g. incontinence, constipation)

- Recognizing, reporting and responding to common symptoms such as pain, nausea, dyspnea, anxiety, confusion etc.
- Understanding medications and their administration
- Medication alternate dosage conversion and route back up if unable to swallow

Psychosocial issues:

- Respecting their choice to remain at home
- Helping them to maintain a sense of control
- Providing and guiding opportunities to heal and/or strengthen relationships
- Anticipatory grieving
- Teaching and reassurance in providing care
- Applying a team effort to help ease the burden of care (nursing, social work, psychology, pastoral care, volunteers, family doctor)

Spiritual Issues:

- Clearing up unfinished business
- Finding meaning
- Beliefs in after life
- Healing
- Creating final memories
- Giving final gifts
- Find spiritual peace
- Saying good-bye.
- Connecting with their pastor or a spiritual supporter

Other:

- Autopsy
- Organ, tissue and body donation information

Mr. Thompson shares with Virginia that he wishes he was gone already. Separately, his wife confides to Virginia that she is praying for it to be over. Both feel very sad and guilty for their thoughts and emotions. Virginia discusses with Mr. Thompson and his family the many normal feelings they are having and describes the term "**anticipatory grieving**". She explains that grief can begin before the death due to awareness of the impending loss and recognition of associated past, present and future losses. Virginia reinforces with the family that the amount of grief experienced in anticipation of the loss does not necessarily diminish the grief that the family will also experience after Mr. Thompson's death. Realizing these feelings are often experienced by many others helps alleviate some of their concerns. Virginia also re-assesses Mr. Thompson to ensure that all his physical symptoms are well controlled and all the proper supports are in place for the family. She regularly re-assesses their desire to remain at home, which they still wish to do and updates her documentation on this.

Supporting the Family

The daughter feels inclined to protect her children ages 3, 7 and 14 from what is happening but is also concerned about how to prepare them for their grandfather's eventual death. Her father looks forward to the visits from her children and would like to speak more openly to them about what is happening to him. Virginia and the Social Worker explain to the daughter, her husband and Mr. and Mrs. Thompson that it is important to talk to all of the children about what is happening to their grandfather because, even if they have not brought it up, it is likely they are well aware of the changes in their grandfather and may be thinking and worrying about it. If the children are not given the opportunity to talk and have their questions answered, they may use their imagination to understand what is going on, and it may be worse than what is actually happening. Virginia discusses the typical understanding of death and concerns of children in different developmental stages:

1. Infants (0 - 2 years). Infants cannot really understand death, but they do pick up on the emotions of those around them. They may need extra time and consistency in their routine.
2. Pre-school (3 - 5 years). Children of this age tend to see death as something reversible and impermanent. They do understand that something huge has happened in their lives when someone dies. They may need reassurance that they did not in any way cause the death or illness to occur.
3. School Aged (6 - 12 years). Children of this age can understand that death is permanent and a better grasp of the enormity of the loss. They may still have concerns that they caused the death or illness in some way.
4. Adolescence (13 - 18years). Adolescents recognize that death is permanent and universal but that it will not necessarily happen to them or their family. They may have existential questions about meaning of life and death. They tend to turn to their peer group for support.

Virginia encourages the parents to talk to the three children together as well as separately. She suggests starting by finding out what the children already know and if there is anything they have been worried about. She suggests they explain the illness and expected death in clear, concrete language. She provides a list of books that may help children of different ages understand death. She also encourages the family to involve the children in caring for their grandfather in small ways that they feel comfortable with, and to find activities that they can do with their grandfather that they have always enjoyed doing together (reading stories, listening to music, drawing pictures, etc.). She also suggests letting the children's teachers know what is happening so they can be alert for any changes in behavior and provide extra school counseling support if needed.

Mr. and Mrs. Thompson's son, who has had ongoing physical and emotional distance from his father, calls regularly and says he is depending on the family to tell him when he should come home. This is putting a heavy burden on the family at home and they have asked Virginia what they should do. Virginia, along with the social worker, explores the son's relationship in the family and such issues as:

- Is there financial hardship if he comes home too soon and is unable to return for the funeral?
- Does he actually want to be with his father when his father is alert and able to interact?
- Does he want to try to be home more for the wake and funeral?

Virginia suggests they explain to him that they can only tell him the physical changes that are happening but cannot predict when exactly they think death will occur. The son will need to decide when he wishes to come and the family will support that decision. The son, upon speaking with the social worker, Virginia and the family about the options, decided to come home early and spent some quality healing time with his father and family.

****

Virginia keeps in mind that while most people have seen a deceased body, many may not have been actually present for and provided care during the dying process, last hours and the death event. With offering her appropriate knowledge, management and skill to the family it is possible for Virginia to help provide the smooth transition for the person and loved ones for a comfortable home death.

Although the couple has been quite open about dealing with everything, they have acknowledged that sometimes they are not sure what to ask about or to prepare for. As Mr. Thompson, with his dry humor, says "I've never died before and sure would like to get it right so it is easy for me to go as peacefully as I can and for my family to be able to carry on." His wife, children and grandchildren are also looking for guidance and direction to be able to handle the final days and hours.

In her visits and conversations with Mr. Thompson, his wife and daughter, Virginia now leads the communication around preparing for the final days, being aware of and tuned into what they may wish to hear and discuss and what they may not wish to hear or talk about on each visit.

Signs and Symptoms of Imminent Death

Physiological Signs of Imminent Death:

- Reduced or fluctuating level of consciousness, withdrawal, possible restlessness, confusion, hallucinations
- Decreased oral intake, no fluids or only sips, difficulty swallowing
- No urine output or small amount of very dark urine (anuria or olgiuria)
- Progressing coldness and purple discoloration in legs and arms
- Laborious breathing; periods of no breath (Cheyne-Stokes breathing),
- Bubbling sounds in throat and chest (death rattle)

Virginia recognizes that these imminent changes need to be communicated in “lay person” terms and takes the time to explain, alleviate fears, and to go through the booklet that their service has drafted for loved ones to be more prepared. The booklet was developed in order to assist families, friends, and caregivers understand some of the signs and symptoms that may occur in the final stage of life and to give some advice on comfort measures. The families finds this booklet very helpful and keep it close by to refer to as Mr. Thompson 's condition continues to decline.

Symptom Management

Mr. Thompson has some pain that has been controlled by taking oral opioids regularly. He has complained of increasing fatigue, no appetite and has had occasional nausea, dyspnea and constipation, which are also being treated. Virginia does regular assessments and documentation using validated tools as his condition and symptoms change.

Mr. Thompson is now at a stage where it is becoming difficult to take any medications by mouth. Virginia had proactively worked with the family doctor to reassess present medications, to discontinue redundant medications and to prepare for alternative administration routes for essential drugs (e.g. SC=subcutaneous, PR=rectal, TD= trandsdermal, SL=sublingual). For SC medications, she prepares to insert an indwelling SC butterfly needle and teaches the family and caregivers how to use it.

The family have also asked if there are some things that may happen out of the ordinary that they should be prepared for**.** Virginia lets them know about some of the uncommon uncontrollable events prior to death such as hemorrhage and seizure. With hemorrhaging Virginia recommends having dark towels on hand to use and that there is a medication (SC Midazolam) that they will be taught to give. With a seizure the family is advised on how a seizure may look and for them to try to remain calm, not leave, move or restrain Mr. Thompson, have side rails and bumper pads on the bed, speak gently and reassuringly, and to then to call for help if needed.

The Final Hours

In the final day when she visits, Virginia notes that Mr. Thompson is unresponsive and his PPS is now 10%. The grandchildren are at home. She takes extra time with the family to ascertain their comfort level with being there when the death occurs and tells the grandchildren that even though their grandfather cannot speak to them right now he can feel their presence and love. She reviews with Mrs. Thompson and her children how to know when death has happened, whom to call, and what to expect about pronouncement, certification of death and the removal of the body. Most importantly, she reminds them that they should not call 911 or an ambulance as this is an expected death and the family doctor has notified the appropriate people about this(e.g. police, coroner etc.). The funeral home is aware that they will receive a call from Virginia and/or the doctor when the pronouncement and certificate are completed to come and pick up Mr. Thompson.

