UBC Department
of Family Practice

CARE FOR ELDERS

Palliative Care

•Case Study•

June, 2004

Acknowledgments:

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For information on other modules please contact:

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Palliative Care: (2004)

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Palliative Care

Goals and Learning Objectives

At the end of the Palliative Care module, you will be able to:

1. describe how hospice palliative care/end of life care encompasses disease modification and symptom management within various disease trajectories,

2. describe the dimensions of whole person care.

3. demonstrate the significance of the family as the unit of care in hospice palliative care/end of life care,

4. identify unique characteristics of hospice palliative care/end of life care for elders,

5. incorporate the dimensions of diversity (culture, gender, race…) of clients (Stan and Betty) in hospice palliative care/end of life,

6. address issues of continuity, and transitions in providing hospice palliative care /end of life care across the continuum of care,

7. discuss the synergy and support provided by the interdisciplinary care approach to hospice palliative care/end of life care,

8. explore strategies for managing conflict within families and within the team,

9. create a patient/family centered care plan for Stan and Betty which addresses:
    - pain and symptom management
    - spirituality and existential issues
    - psychosocial issues
    - ethical and legal issues
    - quality of life
    - advance care planning
    - death management
    - grief, loss and bereavement,

10. identify skilful ways of delivering “bad news”,

11. reflect that hospice palliative care /end of life care can be very rewarding and emotionally challenging work for health professionals, and

12. identify how you will address your own self care needs.

Stan and Betty : Two Lives

Introduction

Mr. Stan Johnson is a 73 year old Caucasian retired millwright. He worked in the lumber industry and has a grade 8 education. He chain smokes 3-4 packs/day. His first wife died of breast cancer 15 years ago. Mrs. Betty Wilson, 65, lives common-law with Stan. She is First Nations, and has a Grade 10 education. She married young and raised 6 children in her remote Northern village. She is an excellent cook, which she enjoys greatly and also makes jewellery. She has type 2 diabetes mellitus and congestive heart failure and is mildly overweight. She has shortness of breath with exertion. Her first husband was alcoholic and died of liver cirrhosis 12 years ago. After her husband died, she became friendly with Stan and moved in with him 10 years ago before moving o the small rural town in which they now reside. He drives, she does not.

Previously, Stan did most of the grocery shopping and housework because of her difficulty with ambulation and bending over. Betty does the cooking. Her children and siblings still live in their remote village. Stan has a daughter Laura, 44, who lives in town. He has one son who lives in a large city 800km away, and who has had little contact with his father. Laura has two teenaged children. Laura is very devoted to Stan but has had some issues with his relationship with Betty, although she admits “Betty has been good for him”.

Stan is a member of the Legion and goes in every week for a beer, and plays darts. Betty has few other contacts in town, has missed her family but was willing to move with Stan so that he could be closer to Laura. Betty’s father was a spiritual leader within his Nation. She is converted to Anglicanism and attends church regularly.

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Part I.

Stan develops a cough and some bloody sputum. He goes in to see their family doctor Dr. Hagedoorn. After some tests, Dr. Hagedoorn sets up a meeting with Stan to tell him about the diagnosis of non-resectable lung cancer.

Questions:

1. How should Dr. Hagedoorn break the bad news to Stan?

Part I. ***Continued***

Dr. Hagedoorn asks Betty to be present. He explains gently that the radiologist has seen evidence of a tumour on one of Stan's lungs, and that the tumour has spread. Stan asks what that means. Dr. Hagedoorn responds that unfortunately the tumour has spread to the extent that it is not possible for the surgeons to operate and remove it. Stan asks what else can be done. Dr. Hagedoorn explains that while there are not too many options for removal of the tumour, there are several options available to alleviate Stan's symptoms and to ensure that he will be comfortable and free from pain. Betty begins to cry uncontrollably. Stan sits quite motionless and without affect. Betty tries to hug Stan but he sits rigidly staring ahead. Dr. Hagedoorn sits for a few minutes without saying anything more. After a few minutes, he asks Stan and Betty if there are any questions he can answer. There is silence. Dr. Hagedoorn says that he will leave now but that he can be available over the next few days to answer any questions or if he is needed. He gives Stan and Betty a telephone number where he can be easily reached and where he can be called at any time. Dr. Hagedoorn then makes another appointment with them for a few day's time.

He refers Stan to home care nursing. When Shelley, the HC nurse calls at Stan's house, he is somewhat hostile to her and wants to be left alone. "I feel fine. Betty can look after me!" The home care nurse calls once a week and talks to Betty to see how they are doing. Betty does tell Shelley that she is becoming more anxious, frightened, and short of breath and is afraid that she won't be able to cope with Stan's illness and death. Stan doesn't want anyone, including Betty, to bother Laura, his daughter. Betty talks to her minister and the minister asks a hospice volunteer to visit. When the volunteer comes to the door, Stan yells at her "Who the hell are you? I don't need any visitors", and turns her away. The volunteer and Betty are both quite upset but don't know how to deal with Stan.

