Ian Anderson Continuing Education Program

in End-of-Life Care

Module 6

PSYCHOLOGICAL SYMPTOMS

A Joint Project of Continuing Education and the Joint Centre for Bioethics, University of Toronto
and The Temmy Latner Centre For Palliative Care, Mount Sinai Hospital

Objectives

The physician will be able to:

1. Describe the physical, psychological, social and spiritual issues of dying patients and their families and their impact on suffering and quality of life.
2. Assess, diagnose and manage anxiety, delirium and depression in dying patients.
3. Describe family systems and assess families.
4. Demonstrate skills in providing educational and supportive counseling to dying patient and their families.
5. Describe normal grief and be able to identify complicated grief.
6. Describe and manage the grief of patient and family.
7. Identify community resources for grief management.

Introduction: General Psychological Issues

1. It is not possible to die without having some psychological distress or suffering.
2. Feelings of helplessness, hopelessness, anxiety, sadness, depression and/or general psychological malaise are frequently seen in advanced life-threatening illness.
3. However, those feelings need to be acknowledged and addressed and not seen as inevitable consequences of dying that cannot be managed. It is a matter of quality of life.
4. Physical and psychological symptoms interact with each other to further complicate diagnosis and management of distress. There are a number of factors that influence the development of psychological morbidity:

People die as they have lived. It is not a realistic goal to try and change the personality of the patient or change families from dysfunctional to functional during an advanced progressive illness at the end of life.

5. Patients and their families at the end-of-life struggling with advanced illnesses are very vulnerable to the development of major psychiatric disorders.
   - In a study by Minigawa of 109 terminally ill patients, 57.3% met the criteria for a specific psychiatric disorder.[1]
6. The evidence suggests that many of these disorders are under-diagnosed and under-treated.
7. The initial reaction to a diagnosis of a life-threatening illness is one of acute grief with disbelief, anger, shock, sadness and anxiety.

Counseling and psychotherapy are learned therapeutic tools and therefore palliative care team members and other care providers require adequate training in these therapies. Harm may occur if well-meaning but untrained care providers deal with issues in a just a “common sense” approach or with unstructured assessment and counseling approaches.

Possible Factors Influencing the Risk of Psychological Morbidity

Area	Factors
Physical Issues	❑ Stage of illness, particularly advanced stage. ❑ Type of illness. ❑ Functional limitations. ❑ Physical symptoms, particularly pain and weakness. ❑ Anorexia/cachexia syndrome. ❑ Neurological dysfunction such as difficulty concentrating, dysphasia. ❑ Endocrine disturbances. ❑ Organic psychological disturbances such as delirium and depression. ❑ Changes in body image.
Psychological and Family Issues	❑ Previous psychiatric history and family dysfunction. ❑ Individual and family coping strategies. ❑ Substance abuse. ❑ Family abuse and violence. ❑ Unresolved grief. ❑ Post-traumatic stress disorder. ❑ Lack of preparation for death. ❑ Spirituality.
Treatment Issues	❑ Medications including opioids, chemotherapy, corticosteroids. ❑ Dependence on life support machinery or other aids. ❑ Radiotherapy. ❑ Multiple physician care providers with lack of coordination and/or communication.
Social factors	❑ Socioeconomic status. ❑ Financial issues. ❑ Culture and ethnicity. ❑ Religion and/or belief system. ❑ Family history of illness. ❑ Lack of supports. ❑ Availability of medical support services such as palliative/hospice care, home care or other components of health care.

Modified after Breitbart[2]

8. Management of psychological distress will require a holistic approach that examines all the matrix of factors in the above table.

The importance of treating psychological distress in terminally ill patients:
Psychological Distress (e.g., major depression, adjustment disorder, etc.: ❑ Impairs capacity for pleasure, meaning, and connection ❑ Erodes quality of life ❑ Amplifies pain and other symptoms ❑ Reduces patient's ability to do the emotional work of separating and saying goodbye ❑ Causes anguish and worry in family members and friends ❑ Psychological distress, particularly depression, is a risk factor for suicide and for requests to hasten death Source: *Ann Int Med* 2000;132:209-18

Rx-Management

Review of Psychological & Educational Treatment Modalities in Terminally Ill Patients