Signs of Death:

- Cessation of heart beat and respiration
- Pupils fixed and dilated
- No response to stimuli
- Eyelids open without blinking
- Decreasing body temperature
- Jaw relaxed and slightly open
- Body color is a waxen pallor

The Death Event

Mr. Thompson died peacefully the next day surrounded by all his family with their pastor present. They called Virginia who arrived shortly afterwards. Beginning the grieving process, the family took some time to be alone with Mr. Thompson, reminisce with each other, and notify other family members before the family doctor arrived to complete the death certificate. They were grateful that the end of life and after death care of Mr. Thompson took into consideration their cultural and religious beliefs and practices and that respect was still shown to Mr. Thompson as his body was prepared and cared for after death. They then called the funeral home to notify them to come to receive Mr. Thompson.

Follow up

Virginia had established a close relationship over many months with Mr. Thompson and his family and because of that, she attended the wake and funeral. A few weeks later, she also paid a follow up family visit to establish closing her connection and to offer them some information about children and grief and on bereavement supports available to all the family in their areas if needed.

The family shared with Virginia and the team that they will always remember their caring words, actions, guidance, knowledge and attention to detail that helped make their meaningful journey and to move ahead to heal.

Virginia firmly believes that being privileged to make the remarkable journey with experienced knowledge, attitude and skills, alongside the dying and their families is the essence of her ongoing HPC nursing personal and professional growth and satisfaction.

HPC Nursing Competency Category 5

Loss, Grief, and Bereavement Support

HPC Nursing Competency Category 5 - Loss, Grief, and Bereavement Support

INTRODUCTION

In this competency the HPC nurse will recognize that hospice palliative care spans the continuum from the diagnosis of a life limiting illness until death of the person which includes grief and bereavement. The unique body of knowledge of HPC nursing practice includes assessment of grief and bereavement needs.

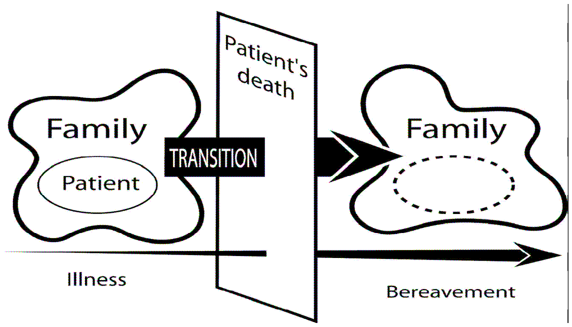
The HPC nurse is expected to demonstrate knowledge around loss, grief and bereavement; assist the family in understanding the concept of loss and the process of grief and bereavement, considering developmental stages and to make referrals as needed. The HPC nurse also is expected to identify types of grief, recognize the manifestations of grief and the differences between depression and grief while identifying persons at risk for complicated grief. The HPC nurse assists the family to anticipate and cope with their unique grief reactions to loss and death, considering the unique needs of children at various developmental stages and assists the family to recognize the person's legacy and facilitates the family's transition into ongoing bereavement services and programs, where indicated.

CASE

Anne is a nurse orientating to the hospice palliative care service of an inpatient unit and consultative services. She is attending the weekly interprofessional team meeting. At these meetings, the team regularly reviews the person/family cases and the whole person issues surrounding them.

Anne hears that the palliative care philosophy includes the person and families as the unit of care and that grief guidance/support focuses on the person and family before the death, and continues to focus on the family after the person's death. The palliative care team's goal is to help facilitate, when and where possible, healthy healing family transitions in the face of loss.

The team meeting includes discussion of recent deaths and how each person and family was prepared for the death and how the family is coping now, especially with their grief. Anne recognizes her need to improve her knowledge, assessment, and intervention skills in this area. She would like to be able to better understand the common, natural responses to loss that will assist her to prepare and guide dying persons and their families with the grieving process. As well she wants to increase her understanding of the difference between those with "uncomplicated" grief whom she can assist, and those who may have more complicated grief requiring a referral to professionals with skilled expertise in grief counseling.



Loss Anticipatory Grieving Grieving: Uncomplicated or Complicated

(Adapted from Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care, 2002, Page 13)

Definitions

Anne reviews a number of terms related to grief:

Loss: A generic term that signifies absence of a person, object, position, ability or attribute. Losses that occur during the dying, grieving, or bereavement processes include:

- loss of significant person, relationship, body image or function, health, sexual function, control, religious beliefs
- loss of job, income, home, property or treasured objects
- loss of plans, hopes and future dreams
- loss of role, identity, independence, innocence, freedom, safety
- loss of life

Grief: The "normal" response to the loss of someone or something precious. It is a process which includes psychological, social and somatic reactions to the perception of loss.

Mourning: The social expression of grief from a loss performed after death including rituals and behaviors specific to culture and religion.

Bereavement: The loss of a close or loved one. The state of having suffered a loss.

Anne is assigned to care for Mrs. Matthews who is dying from metastatic breast cancer. Mr. Matthews is struggling to face the impending loss of a loved partner who shared his world for 20 years. He is trying to take on many of her previous roles including: parenting their 10 year old son and 15 year old daughter, paying bills, housekeeping, grocery shopping, and cooking. He is dealing with many fluctuating emotions, including that he feels like "she is already gone" and is searching for understanding with this. He feels he should be "handling this better". Anne shares with him that part of his grieving process can start long before his wife's actual death. Similarly, she shares that his wife is also likely grieving the loss of her multiple roles and identity (wife, mother, friend, daughter, lawyer, and colleague), activities (soccer mom, volunteer, bridge player, and skater) and everyday experiences that she can no longer take part in. What Mr. Matthews and his wife are experiencing can be referred to as **"anticipatory grieving"** and in her nursing role, Anne and the team will strive to support and guide them as they deal with their many feelings and emotions around these losses.

Mrs. Matthews has said to Anne "I am going to miss so much with my children. Do you think my children will remember me?" Anne, along with various members of the team explore with Mrs. Matthews ways for her to create a legacy to help her children keep her close at heart. Mrs. Matthews decides to include her children in making videos of her sharing stories and memories of the past and separately recording special messages for them about her hopes and dreams for their future. Virginia acknowledges that though it is a difficult but empowering task for Mrs. Matthews to spend extra time with her children and make these videos it will be a lasting special memory for her family.

Mr. Matthews raises his concerns about the children and how they will respond to their mother's death. Anne and the social worker meet with Mr. Matthews to share information on children's understanding of death, common reactions to a death and how to support them. She shares these pamphlets and the Web sites to access the pamphlets that will be of help:
http://victoriahospice.org/files/bereavement-brochures/VicHospDealingGrief.pdf and
http://www.victoriahospice.org/files/bereavement-brochures/VicHospGriefJourney.pdf and
http://www.victoriahospice.org/files/bereavement-brochures/VicHospThngsRmmbr.pdf and
http://www.victoriahospice.ca/files/bereavement-brochures/VicHospDifficultGrief.pdf.

