

Promoting Seniors Mental Health In Cancer Care: A Guide for Front-line Care Providers

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April 2008

This Guide provides an overview of the intersection between cancer and seniors' mental health, identifies the associated challenges older adults may experience, and provides practical information for supporting seniors' mental health during cancer care.



For the B.C. Psychogeriatric Association

Production of this publication was made possible through a financial contribution from the Public Health Agency of Canada.

Disclaimer: Every effort has been made to ensure the accuracy of the information provided, and is correct at the time of printing. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

Acknowledgements: We would like to thank all those who contributed to this project by sharing their experience, knowledge and perspectives.

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INTRODUCTION TO THE GUIDE

Penny MacCourt, PhD, MSW & Kimberley Wilson, MSW, BAsC

Overview of the Project

In 2007, the British Columbia Psychogeriatric Association (BCPGA) was awarded funding from the Canadian Strategy for Cancer Control, Public Health Agency of Canada to contribute to developing the capacity of the health care system to support the mental health needs of older Canadians with cancer.

This Guide, developed in partnership with the Canadian Coalition for Seniors Mental Health (CCSMH) was produced in response to this identified need. It provides an overview of the intersection between cancer and seniors' mental health, identifies the associated challenges older adults may experience, and provides practical information for supporting seniors' mental health during cancer care. The terms "senior", "older adult" and "older person" are used interchangeably throughout the Guide to refer to the primary population focus for the Guide, that is, those aged 65 and older. The recommendations and information may apply to those younger based on their co-morbidities and risk factors.

The Guide was authored by front-line clinicians and other experts in aging, cancer and/or seniors' mental health and is directed to front-line service providers in any setting who provide care to older adults with cancer.

The Guide highlights many of the common issues that older adults and their care providers may encounter. Importantly, this Guide is not specific to any one type of cancer. The authors recognize and acknowledge that the symptoms, treatment, and psychosocial impact of cancer may vary due to diagnosis. As well, the authors recognize and acknowledge the heterogeneity of older adults and note that resiliency and risk factors associated with a cancer diagnosis are unique to each individual.

Why is this Guide Needed Now?

First, there have been new developments specific to seniors' mental health and to cancer that have created a need to bring together experts from several areas to collaborate on the development of a collective resource. There is a window of opportunity for a common focus on issues related to the psychosocial/mental health care of seniors with cancer. An important factor driving this opportunity is the growing recognition that the proportion of older Canadians in the population is increasing dramatically. By 2021, older adults (i.e. those 65 years and older) will account for almost 18% of our country's population (MacCourt & Tuokko, 2005).

Second, cancer increasingly is recognized as a disease of older Canadians. The highest risk factor for cancer is age. Table 1 illustrates recent statistics for the distribution of cancer (all sites) as a function of age group and sex in Canada.

Table 1.**Distribution for All Cancer Sites Combined by Age Group and Sex, Canada, 2006**

Age Group	Population (000s) 2006 Estimates			New Cases 2006 Estimates			Deaths 2006 Estimates		
	Total	M	F	Total	M	F	Total	M	F
0-19	7,595	3,887	3,707	1,250	680	590	180	95	80
20-29	4,309	2,187	2,122	1,800	810	960	230	120	100
30-39	4,623	2,326	2,298	4,400	1,550	2,800	740	300	430
40-49	5,367	2,696	2,671	12,700	4,500	8,200	3,200	1,400	1,850
50-59	4,429	2,198	2,231	28,500	13,300	15,200	8,800	4,400	4,400
60-69	2,791	1,352	1,439	38,400	22,100	16,300	15,000	8,400	6,500
70-79	1,868	844	1,023	39,200	22,600	16,600	20,900	11,900	9,000
80+	1,143	399	744	26,800	12,900	14,000	21,300	10,400	11,000
All Ages	32,125	15,889	16,236	153,100	78,400	74,700	70,400	37,000	33,400

Note: Incidence figures exclude non-melanoma skin cancer (basal and squamous). Total of rounded numbers may not equal rounded total number. Please refer to *Appendix II: Methods* for further details. 2006 population projections were provided by the Census and Demographics Branch, Statistics Canada.

Source: Surveillance Division, CCDPC, Public Health Agency of Canada

Cancer in late life is complicated by co-morbidities associated with age-related chronic illnesses and concurrent medication use. These factors pose further challenges for the already complex medical treatment of cancer. Not surprisingly, although cancer affects all aspects of a person's life, almost all care and services traditionally have been centered on the disease itself. At all ages, the personal experience of cancer and its psychological and social consequences tend to be relatively overlooked throughout the disease course. The situation may be even more bleak for older adults. These individuals may find themselves with fewer resources (e.g., financial and social supports), more functional issues, and other age-associated challenges that set them apart from younger adults. Their mental health needs may be different than those of younger adults, but like younger cancer patients, they may find their needs under-recognized and under-served. In that caregivers of older adults with cancer are often older spouses, both caregivers and care recipients may experience depression and other mental health problems. Depression occurs in 10-25% of adults (Pirl, 2004) with cancer, and has been associated with poorer quality of life, in addition to increased impairment of immune response and poorer survival.

Clearly, treatment and psychosocial support for older adults with cancer should be tailor-made to their special needs. However, currently little attention is paid to linking the care of seniors who are affected with cancer to promoting or supporting their mental health, or to addressing mental health problems.

How Was this Guide Developed?

An environmental scan (that is, a scan of the literature and a series of key informant interviews) was conducted to assess how seniors' mental health is currently promoted and supported in cancer care.

The scan identified current literature, resources and relevant websites. The key informant interviews were guided by the Seniors' Mental Health Policy Lens (MacCourt & Tuokko, 2005) and were conducted with experts from across Canada in the cancer and seniors' mental health fields. The Seniors Mental Health Policy Lens is an analytical tool developed by the British Columbia Psychogeriatric Association with funding from the Public Health Agency of Canada. The tool is used to develop or critique policy, legislation, programs and services for unintended negative effects on older adults' mental health and wellbeing. The working definition of "mental health" used by the Seniors Mental Health Policy Lens holds that mental health can be understood on a broad continuum from wellness through illness (MacCourt and Tuokko, 2005) . Mental health is conceptualized as an individual resource, but one which is affected by social context.

The results of the environmental scan were presented to a multidisciplinary group of front-line clinicians and other experts in aging, mental health and/or cancer who attended an invitational workshop in June 2007. After debating the options for how best to take advantage of this opportunity to contribute to cancer care for seniors, workshop attendees decided to focus on providing front-line clinicians with information about the distinct challenges that cancer presents for the mental health of seniors. The project plan was then circulated to a broader group of cancer and seniors' mental health stakeholders for endorsement, and potential authors were identified and invited to contribute to the Guide.

Front-line clinicians and other experts in aging, seniors' mental health and cancer care committed to authoring sections of the Guide based on their area of expertise. Several teleconferences were held among the group to formalize the work plan and logistics. Individual authors were responsible for identifying the appropriate resource literature for their respective sections. All sections went through several rounds of editing to enhance the cohesiveness and utility of the Guide. External reviewers (service providers, and seniors and family members who had experienced cancer) were solicited to comment on the final product. A list of references and resources related to each topic is included at the end of each section. In March 2008, the Guide (English and French versions) was complete and the dissemination process, including electronic availability and targeted mail out begun.

Who Should Use this Guide?

This Guide was created specifically as a primer for front-line workers who provide care to older adults with a cancer diagnosis, in any service environment. The authors recognize that front-line workers come from a variety of disciplines. Personal support workers, nurses, physicians and other professionals who provide services to older adults with cancer may not have received specific training in either cancer and/or seniors' mental health. This Guide will be useful for home care staff, hospital staff, outreach teams, and cancer clinic staff. In many instances, patients and family members will also benefit from reviewing the information provided in this Guide, particularly the practice tips provided at the end of each section. Readers can refer to the references provided for more in-depth information on each of the topics addressed in the Guide.

Organization of this Guide

In Section 1, we set the stage by making the links between mental health, cancer and aging. We begin with a brief discussion of the mental health challenges for seniors during cancer care and how these can be addressed through mental health promotion. This discussion is followed with overviews of cancer, cancer treatment, and the cancer care system in relation to seniors. Next, overviews of physical changes and functional changes associated with normal aging are presented. The section ends with a discussion of cancer and co-morbidities. In Sections 2, 3 and 4, topics identified by project partners and workshop participants as critically important aspects of care for patients, family members and front-line health care providers, are discussed. For each topic there is a synopsis of the issue, a list of resources for more detailed review, and a summary page highlighting the key clinically-relevant take home messages or practice tips that we hope will be assimilated into practice.

Access and Citation

When citing this Guide in its entirety the suggested format is as follows:

MacCourt, P., Wilson, K.J., Kortés-Miller, K., Gibson, M., & Fitch, M.I. (Eds.). (2008). *Promoting Seniors' Mental Health in Cancer Care: A Guide for Frontline Providers*. Victoria, British Columbia: British Columbia Psychogeriatric Association.

If citing an individual section, please reference the author and section title as listed in the Guide.

This Guide is available at www.seniorsmentalhealth.ca and www.ccsmh.ca.

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SECTION ONE: SETTING THE STAGE

Seniors' Mental Health and Cancer Care

Penny MacCourt, PhD, MSW

Understanding Cancer and Cancer Treatment

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Understanding the Cancer Care System

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Aging Changes

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Transitions for Older Adults

Sharon Galloway, RN, MSN, GNC

Cancer and Co-morbidity in Seniors

Marilyn Macdonald, RN, PhD

Special Considerations for Assessment of Older Adults

Anne Earthy, RN, BN, MA, GNC (C)

SENIORS' MENTAL HEALTH AND CANCER CARE

Penny MacCourt, PhD, MSW

Background

With the growth of the aging population comes an increasing number of seniors who are at risk for experiencing mental health problems (Sullivan, Kessler, LeClair, Stolee, Whitney, 2004). Mental health is a broad concept that is best understood as a continuum from wellness through illness, like physical health. Health care needs range from promotion of good mental health to treatment of serious illness. Mental health can be promoted and supported (or not) wherever the individual is situated on the continuum of wellness to illness. Various interconnecting factors influence mental health and there is general agreement that mental health status is determined by a complex interplay of individual characteristics, and cultural, social, economic and family circumstances at both the macro (society) and micro (community and family) levels (“Mental Health Promotion Best Practice Guidelines”, 2007). Thus, while mental health is conceptualized as an individual resource, it is one that is influenced by the individual’s social context.

In late life, mental health problems (including mental disorders) usually occur in the context of medical illness, disability and psychosocial impoverishment. Physical changes and chronic health conditions can have substantial impact on the psychological and social wellbeing of older adults by, for example, reducing opportunities for social engagement and relationships and their associated benefits.

Life events and transitions that occur as *part* of the normal aging process disrupt or threaten to change an individual’s normal routines and activities and consequently can affect an individual’s wellbeing. Life events which affect the majority of seniors include: retirement; reduced income levels; physical changes (including illness); and changes in social support networks (including caring for another individual, and coping with the death of a spouse and peers). These events may negatively affect seniors’ wellbeing by increasing social isolation, loneliness, depression, and suicidal thoughts.

Policies (legislative, organizational, service related, etc.) play an important role in creating the social milieu in which older adults live, and therefore can impact on their mental health. For example, Pharmacare policies that do not pay the full amount for medications related to cancer care can create significant stress for older adults with low incomes, compromising their physical and mental health. Likewise, lack of adequate, affordable and appropriate transportation can block access to needed health and social resources.

The social milieu in which older adults live can promote or undermine their mental health. We live in an ageist society which stigmatizes older adults. This can have serious repercussions for mental health directly (e.g., individual self-esteem) and indirectly (e.g., in how we value society’s oldest members and how we define and meet their needs). Ageism in and of itself is a challenge to the mental health of older adults. Negative stereotyping of older adults (e.g., referring to hospitalized older adults as “bed blockers”, anticipated apocalyptic effects of the aging population on the health care system, the perception that older adults are a drain on the economy) promotes age discrimination and perpetuates ageist attitudes.

Although risks to mental health increase with advancing age, mental health problems are not an inevitable consequence of old age. The relationship between risk and protective factors is complex - it is not the presence of risk or protective factors but rather the interaction and accumulation of these factors over time that influences the development of mental health problems and mental disorders (Donovan, James, Jalleha & Sidebottom, 2006). The mental and emotional health of people of all ages is related to how well they cope with or adapt to the stresses and changes in their lives. This concept is referred to as resiliency. Ryff, Singer, Love & Essex (1998) conceptualize resilience as a dynamic process that results from multiple protective factors that include: psychological resources/personality characteristics such as perceived control and self-efficacy; socio-demographic resources such as education, income, and occupational status; and social-relational resources such as social support and social networks.

Cancer and Seniors' Mental Health

Cancer is one of the diseases older adults may face. Given the stigma attached and the associated fear of pain and death, cancer presents a challenge to people of all ages. As seniors and their families live through the cancer journey they carry their physical, emotional, social, psychological, spiritual, informational and practical needs and resources with them. For seniors who are already experiencing other challenges, the cancer journey can exacerbate these issues and create new ones, increasing the risk of mental health problems such as anxiety and depression. At the same time, protective factors that might buffer them from the risks posed to their mental health (e.g., a strong social support system, adequate income) may be reduced. For example, a married senior with good health, supportive family and friends nearby, and sufficient financial resources to access all the health and personal services and social supports needed has a greater buffer from the mental health risks of cancer when compared to a single, socially isolated senior with significant functional or health issues who is living close to the poverty level.

Cancer itself can influence whether or not an individual is able to meet his/her own needs. An individual's capacity to act may be compromised by treatment side effects, pain, emotional distress or a sense of crisis. The way the individual usually meets his/her needs may not be feasible due to the effects of the cancer. Different skills and supports and new knowledge and information may be needed to cope with the situation ("Supportive Care/Cancer Rehabilitation Workshop", 2002).

In a study exploring older Canadians' perspectives on the mental health challenges of late life, participants said that the mental health challenges they face could be better met if psychosocial approaches such as support groups and social activities, housing, transportation, health care promotion and prevention, and a wellness-oriented, holistic model of care, were implemented (MacCourt & Tuokko, 2005).

Seniors' Mental Health and the Cancer Care System

Current policy and services related to cancer care are typically situated within a biomedical model with relatively little emphasis on psychosocial care. The biomedical model focuses on individual pathology and leads to the organization of services and programs that focus primarily on the diagnosis and treatment of tumours. There is a primary focus on cure and acute care. This paradigm has led to the neglect of the development of broader non-medical interventions and community-

based services required to support seniors' mental health (Gattuso, 2001). For this project, using the Seniors Mental Health Policy Lens (MacCourt & Tuokko, 2005) as a framework, key informants in the cancer field from a variety of disciplines and areas of practice across Canada were asked how well the current cancer care system meets the mental health needs of older adults. Overall, respondents felt that these needs are not well met, stating that there is a wide variation in the availability of services to deliver psychosocial, rehabilitative and palliative care generally. They reported that relatively few older adults receive intervention by psychosocial experts. Respondent said that services are not adapted to functional, communication or other challenges that seniors may bring to the cancer experience, and that service providers in cancer care seldom have training in gerontology or geriatrics. Respondents also reported that seniors with lower incomes faced economic barriers to accessing needed medications and non-medical supplies.

Promoting Seniors' Mental Health in Cancer Care

Recognition of the impact of psychosocial factors on seniors' mental health and the importance of integrating psychosocial approaches into the cancer care system within a more holistic model and concept of wellness is imperative to meeting the mental health needs of older adults with cancer. Key aspects of mental health for older adults involve autonomy, self-esteem, relationships and social supports, all of which can be fostered through mental health promotion (MacCourt & Tuokko, 2005).

The goals of mental health promotion are to enhance resiliency and protective factors along with decreasing risk factors and inequities. At an individual level, mental health promotion emphasizes the development of personal and social skills. At a social and environmental level, it emphasizes public and mental health policies, supportive and healthy environments, and community action ("Mental Health Promotion Best Practice Guidelines", 2007).

The key informants on this project suggested that seniors' mental health needs during cancer care could be better met with:

- More individualized care in a person-centered system;
- Greater access to expert psychosocial interventions that involve removing or reducing the practical, social and economic challenges, and counselling to facilitate adaptive coping mechanisms;
- Appropriate communication that takes into account age-related sensory and cognitive changes;
- Increased resources for increased needs associated with an aging population;
- Seniors advisory group in each cancer care centre to inform services;
- Health care providers with gerontology backgrounds added to oncology teams;
- Community-based treatment that is supported with adequate personal, home and social support services;

- Improved continuity of care between agencies and service providers (e.g., cancer care centre, home support agencies, general practitioner, hospitals);
- Elder friendly adjustments to clinics (e.g., more time for consultation, accessible bathrooms, comfortable seating) and to practices (e.g., outreach services);
- Navigators to assist seniors to access appropriate information and services when required; and
- Programs to eliminate barriers to obtaining medication and non-medical needs related to cancer care (e.g., home support, ostomy supplies, wigs, nutritional supplements, transportation).

In conclusion, a paradigm shift is required to create social environments and health services supportive of seniors' mental health during cancer care. Values and core principles that promote a culture of caring need to be applied to policy, programs and services for elderly persons with cancer who are at risk of, or have, mental health problems. This would radically change the way cancer care services are defined, delivered and funded, resulting in a greater emphasis on mental health promotion and psychosocial and supportive interventions.

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UNDERSTANDING CANCER AND CANCER TREATMENT

Margaret I. Fitch, RN, PhD

What is Cancer?