Intervention	Goals	Desired Results
Educational ❑ Written information & education sessions	❑ ↓helplessness & ↓ inadequacy due to lack of knowledge ❑ Provide disease & treatment information ❑ Demonstrate coping/ communication skills. ❑ Provide treatment information	↓anxiety ↓problems associated with treatment ↑compliance ↓depression
Behavioural Therapy ❑ Progressive muscle relaxation, hypnosis, deep breathing, meditation, biofeedback, passive relaxation, guided imagery	❑ ↓psychological stress ❑ ↓physical complications	↓adverse effects of treatment such as chemotherapy ↓ anxiety ↑immune function ↑locus of control
Individual Therapy ❑ support, compassion, empathy, emotional engagement	Crisis intervention ↓psychological distress ↑coping skills	↓emotional distress ↓confusion ↓social isolation ↓sexual dysfunction ↓physical distress ↑function ↑coping skills ↑quality of life
Group Interventions/Therapy ❑ support, coping, sharing	↑coping skills Issues of death and dying Enriching life and the dying process. ↓family & communications problems	↓anxiety, fatigue, depression, panic ↑function ↑body image ↓social isolation ↑strength of relationships ↑quality of life ↑perceptions of death & dying ↑disease knowledge ↑communication skills ↑family grief resolution
		Modified after Porter et al[3]

The CAR$_X$E Approach – Depression

Comprehensive Care Considerations

1. Do not assume that feelings of helplessness, hopelessness, and being depressed and/or miserable are inevitable consequences of advanced life-threatening illness. Most patients with a serious illness experience periods of intense sadness and anxiety accompanied by depressive symptoms.
2. As depression is a source of intense suffering, physicians will want to be particularly diligent at assessing and detecting associated signs and symptoms. Persistent symptoms of depression are not "normal" for patients at the end of life. It is a myth that feeling helpless, hopeless, depressed, and/or miserable is an inevitable consequence of advanced life-threatening illness.
3. These feelings are usually present for a relatively short period (days to weeks), and then resolve and then recur some time later. However, in a variable number of patients, these feelings persist (between 25% and 77%, depending on the study).
4. The earlier depression is diagnosed, the more responsive to treatment it is likely to be. Treatment for depression may help patients feel better and have the energy and interest to achieve their final goals before they die. This applies to teenage and young adult patients as well.
5. Unfortunately, in our society, depression is often viewed as something to be ashamed of, or as a sign of weakness. Through patient and family education, the physician can help correct this misconception.
6. Risk factors include poorly controlled pain or other symptoms, progressive physical impairment, advanced stage of disease, medications, pancreatic cancer, left hemispheric stroke, spiritual pain, lack of social supports, stressful life events unrelated to illness, and other factors that apply within the general population.

Assessment

1. Somatic symptoms are common in patients with advanced illness and are rarely useful in diagnosing depression.
2. Assessment of depression in patients with advanced illness rests on recognition of psychological and cognitive symptoms, of which the most reliable are persistent dysphoria, anhedonia, feelings of helplessness, hopelessness, and worthlessness, and loss of self-esteem.
3. In the general population, somatic symptoms (e.g. changes in appetite, weight, energy level, libido, or sleeping) are important when making a diagnosis of depression (DSM-IV, American Psychiatric Association, 1994). However, somatic symptoms are almost invariably present in patients with advanced illness.
4. Therefore, assessment of depression in patients with advanced illness must focus on psychological and cognitive symptoms that are indicative of the diagnosis.

5. Where possible, include the observations of family, friends, and other members of the health care team, as they may provide considerable information to add to the history. You may need the assistance of a child psychologist, child life specialist, or social worker if the patient is a child or adolescent.
6. The most reliable symptoms of major depression are persistent dysphoria, anhedonia (loss of pleasure), feelings of helplessness, hopelessness, and worthlessness, and loss of self-esteem. Other diagnostic criteria include feelings of excessive guilt, pervasive despair, bothersome ruminations about death, and thoughts of suicide.
7. Pain not responding as expected, sad mood with flat affect and anxiety, irritability, or unpleasant mood may be significant signs of depression.

The screening question, "Do you feel depressed most of the time?" is a sensitive and specific question in this population.

8. Requests to hasten death may be a marker of undiagnosed depression. More specific screening tools (such as the Beck Depression Inventory) for the identification of depression are available.