Developmental Perspective on the Experience of Grieving Children	
Children and Grief…Ages 9-12	Children and Grief…Ages 13-17
Understanding of Death	
- Become less egocentric and develop social concerns - Transition from concrete to more abstract thinking: - Understand the universality and inevitability of death, seen as removed in time from themselves. - Can generalize about death and understand its magnitude. - Begin to believe that death can happen to anyone and struggle with this. - See death clinically and fear it may be painful and scary. - See death as part of life; natural, universal and permanent. - Interest in what happens to person's body and spirit after death; fear non-existence and separation.	- Intellectually able to understand implications of death as an adult would. - Convinced they are invincible – a death, especially in peer group, shatters that illusion. - Feel shocked that it could happen to their family and confused about how to react. - Overwhelmed by intensity of the emotions. - Sense of isolation and loneliness even among friends and family, feel different. - Vacillate between acting like an adult and a child.
Common Reactions	
- Anxiety and general fearfulness. - Covering up emotions and trying to appear normal. - Concern about other survivors. - Concern about personal future and security. - Regressive behavior: bed-wetting, nightmares, acting out. - Withdrawal or endless questions about the death.	- Withdrawal, difficulty in finding a balance. - Guilt about things said or not said, done or not done. - Fear or disgust of the body. - May want to remember only good things about the person. - Blame others for the death and how it affects their life. - Feel totally empty and exhausted, may not cry. - Difficulty with eating or sleeping.
What Helps	
- Honest and accurate information about the death. - Opportunities to ask their own questions. - Reassurance about their future, e.g. if the other parent died, who would care for them and how. - Adults to model "appropriate" grieving. - Respect for the privacy of their thoughts, feelings, and writings. - Inclusion, as wished, in adult activities associated with the death; rituals, funeral, discussions, plans.	- Honest and accurate information about the death and its circumstances. - Support from peer group who are seen as major support rather than family and teachers. - Inclusion in discussions and decision-making, as wished. - Opportunities to spend more time alone. - Balance between having time to be a child and time to take on some adult responsibilities. - Keeping a journal or diary.

(Source: Developmental Perspective on the Experience of Grieving Children: Their Understanding and Reactions, and Supportive Interventions. Victoria Hospice Society 2006)

Mr. Matthews also questions how he will ever cope after his wife's death as he has never had a loss so deep before. Anne tells Mr. Matthews that he will need ample time to grieve and discusses and shares some literature on the phases of grief along with the fact that grief fluctuates and can continue to a certain degree throughout his lifetime particularly during special events, holidays and anniversaries.

Phase 1: When a Death Occurs

Grief Task: To begin to move from denial to acceptance or cognitive understanding that the death has really occurred

Grief Process:

- Immediately following a death, there is a sense of shock, numbness and disbelief that can last minutes, hours, or weeks.
- The person may feel panicked or overwhelmed, and experience strong physical reactions.
- When there has been a lengthy illness, caregivers may experience a sense of relief, both for the person who died and for themselves

This period allows the person to absorb reality and take information in at a slower rate and to prepare for new adjustments that lie ahead.

Phase 2: Confronting the Pain

Grief Task: To acknowledge, experience and work through feelings that arise: to adjust to a life without the person who died

Grief Process:

- As the numbness wears off, the bereaved person will begin to experience the intense pain of grief.
- This may surprise and frighten them but is natural and expected. People express their despair and yearning in emotive and/or physical ways.
  - Physical : heart palpitations, hollowness in stomach
  - Social: withdrawal
  - Emotional: flat affect or crying, numbness, sadness, fear, anger, guilt, relief
  - Cognitive: disbelief, confusion or poor concentration
  - Behavioral: impaired work performance, avoiding reminders of the deceased, overactivity
  - Spiritual: anger or questioning at God, re- evaluation of faith, searching for meaning, etc.

The time required for this phase will be affected by:

- the quality of the person's support
- other losses
- preparation for the death
- the nature of the relationship
- their general approach to life

Phase 3: Re-establishing Connections

Grief Task: To re-invest energy in new activities and relationships: to create a new or different relationship with the person who died

Grief process:

- As their grief subsides or "softens' the bereaved person regains the energy and desire to reconnect with the world. This shift in perspective allows people to begin incorporating the death into the past rather than present experience.
- Ongoing grief, however, will remain part of their life.

(Source: Phases Adapted from Medical Care of the Dying pages 649-651, 2006)

In her ongoing support of the family Anne remains alert for symptoms that may indicate troubled grief while at the same time providing support and counseling to help the family normalize their often-difficult responses to grief. She also reviews the predictors of poor bereavement outcome or increased risk of **"Complicated Grief"** where the person's grief is of greater intensity and lasts for a longer period of time:

- Who the person was e.g. loss of child
- The nature of the attachment/relationship e.g. ambivalent, dependent,
- Mode of loss/death e.g. unexpected, criminal
- History of psychiatric illness or poor coping
- Lack of social support (perceived or real)
- Losses resulting in major changes
- Negative financial changes
- Loss of role
- Multiple prior losses
- Poor responses to previous losses
- Loss that cannot be openly acknowledged, publicly mourned, or socially supported (Disenfranchised Grief)
- Failure to accomplish the necessary grief work (Unresolved Grief)

The Death Event and After

Mrs. Matthews dies comfortably surrounded by her family in the PCU. In her ongoing supportive role, the social worker reminds Mr. Matthews that she will be in touch to see how he and the children are coping at various times over the year and be available to them if needed. Anne and/or the PCU also will be in touch and notify the family about a Remembrance Service held regularly for families.

Prior to and at the funeral home visit, Anne has been approached by several friends of the family saying they don't know what to say to someone who is grieving and wonders if she has some information or advice to give them. Anne shares the following basic handout that others have found helpful:

Suggestions for Communicating with Grieving Families

DON'TS	DO'S
➢ Don't dominate conversation ➢ Don't ask one question after another without a break ➢ Don't use clichés such as "I know just how you feel" or "At least you had good years etc." or "This will bring your family closer." ➢ Don't pass judgment ("You should be feeling better by now") ➢ Don't avoid them because you are uncomfortable ➢ Don't change the subject when they talk about their loved one ➢ Don't answer a question when you know you don't have the appropriate answer ➢ Don't give advice, particularly medical or legal unless you're an M.D. or a lawyer ➢ Don't suggest they or their loved one received inadequate care ➢ Don't make comments like "they should have received care sooner"(they may already have doubt and guilt) ➢ Don't talk only with one relative (include others) ➢ Don't personalize comments but identify emotions (i.e. "It sounds like you're pretty angry") ➢ Don't use spiritual sayings that may provoke unpleasant emotions or memories. ➢ Don't minimize the loss. ➢ Don't attempt to tell the bereaved how he or she feels. A statement such as, "You must be relieved and he/she is no longer in pain" is inappropriate.	➢ Do listen more than you talk ➢ Do answer their questions and refer to the most appropriate people ➢ Do contact/call them when you say you will ➢ Do refer to loved ones by name and talk about special features ➢ Do be genuine and caring ➢ Do allow them to express their feelings and tell their story without passing judgment ➢ Do reach out to the bereaved and acknowledge their loss ➢ Do encourage them to be patient with themselves and not expect too much ➢ Do ask about the funeral / memorial service (if there was one) ➢ Do ask about other family members (siblings, spouses, grandparents) ➢ Do ask if they have any special requests for you ➢ Do remember them on special occasions or give a call and let them know you were thinking of them ➢ Do say a simple, "He/she will be missed," or "I'm sorry." ➢ Do accept how they are feeling or behaving. ➢ Do accept and be comfortable with silence. Silence is better than idle chatter. ➢ Do remember to ask a bereaved person how she or he feels. ➢ Do realize it is not necessary to say anything.

At the Remembrance Service six months later, Anne is talking with Mr. Matthews and he is saying that his friends are pushing him to "get on with life" and they feel he is depressed and needs help. Mr. Matthews feels he gets "down" certain times when he thinks of his wife and his loss but he doesn't feel that he is depressed. Anne tells Mr. Matthews that the deep sadness of grief often resembles depression. Anne explains some of the differences between grief and depression and notes that they are often a challenge to distinguish from each other. She also advises and reminds him of the contact information for the social worker and/or grief counselor if he is still concerned about this and needs some further clarification and support.