Questions:

2. What strategies would you use for open communication with Stan and Betty?

3. What should be discussed at this point for advance planning?

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Part II.

Shelley obtains a referral for Betty, and Stan seems comfortable having Shelley come to their home to talk to Betty. After a couple of visits, Stan develops some trust in Shelley and they both agree to her periodic visits to monitor their medications and medical issues. They discuss his disease, but Stan insists Shelley not contact Laura. He would prefer to talk to Laura himself.

Six months later Stan has frequent headaches and he begins to complain about difficulty with his vision. He begins to be unsteady on his feet. Betty tells Dr. Hagedoorn that he seems occasionally confused. Dr. Hagedoorn arranges for Stan to have a CT scan of his head in the nearest city, accompanied by Laura. This motivates Stan to discuss his diagnosis with Laura. It shows several metastasic lesions. The neurologist tells Laura and Stan that Stan has less than 3 months to live without treatment, or 6 months with treatment. He offers palliative radiation therapy in the city, which is a 3 hour drive from home, but Stan refuses. He says "It's too much trouble to drive out here; if my number's up, then just let it be!" The neurologist prescribes a small dose of decadron 4mg twice a day and his symptoms improve. He is sent home with Laura.

Dr. Hagedoorn puts Stan on the BC Palliative Care Benefits Program.

Questions:

1. What will be the benefits of the BCPCB program for this family?

Part II. ***Continued***

Stan is now having difficult doing household tasks and helping with groceries. He is unable to drive and they are now housebound. Laura begins to drop off groceries for Stan and Betty. Betty wakes up during the night with chest pain; she is taken to hospital and is found to have had a myocardial infarction. She needs to stay in hospital for at least a few days. Laura would like to have Stan move in with her but Stan refuses. Laura spends increasing amounts of time at Stan's house, leaving her with little time for her own family. Laura calls Dr. Hagedoorn, saying she can't cope. Dr. Hagedoorn calls Shelley, the home care nurse, and asks her to reassess Stan and his care needs.

Questions:

2. How should the team assess the family's care needs and risk factors?
   What interventions might you consider implementing for Stan?

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Part III.

Shelley arranges home support workers for Stan, to provide bathing assistance and personal care for two hours, three times a week. Stan accepts reluctantly. Laura delivers meals and comes over every day to check on Stan. Betty is discharged from hospital, but there has been limited discussion with Laura and community support to facilitate her return. Betty is more short of breath and has poor exercise tolerance. Stan tries to cut back home support. Betty is very stressed by this and explains to Stan that she cannot provide the care he now needs. Shelley is concerned about their marital discord.

Questions:

1. How does the hospice/ palliative care trajectory apply to both Stan and Betty?

2. What issues should have been discussed with the community to facilitate Betty's return?

Part III. ***Continued***

Shelley sets up a care conference in the home with Stan, Betty, and Laura. At the meeting, it is suggested that Betty's children and family might provide some support. Betty's daughter Susan is called and comes down from their village. Susan is concerned about Betty's health, providing care for Stan. She suggests that she bring Betty back home with her. She wants to care for Betty in the context of her family's cultural background. Betty is conflicted between her attachment for Stan and her family's wishes.

Questions:

3. What are the major ethical issues involved in this case?

Part III. ***Continued***

Another family meeting is now set up with Dr. Hagedoorn, Shelley, Laura, Susan, Stan and Betty. Dr. Hagedoorn reviews Stan's and Betty's medical issues, prognoses, and the impact of caring for Stan on Betty's health. Dr. Hagedoorn says Betty has end-stage congestive heart failure and has a prognosis of approximately a year. Shelley re-frames the discussion to be around risks and ethics. Shelley asks Stan and Betty "What do you both want?" They state that they both want to stay together. They discuss the risks to Betty; if she stays, there is potential for deterioration in her health. If she leaves, stress and anxiety over the loss of Stan. The risks to Stan: further deterioration in his health, loss of support from Betty, depression and even suicidality.

Questions:

4. Develop a comprehensive care plan for Stan and Betty, using the domains of Whole Person Care. How would you discuss this with Stan and Betty? How should risk factors be monitored?