Suicidal thoughts are an important symptom of depression.

9. All patients with depressive symptoms should be assessed for their risk of suicide. Similarly, suicidal thoughts are an important sign of depression, even in patients with advanced life-threatening illness.
10. It is a myth that asking about suicide will "put the idea into someone's head." To the contrary, allowing patients to discuss the thoughts they are having may reduce the likelihood they will actually commit suicide, particularly if the physician acknowledges their feelings and desires, and addresses the root causes of their distress.
11. Patients with recurrent thoughts of suicide or serious plans should be considered at high risk. Immediate consultation with a mental health specialist experienced in this area is indicated.
12. Ask an experienced psychiatrist for assistance as appropriate.

Rx-Management

1. To treat depressed patients who are living with life-threatening illness, use a combination of supportive psychotherapy, cognitive approaches, behavioral techniques, and antidepressant medication:
   - **Psychotherapeutic interventions:** Individual and group counseling have both been shown to reduce depressive symptoms. In addition to formal sessions with psychiatrists, psychologists, or other mental health professionals, nurses, social workers, and chaplains may also be able to conduct both formal and informal sessions, depending on their training.
   - **Cognitive approaches:** Time spent talking with patients about their feelings and re-framing their ideas may be very helpful. These approaches can be used by the primary physician, as well as other colleagues.

- **Behavioural interventions:** Relaxation therapy, distraction therapy with pleasant imagery, etc., have been shown to reduce depressive symptoms in patients with mild to moderate levels of depression. Complementary and alternative medical approaches may be useful adjuncts.
- **Antidepressant medications:** A variety of medications that will be discussed below work with all severities of depression. They work better than psychotherapy alone in severe depression.

2. Physicians can weave supportive counseling that uses aspects of brief supportive psychotherapy into routine interventions. Include family members whenever possible.
3. Refer seriously depressed or anxious patients for formal psychotherapy.
4. Supportive counseling has many goals. The interaction itself may be therapeutic. During the discussions, the physician can provide the patient with an improved understanding of his or her prognosis, potential treatments, and outcomes. These may help the patient put perceptions, expectations, needs, fears, and fantasies about his or her illness and death into a different perspective. Discussing short-term goals, and identifying and reinforcing the patient's previously demonstrated strengths and successful coping techniques will help to establish or reestablish the patient's sense of self-worth and meaning.
5. New coping techniques such as relaxation, meditation, guided imagery, or self-hypnosis can be introduced. The physician can spend time to educate the patient and family members about modifiable factors that contribute to anxiety and depression.
6. The principal medications used for the treatment of depression include psychostimulants, selective serotonin reuptake inhibitors (SSRIs), and tricyclic and atypical antidepressants. Specific drugs and doses are listed in the table below.

Antidepressant Drugs

DRUG	USUAL DOSES	COMMENTS
Tricyclic Antidepressants		
amitritpyline	start with 10-25mg HS and increase to 75-150mg HS	Most sedating & most anticholinergic effects
nortriptyline		Less sedation & anticholinergic effects
desipramine		Less sedation & anticholinergic effects
imipramine		Moderate anticholinergic effects
doxepin		
SSRIs		
sertraline		Short half-life
paroxetine	10-40mg once daily	Short half-life, no active metabolites

fluoxetine	10-40mg once daily	Long half-life
Psychostimulants		
methylphenidate	5-10mg twice daily	Avoid evening or HS dosing
dextroamphetamine		
Atypical Antidepressants		
venlafaxine	37.5-75mg daily	Short elimination half-life
trazadone	25-100mg HS	Sedation, hypotension