Grief and Depression

A significant loss may trigger or exacerbate a clinical depression, however:

- Most often the depression felt in grief is related to their current situation
- In grief the bereaved person's focus is on the person who died and the loss
- People who are depressed are more likely emotionally flat and focused on themselves

Aspect	Grief	Depression
Mood states	Range and variability of moods and feelings. Quick shifts from sadness to normal state in the same day. Variability in mood, activity, appetite, communication, sexual interest in the same week.	Moods and feelings are low, more static, little variability. Consistent sense of depletion, psychomotor retardation, anorexia, decreased sexual interest – OR – Compulsive communication, eating, or sexual behavior.
Expression of anger	Capable of expression, internally or externally directed.	Absence of externally directed anger, internally directed.
Expression of sadness	Weeping.	Difficulty weeping or controlling weeping.
Self-concept	Guilt associated with aspects of the loss. Experience the world as empty and meaningless. Preoccupation with the loss.	The loss confirms they are bad or worthless. Focus on punitive thoughts, guilt has global aspects. Preoccupation with self.
Responsiveness	Periodic, want solitude but respond to warmth and involvement.	Static, fear being alone or are unresponsive to other.
Pleasure	Sporadic restriction, retain sense of humor.	Restrict all pleasure, loss of sense of humor.
Reactions of others	Others want to offer support.	Others often feel irritated.

(Source: Transitions in Dying and Bereavement, Victoria Hospice Society, page 342, 2003)

The social worker has seen Mr. Matthews and his children over the course of the year since his wife's death and feels that they are coping well with their grief. Mr. Matthews decided to attend a grief support group for spouses and found it very helpful for him to hear about similar losses. He said the group helped him understand even more that what he was thinking and feeling were normal and gave him permission to keep the precious memories while still working to move forward in his life.

Mr. Matthews returned to the PCU with flowers on the anniversary of his wife's death to thank Anne, the social worker and the team for their special care of his wife and the family. He especially wanted to thank them for the information and guidance in helping him and the children to be able to prepare for and understand their grief in its many phases and forms.

On the thank you card Mr. Matthews gave to the staff was this memorable quote:

"Memory can tell us only what we were, in company with those we loved; it cannot help us find what each of us, alone, must now become. Yet no person is really alone; those who live no more echo still within our thoughts and words, and what they did has become woven into who we are"

Jewish proverb

HPC Nursing Competency Category 6

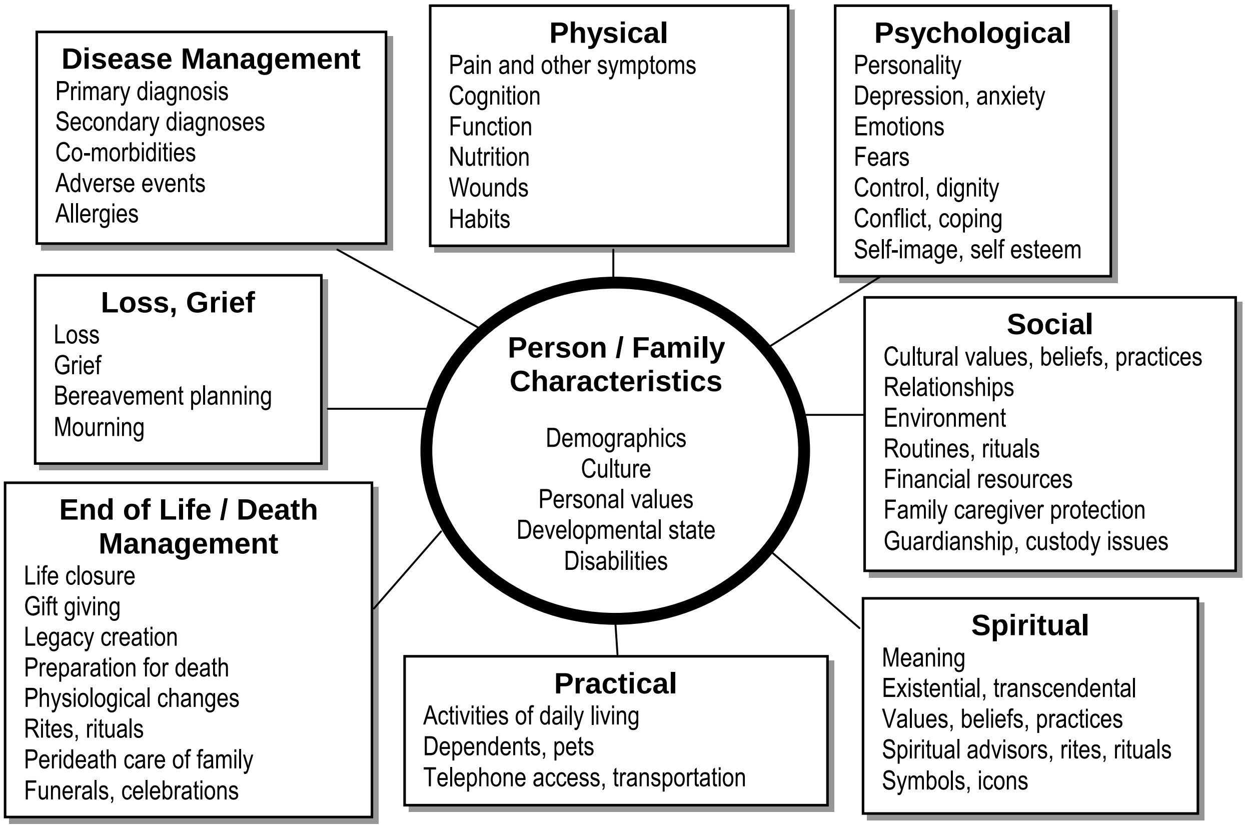
Interprofessional / Collaborative Practice

HPC Nursing Competency 6- Interprofessional / Collaborative Practice

The focus of Competency Category 6 is the provision of care to persons and families through the collaborative practice of an interprofessional team approach.

CASE
Alyson is a 14 year old girl with metastatic Ewing's Sarcoma. She was diagnosed 9 months ago and has spent much of her time in a tertiary pediatric centre located 3 hours from her home in a small tight knit community. She is an only child and lives with her parents and grandma in the family 100 year old, 2-story house. She has just made the decision to discontinue a Phase 1 trial of chemotherapy because of further progression of her disease, numerous side effects, a desire to return home for her Grade 8 graduation, and to stay home forever if possible. Alyson is an outgoing, very mature teen and has been actively involved in all discussions and decisions about her care since diagnosis. While Alyson and her family are anxious to get home they are all very nervous about leaving the safety and security of 24 hour care by the tertiary pediatric centre team they have come to know so well.

Rebecca is a nurse on a small community HPC team where Alyson and her family live. Rebecca has been with the team for 3 years and was a tertiary care pediatric nurse for 10 years prior to that. She is the only person on the community team with extensive pediatric experience, and this is the first time the team has been asked to provide care for a terminally ill child who wishes to die at home. Rebecca speaks with the HPC Clinical Nurse Specialist on the tertiary Pediatric Palliative Care Team to find out more about Alyson and her current care needs. They decide to have Rebecca meet Alyson, her family, and the pediatric team at the pediatric centre in order to learn first hand about Alyson's care and to smooth the transition home. Rebecca uses the domains of care for adults from the Canadian Hospice Palliative Care Association (CHPCA) Principles and Norms of Practice (page 15) to ensure that she has a comprehensive whole person understanding of Alyson, her family, and their needs.