Cancer is a general term related to the abnormal growth of cells. It starts when one cell receives the wrong message about growing. As the one abnormal cell becomes two abnormal cells and the four become eight abnormal cells, eventually the multiplication of abnormal cells becomes a lump that is called a tumour. A change in the genetic code of the cell has led to that cell not knowing when to stop growing and, once “turned on,” it will continue multiplying in an uncontrolled manner.

The multiplication or dividing of these abnormal cells takes place at different rates, depending on the type of cancer. Fast growing cancers may double in one to four weeks where slow growing cancers may double over two to six months. It can take up to five years for the duplication process to happen 20 times. At that point the tumour may contain a million cells and still only be the size of a pinhead. Hence there is a “silent” period after the cancer has started to grow when there is no lump or mass that can be detected. It may take as many as 30 doublings before the lump can be felt or seen on an x-ray. By that time there can be as many as one billion cells.

It is important to realize that not all abnormal growths or tumours are cancers. Tumours may be benign or malignant. Benign tumours usually stay in one place, have smooth borders, do not invade the surrounding tissue, and do not cause much difficulty (i.e. freckles, moles, fatty lumps in the skin). Malignant tumours or cancers, on the other hand, have two characteristics that are significant for the health and wellbeing of the individual. Firstly, they have no clear cut border and can directly invade other tissues which surround them. Secondly, they have the ability to spread to other parts of the body. Small pieces or cells can move to other parts of the body and, in some cases, take root there and grow. This process is called metastatic spread. It is these two characteristics that govern the approaches to diagnosis and treatment of cancer.

The other important aspect to know about cancer is that it is a general term for more than 200 different diseases (see Table 1). Although all the diseases have the same characteristics regarding abnormal cell growth, each disease behaves a little differently. Breast cancer is a different disease than lung cancer. Lung cancer is a different disease than bowel or brain cancer. This wide variety of diseases makes it challenging to diagnose and treat cancer. It also makes it confusing for patients and families to comprehend what may be happening during their care process.

How is Cancer Detected?

The actual diagnosis of cancer can be made in different ways. It depends on the type of cancer and how far the cancer has grown (i.e. the stage of the cancer). The evidence is clear that the earlier a cancer is identified and treated, the greater the chances are that the cancer can be cured or controlled. However, detection of some cancers at an early stage is a challenge.

Cancer may be detected by the person themselves or during an examination by a health care professional. The symptoms that may become evident arise because the tumour has grown to a size that allows its presence to become apparent in some way (i.e. pressure, bleeding, a mass or

interference with the organ's function). There are seven early warning signals that should lead to further investigation:

- C**hange in bowel or bladder habits
- A** sore that does not heal
- U**nusual bleeding or discharge
- T**hickening or lump in breast or elsewhere
- I**ndigestion or difficulty swallowing
- O**bvious change in mole or wart
- N**agging cough or hoarseness

Once suspicions are raised, further diagnostic tests are needed to confirm a diagnosis of cancer. These tests could include examinations (physical, endoscopy), tests (blood, stool, body fluids), images of body organs (e.g., x-ray, nuclear scan, angiography, CT scans, magnetic imaging, ultrasound), and analysis of tissues under a microscope (cytology or the study of cellular material removed from the body). This latter approach may require bone marrow aspirations or tissue biopsies. Often a combination of tests is ordered before a definitive diagnosis is made.

A major challenge for individuals who are undergoing diagnostic work-up for cancer includes waiting for the test procedures and understanding all of the test results. Often the language used to describe the results is new to the person and his or her family members. Individuals can feel very alone, isolated and vulnerable during this time. It is often described as one of the most highly anxious times.

How is Cancer Treated?

Once there is a definitive diagnosis of cancer, the next step is to determine the best treatment approach for each patient's situation. There are several treatment modalities used for cancer. The determination about which modality will be used, when it will be used and in what combination with any other modality, depends upon the type of cancer and the extent of the spread of the cancer at the time of diagnosis. This information will have been gathered during the diagnostic testing period.

Treatments for cancer are divided into two categories based on their capacity to deal with local (tumour in situ) or widespread disease (disseminated or metastatic disease). Surgery and radiation therapy are considered local treatments while chemotherapy and biological therapy are considered effective for widespread disease. Sometimes two or more modalities will be used in order to remove the tumour bulk from its local position and also deal with any cells that may have already traveled to another part of the body. For example, with some types of breast cancer, surgery will be performed initially followed by radiation and then chemotherapy. The latter is called adjuvant treatment and is aimed at possible metastatic spread of microscopic disease to other parts of the body.

Making a treatment decision also includes consideration of personal factors and should always include consideration of the individual's preferences and quality of life. The risks and benefits of any treatment should be adequately discussed. Consideration is often given to age and co-morbidities in light of the expected side effects and impact on the individual. Co-morbidities may also dictate what treatment options are available. For example, surgery may be risky for an individual with cardiac disease.

The side effects of each treatment modality differ and will be linked in some measure to the part of the body that is being treated as well as the extent of the treatment or how aggressive it is. In general, combination therapy has more of an impact upon individuals.

Surgery plays a crucial role in treating cancer and is used in a variety of ways: to prevent or lower the risk of cancer developing (i.e. in precancerous conditions), to stage the disease, to remove the primary tumour, to remove other tumours (metastatic tumours), to relieve symptoms, to reconstruct or rehabilitate, or to support other forms of therapy (i.e. insert a line or piece of equipment for chemotherapy administration). Surgery will require a hospital admission in the majority of cases, with the concomitant pre-operative preparation, post-operative care, and a period of recovery following discharge. Wound care, pain management, and functional recovery are key issues for care planning.

Radiation therapy will be given to about half of all individuals with cancer as part of their overall treatment and care. It may be given as the only and primary treatment or in combination with other modalities. It uses high energy x-rays, electron beams or radioactive isotopes to kill cancer cells, without exceeding safe doses to normal tissues. It effectively interferes with the division of the cells it touches. Radiation therapy may be given in a variety of ways as an internal treatment or an external treatment. The method used is selected on the basis of the biology of the tumour, the anticipated side effects, the different sources of radiation and how they affect the body tissues. Most often, radiation treatment is given in several doses (called fractions) that may be administered on a daily basis over several weeks. The actual schedule of doses depends on the overall amount of treatment and the type of radiation.

The side effects of radiation will vary depending upon the part of the body involved in the treatment. They can be described as generalized (systemic effects on the whole body such as fatigue) or localized (area of the body treated such as diarrhea, nausea, skin irritation, hair loss). Not everyone experiences side effects from their radiation treatment. The impact varies from person to person but in some situations is severe.

Chemotherapy, the treatment of cancer tumours with chemical agents or drugs, may be recommended as a treatment for several reasons: to cure a specific cancer, to control cancer growth, to relieve symptoms (i.e. pain), to shrink tumours before surgery or radiation, or to destroy microscopic metastases after surgical removal of tumours. Chemotherapy agents or drugs interfere with the division of cancer cells. As a systemic treatment, the drugs travel throughout an individual's body and attack cells in the process of dividing. This would mean the targets are cancer cells in their rapidly dividing state. However, because of this systemic administration, chemotherapy can also interfere with the division of normal body cells. It is the interference with any rapidly dividing normal body cells that result in the side effects of chemotherapy: nausea, hair loss, diarrhea, finger and toe nail abnormalities, etc. The type and combinations of drugs, as well as the dosage, will result in different degrees of side effects.

Chemotherapy can be given through various routes (e.g., oral and intravenous) and methods (e.g., implanted infusion pumps, ambulatory pumps, etc.). Which route and method to use depends on several factors such as the type of drug, the size of the dose needed, and the anticipated side effects, as well as the patient condition and preference. A complete discussion of all of these factors ought to be conducted before therapy is initiated. Finally, there are various schedules or protocols for administering chemotherapy. Patients may receive daily, weekly, or monthly doses over several months.

Biological therapy is a relatively new way of treating cancer. This therapy is based on the idea that the body's immune system can play a role in destroying cancer cells given that the usual role for the immune system is to destroy and eliminate foreign substances (e.g., bacteria, viruses) in the body. There are five ways to improve how the immune system works: active stimulation, adoptive strategy (passing on new information to the immune cells), restorative strategy (replacing depleted immune cells), passive strategy (giving the immune cells weapons to help in their attacks) and tumour cell modulation (helping to highlight and target cell components). Presently, there are several types of biologic agents: interferons, interleukins, colony stimulating factors, T-cells, tumour vaccines, tumour necrosis factors, and gene therapy as well as antibody therapy (e.g., monoclonal antibodies).

The knowledge about this type of therapy is advancing rapidly and holds great promise for the future. Biological approaches are now the treatment of choice in some cancers. However the field is still unfolding. Future possibilities exist for targeted therapies to be developed and for them to be given on the basis of an individual's specific genetic tumour analysis.

The nature of the therapies, however, means different side effect profiles from the more traditional chemotherapies. Side effects vary and include neutropenia, fever, cardiac arrhythmias, fatigue, and allergic type reactions.

Recurrent and Metastatic Disease

Once the initial course of treatment is finished, patients are monitored closely. As long as there is no further evidence of cancer, the monitoring appointments are further and further apart over time.

Patients may face a recurrence of their disease (same type of cancer), a progression of their disease (spreading of the cancer to other parts of the body), or a new primary cancer (another type of cancer). These events will necessitate complete diagnostic testing again and another round of treatment planning and decision-making. Depending on the type of cancer, some recurrences can be treated successfully and the person experiences no further evidence of disease. For others, recurrence heralds a progression toward metastatic disease and, ultimately, death from the cancer. Advances in treatments, however, have led to significantly better capability to control metastatic spread and increased survival time. This has resulted in some cancers being conceptualized as chronic diseases. Advances in symptom management have also increased the capacity to manage pain and other symptoms effectively, both during the metastatic interval and end-of-life care. Presently, taking all types of cancers into account, approximately 49% of those diagnosed with cancer die of their disease. However, mortality rates vary by type of cancer (see Table 2).

Survivorship

The advancements in cancer treatment over the past 20 years have led to a growing cadre of cancer survivors. It is estimated there are one million Canadians living disease-free after diagnosis and treatment of cancer. Individuals who have experienced this cancer journey have perspectives and wisdom to help us improve treatment and care approaches in the future. However, this group is also a vulnerable group. They require care for late and long term effects of the cancer treatment. In many instances, we are still learning about how to best care for these challenges.

Table 1. Estimated Age-Standardized Incidence Rates for the Most Common Cancers by Sex and Province, Canada, 2007

Rate per 100,000	Canada ¹	NL*	PE	NS	NB	QC	ON	MB	SK	AB	BC
Males											
All Cancers	454	418	523	529	494	477	437	470	464	478	421
Prostate	122	113	169	136	128	95*	129	120	151	154	123
Lung	68	54	2	86	91	94	58	66	59	58	53
Colorectal	62	83	65	76	59	68	60	65	63	59	54
Bladder**	27	27	33	37	33	37	18	30	30	29	30
Non-Hodgkin											
Lymphoma	20	13	25	24	22	19	20	22	21	19	21
Kidney	16	13	17	20	21	17	17	19	16	15	12
Leukemia	14	7	19	13	12	14	14	14	17	17	12
Melanoma	13	14	20	22	13	7	16	11	10	15	16
Oral	11	16	8	15	12	11	11	15	10	10	10
Stomach	10	15	9	10	11	11	10	12	9	9	9
Pancreas	10	3	13	10	13	12	8	11	9	10	9
Brain	8	10	6	8	8	9	8	8	7	8	7
Esophagus	6	5	8	8	7	6	6	5	5	7	6
Liver	6	3	2	3	2	6	5	4	2	6	7
Multiple Myeloma	6	4	6	6	6	6	6	6	5	5	5
Females											
All Cancers	358	310	403	386	362	371	357	376	344	368	328
Breast	104	101	111	101	100	111	104	107	98	106	93
Lung	50	35	49	52	48	60	46	51	42	49	46
Colorectal	41	51	58	50	41	41	41	43	40	38	37
Body of Uterus	19	17	19	19	17	17	20	24	21	21	18
Thyroid	16	11	5	9	12	14	23	9	9	16	9
Non-Hodgkin Lymphoma	15	12	12	14	14	14	15	15	13	14	14
Melanoma	11	12	23	18	15	7	12	9	10	13	11
Ovary	11	7	9	10	12	12	12	13	10	9	9
Pancreas	8	2	8	9	9	9	7	8	6	8	9
Kidney	8	8	8	11	11	9	9	9	8	8	6
Leukemia	8	5	7	8	8	8	8	9	10	9	7
Cervix	7	8	10	11	8	6	7	7	9	10	7
Bladder**	7	7	7	10	9	9	5	8	9	8	9
Brain	6	4	6	6	6	7	6	5	6	5	5
Oral	5	5	5	6	4	5	5	6	5	5	5
Stomach	4	6	3	4	4	5	4	5	4	5	4

* Likely an underestimate of the number of cases for the years used to generate the 2007 estimates

** Inter-provincial variation. Ontario does not currently report in situ bladder cases. See text.

¹ Canada totals include provincial and territorial estimates. Territories are not listed separately due to small numbers.

Note: Rates exclude non-melanoma (basal cell and squamous cell) skin cancer and are adjusted to the age distribution of the 1991 Canadian population. Caution is needed if the 2007 estimates are compared to previously published estimates. These estimates may vary from actual figures.

Source: Surveillance Division, CCDPC, Public Health Agency of Canada

Canadian Cancer Society National Cancer Institute of Canada: *Canadian Cancer Statistics 2007*

Table 2. Estimated Age-Standardized Mortality Rates for the Most Common Cancers by Sex and Province, Canada, 2007

Rate per 100,000	Canada ¹	NL*	PE	NS	NB	QC	ON	MB	SK	AB	BC
Males											
All Cancers	212	253	229	248	239	241	204	214	216	194	180
Lung	61	76	79	77	81	83	52	53	55	49	47
Colorectal	26	36	31	31	26	30	25	28	26	22	21
Prostate	25	29	27	27	30	22	24	26	39	29	21
Pancreas	9	10	9	12	11	10	9	10	10	9	9
Non-Hodgkin											
Lymphoma	9	6	8	11	11	9	10	11	8	8	9
Leukemia	8	6	8	8	7	7	8	9	9	8	7
Esophagus	7	6	8	9	6	5	7	8	8	7	8
Bladder	7	9	6	8	7	7	7	7	7	6	7
Stomach	6	13	8	6	6	8	6	5	5	5	5
Brain	5	6	2	6	5	7	5	5	5	5	5
Kidney	5	7	8	7	6	6	5	7	5	6	5
Oral	4	6	5	5	4	4	4	4	3	4	4
Melanoma	3	2	3	4	2	2	4	3	2	2	3
Multiple Myeloma	3	2	5	4	3	3	3	3	3	2	3
Liver	3	2	1	1	1	4	3	1	2	2	2
Females											
All Cancers	148	161	153	169	151	156	146	154	146	143	134
Lung	40	39	53	50	35	47	38	36	34	40	37
Breast	23	27	27	27	23	24	23	25	22	22	20
Colorectal	16	25	23	22	17	18	16	17	15	13	14
Pancreas	8	7	8	9	8	8	8	8	7	7	8
Ovary	7	9	6	8	7	6	8	8	8	7	8
Non-Hodgkin Lymphoma	6	5	7	6	6	6	6	7	7	6	6
Brain	4	4	4	4	4	4	3	3	4	4	3
Leukemia	4	3	4	4	3	4	4	5	5	5	4
Stomach	3	7	1	3	3	4	3	3	3	3	3
Body of Uterus	3	3	3	4	3	3	3	3	2	3	2
Kidney	3	4	3	3	4	3	2	3	3	3	2
Oral	2	0	2	2	1	2	2	2	2	2	2
Melanoma	2	1	1	2	1	1	2	1	1	1	2
Cervix	2	4	3	3	3	1	2	2	2	2	2
Bladder	2	2	1	2	2	2	2	1	2	2	2

¹ Canada totals include provincial and territorial estimates. Territories are not listed separately due to small numbers.

Note: Rates are adjusted to the age distribution of the 1991 Canadian population. Caution is needed if the 2007 estimates are compared to previously published estimates. These estimates may vary from actual figures.

Source: Surveillance Division, CCDPC, Public Health Agency of Canada

Canadian Cancer Society National Cancer Institute of Canada: *Canadian Cancer Statistics 2007*

UNDERSTANDING THE CANCER CARE SYSTEM

Margaret I. Fitch, RN, PhD

There are over 200 different kinds of cancer. Each type has a different pathway of discovery, diagnosis, and treatment. Even within one type such as breast cancer, there are differences. It is a complex disease and demands expertise to eradicate or control.

How is Cancer Care Delivery Organized? Where is Care Provided?

The delivery of cancer care is a complex proposition. From family physician offices or screening centres, individuals who have suspicious findings often find themselves being referred to surgeons or to oncologists. This may require travel to another location or hospital in another community, as well as interaction with a new set of health care providers. It often means the individual feels they are embarking on a journey within a “foreign world”. The destination is not certain nor is the route clear. The language has many new words and communication can be challenging.

Cancer care is considered a specialty and is provided in special centres or programs. In particular, radiation is only provided in specific locations due to the nature of the equipment and safety precautions. Chemotherapy may be provided in oncologist offices, ambulatory centres, hospital units or community home settings. However, in all settings there is a need for health care practitioners to be specially educated for cancer care delivery and to follow approved standards of care and practice guidelines. Research plays a strong role as a foundation for care decision-making within the clinical settings. Often patients are invited to participate in clinical trials as part of their treatment and care.