7. The time available for treatment will strongly influence the choice of medication for initial therapy.
8. When reversal of depression is an immediate short-term goal, a rapid-acting psychostimulant is the best choice. If a response in 2 to 4 weeks is acceptable, an atypical or SSRI may be an appropriate choice.
9. With all antidepressant medications, dosing should “start low and go slow.” Titrate the dose to effect and tolerability. Warn patients about possible adverse effects, which will usually ameliorate within a few days. If patients are not responding as expected, seek consultation with an experienced colleague, such as a psychiatrist.
10. The psychostimulants methylphenidate and dextroamphetamine are under-appreciated and under-utilized for their antidepressant qualities. They act quickly (in days) and produce minimal adverse effects. Some patients report increased energy and an improved sense of well being within 24 hours. Methylphenidate is usually started at 5 mg in the morning and at noon, and then titrated to effect.
11. Psychostimulants can be used alone or in combination with other antidepressants. They may be continued indefinitely as their antidepressant effect persists over time. Tolerance to the antidepressant effect does not appear to develop. They may also be used to diminish opioid-induced sedation. Their potential as adjuvant analgesics has been reported.
12. Psychostimulants may produce tremulousness, anxiety, anorexia, and insomnia. These adverse effects should be monitored. If discontinued, psychostimulants should be tapered off slowly.
13. Selective serotonin reuptake inhibitors (SSRIs, e.g., fluoxetine, paroxetine, sertraline) usually begin to act within 2 to 4 weeks. They are highly effective (70% of patients report a significant response). Low doses may be sufficient in advanced illness. Once-daily dosing is possible. SSRIs cause less constipation, sedation, and dry mouth than the tricyclic antidepressants, though nausea may be worse with the SSRIs.
14. Tricyclic antidepressants (e.g., amitriptyline, desipramine, doxepin, imipramine, nortriptyline) may not be first choices as first-line therapy to manage depression unless they are being used as adjuvants to control neuropathic pain. Titration to achieve an adequate dosage may take 3 to 6 weeks, delaying the onset of therapeutic action. Anticholinergic adverse effects (e.g., dry mouth, constipation, orthostatic hypotension, blurred vision, urinary retention, delirium) and cardiac conduction delays (proarrhythmic) are all seen with some frequency. If a tricyclic

antidepressant is to be used, the secondary amines nortriptyline and desipramine are preferable as they tend to have fewer side effects.

15. The group of atypical antidepressants including trazodone, and venlafaxine. Their precise role in patients with advanced disease is being studied.
16. Non-pharmacologic management. Although this module focuses on equipping physicians with the medical knowledge, attitudes, and skills to manage depression, this does not exclude the role of non-pharmacologic management of depression. Use appropriate colleagues and team members to help address the emotional and spiritual issues that overlap and influence clinical depression. Complementary and alternative methods may be useful adjuncts for some patients. It is beyond the scope of this module to discuss these in detail.

Evaluation

1. Patients who are depressed should be followed regularly and fairly frequently by team members.
2. Any patient with suicidal ideation may require psychiatric evaluation and/or hospitalization.
3. Lack of response to medication should be documented and changes made quickly.

The CAR_xE Approach – Anxiety

Comprehensive Care Considerations

1. Anxiety is commonly experienced over fears and uncertainties about the future and therefore some degree of anxiety is common in all patients and families.
2. Their distress may be related to any of a number of physical, psychological, social, spiritual, or practical issues, or it may be a component of many other syndromes (e.g., an underlying panic disorder that is unmasked by advanced illness).
3. All patients will require counseling and support as well as medication.

Assessment

1. Anxiety usually presents with 1 or more symptoms or signs including agitation, restlessness, sweating, tachycardia, hyperventilation, insomnia, excessive worry, and/or tension.
2. As anxiety may have many different origins, assessment may be complex. Input from family, friends, and other members of the interdisciplinary team may be invaluable.
3. Attempt to differentiate between primary anxiety and delirium, depression, bipolar disorder, and medication side effects.
4. Look for insomnia and other reversible causes of anxiety such as alcohol, caffeine, or medications (e.g., increased doses of beta-agonists and methylxanthines for the management of dyspnea)

Rx-Management

1. Non-pharmacologic management must always be a part of the management of anxiety. The majority of patients will be receptive to compassionate exploration of the specific issues that are causing or exacerbating their anxiety.
2. Concerns about finances, family conflicts, future disability, and dependency, and existential concerns will not resolve with medication. Instead, they will benefit from counseling and supportive therapy.
3. Involve other appropriate disciplines such as nursing, social work, and chaplaincy.
4. Complementary and alternative medical approaches may help some patients.
5. Issues of grief and loss are important dimensions to understand, particularly in evaluating anxiety and psychological distress. See the section on grief that follows.
6. When it appears that pharmacologic therapy will be beneficial as part of a total plan of care for anxiety, benzodiazepines are generally the medication class of choice. Choose an agent based on the desired half-life. Longer half-

life medications have a more sustained effect, but may accumulate. Shorter half-life medications may have a greater risk of withdrawal and rebound anxiety.