Person / Family Characteristics
Demographics
Culture
Personal values
Developmental state
Disabilities

Disease Management
Primary diagnosis
Secondary diagnoses
Co-morbidities
Adverse events
Allergies

Physical
Pain and other symptoms
Cognition
Function
Nutrition
Wounds
Habits

Psychological
Personality
Depression, anxiety
Emotions
Fears
Control, dignity
Conflict, coping
Self-image, self esteem

Loss, Grief
Loss
Grief
Bereavement planning
Mourning

Social
Cultural values, beliefs, practices
Relationships
Environment
Routines, rituals
Financial resources
Family caregiver protection
Guardianship, custody issues

End of Life / Death Management
Life closure
Gift giving
Legacy creation
Preparation for death
Physiological changes
Rites, rituals
Perideath care of family
Funerals, celebrations

Practical
Activities of daily living
Dependents, pets
Telephone access, transportation

Spiritual
Meaning
Existential, transcendental
Values, beliefs, practices
Spiritual advisors, rites, rituals
Symbols, icons

Alyson’s community is very close and have followed and offered support to her and her family since her diagnosis. Alyson and her parents consider the small community their extended family.

Rebecca organizes a team meeting for the following afternoon. She arranges for the physician, social worker, and spiritual care person on her community team to speak directly with the physician, social worker and spiritual care person on the tertiary pediatric unit team in order to facilitate a smoother transfer of care. The next day she goes to Alyson’s home with the occupational therapist to meet Alyson’s grandma who shows them around the house so they can assess what might be needed to support Alyson’s physical care and comfort at home. Rebecca also contacts Alyson’s school, the community’s emergency medical services and home care to invite a representative from each to attend (in person or by conference call) the team meeting.

Rebecca is aware that several of her community team members and the home care nurses are quite concerned at the prospect of caring for a terminally ill child. She reviews the CHPCA Pediatric Hospice Palliative Care: Guiding Principals and Norms of Practice and finds the details of the domains of care that children and families may need are very similar to the adult ones, with the addition of a section on developmental issues. She decides to use the adult domains of care to present Alyson’s situation in order to remind the team of the similarities in approaching this situation and how they approach all families they care for, and underlines the issues that are more unique to a child’s situation and developmental needs. Rebecca facilitates the team meeting. Since there are additional people from the community in attendance she starts by having everyone introduce him or herself and say something about their usual role in caring for persons and families. Rebecca then presents Alyson’s situation using the domains of care model:

Alyson
Mr. & Mrs. Price
Mature 14yo girl
Caucasian
Only child
Lives with parents
Mother quit her job
Father on sick leave

Disease Management
- Ewing's Sarcoma in pelvis diagnosed 9 months ago
- Large metastases in lungs and in spinal cord
- Paralysis to lower extremities

Physical
- Neuropathic pain managed with morphine pain pump via central line and adjuvants
- Some dyspnea
- Concern she may become suddenly dyspneic and have a pulmonary bleed
- Needs urinary catheter and manual disimpaction for bowels
- Alyson weighs 120lbs

Psychological
- Vivacious, outgoing, self-assured, independent teen
- Family very fearful of being home without 24 hour care
- Father has a history of depression
- Although a minor, Alyson has made most of her own care decisions

Loss, Grief
- Alyson appears to be coping well with many losses but has teary moments and hates to be alone
- Parents quite devastated at impending death of only child but put on a brave face
- High risk for complicated grief
- Concern for impact of death on peers and teachers

Social
- Very close relationship with several school friends
- Used computer to keep in close contact with friends while in hospital – no home computer
- Children's Wish Foundation to support her attendance at Grade 8 graduation in 2 days
- Health insurance will cover some 24 hour care but the family is on reduced income due to sick leave

End of Life Care
- Alyson has been making lists of who to give many of her possessions to
- She wants to create a scholarship in her name
- Some funeral plans made
- The family has had some preparation from the pediatric team on what to expect including the possibility of a sudden event leading to death

Practical
- Bedroom on second floor
- Steep, narrow staircase in home
- Alyson is adamant that she wants to be in her own room and bed
- Family has one small car

Spiritual
- Family not members of particular faith community
- Alyson asks everyone she meets about their beliefs regarding an afterlife
- Alyson has been wondering about getting baptized

After reviewing each domain with the team, Rebecca outlines the immediate goals of care as established when she met with the family at the pediatric centre:

1) to be transferred home
2) to attend graduation in two days
3) to have excellent pain and symptom management and support for Alyson, her family and her peers
4) to spend final days at home

Community team members are a bit overwhelmed, particularly given the timeline, but eager to achieve these goals. Rebecca reminds them that no one is alone in meeting the goals, and when everyone works collaboratively it will all happen. She also reminds them of the importance of communicating regularly with each other. The team makes a list of what needs to be done and who will be responsible for each item:

- Rebecca or her designate will coordinate ongoing care.
- Occupational Therapist to provide and install assistive devices in the home to facilitate care in Alyson's bedroom and to arrange for loan of a lightweight wheelchair and install bars on staircase
- Home Care Coordinator to arrange 24 hour nursing care in the home for one week, and then plan to reassess. Rebecca will provide an in-service on central line care and review of Alyson's other needs.
- Social Worker to access financial support for nursing and/or other care and connect with Alyson and family to provide support.

- Spiritual Care Person to connect with Alyson and her family to offer support when needed. Alyson and family have indicated they may wait until after graduation to meet.
- Community Emergency Medical Services Coordinator to arrange transfer home by ambulance and to have Community Volunteer Response Team available, but inconspicuous, at the graduation. They are willing to carry Alyson up and down the stairs as it is not possible for a stretcher to fit.
- Pediatric and Community Physician collaboratively develop order sheets with details of acute symptom management plans in case of a sudden event while noting that resuscitation is not be attempted. Resuscitation had been discussed with Alyson and her family a few weeks ago by the pediatric team and they were all in agreement with the plan not to attempt resuscitation.
- Community Pharmacist creates emergency medication kits to fit with the physician orders and to have available in the home and for the paramedics.
- School principal and division Guidance Counselor will discuss the situation with the teachers and the school crisis support team. The crisis support team will be on call during graduation and ready to provide support to students and staff in the coming weeks.
- Rebecca reports that the Children's Wish Foundation has arranged for limousine transportation to graduation and an esthetician to come to Alyson's house to do her nails and make-up. A special wig, vibrant red gown, and silver shoes have already been chosen by Alyson and purchased. A special photographer has been arranged to capture the whole day. The Foundation has also arranged for high speed wireless internet to be installed in the home and Alyson is bringing her new laptop home with her.

Rebecca summarizes the meeting and circulates the documented goals and plan later that day. She makes sure copies of the physician order sheets are placed in all of the appropriate areas. She contacts the tertiary Pediatric Team to let them know all of the plans that are in place.

Alyson arrives home the next morning by ambulance. Rebecca meets her there and introduces the nurse who will be staying for the day. Rebecca outlines all the plans that are in place and assesses that these meet with the Alyson's and her family's expectations and needs.

Alyson, her parents and grandma attend graduation the next evening. All supports are in place and the evening goes beautifully!

Rebecca organizes a meeting with Alyson, her parents and community team members the following week to update the care plan now that the immediate goals have been achieved. Alyson has been quite stable, and the decision is made to cut back on nursing care to 8 hours at night plus daytime visits by trained personal support workers to do catheterizations and other personal care. After the meeting, Rebecca spends some time with Alyson's parents and grandma reviewing symptoms that might be expected and the plans for what to do for each symptom.

Over the next few weeks with the assistance of the Spiritual Care Person, the Social Worker, and Rebecca, Alyson fulfils her wish to be baptized, gives away several of her possessions, writes a will, and completes planning of her funeral. During this time Rebecca checks in frequently with members of her team to ensure they are coping well with the situation. She also provides frequent updates to the tertiary Pediatric Team.

Early one morning, Rebecca receives a call from the home care nurse to say that Alyson has died. Alyson became suddenly breathless just before the night nurse was due to leave the house. Medications were given appropriately and quickly by the nurse. Alyson's parents and grandma were at her side and she died quite peacefully. Rebecca contacts the Social Worker and Spiritual Care Person who go to the home to support the family and the Physician to pronounce her death. Rebecca contacts the school principal who initiates their crisis protocol to contact teachers and have the crisis support team at the school to tell the students and provide ongoing support. Rebecca also contacts all of the team members who were involved with Alyson and her family, and the pediatric team to tell them of Alyson's death. Rebecca then goes to the house to support the family and team members, and offers to contact the funeral home when they are ready.