Physicians specialize in the delivery of particular cancer treatment modalities. As a result, the patient may interact with a cancer surgery specialist, a radiation oncologist, and a medical oncologist. Each may be in a different setting despite the attempts to have them working collaboratively. Most regional cancer centres and hospital-based cancer programs now offer multidisciplinary team care where all specialists are present and working together to decide about a person's treatment needs.

In addition to physicians and surgeons, the cancer care team includes a wide range of other cancer specialists including cancer nurses, social workers, nutritionists, and psychosocial counsellors. The actual composition of the team will vary from setting to setting. These professions have important roles in assisting patients and families in coping with the multiple challenges that occur during the cancer experience. Other important partners in the cancer care process are the volunteer-based agencies. These agencies provide information and support for cancer patients and their family members. Examples of these agencies are: Canadian Cancer Society, Wellspring, Willow (Breast Cancer), Lung Cancer Canada, and Ovarian Cancer Canada. The provision of peer support is cited by cancer patients as very important in coping with their illness-related challenges.

What are the Current Challenges in the Cancer Care System?

There are challenges presently within the cancer care system that have an impact on patients and families:

- The advances in science and technology are leading to new types of therapies or treatments and new approaches to treatment administration. As the complexity increases there is more for health care providers to learn about care techniques.
- Over the next 20 years, it is projected there will be an increase in the incidence of cancer (see Graph 1), in part due to lifestyle factors (e.g., tobacco use, obesity). However, the major influence will be because of the population demographics. The large proportion of Canadians who will be older than 60 years will account for many of the actual cases of cancer (see Table 1). After all, age is the greatest risk factor in cancer. The increased demand for cancer care will be a huge pressure on health care resources.
- There is a projected shortage in all health care professions. Such a shortage will mean fewer people available for specialty care. Those who are in the field will be carrying large caseloads/ workloads.
- The drive toward community-based care will mean more cancer treatments will be in ambulatory and home settings. Less time in hospital and reduced time interacting with health care professionals present challenges in educating patients/family members and monitoring patient status and symptoms. The trend toward including self care and empowerment strategies in many patient/family education programs is an attempt to place patients in a good position to be a partner in the care process.
- There is concern across Canada that the cancer care system is fragmented and continuity of care is not achieved in many settings. Patients and families struggle to know about resources and available help.

What are the Challenges for Individuals Diagnosed with Cancer?

Cancer and its treatment have more than a physical impact. There are social, emotional, psychological, and spiritual consequences as well. Throughout a person's journey in the cancer system, there are challenges to be handled and changes to be managed. Most people will say nothing is ever quite the same again after a cancer diagnosis and the journey through the cancer experience is one of many transitions (see Table 2).

The actual pathway through the cancer system may vary from person to person (see Figure 1). Individuals with different cancers enter the cancer system at different points and follow different courses. The pathways are influenced by what type of cancer is diagnosed, how advanced the disease is, and the nature of the treatment recommended. Many people find the cancer system confusing and they experience uncertainty and frustration finding out about their expected care trajectory and the resources available to them.

When illness strikes, an individual's ability to meet his or her own needs may be compromised. Usual ways of caring for one's self may not be effective. Inevitably there will be a need for new information and, perhaps, new social connections. Many individuals have indicated that access to information and support, as well as good communication with their cancer care team is critically important to their ability to cope with this stressful event in their lives. However, patients have reported difficulties accessing relevant, easily understood information, especially at diagnosis; accessing peer and professional support; and maintaining satisfactory communication exchanges with members of the cancer care team.

The last ten years have seen a remarkable increase in available information about cancer and cancer treatments. The Internet has facilitated access to this information. However, cancer patients are often overwhelmed by all the information and experience a challenge in applying the information to their own unique situation. They require the exchange with a knowledgeable cancer care practitioner to understand what information applies to them and is relevant to their situation.

The availability of support services, both peer or professional, is quite varied across the country. Urban settings tend to have a greater number of services, however those tend to be designed for English speaking, educated individuals. Programs tailored to age or ethnicity are slowly beginning to emerge. Technology also holds excellent promise for providing services to those who live in rural and remote settings (e.g., online education and support).

One of the most important components of care for cancer patients is to be treated as a person, to be respected as a unique individual with knowledge and wisdom about one's own body and about life and how it is to be lived. This is experienced during exchanges and dialogues with health care providers and is achieved through working with patients as partners in the cancer care team. Person-centered care means taking an individual's preferences and concerns into account when care decisions are being made. Unfortunately, not all patients are able to experience such a partnership.

What are the Particular Challenges for Older Adults Diagnosed with Cancer?

Cancer is predominantly a disease of the older population (see Table 1). Surprisingly, little attention has been given to the preparedness of the health care system to meet the converging demands of older adults, the long term follow-up required as a result of successful cancer treatments, and the available retirement resources of this group.

To date, there is limited information on the effects of treatment for the older adult as this portion of the population is often excluded from treatment clinical trials research. Many of the supportive care needs that provide for quality of life have not been specifically studied. Issues such as symptom management, preferences for information, communicating with health professionals, and decision-making for ongoing care may require unique interventions to support this rapidly growing segment of the population (Yancik, 2005).

It is estimated that, as of July 2007, 13.2% of men in Canada and 14.9% of women will be over the age of 65 (Statistics Canada, 2007). Turning to cancer statistics, just under half (43%) of all cancer diagnoses are found at the age of 70 and over half (60%) of all cancer deaths occur in the same age group (Canadian Cancer Statistics, 2007).

Research has revealed that older patients are less likely to be treated using curative therapies (O'Connell, Maggard & Yo, 2004; Tallarico, Figueiredo, Goodman, Kreling & Mandelblatt, 2007). The perceived barriers that result in treatment being withheld include functional status, social support, and transportation of the older adult (O'Connell et al., 2004). Concerns are often raised about older adults' tolerance for toxicities, and the impact of co-morbid conditions on overall outcomes. Compromised functional status and adequate social support to maintain independence and overall quality of life are also cited as key factors for physicians in offering treatment choices to older adults (Tallarico et al., 2007).

Clearly, the older adult facing a cancer diagnosis may be facing a variety of challenges. There may be other pre-existing health problems or chronic conditions that will influence treatment decisions. The decreased mobility, diminishing cognitive status, and increasing frailty that accompanies growing older may limit the tolerance a person has for cancer treatments and their accompanying side effects.

The cohort of older adults may also struggle with issues of literacy, poor eyesight, and diminished hearing capacity. All will influence their capacity to attend to and absorb the information about cancer and treatment. Adjustments are needed in teaching materials, teaching time, and educational approaches.

Finally, attitudes of ageism may exist within care providers. This attitude can affect the way older adults are spoken to, included in conversations, and involved in decision-making about their care.

From the perspective of seniors' mental health, there are three groups to consider:

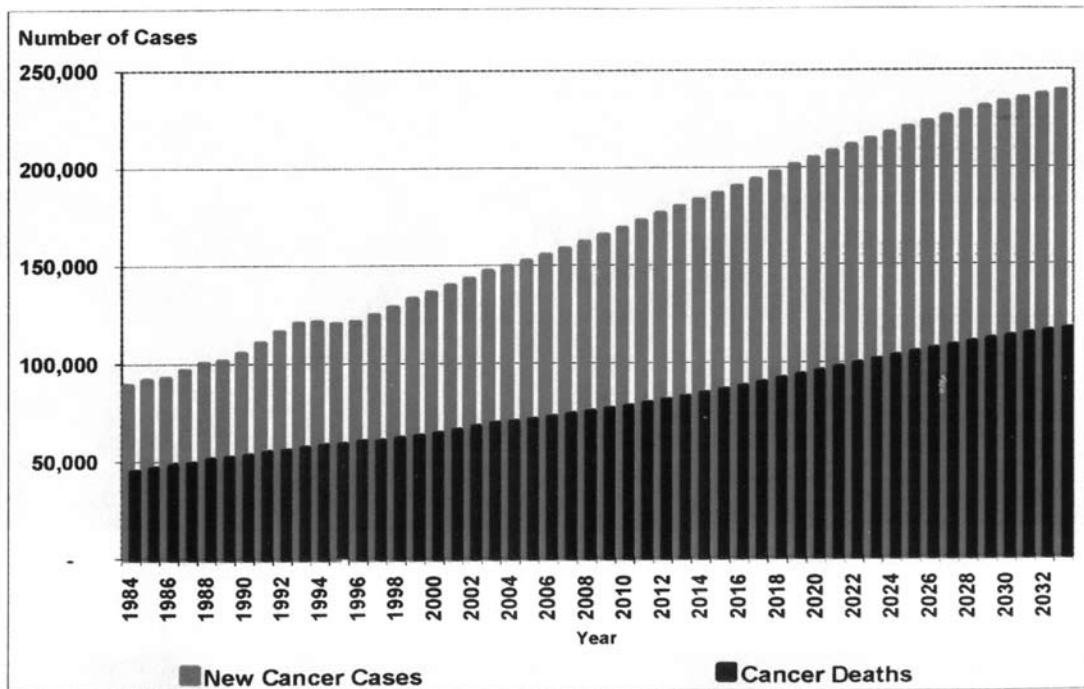
Individuals facing a cancer diagnosis and course of treatment will experience an emotional, psychosocial, and spiritual impact. This is part of the cancer experience. As a result, all individuals will benefit from easy access to relevant information, emotional support, good symptom management, and effective interaction (communication) with the cancer care team. Some will manage well with this level of intervention while others will benefit from referral to a psychosocial counsellor. Approximately 35% may require such a referral (see Figure 2).

Individuals who enter the cancer journey with pre-existing mental health co-morbidity, will be coping with not only the impact of the cancer but also the ongoing impact of their mental illness. They may need very particular and tailored interventions, depending on the co-morbidity.

The third group to consider in terms of mental health are the family members or caregivers. They will feel the impact of the cancer experience and struggle with their own emotional responses. They too may be older adults and have co-morbid disease or chronic conditions. They also need to be included in care planning and decision-making. Additionally, they may require referral to psychosocial counsellors for assistance in dealing with their own needs.

Graph 1.

Canadian Estimated and Forecast Cancer Trends, Males and Females, All Ages, All Cancers (1984 to 2033)



Source: RiskAnalytica Life @ Cancer Risk (2004)

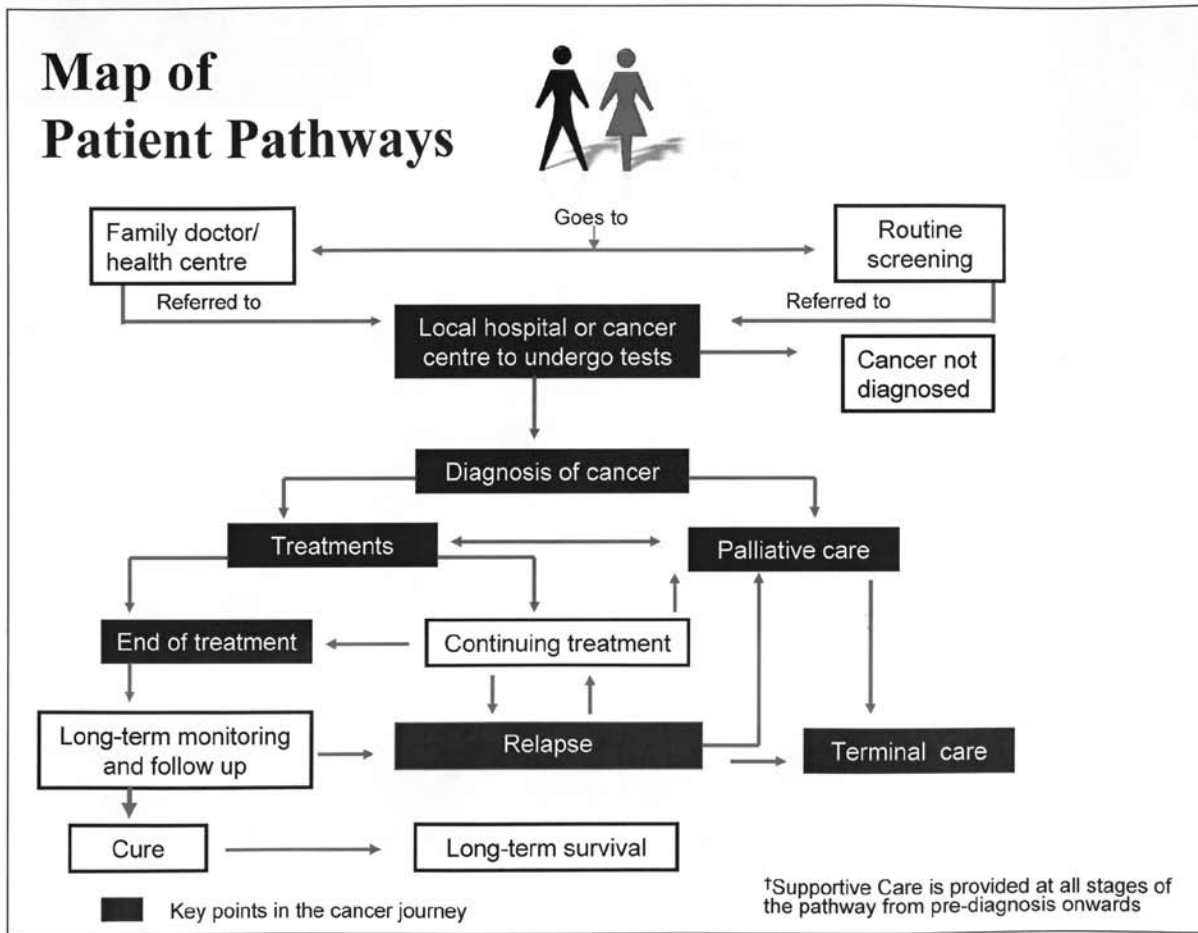
Table 1.

Age Group	New Cases - 2006 Estimates		
	Total	Male	Female
0-19	1,250	680	590
20-29	1,800	810	960
30-39	4,400	1,500	2,800
40-49	12,700	4,500	8,200
50-59	28,500	13,300	15,200
60-69	38,400	22,100	16,300
70-79	39,200	22,600	16,600
80+	26,800	12,900	14,000
All Ages	53,100	78,400	74,700

Note: Incidence figures exclude non-melanoma skin cancer (basal and squamous). Total of rounded numbers may not equal rounded total number.


Source: Surveillance Division, CCDPC, Public Health Agency of Canada

Figure 1.



Source: Fitch, 2003

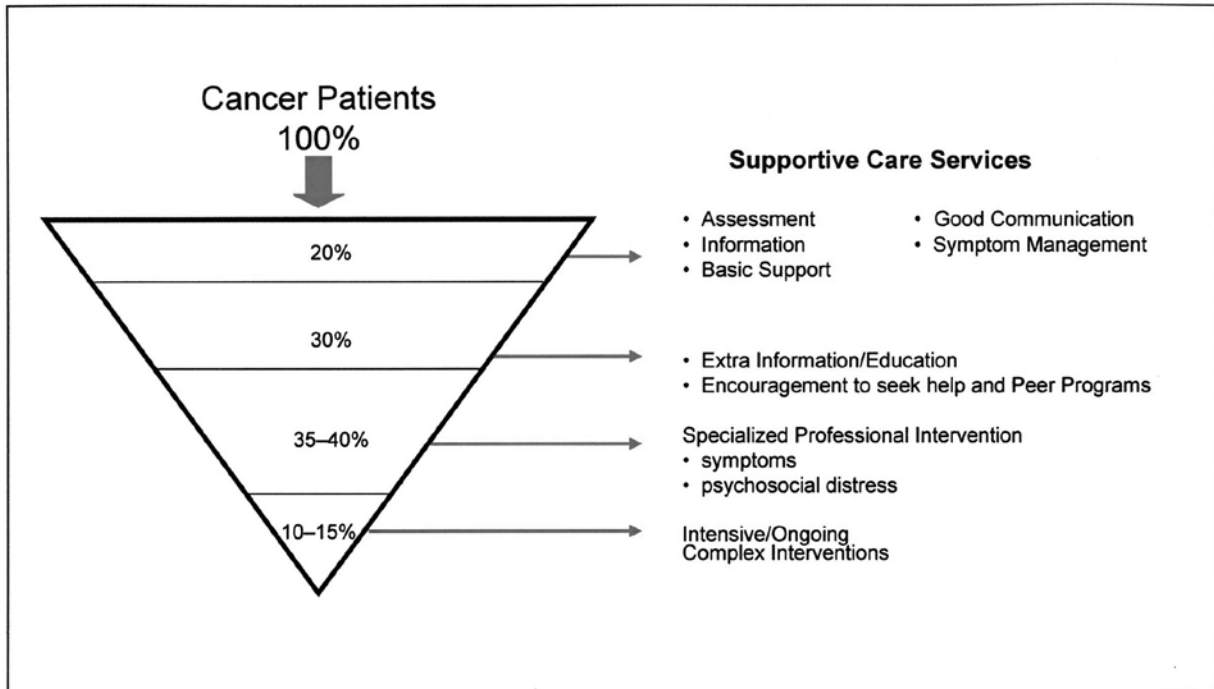
Table 2.

Times of Transition	
<ul style="list-style-type: none">• finding an abnormality• seeking an opinion/diagnostic testing• hearing a diagnosis• starting treatment• finishing treatment• getting back to normal• experiencing a recurrence• requiring palliative care• approaching death• dying...death• grieving the loss	

Note: The cancer journey is one of many transitions. As life events unfold, the inherent changes can bring about social, emotional, and practical consequences together with challenges in coping and adaptation for the individual with the illness as well as family members and friends. The transition points as described by patients are appropriate times for focused assessment.

Source: Fitch, 2000

Figure 2.