7. Whichever medication is chosen, start with low doses and titrate to effect and tolerability.
8. As needed medication may suffice for most patients with intermittent mild anxiety. Severe anxiety states will require regular medication in appropriate doses.
9. Remember that benzodiazepines may worsen memory, particularly in the elderly, or cause confusion and agitation in patients with preexisting cognitive impairment.
10. When discontinuing benzodiazepines, taper them slowly.

Some Examples of Tranquilizers

DRUG	DOSE	COMMENTS
Benzodiazepines		
diazepam	2-10mg once daily to TID	Long half-life
clonazepam	0.25-1.0mg once daily to BID	Long half-life
lorazepam	0.5-2.0mg SL up to QID	Moderate half-life
alprazolam	0.125-0.5mg up to QID	Short half-life
oxazepam	15-30mg up to QID	Relatively short half-life
Major Tranquilizers		
chlorpromazine	25-50mg QID p.o. or i.m.	Sedation, Parkinsonian side effects
loxapine	5-10mg QID p.o. or i.m.	Sedating, Parkinsonian side effects
methotrimeprazine	10-25mg QID p.o.	Sedating, Parkinsonian side effects
haloperidol	2-10mg once daily to QID p.o./s.c.	Less sedating, hypotension

11. Atypical antidepressants like trazadone may be useful for patients with mixed anxiety and depression, or for patients with chronic anxiety, or panic disorder. If only a hypnotic effect is needed, trazodone is a useful alternative (25–100 mg po q hs).
12. Severely anxious or agitated patients may require major tranquilizers for control of symptoms particularly if delirium or cognitive dysfunction is present.

Evaluation

1. All palliative care patients should be monitored for increased anxiety.

2. All benzodiazepines have a risk of tolerance, dependence and withdrawal symptoms. Patients on these medications on a regular basis require careful and regular monitoring.

The CAR_XE Approach – Grief

Comprehensive Care Considerations

Although grief is a normal reaction to anticipated bereavement, discussions about terminal illness can be difficult for both patient and physician. These conversations can be easier when the topics of living wills and advanced health care directives have been raised during earlier, routine patient visits. Patients need reassurance that appropriate care will continue through the processes of dying and death.

1. The physician has three main responsibilities to help dying patients through the grieving process:
   - to recognize the grief reaction,
   - to develop grief management strategies for the patient and family, and
   - to recognize "abnormal" grief, which may require drug therapy or psychiatric intervention.
2. Few patients identify themselves as needing help with grief reactions. One useful tool is to discuss common responses in grieving with both the patient and family (see table).
3. Grief has traditionally been described in terms of stages. More recently, experts emphasize that grieving is not a neat and ordered process, but rather a mixture of emotions and responses. Each person's experience of grief is unique.

Assessment and Rx-Management

GRIEF COMPARED TO DEPRESSION IN THE TERMINALLY ILL	
Characteristics of grief	**Characteristics of depression**
Patients experience feelings, emotions and behaviours that result from a particular loss	Patients experience feelings, emotions and behaviours that fulfill criteria for a major psychiatric disorder; distress is usually generalized to all facts of life
Patients may cope with distress on their own	Medical or psychiatric intervention is usually necessary
Patients experience somatic distress, loss of usual patterns of behaviour, agitation, sleep and appetite disturbances, decreased concentration, social withdrawal	Patients experience similar symptoms, plus hopelessness, helplessness, worthlessness, guilt, and suicidal ideation
Grief is associated with disease progression	Depression has an increased prevalence (to almost 80%) in patients with advanced disease; pain is a major risk factor
Patients retain the capacity for pleasure	Patients enjoy nothing
Grief comes in waves	Depression is constant and unremitting
Patients express passive wishes for death to come quickly (up to 45% have fleeting suicidal thoughts)	Patients express intense and persistent suicidal ideation
Patients are able to look forward to the future	Patients have no sense of a positive future