Several team members attend Alyson’s funeral a few days later.

Rebecca organizes a team meeting to discuss and debrief on the experience of caring for a terminally ill child. The meeting includes snacks and the opportunity for team members to share feelings, experiences and support each other in their sadness and grief over Alyson’s death. Plans are also made between Rebecca, the Social Worker, the Spiritual Care Person and the Community Grief Support Network to assess and offer bereavement follow-up care to the family and the community.

HPC Nursing Competency Category 7

Education

HPC Nursing Competency Category 7 - Education

Competency Category 7 focuses on the ability of the HPC nurse to take a lead role in promoting the awareness and growth of palliative and end of life care attitudes, practices, competencies and knowledge with the person and family, members of various professions, volunteers, the wider community and the public. Each interaction becomes an opportunity for education to build enhanced understanding and capacity professionally and interprofessionally and to assist our society. Several of the competencies within this category are illustrated throughout the cases highlighting education as an integral role of the HPC nurse.

INTRODUCTION

Education provided by the HPC nurse may take many forms including such avenues as formal presentations at conferences or in university or college courses; informal presentations at rounds, inservices, or journal clubs; and one-to-one teaching of colleagues and terminally ill persons and their families as the opportunity or need arises. The HPC nurse is often called upon to help or participate in developing educational tools, guidelines, policies, brochures, and pamphlets that will assist in providing relevant information and guidance in the care of the terminally ill person and family.

When providing information and guidance particularly to persons and families, it is important to first assess their understanding and needs. Questions to consider in this assessment could include:

- What information are they asking for? What information do they need to know?
- How do they like to receive their information? (written, verbal, both)
- Would they like to know every detail and reason behind everything or just the basics?
- Would they prefer for you to talk to the person or the family first, or everyone together at once?

The HPC nurse must keep in mind that there can be different learning styles and preferences within a family. As well, needs and preferences may change over time so ongoing reassessment is needed. Similarly, if the HPC nurse is working with a family previously unknown to him/her, an assessment of what they already know should be one of the first areas that need to be covered. The HPC nurse is not to assume that everyone is well informed.
The information and education that the HPC nurse shares should be relevant, timely and congruent with the person and family's goals of care. An important point to remember is that the person and family's anxiety, stress and fear related to the situation may sometimes make it difficult for them to take in new information. Learning, developing and applying good communication strategies is of utmost importance for the HPC nurse. Providing information verbally as well as in written format, and then following up to reinforce the information is essential. The Canadian Hospice Palliative Care Association (www.CHPCA.net) has appropriate educational materials to share with persons, families, volunteers or for the HPC nurse to use in education sessions. The Canadian Virtual Hospice (www.virtualhospice.ca) provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

CASE

Ashley is a HPC community liaison nurse on a palliative care team. She is scheduled to conduct an inservice that morning at a long term care facility. She has also been informed that Mrs. Greenwood, a 94 year old woman with advance dementia and on her third bout of aspiration pneumonia, will be returning to the facility from an acute care hospital. Despite a trial of attempted active acute care interventions (antibiotics, IV therapy, physiotherapy) Mrs. Greenwood still remains extremely weak, non-communicative and unable to swallow. An advance care plan had already been made and now has been further discussed and agreed upon with the family, and palliative and long term care team which states that, if a situation such as this occurred again, the goals and focus of care would be supportive comfort care in long term care only. There would not be attempts to force food or fluid or to ambulate at this stage. The consensus is to allow the natural process to take its course with dignity and good symptom control.

Mrs Greenwood is expected to live for only a few days and is returning to stay at the long term care facility which has been her “home” for 10 years. The director of long term care is concerned that some of her staff will have difficulty with the end of life plan of care as many of them are quite new, from an acute care background, and have stated that they have not dealt much with this type of care situation before.

Ashley greets the new staff and begins the inservice with some exercises to encourage the staff to reflect on their own personal values and beliefs related to death and dying and appropriate realistic interventions at this end of life care stage. She then generates discussion on the principles of palliative care generally and then more specifically in terms of how they apply to Mrs. Greenwood’s situation. Ashley highlights the benefits versus burden and the quality versus quantity of life issues and interventions that would not help Mrs. Greenwood at this stage (force feeding, getting up in a chair, tub baths, frequent turning etc.) due to her imminent dying stage and the current goals of care. Ashley focuses most of her teaching time on the things that can and should be done to ensure Mrs. Greenwood comfort (mouth care, pain and symptom management, skin care, support for Mrs Greenwood and her family, etc.). The group share how their personal values and previous professional acute care experiences may indeed come into conflict with the advance plan and the family’s values or decisions that have been made. They are appreciative of Ashley’s inservice, experience and knowledge in HPC nursing practice which helps them explore and understand the concepts of holistic care at this final stage. They agree that it is important to provide good comfort supportive care according to the care plan and the family’s wishes. After the session Ashley spends some extra time to support and further answer concerns with a few staff members who seem to still be having particular difficulties and has assured them that she will follow up on how they are coping if needed.

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After the inservice, Ashley receives a call from another nurse who is new to the palliative care consult team. The novice hpc nurse is caring for a man who is currently taking Hydromorph-Contin 3 mg q12h and Tylenol PRN. The family physician has just written an order to convert him to a Fentanyl patch 25 mcg/h q3days because the man is no longer able to take his pills. The novice hpc nurse has not had much experience with opioid conversions or the Fentanyl patch and asks Ashley to review the order with her. The man has been comfortable on the po Hydromorph-Contin and the novice hpc nurse wonders why the he is just not converted to the sc Hydromorphone. The man and family are wondering if they could try that method as well before going to a patch.

The current order of Hydromorph-Contin provides 6 mg of Hydromorphone in a 24 hour period. Using a conversion table guideline the new Fentanyl patch order is roughly equal to 18 mg of oral Hydromorphone in a 24 hour period. Ashley shares with the hpc novice nurse that the Fentanyl patch as ordered will likely be too much to begin with (triple the current dose). Ashley reviews with and teaches the hpc novice nurse how to calculate and convert to a subcutaneous (SC) dose of Hydromorphone which should be discussed with and possibly suggested to the physician. Using a 2:1 ratio of short acting oral to parental, the appropriate dose is Hydromorphone 3 mg over 24 hours which could be given as Hydromorphone 0.5 mg SC q4hr with an additional order for Hydromorphone 0.5 mg SC available hourly as a breakthrough dose as needed. Ashley coaches the hpc novice nurse on how to approach the physician to further ascertain his decision making around this conversion and route, to relay the person and families wishes, and if it would be more appropriate to start with an order for sc pain medication at this time. Ashley tells the hpc novice nurse to page her back to let her know the outcome and also to continue to connect if she can be of further assistance and support.

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Ashley has a student nurse James with her for the afternoon. They attend palliative care interprofessional rounds and Ashley and the individual team members teach James about the importance of interprofessional practice in palliative care and their various roles and responsibilities on the team. They conduct team rounds to visit some patients and families on the PCU and James gets a first hand view of Ashley and the palliative interprofessional team in practice.