Note: From an overall perspective, 20% of all cancer patients will manage well with basic supportive cancer care interventions. An additional 30% will also need additional information, education and encouragement. Another 35-40% will benefit from specialized professional intervention and another 10-15% will need ongoing intensive supportive care intervention. The clinical challenge is to assess patients' needs and determine the level and type of resources that are needed in a timely manner.

Source: Fitch, 2003

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AGING CHANGES

Sharon Galloway, RN, MSN, GNC

Aging is a process that begins at birth, with building of the organism until the late teens or early twenties followed by a slow decline in the functional capacity of the organ systems. (Ebersole, Hess, Touhy & Jett, 2005, p. 84). Aging is a universal, unavoidable and individualized experience for each person.

The information presented here was prepared for the British Columbia Gerontological Nurse's Association and published in their Spring 2007 newsletter. Major physiological changes are highlighted here and the references provide more details.

System	Physiologic Changes	Expected Signs or Symptoms	Nursing Implications
Eyes	<ul style="list-style-type: none"> • Loss of elasticity • Lens thickens and discolors • Decreased pupil size • Macular degeneration 	<ul style="list-style-type: none"> • Eyelids drop or turn inward • Colour distortion • Decreased tolerance for glare • Cataracts • Slower dark and light adaptation • Narrowing of visual field • Presbyopia 	<ul style="list-style-type: none"> • Provide for brighter lights (3x the light is required) and colour contrasts to increase discrimination • Adjust lighting to decrease glare • Clean glasses • Approach the person from the front not the side
Ear	<ul style="list-style-type: none"> • Thickening of tympanic membrane • Ear wax build up • Sclerosis of inner ear 	<ul style="list-style-type: none"> • Presbycusis • Increase auditory reaction time • Loss of high frequency sounds 	<ul style="list-style-type: none"> • Face older adults when interacting • Speak in lower tones • Assess for wax in ears
Nose, Mouth, Throat	<ul style="list-style-type: none"> • Atrophy of taste buds • Loss of efficiency in relaying flavours • Decrease sense of smell • Retraction of gums 	<ul style="list-style-type: none"> • Changes in dentition • Decreased taste buds for sweet and salty; mostly able to taste bitter and sour 	<ul style="list-style-type: none"> • Seasoning of food may need to be increased • Assess for ill fitting dentures
Gastro-intestinal System	<ul style="list-style-type: none"> • Weakening of intestinal wall • Reduced gastric acid • Slower neural transmission • Decrease esophageal peristalsis • Decrease in secretion of digestive juices 	<ul style="list-style-type: none"> • Food intolerances, difficulty with digestion • Reflux • Constipation and incontinence • Diverticulosis • Vitamin deficiency 	<ul style="list-style-type: none"> • Assess elimination patterns • Allow more time for eating • Space meals out • Ensure 1500-2000 ml/day fluid • Promotion of 6 small meals/day
Musculo-skeletal System	<ul style="list-style-type: none"> • 30% reduction in muscle mass • Skeletal changes (bone resorption is greater than bone deposition) • Degenerative joint changes • Dehydration of intervertebral disks 	<ul style="list-style-type: none"> • Decrease in strength and stamina • Fractures, osteoporosis • Increased joint stiffness • Decreased height • Gait changes 	<ul style="list-style-type: none"> • Muscle strengthening exercises • Adequate calcium intake, vitamin D • Flexibility exercises and weight bearing exercises

System	Physiologic Changes	Expected Signs or Symptoms	Nursing Implications
			<ul style="list-style-type: none"> • Encourage range of motion exercises • Distinguish muscle weakness from electrolyte imbalance and/or medications side effects • Ensure well fitting footwear • Fall risk is higher
Cardio-vascular	<ul style="list-style-type: none"> • Decreased cardiac output • Conductivity altered • Heart valves thicken • Left ventricle hypertrophy • Decreased stress response • Decreased coronary artery blood flow 	<ul style="list-style-type: none"> • Decrease in peripheral circulation • Decrease in rate, rhythm of pulse • Fatigue, shortness of breath • Dependent edema of lower extremities • Dizziness from too rapid change of position • Increased systolic blood pressure • Pulse takes a longer time to return to a resting heart rate 	<ul style="list-style-type: none"> • Pace activities • Monitor blood pressure • Check for swelling/pitting edema-use of support hose • Elevate feet periodically during day • Instruct on proper way to get up after lying in bed or sitting to avoid blood pressure drop
Pulmonary	<ul style="list-style-type: none"> • Increase AP Diameter • Rigidity of chest wall • Decreased cilia • Fewer alveoli • Intercostal, accessory and diaphragm muscles become weaker 	<ul style="list-style-type: none"> • Decreased cough reflex • Decreased removal of mucus, dust and irritants • Decreased vital capacity • Decreased chest expansion • Decreased endurance • Hyper-inflation of apices; under-inflation of bases of lungs 	<ul style="list-style-type: none"> • Ensure upright position when eating, drinking • Limit exposure to airborne viruses and pollutants • Yearly flu immunization • Encourage deep-breathing, smoking cessation programs • Pace activities, provide adequate rest
Neurological	<ul style="list-style-type: none"> • Decrease in neuro-transmitters • Nerve cell degeneration and atrophy (25-42%) • Decrease in rate of nerve cell conduction impulses • Altered pain perception • Decreased proprioception • Diminished stage 3-4 (deep) sleep 	<ul style="list-style-type: none"> • Difficulty in changing positions or achieving balance • Loss of sensation in extremities • Learning occurs as usual but more slowly • Slower reflexes • More frequent awakenings at night 	<ul style="list-style-type: none"> • Approach learning projects slowly • Use memory aids (calendar, post-it notes, etc.) • Assess mental status as required • Assess environment for safety
Renal & Bladder	<ul style="list-style-type: none"> • Decrease in number of nephrons • Decrease in blood flow, glomeruli, renin and filtration • Decreased bladder capacity • Weak pelvic floor muscles 	<ul style="list-style-type: none"> • Increased creatinine clearance • More time needed for filtration; urine may be more dilute • Increased urinary frequency • Increased potential for inadequate excretion of drug metabolites 	<ul style="list-style-type: none"> • Monitor renal function carefully • Remove barriers of getting to toilet

System	Physiologic Changes	Expected Signs or Symptoms	Nursing Implications
	<ul style="list-style-type: none"> • Replacement of smooth muscle and elastic tissue with fibrous connective tissue in bladder 	<ul style="list-style-type: none"> • Incomplete emptying of bladder/urinary retention 	<ul style="list-style-type: none"> • Assess pattern of voiding with continence log if incontinence is occurring • Toileting strategies as appropriate • Be alert to check for post- void residual
Reproductive Changes (Female)	<ul style="list-style-type: none"> • Decreased estrogen production • Ovaries degenerate • Vagina, uterus and breast atrophy • Sagging and loss of firmness of breasts 	<ul style="list-style-type: none"> • Vaginal dryness • Menopause • Uncomfortable intercourse 	<ul style="list-style-type: none"> • Be sensitive that these changes may impact self esteem • Desire for closeness and for sexual activity does not diminish with age • Be aware of different products to assist with vaginal dryness • Continue to encourage safe sex practices
Reproductive Changes (Male)	<ul style="list-style-type: none"> • Sperm count diminishes • Decrease penis size • Hypertrophy of prostate gland • Decrease in size of testes 	<ul style="list-style-type: none"> • Erectile dysfunction concerns 	<ul style="list-style-type: none"> • As above
Immune System	<ul style="list-style-type: none"> • Decrease in thymus mass and productions • Increase in immunoglobulins 	<ul style="list-style-type: none"> • More susceptible to infections 	<ul style="list-style-type: none"> • Good hand washing • Ensure flu and Pneumovac inoculations are given • Limit exposure to obvious pathogens • Maintain aseptic technique in dressing changes and any invasive procedures
Skin	<ul style="list-style-type: none"> • Loss of subcutaneous tissue • Thinning of dermis • Atrophy of oil, moisture, sweat glands • Loss of elasticity • Paler face 	<ul style="list-style-type: none"> • Wrinkling • Underlying tissue more fragile • Inability to respond to heat or cold quickly • Loss of moisture • Dryness • Prone to hypothermia • Altered thermoregulation 	<ul style="list-style-type: none"> • Handle individual skin with care • Use lotion to lubricate skin • Inspect skin when bathing • Reposition every 2 hours • Hydrate • Wear light cool clothing in hot weather • Maintain warm environment in cooler temperatures

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TRANSITIONS FOR OLDER ADULTS

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The diagnosis of cancer occurs against a back drop of developmental and life stage transitions that reflect the normal aging process.

Ebersole, Hess, Tauhy & Jett (2005) state that psychosocial theories of human development include many variables such as culture, cohort, gender, income, and integration into family, community and social networks which are often not included in the biological model of aging. Many psychological theories of aging contain established tasks or shifts in concerns as one grows older. Noted psychologist Erik Erikson defined the last stage of life as a time when the older adult reviews their life and sees either integrity or despair.

“Sociological aging is the performance of expected social roles appropriate to one’s chronological age, culture and capacity” (Ebersole et al., 2005, p.115). A transition is defined as a period of movement and reorganization that occurs over time. Most transitions throughout the life course include a major shift in social expectations and changes to identity, role, relationships, abilities and patterns of behaviour (Hooyman & Kiyak, 1999). Common transitions for older adults are:

- retirement
- death of a spouse/partner
- changes to the nuclear family
- awareness of mortality
- change in health status and decline in function
- caregiver to care recipient
- reduction in income
- decrease in social contacts

The ability to successfully negotiate transitions and develop new and gratifying roles depends on personal and environmental supports, timing, clarity of expectations, personality, meaning and degree of change required (Ulysee, 1997). Pre-planning and the individual’s emotional and physical reserves are also important conditions that can influence the outcomes of transitions.

Retirement is a common transition for adults. Turcotte & Schellenberg (2006) write that the median age of retirement has dropped in the last two decades. The decline was correlated with the lowering of the minimum age at which individuals could begin to draw benefits from the Canada Pension Plan. Will this now change as we continue to encounter shortages of workers across numerous sectors and changes to mandatory retirement legislation? In terms of “coping with retirement”, it is noted that involuntary retirement is associated with less positive outcomes, such as lower enjoyment in life after retirement.

It is important for care providers to be knowledgeable about the process of lifespan development and how this impacts the older adults that we care for. Each person will have a different, individualized experience of aging. Care providers should be able to support older adults as they

experience many of the aforementioned transitions. As well, we need to be aware that the “norms” that we are familiar with are changing as the Canadian population ages. How will these changes impact policy development and health care practices? Will the better educated older adult in today’s society navigate the transition of functional decline or the experience of a chronic disease more successfully than an older adult who became ill in previous times? What will we need to change as the system attempts to meet their needs? We will certainly need to talk about their expectations and perceptions. At the same time, care providers will need to be aware of older adults who do not meet these new expectations for roles based on their aging experience (poorly educated, impoverished, alone, etc.) and be able to provide health care services to meet their needs as well.

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CANCER AND CO-MORBIDITY IN SENIORS

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The population of Canada as of April 2007 was 32,852,800 and approximately 28% are seniors. As the population ages we can expect to see an increase in the numbers of people being diagnosed with cancer. Current statistics predict that 44% of new cases (159,900) of cancer will be in those 70 years of age and older (Statistics Canada, 2007; National Cancer Institute of Canada, 2007). In addition to the increasing prevalence of cancer with age comes the likelihood of acquiring a number of other chronic diseases such as cardiovascular disease, diabetes, hypertension, arthritis, and chronic obstructive pulmonary disease. As of 1998, only 17% of seniors aged 65-74 and 13% aged 75 and over reported no chronic illnesses (Centre for Chronic Disease and Prevention Control, 2007). The leading cause of death in Canada is cardiovascular disease (32%) (Statistics Canada, 2007) and 15.5% of 75-79 year olds have diabetes (World Health Organization, 1998).

A considerable body of literature exists on the relationship between co-morbidities and cancer survival particular to a wide variety of cancers. Co-morbidity is the occurrence of some other disease in addition to a cancer diagnosis. Because cancer is so many diseases co-morbidity is studied largely by disease. As individuals age, the likelihood of developing some type of chronic (co-morbid) disease increases. Generally speaking, the presence of co-morbidities negatively affects survival in the presence of cancer (Piccirillo, Tierney, Costas, Grove & Spitznagel, 2004). The next few paragraphs outline the relationship between co-morbidity and cancer specific to the lung, endometrium, colon, breast, and prostate.

In patients with lung cancer at the time of diagnosis, the presence of at least one other chronic illness is not uncommon. The evidence remains unclear if the presence of a co-morbidity alone reduces survival. For example, a 2002 study found that co-morbidities in general had a negative effect on survival in lung cancer patients (Tammemagi, Neslund-Dudas, Simoff & Kvale, 2003), whereas subsequent researchers failed to find a clear association between survival and the presence of a co-morbidity. What they did find was that survival depends mostly on age, stage of the disease and treatment. The lack of a clear association between survival and co-morbidity may be due to the fact that the lung cancer usually marches swiftly and is the primary cause of death (Janssen-Heijnen et al., 2004). One additional observation of these researchers was that the elderly with lung cancer usually received less aggressive chemotherapy yet there was evidence that they could tolerate regular treatment regimes. This under-treatment was also noted in the care of older women with endometrial cancer even though evidence exists that the standard therapy is well tolerated despite age and co-morbidities (Truong et al., 2005). Contrary to this, the number of co-morbidities in individuals with colorectal cancer shortens survival. The severity of the comorbid condition significantly negatively influenced survival. Individuals with colon cancer and diabetes had their survival time cut in half and the more co-morbidities they had, the shorter their survival (Meyerhardt, 2003; Wrigley, Roderick, George, Mullee & Goddard, 2003).

In individuals with breast cancer, the presence of co-morbidity is also important but, interestingly, can both positively and negatively impact survival by its influence on the stage at which cancer is diagnosed. Women with gastrointestinal, genito-urinary disorders, musculoskeletal disorders,

cardiovascular disease, osteoarthritis, and benign hypertension have their disease diagnosed at an earlier stage unlike women who suffer from diabetes, endocrine disorders, hematologic disease, and psychiatric disorders who have their disease diagnosed at an advanced stage. The reasons proposed for this difference are: the treatments for conditions such as arthritis with anti-inflammatory agents may contribute to reducing the risk for cancer; and a cellular relationship may exist between the disorder and the cancer that may increase or decrease the risk for cancer. These researchers also advance that the likelihood of diagnosing a cancer should increase for individuals who are being followed regularly for a chronic disease but suggest that perhaps providers become distracted from health prevention by the need for treatment (Fleming, Pursley, Newman, Pavlov & Chen, 2005).

The causes of death in individuals with and without prostate cancer are similar. In other words, dying from some other chronic disease is equally likely in both groups. Where this situation does change is when individuals with prostate cancer have the disease aggressively treated. Then these men are much more likely to die from a treatment-related cause (Newschaffer, Otani, McDonald & Penberthy, 2000).

Co-morbidities have been found to be a predictor of impaired immunity (Castle, Uyemura, Rafi, Akande & Makinodan, 2005) although this does seem to vary to a certain degree with the type of cancer. Cancer treatments typically devastate the immune system, therefore, if individuals already have a pre-existing disease when their cancer is diagnosed, this may alter treatment protocols and survival. In fact, these authors found co-morbidities to be a better predictor of reduced immunity than age.

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SPECIAL CONSIDERATIONS FOR ASSESSMENT OF OLDER ADULTS

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Functional Assessment

Functional Assessment is a comprehensive health assessment defined as “a person’s ability to perform the activities necessary to ensure wellbeing. It is conceptualized as the integration of three domains of function: biological, psychological (cognitive and affective), and social” (Dell Linton & Lach, 2007). This assessment assists in determining the client’s every day competence to fulfill their goals, routines and daily patterns and to determine their perception of health and motivation to reach optimum functioning. A functional assessment aids in getting to “know” the individual by encouraging assessors to “listen to their story” on how they achieve their daily care, what is important to them and what they consider a healthy and meaningful life. One older individual may have a sense of wellbeing if in some pain yet be able to manoeuvre a scooter to visit friends, while someone else may expect to be pain free while walking to the store and become frustrated and angry when they can’t do this. Some will continue to be social, or risk takers while others will withdraw and become more cautious. A functional assessment needs to take all of these factors into consideration to develop a realistic, achievable care plan.

With age, changes often occur slowly and subtly so it is important to be aware of a person’s lifelong habits, patterns of self care and daily routines. Other changes may occur suddenly over several hours to several days. Any change in behaviour or actions, whether it be a change in verbal tones or physical behaviours including a fall, is usually the first indication of a change in an older person’s physical wellbeing. A functional assessment helps to establish a client’s baseline abilities in addition to knowing the physical status of the person.

Many of the physical changes related to aging that can affect functional abilities are described below and in this Guide in the section “Aging Changes”. How the senior experiences cancer may be affected by these physical changes. In addition, care providers will need to take functional changes into account during care.

Mobility

Changes related to the musculoskeletal system contribute to a decrease in mobility and functional abilities. The muscles lose their elasticity and strength with age so are unable to assist in keeping the skeletal structure in the proper position. Further, there is a decline in reaction time, agility and endurance. Fluid loss in the joints and eroding of the joint bone contribute to osteoarthritis, less ability to absorb shock and less range of motion and flexibility. With changes in posture and joint movement the individual often has an unsteady gait and balance and may choose to stay closer to home to decrease the risk of a fall. For every day of immobility or bed rest there is a 5% loss of muscle strength, particularly affecting the lower limbs. Objective assessment such as the Timed Get Up & Go Test (Podsiadlo & Richardson, 2000) can be used to assess the person’s strengths and endurance. The risk for falls can also be assessed by asking if the person has had a fall in the past six months, observing for unsteady gait and balance and assessing for altered safety awareness.