Adapted from *Ann Int Med* 2000;132:209-18

THE PHYSICIAN'S ROLE IN THE PROCESS OF GRIEVING		
	Characterized by	**Physician's role**
Initial shock	Numbness, disbelief, relief, the reality of the loss is not acknowledged	Establish trust and good relationship; explain medical status empathically; avoid "crashing" through defenses
Pangs of grief	Sadness, anger, guilt, feelings of vulnerability and anxiety; regret, insomnia, social withdrawal, restlessness	Accept patient's anger undefensively; provide updated health status reports; facilitate discussion; be a good listener
Despair	Loss of meaning and direction in life. The inevitability of the loss or death is more apparent.	"Be there" for open, supportive discussions; do not rush in with medications or psychiatric referral
Adjustment	Patient accepts the reality of approaching death and may attain a certain peacefulness about it. The patient may ask for deferment of heroic measures, and may experience improved sleep and appetite.	Encourage patient and family to ask questions; spend time at the bedside in an unhurried manner; maintain warm, empathic relationship.

Adapted from: *Postgrad Med* 2000;101:263-70 and *BMJ* 1998; 316:456-8.

Grief is often intertwined with physical symptoms. Appropriate investigations for medical causes should be undertaken, but the grieving process should also be considered as a possible source of symptoms. By validating the patient's feelings, the physician can help the patient understand that grief is a normal reaction to loss.

Evaluation

Adequate pain and symptom management (bowel routines, energy conservation) can help enhance adaptation to illness and the dying process, thus reducing the likelihood of depression.

CASE SCENARIO

The Williams Family

The Use of This Case Scenario

This case scenario can be used in several ways to illustrate psychological issues:

1. The case scenario can be used like the problem based learning cases used in other modules.
2. The Williams Family Case Scenario can also be used as a role-play to demonstrate effectively assessment skills, supportive counseling skills and communication skills. The following section outlines an approach to using role-plays in teaching. In our experience physicians very easily adapt to role-plays in a small or large group environment.

Using Role-Play Effectively

1. The facilitator or one of the participants should read the case description aloud.
2. The facilitator may ask for volunteers and/or assign each role.
3. Those assigned to roles are asked to read the role and not share the role with any other participant.
4. Chairs should be moved to the front of the teaching area.
5. Ground rules for the role-play should be read out for all participants and these include:
   - Role-players must stay in role and are to try and divulge information in their roles in a realistic fashion.
   - Bolded information in each role-play must be divulged in some manner during the session.
   - Any player may ask for time out at any time or the facilitator may call time out. The role-play may resume after the timeout with the same or different players.
   - Those observing the role-play are to remain silent but they are asked to write down observation of process and content and suggestions for change.
6. After the role-play is completed, each player is asked to read out his/her role and asked to discuss how they felt in the role.
7. After the above process is complete, the facilitator will facilitate a discussion of the case issues as they relate to the objectives and content of the modules.

WILLIAMS FAMILY CASE SCENARIO AND ROLE-PLAY

Case Description

Janet is a 61-year-old woman diagnosed with colon cancer with metastases to her lung and liver. She was diagnosed approximately 3 months ago when she presented to her family doctor with a productive cough. She was initially treated for pneumonia but when she did not respond to treatment a chest x-ray was done. The chest x-ray revealed a suspicious nodule. She underwent a series of investigations that resulted in the diagnosis of adenocarcinoma of her colon with metastases to her lung and liver. Janet was not a surgical candidate. She was initially treated with chemotherapy. She developed significant side effects from her chemotherapy and for this reason it was discontinued after 5 courses of treatment. No further treatment is being offered at this time. Her current problems include a chronic cough that keeps her up at night, poor appetite, and generalized weakness. Pain is not a problem. She has had increasing difficulty coping at home. She has been quite anxious and has been to the emergency department with panic attacks and hyperventilation several times.

Janet is originally from Trinidad. She has been living common law with her husband for 30 years. Her husband, James, is not well. He is a diabetic and has mild dementia. He has suffered two strokes in the past, which have left him with some right-sided weakness, and he needs help with his ADL's. She has two children. A daughter, Vanessa, lives in the same apartment building. Her daughter has two young children and is working full-time. Her son, Edward, lives nearby. He has quit his job and is trying to start up his own business. She has a sister, Marie, whom she is very close to. Her sister is organizing Janet's medical care. She is also caring for their elderly demented mother who is living in a local nursing home. Janet has also been very active in her church and has a good group of supportive friends.