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Ashley is then called to the home of Mr. Williams, an 84 year old man diagnosed with prostate cancer with metastasis to the bone, liver and brain. Mr. Williams lives with his daughter, a pediatric nurse, and her family. He has been fairly stable until today when he began experiencing a delirium. Ashley knows Mr. Williams and his family well. His daughter in particular requests to receive all of the details related to her father's care. She is comfortable with medical language but always reminds team members that she cares for children, not adults, and has little experience with adult end-of-life care. Ashley asks for her permission to bring the student James to her visit and asks if it is permissible to talk openly, with James present for the learning experience, about what she is assessing could be the possible causes of this new delirium. The daughter agrees, and Ashley introduces James to Mr Williams and his daughter. After assessing Mr. Williams, Ashley talks through the possible delirium causes:

- progression of brain disease (maximum doses of radiation have been given)
- possible infection (his lungs were clear but he may have a urinary tract infection)
- hypercalcemia (due to his bone metastasis)
- metabolites imbalance (due to his disease process)
- medications (such as his opioid)
- pain (repositioning from morning care or disease progression)
- hypoxemia (likely not an issue as his lungs were clear and has does not seem dyspneic)

Ashley contacts the family physician and shares her assessment and findings. Blood work (calcium, albumin, electrolytes) and a urine culture are ordered as well as Haldol SC for the delirium. Ashley also administers a breakthrough dose of Mr. Williams' pain medication as ordered. Mr. Williams seems somewhat more peaceful following that and Ashley encourages his daughter to give a breakthrough dose of his pain medication prior to his morning and evening care. Ashley also arranges to have an air mattress brought to the home. The daughter is also taught to keep completing the pain and symptom diary to continue to assess her father's delirium and other symptoms, what has or has not helped etc. Ashley reviews the goals of care with the daughter and discusses reasonable avenues for further investigation of possible causes of the delirium and possible treatments once they have the results back from the blood work and tests. She spends additional time in the home supporting the daughter and assessing her needs for extra caregiver support and who to call after hours for assistance. Ashley says she will do a follow up visit tomorrow. After the visit Ashley debriefs with the student James about all that happened to reaffirm the more subtle and extensive aspects of palliative care in assessing and supporting a person and family at home.

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That evening Ashley has agreed to set up and run a booth at a local health and wellness show for the general public. She has a number of pamphlets that she assisted in developing about hospice palliative care (including grief and bereavement) as well as advanced care planning, living wills, community services information, and other services information that are available. She responds to a number of questions throughout the evening especially about hospice palliative care, and goes home that night feeling fulfilled in what she was able to accomplish in teaching and supporting others while caring for the person and family in her day.

It is in continuously integrating education and teaching into everyday practice that the HPC nurse truly works to provide quality comprehensive collaborative interprofessional holistic care.

HPC Nursing Competency Category 8

Ethics and Legal Issues

HPC Nursing Competency Category 8 - Ethics and Legal Issues

INTRODUCTION

Competency Category 8 focuses on ethical and legal issues in the palliative care setting. The HPC nurse must possess effective communication skills and be knowledgeable of the Code of Ethics for Registered Nurses and other team members in order to collaborate with the person, family, substitute decision-maker and interprofessional team. The nurse must also be able to utilize a framework that addresses the psychological, social, physical, spiritual and practical issues associated with difficult ethical and legal issues related to death and dying. These can include such areas as withdrawing/withholding treatment, no code status, futility, medical abandonment, palliative sedation, principle of double effect, disclosure and truth telling and research and resource allocation at end-of life.

CASE

Mr. Michaels is a 50 year old man with a supportive and loving wife of 30 years. He has three adult daughters who are very involved in his care. He was diagnosed with Amyotrophic Lateral Sclerosis (ALS) seven years ago. His disease has now progressed to the stage that he cannot move at all and he uses a number/letter board to communicate. In the last month he has had difficulty swallowing and breathing difficulties have occurred more frequently. They are a close knit family with limited extended family/friends and refuse outside supports. Mr. Michaels has a health care directive and Mrs. Michaels is the proxy as well as the advocate for his health care decisions. Mr. Michaels has clearly stated that he does not want any treatments that may prolong his living or prolong his dying. He has his will completed and the funeral arrangements planned.

Mr. Michaels is admitted to the PCU because he did not want to remain at home as he felt it was getting too hard on his wife and children to witness his suffering as well as to attend to his increasing care needs. Additionally his increased secretions and inability to swallow was becoming an issue. In the past week he had several times when he was choking on his secretions and “could not catch my breath” which were extremely distressing to his family and to him. He has made it known verbally as well as in his advance directive that once he cannot swallow he does not want to receive artificial food or fluid and he did not want to be “hooked up to a machine” if he could not breathe. His doctors estimated his prognosis to be less than a month. One daughter, Peggy, is still having trouble with her father’s decisions.

Two weeks after his admission to the PCU, Mr. Michaels can no longer eat or drink, is having increased fearful episodes of choking, has intractable dyspnea, with his condition estimated to be in the final days. He is concerned that he will soon loose his mental capacity to direct his care. He has previously discussed options with his PCU physician and has expressed his desire to use the option of palliative sedation to ease his suffering. Mrs. Michaels and two of his three daughters are in support of his wishes; however, the other daughter Peggy is not. Mary, the HPC nurse assigned to care for Mr. Michaels enters the room and finds the daughters intently arguing over their father’s bed. Peggy is crying and yells at Mary, “You want to kill my dad! That is murder and I will report you to the police!” Another daughter yells back at Peggy “You are making dad suffer an inhumane dying! Can’t you see how he is suffering? Why can’t you let him go in peace?” After guiding his daughters to further talk about this in the PCU quiet room Mary actively and calmly acknowledges to his children how much they all love their dad and that they want what they each feel is best for him. Mary talks separately with Mr. Michaels and his wife and through mutual consensus promises to arrange a family meeting to discuss issues (most especially around the ethical and legal issues) regarding Mr. Michaels’ present suffering and his request for palliative sedation.

The Ethical Decision-Making Grid

The palliative care team routinely uses the Ethical Decision-Making Grid as a tool to guide their discussion of complex ethical decisions such as is happening with Mr. Michaels and his family. The grid contains four perspectives: medical considerations; person / family factors and preferences; quality of life issues; and other contextual considerations. The ethical principles of autonomy, beneficence, non-maleficence, and justice are also considered in the discussion. The palliative care team members, Mr. and Mrs. Michaels and their daughters, and the hospital ethicist meet to share their viewpoints within each of the four perspectives in the grid.

Medical Considerations ➢ Facts of the medical history ➢ Prognosis ➢ Treatment options, risks vs. benefits ➢ Are treatments being considered consistent with goals of care?	**Person / Family Factors and Preferences** ➢ Person/family understanding of illness ➢ Person's capacity to make decisions ➢ Person's goals
Quality of Life Issues ➢ What does quality of life mean for the person (and family)? ➢ What gives meaning and brings dignity to their life?	**Contextual Considerations** ➢ Whose interests are affected? ➢ What are societal norms and expectations? ➢ What are the thoughts of the caregivers?

(Source: PALLIUM Palliative Pocketbook Page 2-9. Adapted from Kuhl D, Wilensky P. J Pall Med. 1999.)

Medical Considerations (Beneficence (do good) vs. Non-maleficence (do no harm)):

Mr. Michaels is in the last stage of his terminal illness trajectory. His prognosis is likely less than 1 week. On examination he is bedridden and having difficulty communicating, swallowing, and breathing which he now finds absolutely unbearable when awake. He communicates on his number/letter board that his suffering is too physically and emotionally overwhelming and that being awake adds more to his symptom suffering than he ever imagined. The team acknowledges that his fear of choking is a real one given his underlying disease process and it is noted that if he had an episode of choking while conscious he may then require rapid sedation to alleviate his acute suffering. It is possible that he would experience a great deal of suffering in the minutes between when the choking episode begins and when sedation is achieved. The team notes that the present goals of care are to keep Mr. Michaels comfortable and to achieve a peaceful dying and death. The team shares with Mr. Michaels and his family that the primary intent of initiating palliative sedation would be to "do good" to help alleviate the refractory symptoms such as Mr. Michaels is experiencing and that sedation would be applied appropriately according to accepted guidelines. (See web resource at http://www.crha-health.ab.ca/clin/cme/cpg/cpg_PalliativeSedationGuidelines2009v4-2.pdf) The primary intent is to "do no harm" and not to deliberately shorten/hasten death as to do so would not be justified legally, medically, or ethically.