Loss of Senses

a) Sight

Often there is a slow decline in the older person's ability to see and hear. Eyesight changes include loss of accommodation, presbyopia or near sightedness, loss of acuity and central vision, delayed dark and light adaptation, increased sensitivity to glare, narrowing of the visual field and decreased visual information processing. Other factors include altered colour perception, with an increased yellowing of the view and dulling of the blue/green spectrum, and also a decrease in depth perception (Miller, 2004).

b) Hearing

Acuity of hearing declines each year after the age of 40 by a person losing the higher sounds first, and then hard sounds before vowel sounds. This is referred to as presbycusis and contributes to altered speech discrimination (Miller, 2004). There is a predisposition to impacted cerumen and increased opportunity for traumas and infections.

c) Touch

Skin receptors that respond to vibrations decline so tactile sensations are dulled and may not detect hot temperatures (Miller, 2004).

d) Smell

There is a decline in the appreciation of smells, which aids in the sense of taste and in the pleasure of foods.

e) Taste

The turnover rate of taste buds is reduced with age, as is saliva production. Saliva is needed for normal taste sensation, and if the older person has a dry mouth it will alter the sense of taste.

f) Pain

The sixth sensation, referred to as the fifth vital sign, is pain. With age there are more factors that contribute to a person living with persistent pain. They may also experience acute and palliative pain.

Skin

With age the skin loses its elasticity, resilience and ability to repair itself. This is due to the thinning of the dermis and loss of subcutaneous tissue, which helps to cushion the skin from trauma. In addition, the epidermal turnover rate declines by 30-50% by the 8th decade (Dell Linton & Lach, 2007) related to a decrease in the capillary loops that supply the tissue with oxygen and nutrients and removes debris. As a result, it takes longer to repair the skin following a small skin tear or wound and to prevent infection of the skin. The skin also becomes dryer with age, which contributes to itchiness and the development of fissures (small cracks in the skin where bacteria can grow) contributing to infections. Arterial and venous circulations are compromised and can contribute to ischemic pain, edema and or increased risk of ulcers.

Hydration

Fluid assists in maintaining electrolytes, healthy skin, sufficient urine flow and assists in preventing constipation and a variety of infections, including urinary track infections. As the tissue atrophies, the cells within them also atrophy and lose their ability to store fluids. Most older persons should be encouraged to drink at least six glasses (1500 cc's) of water throughout the day and evening.

Nutrition

With age, the stomach loses capacity to expand after a large meal and more frequent small meals are encouraged. If nutrition is not adequate, a person can become weakened and develop a sway in their gait leading to a fall. Food intake is influenced by dental and oral health, ability to chew foods, and factors that contribute to dysphagia, or difficulty swallowing. Indicators for dysphagia include pocketing of food, drooling, coughing or clearing of the throat during the meal, slow chewing and difficulty initiating the swallowing process (Miller, 2004). Up to 70% of frail elderly persons have silent aspiration, a condition where saliva and the bacteria within the saliva travel past a weakened epiglottis into the lungs and contribute to pneumonia (Steele, Greenwordt, Ens, Robertson & Seigman-Carlson, 1997).

Elimination

a) Bowel Function

It is important to try and maintain a person's lifelong pattern of elimination. There are changes within the bowel wall with age. The bowel muscle can become weakened and portions of the muscle may develop pouches or diverticuli. Stool can get pocketed in these pouches and become infected or this stool can attract other stool forming a mass and blocking the passage of normal stool along the bowel to the rectal area. In addition, stool that passes over hemorrhoids may cause discomfort so the body will resist defecation.

b) Urinary Function

There are also changes to urinary patterns with age. There is a decline in the bladder capacity, filtration rate and pelvic floor muscle strength. Nocturia is a concern for many seniors as it interrupts their sleep and increases the risk for falls.

c) Incontinence

There are four types of incontinence:

- urge
- overflow
- stress
- functional incontinence - a condition when the person has difficulty mobilizing to the toilet in time
- and or difficulty in removing their clothing

Summary

These are a few changes related to aging that affect an older person's functional abilities, which are themselves necessary for socialization and engagement with others. Further assessment of cognition, psychosocial, cultural and spiritual aspects will assist in developing a picture of the whole person.

Each of these aspects will affect the person's ability to adapt to a decline in functional abilities. It is essential to recognize normal changes related to aging, identify abnormal conditions and collaboratively develop plans to promote health, comfort and quality of life.

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SECTION TWO: GENERAL CARE CONSIDERATIONS

Communication and Decision-making

Doris Leung, RN, PhD(candidate)

Communication on Sensitive Issues: Facing Mortality and Respecting Culture

Doris Leung, RN, PhD(c) & Lisa Seto, RN, MN

Sexuality: A Neglected Aspect of Care

Jill Taylor-Brown, MSW, RSW

Screening for Emotional Distress

Barry D. Bultz, PhD, R. Psych

Promoting Mental Health in End-of-Life Care

Wendy Duggleby, PhD, RN, AOCN

Understanding Grief and Loss

Jill Taylor-Brown, MSW, RSW

Quality of Life and Self Care Principles

Kimberley Wilson, MSW, BASc

COMMUNICATION AND DECISION-MAKING

Doris Leung, RN, PhD(c)

Why Good Communication Is Important

People with cancer need support to judge the meaning and significance of new events or ongoing challenges as well as the symptoms of their illness. They require encouragement to talk about potentially life-threatening procedures and treatments, to involve others in decision-making about their care and treatment, and to help prepare themselves and their families for decisions that will support quality end of life care. Sensitive communication by health care providers may reduce anxiety and depression for cancer patients (Rutter, Iconomou & Quine, 1996).

Seniors and their families may need specific support to reduce anxiety related to symptoms from a recurrence of cancer or an unrelated health condition, and to differentiate disease-related symptoms from normal aging changes. Patients may remember only 25% of what is presented to them at a meeting with their oncologist (Butow, Dunn & Tattersall, 1995). Hence, they need time and repetition to make sense of all the information they are given. Older people often need support to reduce long-term effects that may impact upon their lifestyle and self-image, rather than knowledge about acute medical treatment (Ganz et al., 1996; Holzner et al., 2001). Therefore, it is important to conduct an assessment of the seniors' level of adjustment and understanding about the cancer illness before providing information. Additionally, health care providers need to assess the seniors' education to determine how helpful the information (verbal or written) is likely to be (Clayton, Mishel & Belyea, 2006).

Communication that demonstrates dignity is an important concern for seniors. Unfortunately, seniors are sometimes treated as passive or child-like recipients of care (Woolhead, Calnan, Dieppe & Tadd, 2004). Undignified treatment in the care of seniors is problematic (Woolhead et al., 2004). Loss of self-esteem occurs in situations where seniors report feeling patronized, excluded from decision-making, and treated as an "object." To some, being called "dear" or "love" is disrespectful. Others report feeling violated by hospital staff when their bodies are exposed during procedures, such as lifting, or when they were not spoken to during physical care. Involving the patient and family in conversations can help the person through moments of stressful and intimate care; however, seniors need to have the opportunity to control the flow of information. When there is a lack of control in what and how much information is given, this can not only cause anger and frustration, but may also trigger worry about their illness (Clayton et al., 2006).

Words also contain meanings that affect individuals' sense of personal dignity or sense of control. Hence, phrases that appear evasive or seem to contain hidden messages such as "I can't promise you that you will live three months or five years" should be avoided. Other phrases such as "There's nothing more I can do for you" are likely to be experienced as abandoning or threatening (Friedrichsen, Strang & Carlsson, 2002). Health care providers must be aware of how language can influence others and clarify the messages they are giving.

Decision-Making Challenges

Making assumptions about the needs and wishes of older people in relation to their views can be problematic. Health care professionals must identify the preferred role of seniors in making decisions, recognizing that as their sense of wellbeing changes, their style of making decisions may change as well. Do seniors prefer an active, collaborative or passive role when making decisions? How and when do surrogates or substitute decision-makers need to be involved? Some older individuals prefer to make all their decisions independently (“activist”) or to completely delegate decisions to their provider, or rely on God, or fate (passive/ “delegator”) (Kelner, 1995). The majority of seniors report a collaborative role while protecting their right either to make the final decision, or to have the provider make the final decision (Clayton et al., 2006; Kelner, 1995). Note that individuals may change their attitudes about their family and health providers’ role in making decisions as their prognosis worsens (Rosenfield, Wenger & Kagawa-Singer, 2000).

According to Vig et al. (2006), surrogates “make up to 75% of medical decisions for patients hospitalized with life-threatening illness and 44-69% of decisions for nursing home residents.” Surrogates may use factors other than the patients’ best interests (from conversations and advanced care directives) to make their decisions, such as believing that an inner sense of shared experiences with their loved one will guide them, relying on their own values and preferences about life, and enlisting the help of others (Vig, Taylor, Starks, Hopley & Fryer-Edwards, 2006). Policies and finances provided by the government are often reported to be inadequate to support the rights of older people (Woolhead et al., 2004). Hence, health care providers need to advocate and support seniors (who are competent and capable) to talk about ways that the seniors can enact living wills and make choices surrounding a preferred place of death.

Patients and their families often meet together with health care professionals in the earlier stages of the cancer illness to request information and details about prognosis. However, nearer the later stages of the illness, family members often talk to clinicians without the patient present (P. Kirk, I. Kirk & Kristjanson, 2004). Perhaps this indicates that family members, as compared to patients, are more concerned with prognosis and the details related to care nearer to the end of life (Kirk et al., 2004). It is important to ensure that this evolution in communication patterns reflects the patient’s wishes, however.

Examples of Ways to Enhance Communication and Decision-Making with Seniors

Chochinov (2006) suggests therapeutic interventions to conserve dignity in palliative end of life care. These may be applied to seniors at any point as supportive care interventions. Some of the questions and interventions are presented in Table 1.

Table 1. Talking to Seniors: Addressing Dignity and Care

Concerns	Diagnostic Questions	Therapeutic Interventions
<p>Illness-related: Symptom distress</p> <p>Medical uncertainty</p> <p>Level of dependence</p>	<p>How are you coping with what is happening to you?</p> <p>Are you getting all the information you feel you need? If not, what other information would you like to know?</p> <p>Has your illness made you more dependent on others? If so, how do you feel about that?</p>	<p>Assume a supportive stance; empathetic listening; referral to counselling.</p> <p>Upon request, provide accurate, understandable information, and strategies to deal with possible future crises.</p> <p>Have patients participate in decision-making regarding both medical and personal issues.</p>
<p>Personal Dignity: Autonomy/Control</p> <p>Maintaining normalcy and hopefulness</p>	<p>How in control do you feel? How would you like to make decisions about your care?</p> <p>Are there things you still enjoy doing on a regular basis? What is still possible?</p>	<p>Involve in treatment and care decisions.</p> <p>Encourage and enable the patient to participate in meaningful or purposeful activities.</p>
<p>Social Concerns: Privacy boundaries</p> <p>Tone of care</p> <p>Burden to others</p>	<p>What about your privacy is important to you? How comfortable are you in hospital around issues of privacy?</p> <p>Is there anything in the way you are treated that is undermining your sense of dignity? If so, what?</p> <p>Do you worry about being a burden to others? If so, to whom and in what ways?</p>	<p>Ask permission to examine patient; proper draping to safeguard and respect modesty.</p> <p>Treat the patient as worthy of honour, esteem and respect; adopt a stance conveying this.</p> <p>Encourage explicit discussion about these concerns, with those they fear they are burdening.</p>

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PRACTICE TIPS: COMMUNICATION AND DECISION-MAKING

- Sensitive communication by health care providers may reduce anxiety and depression for cancer patients.
- Pacing and repetition of information is required for effective communication to occur.
- Communication should preserve the individual's sense of control and personal dignity.
- Health care providers should assess, rather than make assumptions, about the level of involvement older adults want in decision-making about their care and treatment.
- Ongoing assessment is needed, as decision-making preferences can change over the course of the illness.
- Health care providers should familiarize themselves with comfortable and acceptable ways to phrase crucial conversations about illness, personal dignity and social concerns.

COMMUNICATION ON SENSITIVE ISSUES: FACING MORTALITY AND RESPECTING CULTURE

Doris Leung, RN, PhD(c) & Lisa Seto, RN, MN

Facing Mortality

Many seniors with cancer express anxiety related to an increased sense of the inevitability of moving towards the end of life (Pigott, Aranda & Pollard, 2004). Not surprisingly, stories of cancer bring prominence to losing one's self within the threat of mortality (Skott, 2002). The threat of mortality is described as the fear of death, related to fear of the future and its fragility (Yalom, 1980).

The threat of mortality is part of one's psychological health, and a spiritual or existential health concern. The term "existential" is defined as the search for meaning and purpose in one's life, based on more than spiritual or religious ideas. It refers to the "humanistic values, beliefs, attitudes and principles that guide and direct an individual's life" (Whitehead, 2003). Although one's attitude about the threat of mortality may be expressed through religion, the practice of religion does not necessarily lead to feelings of transcendence. Religion is an organized system of beliefs, practices and forms of worship. Often non-religious activities such as meditation, creative activities, or contact with nature also assist with spiritual or existential wellbeing (Blinderman & Cherny, 2005). Although there is no single strict manner or form, a fundamental search for meaning comes from an idea that "all human beings possess an inherent desire and ability to transcend hardship and suffering through their own personal capacity" (Blinderman & Cherny, 2005).

For seniors with a cancer diagnosis, awareness of dying fluctuates from suspended awareness or denial, uncertain, partial, or ambiguous, to active and open awareness (Johnston & Abraham, 2000). Although complete and total denial is uncommon (Adelbratt & Strang, 2000), denial occurs more often in those patients with underlying psychological and emotional distress (Chochinov, Tataryn, Wilson, Enns & Lander, 2000).

Despite 93% of patients reporting they have at least some concern about the value of life and how long they might live (Klemm, Miller & Fernsler, 2000), 25-51% of cancer patients report that their spiritual/existential needs are not met (Moadel et al., 1999). Some individuals will withdraw and/or distance themselves as a way to cope (Johnston & Abraham, 2000). Without a sense of meaning and/or worth in the experience of living with cancer, individuals may not have a sense of control in meeting his/her needs (Carter, MacLeod, Brander & McPherson, 2004) and are significantly more at risk for distress when admitted to palliative care (Morita, Tsunoda, Inoue & Chihara, 2000).

Examples of Ways to Enhance Communication about Facing Mortality

Chochinov (2006) suggests therapeutic interventions specific to death anxiety, conserving resilience or a fighting spirit, and finding spiritual comfort in palliative end-of-life care. These are presented in Table 1.

Table 1. Talking to Seniors: Addressing End of Life Issues

Concerns	Diagnostic Questions	Therapeutic Interventions
Death anxiety	Are there things about (the later stages) of your illness that you would like to discuss?	
Conserving resilience or fighting spirit	What part of you is strongest right now?	
Finding spiritual comfort	Are there things you still enjoy doing on a regular basis? Is there a spiritual or religious community that you are connected with, or would like to be connected with?	Make referrals to chaplain or spiritual leader; enable the patient to participate in their particular spiritual and/or culturally based practices.

Respecting Culture

Statistics Canada (2005) projects that one in five Canadians will be a member of a visible minority group by 2017. Thus, cultural considerations are increasingly important to providing comprehensive, quality care to patients. Culture is a complex concept because there are many different definitions. What is emerging is the need to avoid stereotyping and making assumptions about individuals based on ethnicity or race. Diversity within ethnic groups implies that not all individuals in a group will share the same values, beliefs, and practices (Wong & Tsang, 2004). There are many factors that may affect cultural beliefs such as whether a person is a recent immigrant or first generation immigrant, whether they have language barriers, and whether they have been able to adapt to the language and behaviour of their community (Dunn & Dyck, 2000).

Across cultures, however, there is a great deal of stigma surrounding mental health issues. There is also limited awareness of the nature and extent of mental health issues among health care providers and seniors (Sadavoy, Meier & Ong, 2004). Mental health issues may contribute to a sense of isolation due to language barriers, inadequate living conditions, financial insecurity, and fears of being a burden to others (Sadavoy et al., 2004). Seniors with cancer may also experience family conflict and neglect. All these issues, when compounded with cancer, may disrupt the person's sense of identity and affect their mental wellbeing. These ideas highlight the notion that culture is not static but may change over time and with life circumstances; thus, assessment is essential to understanding the cultural needs of patients.

The concept of “cultural safety” may be useful in assessing the mental health needs of seniors with cancer. Culturally *safe* practices include the “3 R’s”: *recognize, respect, and rights* while culturally *unsafe* practices include the “3 D’s”; *diminish, demean, and disempower* (Anderson et al., 2003). These principles of cultural safety may be applied to all cultures and will help the practitioner provide care to seniors with cancer that is sensitive, examines individual context, and recognizes individual cultural needs without stereotyping.

Examples of Ways to Enhance Communication about Cultural Preferences

Seniors with cancer who are hospitalized may encounter language barriers. This can leave them feeling frustrated at their inability to communicate their needs and to understand their health care providers, leading to isolation and anxiety. Suggestions for communicating with seniors on culturally-sensitive issues are presented in Table 2 (Anderson et al., 2003).

Table 2. Talking with Seniors: Addressing Culture and Language

Concerns	Diagnostic Questions	Therapeutic Interventions
Language barrier		Provide a professional interpreter.
Ongoing communication when professional interpreter not available	Are you comfortable having family members translate?	Sometimes it may be inappropriate for family members to translate. Develop a method of communication that the patient is comfortable with.
Patient's decision-making is compromised	Can you tell me how you want decisions to be made? Would you like family members involved?	Although some cultures are known to share decision-making with family members, this must be assessed to avoid stereotyping.