What are the important issues that need to be addressed in caring for Janet and her family?

WILLIAMS FAMILY ROLE-PLAY
Case Description

Janet is a 61-year-old woman diagnosed with colon cancer with metastases to her lung and liver. She was diagnosed approximately 3 months ago when she presented to her family doctor with a productive cough. She was initially treated for pneumonia but when she did not respond to treatment a chest x-ray was done. The chest x-ray revealed a suspicious nodule. She underwent a series of investigations that resulted in the diagnosis of adenocarcinoma of her colon with metastasis to her lung and liver. Janet was not a surgical candidate. She was initially treated with chemotherapy. She developed significant side effects from her chemotherapy and for this reason it was discontinued after 5 courses of treatment. No further treatment is being offered at this time. Her current problems include a chronic cough that keeps her up at night, poor appetite, and generalized weakness. Pain is not a problem She has had increasing difficulty coping at home. She has been quite anxious and has been to the emergency department with panic attacks and hyperventilation several times.

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Dr. Albert

You have been involved with Janet's family physician for 4 years. You found her cancer and have been following her since her discharge from the cancer centre. Her condition has deteriorated rapidly over the last two weeks and she requires more care at home. Initially, home care was providing enough care. But now she is so weak that she is confined to her bed, requiring more assistance. Marie, her sister, has attempted to make a care plan but is having difficulty finding and organizing people to help. This upsets Marie because she had promised to keep Janet out of hospital.

Marie calls you for help almost daily. You are aware that there are family tensions.

You are also James' doctor and know he cannot cope on his own. Your own father is dying of lung cancer.

WILLIAMS FAMILY ROLE-PLAY

Case Description

Janet is a 61-year-old woman diagnosed with colon cancer with metastases to her lung and liver. She was diagnosed approximately 3 months ago when she presented to her family doctor with a productive cough. She was initially treated for pneumonia but when she did not respond to treatment a chest x-ray was done. The chest x-ray revealed a suspicious nodule. She underwent a series of investigations that resulted in the diagnosis of adenocarcinoma of her colon with metastasis to her lung and liver. Janet was not a surgical candidate. She was initially treated with chemotherapy. She developed significant side effects from her chemotherapy and for this reason it was discontinued after 5 courses of treatment. No further treatment is being offered at this time. Her current problems include a chronic cough that keeps her up at night, poor appetite, and generalized weakness. Pain is not a problem. She has had increasing difficulty coping at home. She has been quite anxious and has been to the emergency department with panic attacks and hyperventilation several times.

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Janet

You are a 61-year-old woman with advanced cancer.
You are quite distressed about your rapidly deteriorating physical condition.
You are concerned about your inability to organize future plans for your husband. You have been his primary care giver and you feel your children are too wrapped up in their own lives to be able to care for him. You see his future days in a nursing home and **this makes you feel guilty, very anxious and depressed**.
You are also feeling like a burden to your family. You can see the stress that your illness is putting on your sister and your children. You are afraid to talk to your children about your illness and the fact that you are dying because you may upset them. But at the same time you want to say your personal good-byes. You are not afraid of dying as you have strong faith in God. You would like to stay at home.

WILLIAMS FAMILY ROLE-PLAY

Case Description

Janet is a 61-year-old woman diagnosed with colon cancer with metastases to her lung and liver. She was diagnosed approximately 3 months ago when she presented to her family doctor with a productive cough. She was initially treated for pneumonia but when she did not respond to treatment a chest x-ray was done. The chest x-ray revealed a suspicious nodule. She underwent a series of investigations that resulted in the diagnosis of adenocarcinoma of her colon with metastasis to her lung and liver. Janet was not a surgical candidate. She was initially treated with chemotherapy. She developed significant side effects from her chemotherapy and for this reason it was discontinued after 5 courses of treatment. No further treatment is being offered at this time. Her current problems include a chronic cough that keeps her up at night, poor appetite, and generalized weakness. Pain is not a problem. She has had increasing difficulty coping at home. She has been quite anxious and has been to the emergency department with panic attacks and hyperventilation several times.