Part III. ***Continued***

Stan eventually accepts that he and Betty need more help in the home on an ongoing basis. They agree to an OT home assessment to review the house and the home situation. Betty's church will continue to provide spiritual support with visits, and volunteers to help Betty with some activities. They have a brief discussion of what Stan and Betty want if there is further deterioration, but there is no resolution by the end of the meeting. Laura and Shelley will keep Dr. Hagedoorn and Susan informed of their status.

5. How do you approach care planning in an interdisciplinary way?
   What does transdisciplinary mean? What activities for Stan and Betty might be handled in a transdisciplinary way?

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Part IV.

The plan that has been developed works fairly well and Stan and Betty do well for another month. Stan and Betty decide to take more time together and spend time in the garden. Betty cooks her special dishes. Laura offers to help Betty make some of the more difficult dishes that Betty is unable to prepare.

Laura and Shelley talk to the couple about further deterioration. Stan and Betty decide that if either of them becomes too sick, they would like to move together into a care home. They discuss levels of care. Dr. Hagedoorn, Stan and Betty sign the DNR forms. Stan says, "If I'm going to be a vegetable, let me go." Stan states that he would like Laura to be his proxy for health care decisions. Betty would like Susan to be her proxy. They discuss funeral arrangements. Finances are to be discussed in the near future.

Stan becomes more short of breath and anxious. Dr. Hagedoorn sees him at home and gets a chest x-ray which shows progression of his tumour. Stan feels he is dying.

Questions:

1. What are the components of medical symptom management and what should Dr. Hagedoorn suggest for Stan?

Part IV. ***Continued***

Dr. Hagedoorn starts him on a small dose of hydromorphone and this relieves his shortness of breath. He is still somewhat anxious, and Dr. Hagedoorn prescribes lorazepam on a PRN basis. Betty and Laura stay at Stan's bedside and feed him small amounts by hand. They keep his mouth moist and he appears comfortable. The Anglican minister visits regularly to comfort Betty.

Stan deteriorates over the next few days with anorexia and dysphagia. He has a seizure and is admitted to the hospital. He develops pneumonia, probably as a result of aspiration. He becomes unresponsive. Laura is asked to make further health care decisions. She calls Stan's son Gord, who arrives that night and wants to be involved. He disagrees with her decisions to not initiate IV and antibiotic treatment. Betty, however, is in agreement with Laura.

Questions:

2. What strategies would you use to manage family conflict?

Part IV. ***Continued***

Dr. Hagedoorn discusses the issues with Betty, Laura and Gord, and they revisit Stan's decision to have Laura as his proxy. They explain in detail to Gord, Stan's disease, prognosis and previous wishes regarding life-sustaining measures. He eventually agrees to Laura's decisions which reflect Stan's wishes. Stan dies.

Shelley supports Betty, Laura and Gordon after Stan's death. They call on Betty's minister who provides immediate support to Betty as well as helping Betty and Laura to plan the funeral. Betty goes up to Shelley and kisses her on her cheek, saying "Thank you for looking after my Stan". She gives Shelley a pair of silver earrings which she made.

Questions:

3. What are the important issues for the family around grief, loss and bereavement?

Part IV. ***Continued***

Susan comes down from the village to help her mother through this period. Betty decides that she will return with Susan to her village to be closer to her family after the funeral. Betty continues to deteriorate at home but it is hard to predict the time-frame of her death. It is fortunate that Betty is able to receive support in her close-knit family.

Shelley admits that she has found Stan's case challenging emotionally. Over the last few months she has cared for a number of patients who have died within a very short space of time.

Questions:

4. What are Shelley's self-care needs? What are some strategies to address those needs?

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Epilogue

Betty moves back to her village with Susan and the rest of the family. Although she has continued health decline, she is supported by her family and village. She dies a peaceful, supported death at home.

Please review the objectives and complete the evaluation form.

Care for Elders Module Evaluation

Module Title: **Date:** **Location:**

Please rate the following statements (✓):	***Strongly Disagree***	***Somewhat disagree***	***Neutral***	***Somewhat Agree***	***Strongly Agree***	***N/A***
1. The organization, room, and timing of the session was adequate						
2. The pre-reading package covered information that was new to me						
3. The pre-reading package was well organized and easy to read						
4. Today's session DID improve my knowledge of interdisciplinary roles, responsibilities and team dynamics						
5. The facilitator was effective in keeping discussion moving forward						
6. The facilitator provided new, critical information as needed						
7. The case complexity or difficulty was appropriate for my level						
8. The discussion in my group was helpful for my learning						

1. Please name **two** changes in your own practice that you will implement as a result of what you learned today.

   1. ____

   2. ____

2. Please name **two** ways in which this session could be improved.

   1. ____

   2. ____

Please return evaluation forms to: Division of Community Geriatrics, Department of Family Practice, UBC
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