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PRACTICE TIPS: COMMUNICATION ON SENSITIVE ISSUES

Facing Mortality

- Most cancer patients express anxiety related to an increased sense of inevitability moving towards the end of life.
- Awareness of dying fluctuates from suspended awareness or denial, uncertain, partial, or ambiguous, to active and open awareness.
- Although most patients report they have at least some concern about the value of life and how long they might live, many also report that their spiritual/ existential needs are not met.
- Some individuals will withdraw and/or distance themselves as a way to cope.

Respecting Culture

- Cultural considerations are increasingly important to providing comprehensive, quality care to patients.
- Health care providers need to avoid stereotyping and making assumptions about individuals based on ethnicity or race.
- Many factors may affect cultural beliefs including time since immigration and language barriers.
- Mental health issues may contribute to a sense of isolation due to language barriers, inadequate living conditions, financial insecurity, and fears of being a burden to others.
- Culturally *safe* practices include the “3 R’s”: *recognize*, *respect*, and *rights* while culturally *unsafe* practices include the “3 D’s”: *diminish*, *demean*, and *disempower*.

SEXUALITY: A NEGLECTED ASPECT OF CARE

Jill Taylor-Brown, MSW, RSW

Why is Sexuality Often Neglected in Cancer Care for Older Adults?

Although aging results in physical, cognitive, and emotional changes that can affect sexuality, there remains the basic human need for touching, expression of love and affection, and intimacy with others. Sexuality is an area often overlooked in the health and overall quality of life of older adults. Prevailing societal myths are that seniors have neither the capacity nor the desire to engage in sexual activity. In addition, sexuality is rarely discussed with people who have been diagnosed with cancer despite the complexity of sexual issues that can arise as a result of the disease itself and/or the treatments associated with it (Schover, Montague & Lakin, 1997).

Care providers appear to be even less inclined to broach the subject of sexuality with seniors, largely because of ageism, but also because of their discomfort in raising the topic (Horden & Street, 2007). Most seniors with cancer will not initiate these discussions because of their own embarrassment, or because they feel it is not appropriate to discuss such matters with others (Shell & Smith, 1994). It is thus incumbent upon the care provider to bring up the subject in an open and non-judgmental way, as it is highly unlikely that patients and/or partners will bring forward their questions and concerns (Robinson, 1998). It is important not to make assumptions, for example, about heterosexuality, monogamy, and the understanding of terminology.

The PLISSIT model, developed by Annon (1974), remains a useful conceptualization of four levels of intervention. He suggests that all patients and partners benefit from the first level which refers to being given *Permission* to talk about sexuality and sexual concerns. The second level involves providing *Limited Information* and dispelling myths and misunderstandings. The third and fourth levels, *Specific Suggestions* and *Intensive Therapy*, are appropriate to be used by those who have specialized knowledge and skill in this arena.

Sexuality and Seniors with Cancer

Many couples whose sexual activity has diminished over the years view the cancer diagnosis as the signal that their physical sexual life is over. For others, sexual difficulties may have existed before the cancer diagnosis. Individuals and couples may feel satisfied in their relationships and their expression of intimacy, despite the fact that they no longer engage in what they think of as sexual activity. Sexuality is complex, and is much more than a biological event. However, many older adults equate sexuality with intercourse, and may not have expanded their repertoire of activities to other means of sexual expression. Although Masters and Johnson's watershed work published in 1966 provided foundational understanding primarily of the biology of human sexuality, more recent conceptual models have been developed to include all domains that affect sexuality and sexual function, including sociocultural, political, economic, psychological, physiological and relationship factors (Katz, 2007).

Recognizing the bio-psychosocial reality of sexuality helps one to understand that cancer and its treatment will have a varied and significant impact on those affected by it. The emotional toll that accompanies cancer, changes in functioning, in self image, perception of desirability, co-morbid

conditions, medications, insomnia, pain, nausea, and fatigue can all have profound effects on the ability and desire to engage in sexual activity. The particular kind of cancer and the specific treatments received for cancer contribute significantly to the type and severity of sexual issues that might arise for older individuals.

The majority of men with prostate cancer are in their seventies while breast cancer is most common in women aged 55-69 (Canadian Cancer Society, 2006). Cancers associated with sexual parts of the body, such as gynecological cancers, breast cancer and prostate cancer have been researched most frequently in regard to sexual impact, with both qualitative and quantitative data, and with many patients and partners reporting significant effects (Canadian Cancer Society, 2006). Women who have had cancer of the cervix or other gynecological cancers, and received vaginal radiation therapy can struggle with vaginal dryness and/or stenosis. Sexual side effects have been reported by men as the most devastating side effect of treatment for prostate cancer, which commonly include reduction in libido and/or the inability to obtain and/or sustain an erection (Katz, 2007).

There are fewer studies pertaining to the sexual side effects of other cancers for older adults. Treatment for head and neck cancers (surgery and radiation in particular) can result either in permanent facial disfigurement, dry mouth, inability to speak orally, and/or difficulty eating, drinking, and swallowing – all of which have enormous impact on self image and self esteem and social relationships. Men and women with head and neck cancers may have difficulty engaging in oral sex and/or difficulties coming to terms with changed appearance. Some may have difficulty communicating affection with words (Dropkin, 1999). Patients with colorectal cancers also have unique sexual issues related to the iatrogenic effects of surgery and treatments. It is not within the scope of this document to discuss the sexual impact of each and every type of cancer or cancer treatment. Schover (1997) and Katz (2007) and others (Auchincloss, 1989; Lamb, 1996) have written excellent books and reviews on this subject and the reader is referred to these resources for more in-depth discussion.

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PRACTICE TIPS: SEXUALITY: A NEGLECTED ASPECT OF CARE

- Sexuality is a multi-dimensional part of human functioning.
- Consideration of the impact of cancer on sexuality should be included as a component of care for seniors with cancer.
- Cancer and its treatment impact sexuality, but health care professionals, patients and partners often are reluctant to initiate discussion about it.
- Bringing up the topic in a sensitive and matter-of-fact way gives those with cancer and their partners permission to ask questions and, if appropriate, be referred for specialized counselling/therapy/treatment.
- Assumptions should not be made about heterosexuality, monogamy, or understanding of terminology.

SCREENING FOR EMOTIONAL DISTRESS

Barry D. Bultz, PhD, R. Psych

Distress in Seniors with Cancer

A diagnosis of cancer brings with it a significant emotional burden of depression and anxiety for individuals, families and communities. In an attempt to “normalize” the emotional experiences associated with cancer, mental health professionals working in cancer care have adopted the term “distress” to characterize the emotional challenges of those facing cancer. “Distress” in this context is best defined by the National Comprehensive Cancer Network/NCCN (1999) as “an emotional experience of a psychological, social and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fears to disabling problems such as depression, anxiety, panic, social isolation, feelings of vulnerability, and spiritual crisis.”

In fact, many of these feelings can range from mild to significant and may appear at the time of being told that one has cancer to periods of time during treatment or after treatment is complete (Bultz, Thomas, Stewart & Carlson, 2007).

In several large international studies, significant levels of emotional distress were found in 35-45% of all cancer patients. Because of these findings several organizations have begun supporting the importance of routinely screening for emotional distress in the cancer patient and are referring to emotional distress as the sixth vital sign in cancer care, implying that monitoring of emotional distress should be undertaken as an essential part of clinical practice (Rebalance Focus Action Group, 2005).

Tools for Screening

Distress (sixth vital sign) should be monitored at each visit and considered like the other vital signs: blood pressure, temperature, heart rate and respiratory rate that are checked routinely (Bultz & Carlson, 2005, 2006; Holland & Bultz, 2006, 2007). In a similar vein, in 1999, because of its prevalence, pain was added as the fifth vital sign (Berry et al., 2001), recommended to be queried as “How is your pain on a 0-10 scale?” with the score of 10 being the most pain.

While there are several standardized measures frequently used for measuring emotional distress, the NCCN practice guideline has advocated for a simple and rapid identification procedure of patients (NCCN, 1999). A rapid visual analog approach (see Figure 1) is used by asking a verbal question, “How is your distress today on a scale of 0-10?” or by making a check mark on the Distress Thermometer. The Distress Thermometer is similar to the pain scale of 0-10 severity and allows a patient to mark their level of “distress.” Clinically, a score of four or greater should be seen as the cut-off for further inquiry about the patient’s experience with cancer or a referral to a psychosocial service should be initiated. The Distress Thermometer, when accompanied by the NCCN Problem List (see Figure 2) where the patient indicates the nature and source of the distress, has proven to be a simple yet fruitful guide for the clinical interview.

Figure 1. Screening Tools for Measuring Distress: Distress Thermometer

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.

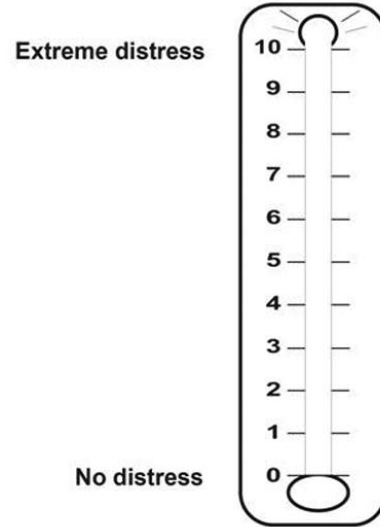


Figure 2. National Comprehensive Cancer Network Problem Checklist

Please indicate if any of the following has been a cause of distress in the past week, including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
			<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
			<input type="checkbox"/>	<input type="checkbox"/>	Breathing
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
			<input type="checkbox"/>	<input type="checkbox"/>	Constipation
			<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
			<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
			<input type="checkbox"/>	<input type="checkbox"/>	Fevers
			<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual
			<input type="checkbox"/>	<input type="checkbox"/>	Appearance
			<input type="checkbox"/>	<input type="checkbox"/>	Memory/Concentration

Trigger Questions for Assessment

When living with cancer, many patients will observe a number of changes in their daily lives. To help patients clarify how they are adjusting and coping, a number of common concerns are listed in Figure 3 and patients are asked to rate their level of distress to determine if they could benefit from support.

Figure 3. Do I Need Professional Support? Self-Assessment Questionnaire for Patients

The following questionnaire (Canadian Association of Psychosocial Oncology, 2003) may help you determine whether you might benefit from professional counseling. Every patient experiences some of these symptoms; there are no right or wrong answers.

During the past two weeks:

1. I have felt anxious or worried about cancer and the treatment I am receiving.
Not at all 1 2 3 4 5 All the time

2. I have felt depressed or discouraged.
Not at all 1 2 3 4 5 All the time

3. I have been irritable or unusually angry and I have not controlled it well.
Not at all 1 2 3 4 5 All the time

4. My sleeping habits have changed.
Not at all 1 2 3 4 5 All the time

5. I have experienced a change in my appetite.
Not at all 1 2 3 4 5 All the time

6. I have had difficulty concentrating at work or at home, or on routine things such as reading the newspaper or watching television.
Not at all 1 2 3 4 5 All the time

7. Cancer and its treatment have interfered with my daily activities.
Not at all 1 2 3 4 5 All the time

8. Cancer and its treatment have interfered with my family or social life.
Not at all 1 2 3 4 5 All the time

9. Cancer and its treatment have interfered with my sexual life.
Not at all 1 2 3 4 5 All the time

10. Pain and discomfort have caused me to limit my activities.
Not at all 1 2 3 4 5 All the time

11. Cancer has caused physical, emotional or financial hardship for me.

Not at all 1 2 3 4 5 All the time

12. Cancer and its treatment have caused changes in my physical appearance and this concerns me.

Not at all 1 2 3 4 5 All the time

13. I have had difficulty coping with the stress I have experienced.

Not at all 1 2 3 4 5 All the time

14. My quality of life during the past two weeks has been:

Excellent 1 2 3 4 5 Very poor

If you find that many of your answers are in column four or five, you may be experiencing significant distress and should consider discussing your feelings with a counselor.

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PRACTICE TIPS: SCREENING FOR EMOTIONAL DISTRESS

- A diagnosis of cancer brings with it a significant emotional burden, labelled “distress”.
- Emotional distress is considered the sixth vital sign in cancer care.
- Like other vital signs (blood pressure, temperature, heart rate, respiratory rate and pain), emotional distress should be monitored routinely.
- A 0-10 Distress Thermometer can be used for routine screening.
- The Distress Thermometer should be accompanied by an assessment of the nature and source of identified distress.
- Useful tools include the National Comprehensive Cancer Network Problem List and self-assessment questionnaire.
- Screening and monitoring of emotional distress should lead to appropriate follow-up assessment and treatment as needed.

PROMOTING MENTAL HEALTH IN END OF LIFE CARE

Wendy Duggleby, PhD, RN, AOCN

Mental Health at the End of Life

Promoting the mental health of seniors who are cancer patients at the end of life is very important as they often develop psychological and psychiatric symptoms. Anxiety disorders, depressive disorders and cognitive disorders are common among persons at the end of life (Jacobson & Brietbart, 1996; Werth, Gordon & Johnson, 2002). Although there is no exact definition of end of life, it is a period of time marked by disability or disease that becomes progressively worse until death (National Institutes of Health, 2004). With higher levels of physical debilitation and advanced disease, the incidence of pain, depression and delirium all increase (Brietbart, Chochinov & Passik, 2001; Bukberg, Penman & Holland, 1984; Massie, Holland & Glass, 1983). The prevalence of severe depressive symptoms has been found to be approximately 77% and as high as 85% for delirium. These symptoms are most commonly found in combination with other psychosocial and physical symptoms (Jacobson & Brietbart, 1996). Many seniors who are at the end of their lives suffer from diagnosable mental disorders, emotional trauma and interpersonal/environmental issues (Jacobson & Brietbart, 1996; Werth et al., 2002). Uncontrolled physical and psychiatric symptoms often interact and impact negatively on the quality of life of seniors dying from cancer.

Physical and psychosocial factors are a potential source of extreme end of life sufferings. Physical symptoms such as pain, hypoxia, nausea and vomiting contribute to mental health issues. The most obvious psychosocial sources of suffering are the patients' perceived threat to their self-integrity, the inherently unpleasant emotional experiences associated with the end of life, and the perceived sense of helplessness in the face of threat (Jacobson & Brietbart, 1996). Common psychosocial issues experienced by seniors who are cancer patients at the end of life include the lack of decision-making abilities, the loss of dignity, the increase in feelings of fearfulness, anxiety, grief, hopelessness, and issues of isolation and separation associated with death and dying (Werth et al., 2002). Seniors with cancer may also suffer from thoughts of being a burden upon their family and friends, financial problems associated with medical cost, and his or her dependence upon significant others (Werth et al., 2002).

Why is this Important for Seniors with Cancer at the End of Life?

Cancer is a major cause of morbidity and mortality in Canada among seniors (Canadian Cancer Society, 2005) resulting in a large number of Canadian seniors being at risk for mental health problems at the end of life. Advanced cancer is distinguished from other end of life processes by the severity of its physical and psychosocial symptoms (Duat & Cleeland, 1982; Foley, 1993). The presentation of symptoms, response to treatments, and the care needs at the end of life are influenced by the normal changes of aging (Amella, 2003). The potential for suffering for seniors at the end of life is a reality and, coupled with the normal changes associated with aging, it is important to promote mental health for these seniors.

Strategies for Promoting Seniors Mental Health at the End of Life

A review of the end of life scientific literature found only 2.9% of the research studies focused on seniors (65 years of age and older) (Duggleby & Raudonis, 2006). However, within this small group of studies, there are some from which recommendations may be made to suggest strategies for promoting seniors' mental health. For example, strategies for promoting seniors' mental health at the end of life should include the prevention and control of symptoms to reduce the incidence of acute confusional states. Good pain control is also essential. A variety of strategies are required to control pain. Pain assessment is the foundation for the use of these strategies, and seniors at the end of life have been found to describe their pain with words that differ from common assessment tools (Duggleby, 2002, "The language of pain"). The best match of their words with an assessment tool was the Visual Analogue Scale of "no pain" at one end and "pain as bad as it can be" at the other end.

A psychosocial supportive hope program has been found to foster hope and improve quality of life in seniors at the end of life. It involves watching an international award winning film on hope in seniors at the end of life and working on hope exercises for a week (Duggleby & Wright, 2005). A review of the scientific literature also suggested that, regardless of age or culture, patients at the end of life wanted information about their illness and prognosis (Duggleby & Popkin, 2006). The expertise of the physician, their relationship with the patient, and the use of hopeful communication styles were important factors in how patients understood the information provided. Honest and factual communication fostered hope and quality of life at the end of life. The research studies which focused on seniors with cancer at the end of life suggest that control of symptoms, fostering hope and providing factual honest information about their diagnosis and illness may promote mental health in this population. More research in the area of promoting mental health in seniors at the end of life is needed to guide practitioners who care for this population.

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PRACTICE TIPS: PROMOTING SENIORS' MENTAL HEALTH IN END OF LIFE CARE

- The potential for suffering for seniors at the end of life is a reality and promoting mental health should be a priority.
- The prevention and control of symptoms such as pain, nausea/vomiting, hypoxia, etc. and reducing the incidence of acute confusional states is essential.
- Control of symptoms, fostering hope and providing factual, honest information about the diagnosis and illness may promote mental health in this population at the end of life.