Janet is originally from Trinidad. She has been living common law with her husband for 30 years. Her husband, James, is not well. He is a diabetic and has mild dementia. He has suffered two strokes in the past, which have left him with some right-sided weakness, and he needs help with his ADL's. She has two children. A daughter, Vanessa, lives in the same apartment building. Her daughter has two young children and is working full-time. Her son, Edward, lives nearby. He has quit his job and is trying to start up his own business. She has a sister, Marie, to whom she is very close. Her sister is organizing Janet's medical care. She is also caring for their elderly demented mother who is living in a local nursing home. Janet has also been very active in her church and has a good group of supportive friends.

Marie

You are a 55-year-old single woman with no children. You are a very active lady involved in a number of community organizations and with your church.
You also help care for your mother who is currently living in a local nursing home. You have currently taken some time off work to help care for Janet but will soon have to go back. Janet turned to you for help when she was diagnosed with her cancer. You promised her that you would do everything to keep her at home.
You are frustrated because you have developed various care plans and asked Janet's children for help but found her children to be unreliable.
You feel that you are doing all the work and are getting exhausted. You realize Janet's time is limited and find that you are so involved in organizing her care and future plans after her death that you have no opportunity to spend quality time with Janet.

WILLIAMS FAMILY ROLE-PLAY

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Vanessa

You are Janet's 28-year-old daughter. You are married with two children: a 1-year-old and a 4-year-old. You are currently working as a parking attendant. This involves shift work and your hours can vary.

You are angry with your aunt. You feel she has taken over your mother's care and has not given you a chance to help and is shutting you out. You feel that your aunt is acting as a dictator telling you what to do instead of involving you in decisions regarding your mother's care.

You want to help but you feel that you are being spread too thin between your job, family, and mother. Marie is making you feel guilty.

You are also afraid of being alone with your mother. You feel helpless when you are with her and don't know how to help. You are also afraid something may happen to her while you are there and you don't know how you will react. You want to tell your mother how much you love her but have difficulty discussing this with her because you are afraid that

you might upset her. You are close to your stepfather and are concerned about what will happen to him after your mother dies.

WILLIAMS FAMILY ROLE-PLAY

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James

You are James, a 72-year-old man. **You are a bit bewildered by your wife's sudden deterioration.** You have been together for 30 years and have expected that you would die before your wife, especially since your health has been failing over the last five years. **You feel that people are not telling you everything about your wife's illness.** You suspect that she doesn't have long to live but haven't been given that information directly**. Everyone seems to want to protect you from the truth but you really want to know because you have always wanted to be legally married to Janet**. This is something that is very important for you to do before she dies. You are also concerned about your future. You realize your children will not be able to care for you if Janet dies. You do not want to go to a nursing home but realize that you will receive the best care there. You are afraid because you do not know what arrangements have been made for you.
You get confused easily and always ask for information to be repeated more slowly.

WILLIAMS FAMILY ROLE-PLAY

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Edward

You are a 32-year-old former postal worker. Recently you quit your job to open a Mac's Milk store in a busy plaza. **You are under a lot of stress.** Your mother is dying and you are having difficulty accepting that**. You are working long hours but your irregular hours mean that your visits to your mother have diminished**. You are married to Jeanette and have 1 child aged 2.
You are worried that the burden of your father's care will fall on your shoulders since you have a house with extra room, unlike your sister.
You too are angry with your aunt, Marie, because she has totally taken over your mother's care, often making questionable decisions in your opinion. **You feel your mother should be admitted to hospital so that she can get stronger. You don't feel the doctor is right in keeping her at home**.

WILLIAMS FAMILY ROLE-PLAY

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Elaine Jones

You are a 46-year-old home care nurse. **You are very concerned about Janet and feel quite close to her**. **You think that Marie is a "saint" for taking care of her sister and you feel Janet's children are not pulling their weight in caring for their mother**. You have advised them to start nursing home papers for James and palliative care papers for Janet but no one seems to be acting on this. You do not feel that the family doctor, Dr. Albert, really has enough experience and want a referral to a home palliative care team.

WILLIAMS FAMILY ROLE-PLAY

OPTIONAL TELEPHONE ROLE-PLAY

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Telephone Call Role-Play

Marie:

- Angry, wants immediate house call, wants you to do something about Janet's continuing deterioration
- Says she cannot cope any longer especially since the children are not helping out
- Initially resistant to suggestion of family meeting
- "Just get Janet in hospital to make her stronger"

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