Person / Family Factors and Preferences (Autonomy):

When the psychiatrist conducted an assessment of Mr. Michaels' mental status he found him rational and clear of thought. All of Mr. Michaels' personal and business affairs are in order; he does not feel he has any unfinished business in his life and depression was and is not a major factor in his request.

Mr. Michaels is an autonomous agent and capable of making his own decisions and setting his own goals in order to maintain human dignity. There are two conditions that must be present for autonomous decision-making: liberty and agency. Liberty means to make decisions freely from undue influence and agency means to have full mental capacity to make a decision based on personal choice. This is explained to the family that Mr. Michaels possesses both of these conditions and he has decided he needs palliative sedation as an intervention to relieve his intractable suffering.

Quality of Life Issues (Beneficence vs. Nonmaleficence):

Mr. Michaels had owned a successful business that he started as a young man. He valued being in control of his own life and destiny. His illness was affecting his quality of life to the point where he was requesting to be asleep so that he did not have to endure further suffering. He felt deep palliative sedation would provide good palliative care and relieve his suffering. It would also improve his quality of life because he would be in control of the decision and would not be living in fear. He felt that without palliative sedation he would have poor quality of life because of his fear of choking and struggling to breathe - with the desire to have his family not witness his unbearable suffering. While his one daughter Peggy recognized his fears and also wanted to prevent a dying full of suffering she expressed her belief that death should not be hastened even indirectly. She was very emotional and admitted that she just was not yet ready to let her dad go.

Contextual Considerations (Autonomy vs. Justice):

Mr. Michaels wanted palliative sedation to ease his intractable suffering. His daughter Peggy felt sedation was an illegal act while Mr. Michaels, other family members and the team felt the appropriate circumstances existed for palliative sedation - the intent was to treat the intractable symptoms of suffering. Peggy still felt there was no difference between palliative sedation and "euthanasia" and that they were both illegal acts. She stated that her father would be rendered in a state of unconsciousness where he would not be able to eat or drink and this would hasten his death as she continued to deny that he presently is not able to eat or drink and does not want feeding or drinking to be given artificially. Peggy also felt that her father was being selfish and only considering his needs and not the fact that she still wanted time to communicate with him. Her mother and her sisters felt Peggy was also being self-centered because she wanted to prolong her father's suffering because of her own needs.

Outcome

Through several team and individual discussions of all of the components of the ethical grid, Mr. Michaels gained a better understanding of the suffering of his daughter Peggy related to his request for palliative sedation. Peggy also better understood the possible scenarios of what suffering and death might look like for her father with and without sedation prior to an acute episode of choking and loosing his breath. The team reviewed the guidelines they have in place to assist in appropriate application of palliative sedation and agreed with Mr. Michaels that palliative sedation could be offered as an ethical course of action. Mr. Michaels requested that this be delayed a few more days to give him some additional time with all of his family, especially to prepare Peggy more. In the meantime, management of his secretions was maximized and a plan for rapid sedation was put in place should he begin to choke or have trouble breathing. Mary, the social worker and pastoral care spent a great deal of time with each family member individually and as a group to provide additional supports. Three days later Mr. Michaels had increasing dyspnea and requested to be sedated. All of his family was with him and supported his request. He was sedated and the team continued to monitor him for any signs of discomfort. Mr. Michaels died in no apparent discomfort two days later.

HPC Nursing Competency Category 9

Professional Development and Advocacy

HPC Nursing Competency Category 9 - Professional Development and Advocacy

INTRODUCTION

Competency Category 9 addresses issues of professional development and advocacy. The HPC nurse must be able to reflect on his/her own professional growth and self-care in order to assist a terminally ill person and their family at end-of-life. The nurse must also be able to identify potential opportunities and barriers to nursing research that will integrate current knowledge based on evidence-informed standards such as clinical practice guidelines and pathways that reflect valuable and effective person outcomes. Most importantly the HPC nurse must be a strong advocate for this often vulnerable population supporting their autonomous decision making at all times.

CASE

Susan is a community visiting nurse. Mrs. Greer is an 80 year old client diagnosed with end-stage liver cancer wishing to remain in her home as long as possible. Mrs. Greer suffers from complex and difficult pain issues and is taking large doses of opioids with equally large doses of breakthrough opioids that she can have every hour if needed. Mrs. Greer lives with her 22 year old grandson who is not very supportive to his grandmother and often takes advantage of her both physically and financially. In the last few months Mrs. Greer's pain control is unmanageable despite increases in her opioid use. She is still clear of thought and seems to be handling the large doses well. It soon becomes clear to Susan that Mrs. Greer's lack of pain control is directly related to her grandson's drug addiction. Mrs. Greer is aware of her grandson using her medication but states, "he needs the pain medication more than me, please do not report him as I need him here." Mrs. Greer is vulnerable to her grandson's theft. Susan is very aware that she cannot bend the rules for the sake of Mrs. Greer's request but rather must question the abusive behavior and change circumstances in order to effectively advocate for her client.

Before initiating the action plan, Susan considers the following:

- The plan must be within the scope and practice of the Registered Nurses Act and the Nurses Code of Ethics;
- The plan must be within the limits of the program policies and job description;
- The plan must be within the HPC nurse's competencies and standard of practice.
- She has taken time to recognize how her personal values and beliefs are related to Mrs. Greer's vulnerable state and the abusive nature of her grandson.
- She also conducts a thorough literature review and contacts the nearest senior centre to review and obtain direction about Elder Abuse.

After a team meeting and consultation with colleagues and program director, Susan works to develop a therapeutic relationship with Mrs. Greer's grandson, while also confronting him about his use of his grandmother's medication. Mrs. Greer's grandson was remorseful about his behavior, said he needed help, and agreed to attend addiction counseling. In the meantime Susan devises a process where Mrs. Greer's scheduled pain medications are in a lock alarmed box that only she and other nurses can access. Mrs. Greer's breakthrough medication is also monitored closely.

After the immediate issue is effectively handled at the individual level Susan conducts a literature review to assess if this is a problem on a national level. She finds other provinces and jurisdictions have similar challenges and in fact the abuse and misuse of prescription opioids in the community is a national concern and the numbers of people addicted to prescription medications is at a threatening level. Susan decides to advocate for and help form a committee with community stakeholders (physicians, nurses, police, pharmacists, and social workers) in order to develop and set forth a regulatory process to change public policy. Susan hopes this group will assist to increase public awareness and provide an avenue to be more cognizant and protective of such vulnerable populations who require opioids in the home and care at end-of-life that may be targeted for abuse by those addicted to opioid and other medications.

CONCLUSION

We hope that these cases have been of additional assistance to those who wish to study for the HPC Certification Exam and enhance their ongoing collaborative care of terminally ill persons and their families.

This poem sums up the essence of what we continue to strive to achieve through improving our knowledge, attitudes, skills and competency in holistic hospice palliative care nursing and interprofessional care giving:

The Hospice Palliative Care Nurse

Who I am is as important and instrumental as what I do.

It is when I am highly skilled and deeply attuned that I do my best work.

It is when I integrate my practice and my presence that I truly practice the art of nursing - the art of Hospice Palliative Care Nursing.

I bring to the patient and family more than I often realize.

I know that:

..If I bring confidence - they are less afraid.

..If I bring compassion - they are comforted.

..If I bring sensitivity - they know I care for THEM.

..If I bring creativity - they know possibilities.

..If I bring a centered and peace-filled presence - they touch
the spiritual in time and space.

..If I bring information - they feel respected and involved.

Janis Brown, RN, MS, MDiv

All the best in your studies and ongoing HPC nursing!

Sincerely,

Darlene, Laurie Anne, Kim, Maryse, and Patty

December 2009