UNDERSTANDING GRIEF AND LOSS

Jill Taylor-Brown, MSW, RSW

Losses are present throughout the cancer experience both for the individual with the illness as well as those closest to them. Cancer and/or its treatments may result in the loss of body parts or functions, the loss of independence and control over daily life, the loss of health, life as it had been known, as well as loss of dreams and expectations for the future. Some losses are easier to recognize and talk about than others. Loss needs to be acknowledged and grieved both by the senior with cancer, and his/her loved ones.

Grief, Mourning and Bereavement

Grief is the normal human response to loss, experienced internally by the individual. Mourning is the outward expression of that grief. Bereavement is the period when grief is experienced and mourning occurs (Rando, 1984).

When cancer results in the death of a loved one, those who grieve may respond in a variety of ways. Reactions to a death may be influenced by a number of factors including the following:

- Culture
- Religion
- The nature of the relationship to the deceased
- Previous coping styles and skills
- Social support
- Access to resources (e.g., financial)
- The pace and course of the cancer
- Previous and concurrent experiences of loss

For seniors who are bereaved, the death of someone close to them may be one of many losses, and represent another gap in a diminishing circle of social support. As their social support networks become sparser, seniors are at risk of becoming isolated in their grief which, in combination with other losses and stressors associated with aging, can lead to a poor bereavement outcome (Worden, 1982).

The grief experience is intimately related to the relationship with the deceased. Seniors whose spouses have died from cancer may not only be losing their spouse, but also their best friend and someone who has performed a variety of roles and tasks in their life. They may be living alone for the first time in their life. These are enormous adjustments. When a child dies before a parent, many people experience this as “against the laws of nature” which is often reflected in the intensity of the grief response. When a grandchild dies, it can be even more complicated as the senior grieves not only for the loss of the grandchild but also the pain that the loss represents for his/her own child. The senior’s own loss history is even more important at these times as the death of a child may bring back memories of a lost pregnancy, baby or child from years ago. Feelings may emerge related to a past painful event if individuals did not have the opportunity to express their grief at the time of the loss. Grieving is difficult and painful work. It does not have prescribed linear stages, a set time

frame, nor a defined ending. It is an ongoing process with ebbs and flows. Grief is experienced physically (aches, feeling unwell, sleeplessness, fatigue, lack of appetite), emotionally, spiritually and cognitively (difficulty concentrating, staying focused). Even many years out, the pain of grief can be as sharp and hard as at the beginning. The difference is that grief surges will not last as long; perhaps only lasting a brief second. Memories, like the relationships themselves, can bring both comfort and pain, although for most people it is memories that ultimately sustain them (Chochinov, Holland & Latz, 1998).

Tasks of Mourning

Worden (1992) has conceptualized tasks of mourning. He suggests that the bereaved must address the following tasks in order to re-engage in life: accepting the reality of the loss (emotionally as well as intellectually); experiencing the pain of grief; adjusting to an environment in which the deceased is missing and “emotionally re-locating” the deceased. This final task involves development of a different kind of relationship with the deceased – finding a new place in one’s life for the lost loved one. It is very important to remember not to “push” people to accomplish these “tasks”.

Societal expectations to “carry on”, to “keep busy”, and behave as if nothing has changed adds to the burden of grief, especially any covert or overt messages from well meaning others that the mourner needs to “get over” the loss. It is difficult for others to witness the pain of grief as the open expression of grief reminds others of their own mortality and that of their loved ones.

Health care providers need to acknowledge the loss and arrange referral if needed to specialized bereavement services. Families may want to continue in the counselling relationship with the health care provider who was part of the cancer care team because of the prior link to the deceased and a sense of a shared lived experience. The lingering questions that accompany a normal grief reaction (Was everything possible done? Did we make the best choices?) can often best be addressed by the provider who has been present throughout the cancer experience.

A willingness to show one’s humanity, authentic use of self, and self-knowledge, are the cornerstones of effective bereavement counselling. It is also important to take a loss history. A current loss brings back memories of earlier losses. The familiar feelings, thoughts and physical responses reverberate with previous experiences and responses and can sometimes take the mourner by surprise. Helping people understand this by normalizing it can be very comforting.

Complicated Grief Reactions

Complicated or unresolved grief reactions are more complex than normal grief responses and require more intensive psychological therapy and sometimes medication. Symptoms include the development of depression or extreme anxiety, substance abuse, the absence of the usual outward displays of grief and the inability to re-engage in life, particularly relationships. Complicated grief is more likely to occur when a death has been sudden, in relationships that have been exceptionally close or ambivalent, and when the sufferer is unable to acknowledge the grief (Rando, 1993). Loss of appetite and weight, inability to sleep, loss of energy and motivation, and thoughts of suicide are all signs of depression. Referral to specialized bereavement services and/or psychiatry would be appropriate in situations of suspected complicated grief and/or depression.

Disenfranchised Grief

Disenfranchised grief is defined as grief that is not acknowledged by others, is not socially accepted, and/or is not publicly mourned (Doka, 1989), and ultimately can result in complicated grief reactions for the mourner. Examples of situations of disenfranchised grief for seniors include death and losses within same-gender relationships, losses within an extra-marital affair, losses that happened long ago to the person, such as miscarriages, still births, adoptions and pregnancy terminations, or any other loss that is not recognized by the individual's family and/or social network. Losses that were experienced years ago with little or no understanding of their life long impact can be particularly difficult for seniors when these resurface later in life. Probably the greatest disenfranchisement for seniors in relation to loss and grief is caused by ageism. Seniors may receive subtle or blatant messages that they should not be as upset or distressed by losses, particularly losses through death as these are to be expected "at their age." They should thus "be grateful" for their own longer life or that of their loved one. This attitude is also felt by family members who are experiencing the death of an older adult. Many find sentiments such as "You are lucky he lived such a long life" (which may be true), to be unhelpful as they fail to acknowledge the impact of the loss.

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PRACTICE TIPS: UNDERSTANDING GRIEF AND LOSS

- Recognize there is no one right way to grieve or mourn and that grief is a normal human process.
- Learn to recognize signs of complicated and disenfranchised grief.
- Refer to specialized bereavement services as appropriate.
- Health care providers should try to be active empathic and compassionate listeners and avoid platitudes (for example, “Time will heal” “God never gives us more than we can handle” and “He lived a good long life”).

QUALITY OF LIFE AND SELF CARE PRINCIPLES

Kimberley Wilson, MSW, BASc

What is Self Care?

Self care, by definition, is an individualized concept which promotes individuals taking responsibility for their health and wellbeing. The process is led, owned and done by the individuals themselves. The concept includes physical and mental health, prevention and care of chronic conditions (Martyn, 2002 as cited in Department of Health, 2006). Use of the principles of self care will encourage coping skills and resiliency to improve and maintain quality of life. Research has indicated that use of self care principles can increase life expectancy, can give individuals better control over their symptoms and can reduce pain, anxiety, and depression levels (Department of Health, 2007). Self care support consists of the following components:

- Devices and technologies
 - Information
 - Skills training
 - Self care support networks
 - Personalized self care plans
 - Community services
 - Professional education
 - Awareness raising
- (Department of Health, 2006)

When working with an older adult, help them to create a personalized self care plan by exploring activities which help to relieve stress and/or promote wellbeing. This may include talking a walk or being physically active, eating sensibly, spending time with family and friends, participating in hobbies and recreational activities, and keeping a positive outlook (Public Health Agency of Canada, 2005).

Social support and having a supportive network is a vital part of wellbeing and self care, and can help to reduce stress, decrease health problems and improve emotional wellbeing. When working with your older adult clients, explore their social support networks to gain a better understanding of their support network. If they do not have a strong network of support and/or if there are components of support they are missing (i.e. practical assistance with activities of daily living, or emotional support), refer them to services in the community. The Canadian Cancer Society has an online directory of community services with a focus on transportation, accommodations during treatment, and support groups. For further information, visit their website at www.cancer.ca (click “Canada-wide”, “support/services” and “Community Services Directory”). There is also a toll-free phone number (1-888-939-3333) for individuals who would like assistance navigating the site or for those with limited Internet access. For provincial resources, please refer to the “Practical Support” section in this guide.

You may find that your client would benefit from professional psychosocial support. A simple self-assessment questionnaire can be found in “Screening for Emotional Distress” in this Guide, which will help individuals to determine if they may benefit from such services.

Why is Self Care Important for the Older Adult with Cancer?

Self care is an important concept across the lifespan. Throughout stressful times in life, including times of losses and transitions, self care is a core aspect of maintaining health and wellbeing. Aging can be defined as the “progressive decline in the functional reserve of multiple organs and systems, increased prevalence of disease and disability, waning social resources, and increased incidence of geriatric syndromes” (Balducci, 2007, p. 234). As a result of these declines and losses, self care is an important component to maintain quality of life during the aging process.

As well, many older adults become involved as caregivers for their spouses. Self care is especially important for caregivers to help prevent caregiver burnout. The process of watching a loved one decline mentally and/or physically is an emotional experience, in addition to the added logistical, financial and practical challenges that come with a caregiving experience. Please refer to the section “Challenging Issues: Caregiver Burden” in this Guide, for information on supporting caregivers in your practice.

Reports have indicated that between 35-45% of all cancer patients experience significant emotional distress (Canadian Association of Psychosocial Oncology, 2003). Older adults with cancer are no different. In fact, seniors who have a diagnosis of cancer differ from their younger counterparts as they have a shorter life expectancy, often have lower tolerance for treatment and require greater support from caregivers during the treatment process (Balducci, 2007). In a study on the psychosocial needs of older cancer patients, two thirds of participants expressed concerns or problems, yet almost half of these individuals did not receive adequate assistance in dealing with their emotional needs (Houldin & Wasserbauer, 1996). As well, a study on the quality of life of elderly persons with cancer found that cancer patients aged 80 years and older had poorer social networks and needed more support from community or home services than their younger participants (Esbenzen, Ostrelind, Roser, & Hallberg, 2004).

In light of the research findings on the distress levels and emotional support required by this population, there is an obvious need to promote self care activities to older adults with cancer.

What Can You Do?

While each individual you encounter will have a unique set of needs, coping skills, support systems and resiliency factors, self care is integral for individuals to be equipped to maintain wellbeing throughout the cancer journey. Although you will not be able to provide this care for your client, in many cases you will be able to empower them and their family members to engage in the activities and supports they need to take care of themselves. At times this may include professional support and counselling and the use of community services. When possible, use this Guide to help your clients understand the need for self care, the types of self care activities, and how to access support.

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PRACTICE TIPS: QUALITY OF LIFE AND SELF CARE PRINCIPLES

- Self care is an individualized concept which promotes individuals taking responsibility for their health and wellbeing.
- Self care can increase life expectancy, can give individuals better control over their symptoms and can reduce pain, anxiety and depression levels.
- Help your client to create a personalized self care plan by exploring activities which help to relieve stress and/or promote wellbeing.
- Social support and having a supportive network is a vital part of wellbeing and self care, and can help to reduce stress, decrease health problems and improve emotional wellbeing.
- Help your client to access community supports and services to fill gaps in the self care and support they require.
- Professional support may be required to help your clients deal with the emotional aspects of their cancer diagnosis.

SECTION THREE: SPECIFIC CLINICAL CONSIDERATIONS

Understanding Pain

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Understanding Delirium

Deborah Burne, RN, BA (Psych), CPMHN(C)

Understanding Depression

Linda Kessler, RN, MHSc

Understanding Severe and Persistent Mental Illness

Ngairé Abernethy, BSW, RSW & Darlene Henry, RPN, RN

UNDERSTANDING PAIN

Anne Earthy, RN, BN, MA, GNC (C)

What is Pain?

Pain is an unpleasant sensory and emotional experience. It is a complex phenomenon, derived from sensory stimuli or neurologic injury and modified by the individual's memory, expectations and emotions (American Geriatrics Society, 2002).

Persistent pain is defined as “a painful experience that continues for a prolonged period of time that may or may not be associated with a recognizable disease process” (American Geriatrics Society, 2002). It is usually present for a minimum of three months and does not serve a useful purpose. The term “persistent pain” is thought to better convey the concept of living continuously with this discomfort than the term “chronic, non-cancer pain.” Chronic pain is not just a symptom but can be viewed as a disease (Stern, 2005). Acute pain, on the other hand, is indicated by a physiological condition, has a distinct onset and is accompanied by an increase in autonomic nervous system signs when the disease/injury is resolved.

There are a number of terms that are commonly encountered in the pain literature with which the clinician should be familiar.

a) Sources of Acute Pain:

Nociceptive Pain may arise from tissue inflammation, mechanical deformation, ongoing injury or obstruction within the somatic or the visceral elements (e.g., inflammatory arthritis, ischemia). This type of pain usually responds well to traditional therapies.

Neuropathic Pain is nerve damage or abnormal processing of signals along pain systems or peripheral or central nerves (e.g., Neuralgia, limb pain, spinal cord injuries). This type of pain treatment is more complex (Registered Nurses Association of Ontario, 2004).

b) **Presbyalgos (old + pain)** is the term coined for age-related differences in sensitivity to and perception of pain and is influenced by nociceptive input, cognition, social supports, pain history, and coping behaviours (Aner, 2004).

c) **Suffering** is the state of anguish one bears with pain, injury or loss – “life pain” that affects others around them. The person feels out of control and overwhelmed by pain (Roy & Thomas, 1995).

d) **Cancer pain** is pain that is related to the disease of cancer itself. The cause of pain is life-threatening (MacCaffery & Pasero, 1999).

Pain Assessment

It is essential to recognize that pain is whatever the experiencing person says it is and exists whenever he or she says it does (MacCaffery & Pasero, 1999). It may be challenging to assess pain in the older person because of the complexity of multiple disease processes, as well as social and financial concerns. There is no proof that the older person has a decreased pain threshold.

Factors that complicate pain assessment include:

- the underreporting of pain by elders who fear it may lead to further investigations and discovery of a life-threatening condition
- being stoic and not wishing to complain
- a fear of addiction and medications that may lead to a cloudy sensorium
- the number and category of medications and/or herbal remedies
- the cognitive abilities of the person

It is important to not only gather a verbal pain history from the client, but also from their social supports. These individuals will be able to provide information on how the person spends their day and demonstrates discomfort, for example. A useful cueing tool that has been developed to guide a pain interview with a client, their family and supports is:

- O** = Onset
- P** = Pattern/Place
- Q** = Quality
- R** = Relieving/Aggravating factors
- S** = Sleep/Severity
- T** = Treatment
- U** = Understanding
- V** = Values /Concerns

Observation is another important component of a pain assessment. Health care providers are encouraged to observe facial features and body reactions as an expression of pain when the person is touched or is moving. It is helpful if a consistent pain assessment tool is used so that verbal and nonverbal indicators can be assessed following treatment and tracked over time. Older adults may provide more reliable information if they are asked to respond to a 5-point scale rather than the usual 10 point scale. It is thought that having fewer choices contributes to more accurate responding by those who can be overwhelmed by too many options. In addition, it has been found that older adults best relate to a vertical pain scale. A pain thermometer, with numbers (0-5) and sometimes related wording (no pain, slight, mild, moderate, severe, extreme pain) is often used in pain assessments with seniors. In addition, it is critical that health care providers get to know their clients so that they can identify subtle changes in their functional abilities.

Pain Control

“Non-pharmacological interventions for persistent pain have been shown to be effective if used alone or in combination with appropriate pharmacological strategies” (American Geriatrics Society, 2002). The older person and their supports should be encouraged to use a variety of self help techniques such as distraction, heat and cold, and positioning and exercise.

Principles of pharmacological interventions include: start low and go slow beginning with a regularly prescribed dose with a prn order (as needed) for breakthrough pain and before activities. It is important to note that with age, the duration of pain relief becomes longer than the peak analgesic effect because of a lower volume of distribution and delayed clearance. It is beyond the scope of this Guide to provide details on the selection, specific dosing and appropriate route for administering pain medications to treat cancer pain, co-morbid chronic conditions that give rise to persistent pain, and episodic acute pains that the older person with cancer may experience, but there are many resources, including clinical practice guidelines, available to inform health care practitioners who prescribe and/or monitor analgesic use.

Persistent Pain and Seniors with Cancer

A pain prevalence study that was conducted in Canada in 2002 using a stratified random sample of 2,012 adult Canadians found that 29% of the respondents reported they had persistent pain, with increased frequency in women and older age group and almost half were unable to attend social and family events (Moulin, Clark, Speechley & Morley-Forster, 2002). Physical changes related to aging such as arthritis, bone and joint disorders, back problems and other chronic diseases imply that many older people will suffer from persistent pain. “It has been estimated that 25-50% of community-dwelling older people suffer important pain problems... and that 45-80% of nursing home residents have substantial pain that is under treated” (American Geriatrics Society, 2002). A telephone survey found that one in five older Americans (18%) are taking analgesic medications several times a week or more and that 64% were taking prescription medications for over six months (American Geriatrics Society, 2002).

Thus, many older persons live with persistent pain. They cope by often limiting their activities and socially withdrawing. This can contribute to depression, constipation, poor nutrition, sleep disturbances and increased risk of falling. For a variety of reasons many older persons do not like to reveal the extent of pain they are experiencing but will refer to the state as a sore, hurt, an ache or a discomfort.

It is important to realize that, in addition to cancer pain related directly to their illness and acute pain and discomforts related to treatment for their cancer, many older adults experience additional persistent pain related to other chronic conditions.

Duty to Promote Comfort

The Canadian Pain Society (2004) has stated that “health professionals have a responsibility to assess pain routinely, to believe patients’ pain reports, to document and communicate the results and to intervene in order to prevent pain.” Recent research shows that health care providers lack knowledge of analgesic use and treatment options, and pain is under-treated in 70-75% of patients

with all types of pain (Gallagher, Hawley & Yeomans, 2004). Professional groups and Ministries of Health have identified that persistent pain “is the most frequent cause of suffering and disability that seriously impairs quality of life” (Morley & Flaherty, 2002). Since all persons have the right to the best pain relief possible, it is essential that health care providers work with older adults to understand their pain and to use a variety of modalities to make them comfortable. As the Registered Nurses Association of Ontario (2004) has stated: health care professionals are legally and ethically obligated to advocate for change in the treatment plan where pain relief is inadequate. Thus, an understanding of pain in all its forms is needed to improve care for older adults who have cancer. Relief of suffering is a vital component in the preservation of mental health and quality of life.

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PRACTICE TIPS: UNDERSTANDING PAIN

- Pain is an unpleasant sensory and emotional experience.
- Health care providers should familiarize themselves with common terminology and concepts from the pain literature such as acute, persistent, chronic and cancer pain.
- Multi-dimensional pain assessment, including pain ratings, behavioural observation and clinical interview is the cornerstone of good pain control.
- Both non-pharmacological methods and analgesics should be considered in developing a pain control strategy for an older adult.
- Older adults with cancer may experience pain related to the cancer directly, acute pain and discomforts related to treatment for their cancer, and persistent pain related to other chronic conditions.
- Health care providers have a duty to provide good pain control.
- Relief of suffering is a vital component in the preservation of mental health and quality of life.

UNDERSTANDING DELIRIUM

Deborah Burne, RN, BA (Psych), CPMHN (C)

What is Delirium?

Delirium is a common condition that has serious implications and harmful consequences for seniors (MacLeod, 2006). The likelihood of experiencing a delirium increases with age, from 1.1% for the over 55 age group to 13.6% for the over 85 segment of the population (White, McCann & Jackson, 2007). Delirium is considered a medical emergency that is unrecognized and misdiagnosed in 32-67% of patients (Boyle, 2006). Although delirium is potentially reversible, if undetected and untreated, it leads to diminished and irreversible functional and cognitive decline and death (White et al., 2007; Boyle, 2006). Primary prevention may be the most effective treatment strategy to address the problem of preventable delirium found in 30% of older patients (Potter & George, 2006).

The hallmarks of delirium are a disturbance of consciousness and a change in cognition that develops abruptly over a short period of time, with fluctuations in the pattern of symptoms over a 24 hour period. Delirium is most often a manifestation of an underlying medical condition or is drug or substance related (British Geriatrics Society and the Royal College of Physicians and Surgeons, 2006).

According to well-accepted and standardized criteria, a diagnosis of delirium is made when the following symptoms are present (White et al., 2007; Boyle, 2006; Canadian Coalition for Seniors' Mental Health [CCSMH], 2006):

- Disturbance of consciousness with shifting states of alertness, short attention span, wandering thoughts, distractibility and difficulty remaining on topic.
- Changes from previous cognitive performance in memory with disorientation, (person, place, time and purpose), language disturbance and misinterpretation of the environment.
- Abrupt onset of changes that occur over a short period of time fluctuating during the day with inconsistencies in behaviour, diurnal disturbance of the sleep/wake cycle with day/night reversal, aggravation of symptoms at night and morning, night alertness and agitation with disturbed motor behaviour leading to hyperactivity, hallucinations, delusions and illusions.
- Evidence of a medical cause supported by comprehensive assessment.

There are two broad subtypes of delirium – hyperactive and hypoactive – as well as a mixed subtype with features of both the hyperactive-hyperalert and hypoactive-hypoalert types.

1. **The hyperactive type** is the most easily recognized with patients exhibiting behaviours that range from fidgety, restlessness, verbally to physically aggressive, hallucinations, illusions and other atypical perceptual experiences that draw attention to the presenting symptoms.

2. **The hypoactive type** – In contrast to the hyperactive type, the hypoactive-hypoalert type of delirium is most frequently overlooked in busy institutional settings as the patient presents as lethargic, withdrawn, drowsy, displays a flat affect, is disoriented and responds to questions slowly and may be difficult to engage in meaningful communication. Studies indicate that hypoactive or quiet delirium occurs most frequently yet it is the least often recognized (British Geriatrics Society and the Royal College of Physicians and Surgeons, 2006). This subtype is often misdiagnosed as depression (CCSMH, 2006). However delirium occurs in response to multiple causes that produce symptoms common to other psychiatric disorders such as dementia, depression and psychosis. Differentiation of delirium, depression and dementia is a central component to the detection of delirium (Boyle, 2006; CCSMH, 2006). The fluctuating consciousness of delirium sets it apart from dementia, a disorder of cognition with no alteration in arousal or attention. Dementia patients have impaired cognition yet are alert and able to pay attention while delirium is marked by attention deficits (Del Fabbro, Dalal & Bruera, 2006). Depression is a mood disorder that is not associated with cognitive impairment or disorientation. Delusions and hallucinations may be present but orientation is not affected (Greenberg, 2003).
3. **The mixed type** is described as the occurrence of unpredictable variations between the hyperactive-hyperalert and the hypoactive-hypoalert types of delirium reported during a 24 hour period or over the course of several days. This type of delirium is associated with a serious alteration in the underlying clinical condition (White et al., 2007).

Subsyndromal Delirium (SSD) is a condition where one or more of the symptoms associated with delirium are identified. Patients with delirium symptoms that do not meet the full criteria for delirium require the same treatment as those with a delirium diagnosis. It has been reported that older adults with dementia admitted to community care following an acute hospitalization will experience superimposed or subsyndromal delirium (Marcantonio, Kiely, Simon, Orav, et al., 2005).

Assessment and Management of Delirium

Based on the complexity and multifaceted features of delirium, identification, diagnosis and management pose challenges for the delivery of prompt and efficacious health care as elderly patients that develop delirium have a 22-76% chance of dying during hospitalization (Roth & Modi, 2003). The detection of delirium is influenced by the lack of knowledge and education about the multiple presentations of delirium and commonly held views about aging (Marcantonio et al., 2005). The diagnosis of delirium can be established quickly and accurately using the Confusion Assessment Method (British Geriatrics Society and the Royal College of Physicians, 2006). Multiple screening tools exist to detect delirium as discussed in the references listed (British Geriatrics Society and the Royal College of Physicians, 2006; CCSMH, 2006; Del Fabbro et al., 2006; Roth & Modi, 2003; Kelly et al., 2006; Hoofring et al., 2007; RNAO, 2003, 2004; Waszynski, 2007).

The primary focus of management for delirium is the identification and treatment of the underlying cause (British Geriatrics Society and the Royal College of Physicians, 2006). Other strategies include ongoing delirium risk assessment, support for physiological stability, reduction of risk factors, development of communication and therapeutic alliances, multi-component team interventions, assessment and modification of environmental issues and evaluation of strategy outcomes (British

Geriatrics Society and the Royal College of Physicians, 2006; CCSMH, 2006; RNAO, 2003, 2004). As medication is often the cause of delirium and also a treatment option, reducing the use of sedatives and major tranquilizers is a principle for pharmacotherapy. Various medications and factors for consideration are reviewed in the references noted (Greenberg, 2003; Bosisio, Caraceni & Grassi, 2006).

Why is Delirium Important to Seniors with Cancer?

Cancer is a life threatening disease that accompanies age-related conditions that complicate the course of the illness (Thorne et al., 2004). Delirium is the second most common psychiatric diagnosis found in seniors with cancer (Boyle, 2006). Delirium is present in 28-48% of cancer patients admitted to hospital or hospice (Centeno, Sanz & Bruera, 2004). Delirium occurs in 14-55% of seniors with cancer following admission and in 90% of patients in the end stages of advanced cancer (Bond, Neelon & Belyea, 2006). Delirium in seniors with cancer is a medical emergency that requires immediate systematic assessment and intervention to treat underlying causes and prevent diminished functional and cognitive capacities, permanent disability and death (Staniszewska & Kloszewska, 2007). Comprehensive geriatric assessment is indicated for all older cancer patients to improve and sustain functional capacities and enhance survival (Extermann, Aapro, Bernabei, et al., 2005). Although delirium is an established diagnosis that often precipitates admission to hospital and palliative care there is a systemic failure in health care to identify delirium in older persons with cancer (Boyle, 2006; Flood et al., 2006; Ljubisavljevic & Kelly, 2003; Rigney, 2006).

Undetected and misdiagnosed delirium impacts negatively on the quality of life of older persons. Outcomes include high morbidity and mortality, longer hospital stay and relocation to community care (MacLeod, 2006; Gemert van & Schuurmans, 2007). Delirium is reversible in almost 50% of identified cancer patients (Del Fabbro et al., 2006) except in the last 24-48 hours of life (Roth & Modi, 2003). Screening cancer patients for delirium is vital to identify potentially reversible delirium in terminal illness and provides opportunities to reduce the impact of the symptoms and enhance the quality of life and care (Bond, Neelon & Belyea, 2006; Morita, Tei, Tsunoda, Inoue & Chihara, 2001).

Seniors with cancer are predisposed to delirium due to age, advanced illness, pre-existing cognitive impairment and other medical illnesses that increase the risk for delirium (Boyle, 2006; Bond et al., 2006). Sensory changes associated with aging can affect perception and understanding that can lead to further compromised understanding, diminished interaction with others and decline in cognitive operations (Greenberg, 2003; Flood et al., 2006).

The symptoms of delirium often present in response to cancer treatment and are accepted as a normal consequence in the latter stages of cancer (Ross & Alexander, 2001). Delirium is a frequent complication of cancer and contributes significantly to the emotional distress and suffering experienced by seniors, their families and caregivers. The accompanying cognitive and behavioural factors complicate and impede communication and interfere with the quality of the dying process (Breitbart, Gibson & Tremblay, 2002). Delirium in older cancer patients complicates the adaptation to the disease and the capacity for self determination (Thomé et al., 2004). Delirium can interfere with integration of the psychological issues associated with cancer and coming to terms with personal mortality (Thomé et al., 2004). The presence of delusions in delirium is a major predictor for distress (Breitbart et al., 2004; CCSMH, 2006). The fluctuations in consciousness and changes in cognition

affect the older person's ability to communicate responses to cancer treatment and participate in care decisions. Without involvement of the patient and family, health care personnel are required to direct the course of intervention based on the subjective observations that may not accurately reflect the reality of the patient (Boyle, 2006).

Mood changes perceived and accepted as normal emotional responses to cancer such as anxiety, sadness, panic, terror and fear may indicate psychological distress. This distress tends to be accepted as normal behaviour and is under-diagnosed and untreated in palliative care (Kelly et al., 2006). These same symptoms also herald the early stages of delirium. A patient's report of seeing and communicating with deceased loved ones does not necessarily indicate delirium or disorientation. Such expressions have provided comfort to terminally ill patients and may not require treatment as hallucinations (Ross & Alexander, 2001). Suicidal thoughts and actions can also occur and may be attributed to depression when delirium is present (Greenberg, 2003).

These delirium episodes may be remembered with the more severe episodes forgotten, however, a delusion remembered can cause further distress for the patient and family. Experiencing the mental status and behavioural changes associated with delirium may intensify patient and family feelings of helplessness and limits the capacity for continuing family connection. These processes serve to influence social disconnect and communication difficulties contributing to isolation (Greenberg, 2003).

Terminal restlessness, anguish, terminal agitation and pre-death restlessness refers to a grouping of unsettling behaviours that commonly occur in the last days of life. Symptoms associated with this disorder parallel symptoms common to delirium. A recent study indicates that terminal restlessness disorder observed as part of the dying process may indicate the existence of treatable and reversible delirium (Thomé et al., 2004). Monitoring for delirium in older cancer patients throughout the course of the disease may be a significant factor in sustaining quality of life and enhancing extended communication (Kelly et al., 2006).

Delirium can also mimic expressions of pain in older cancer patients commonly seen at end of life such as grimacing, moaning, restlessness and changes in cognition (Greenberg, 2003). Delirium is potentially a reversible phenomenon when the causative factors are identified and treatment is implemented quickly. However accurate diagnosis is confounded in cancer care as delirium is not viewed with the same importance as pain in the cancer care setting. Oncology health care personnel often lack knowledge about the complexities of delirium and the reversible possibilities of the condition that may minimize the effects and possibly shorten the duration of delirium and diminish the distressing symptoms for the patient and family (Hoofring, Olsen & Taylor, 2007).

Older persons can expect that delirium may be a consequence of cancer and treatment. Identifying the presence of delirium is the first step towards determining the underlying cause to treat, reverse and resolve the symptoms. It is of extreme importance that older cancer patients, their families and caregivers be familiar with the early signs of impending delirium and are aware of the identified predisposing and precipitating factors. This information will assist in the early identification and prompt treatment of the symptoms to minimize the effects of delirium (Greenberg, 2003; Ross & Alexander, 2001).

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PRACTICE TIPS: UNDERSTANDING DELIRIUM

- Older persons with cancer are at high risk for delirium due to precipitating and predisposing factors that impact on the course of cancer treatment and care.
- Delirium is a frequent complication of cancer and contributes significantly to the emotional distress and suffering experienced by seniors, their families and caregivers.
- Delirium requires immediate comprehensive evaluation and intervention to address the underlying cause(s).
- Delirium is common to older persons with cancer in hospital and is un/misdiagnosed in 40% of admissions to palliative care.
- Delirium is potentially reversible in 50% of older persons with cancer.
- Delirium in cancer care is often undetected and untreated as delirium behaviours are often accepted by caregivers as a normal occurrence in the disease and end of life process.
- Delirium is often a complication of medications used in cancer treatment and pain management.
- Delirium identification requires that care providers have the skills to differentiate delirium from depression and dementia.
- Delirium in cancer patients may be misinterpreted as pain.
- Delirium can interfere with integration of the psychological issues associated with cancer and coming to terms with personal mortality
- Collateral information from family/significant others re: an older person's baseline normal behaviour, cognition, sensory deficits and daily routines are critical to the early detection, diagnosis, treatment and management of delirium.
- Oncology care providers of older persons receiving cancer care and treatment must maintain a high suspicion for and develop the skills to identify, prevent, reverse and treat delirium to support quality of life experiences for patients and families.

UNDERSTANDING DEPRESSION IN OLDER ADULTS WITH CANCER

Linda Kessler, RN, MHSc

Depression is a biologically-based illness that influences a person's thoughts, feelings, behaviour and physical health. In seniors it is associated with emotional distress and suffering and can also lead to impaired physical, cognitive and social functioning. Despite the increase in morbidity and mortality associated with depression in seniors, it is often unrecognized or under-treated. Two principle reasons for this lack of recognition in seniors are: the difficulty in distinguishing symptoms related to depression from other illnesses or disorders; and that the symptom profile for depression in seniors is somewhat different than for other adults (Conn, Hermann, Kay, Rewilak & Schogt, 2007).

Depression in adults is characterized by symptoms of: depressed mood; markedly diminished interest or pleasure; significant change in weight or appetite; sleep disturbance; psychomotor agitation or retardation; fatigue or loss of energy; feelings of worthlessness or excess of inappropriate guilt; loss of concentration; recurrent thoughts of death or suicidal ideation.

A diagnosis of "depressive illness" requires at least five of the symptoms being present for at least two weeks with at least one of the symptoms being depressed mood or loss of interest or pleasure (American Psychiatric Association, 2000).

In seniors, depression is not always characterized by depressed mood as a primary symptom but rather tends to present with more cognitive signs and symptoms, hypochondriasis, and more frequent completed suicide. Somatization, or hypochondriacal symptoms, is the most common way for depressed seniors to present when visiting their health practitioners. This somatic presentation includes such symptoms as weakness/dizziness, numbness, the sensation of a lump in the throat and muscle soreness (Sheehan, Bass, Briggs & Jacoby, 2003).

Standardized assessment tools or assessment guidelines can be helpful in identifying depression. An assessment guideline that was developed specifically for identification of signs and symptoms of depression in seniors and may guide the therapeutic interview is SIG: E CAPS (which stands for a prescription for energy capsules) (Jenke, 1989). The acronym represents:

- S Sleep is disturbed**
- I Interest is decreased**
- G Guilt (common to have feelings of guilt or regret)**

- E Energy is less than usual**

- C Concentration is poor; memory problem may be more noticeable**
- A Appetite is disturbed, usually a loss of appetite**
- P Psychomotor retardation or agitation**
- S Suicidal ideation, including passive wish to die, is frequent**

Why is Depression Important for Seniors with Cancer?

The rate of depressive disorder in seniors with cancer varies depending on the type of cancer, but the average is approximately 25%. Some cancer types that are more highly associated with depression include oro-pharyngeal, pancreatic, breast and lung. Other cancers such as colon, gynecological and lymphoma are less highly associated with depression (Massie, 2004). One of the challenges in assessing for depression is the difficulty in separating symptoms associated with depression from those associated with cancer. As mentioned, sadness is not always endorsed by the seniors who are depressed. An important symptom is the individual's ability to derive pleasure from events or activities they value (e.g., visits from grandchildren). Another prominent symptom in the older person may be a report from the individual themselves or from someone close to them of an increase in irritability. There may also be changes in psychomotor activity which may present as a decrease (psychomotor retardation) or an increase (psychomotor agitation).

A diagnosis of cancer, as in any life threatening illness, may lead the individual to suicidal thoughts or ideation. Although such thoughts are not unusual they usually are fleeting. Sustained suicidal thoughts must flag prompt comprehensive assessment and intervention. Even in the face of life threatening illness, suicidal ideation must be flagged as an "abnormal" finding.

It is important that depression be identified and appropriate interventions be implemented as depression is a treatable illness across the lifespan and treatment should be pursued to maximize quality of life (Brock, 2000). Depression, if left untreated, has also been found to influence a person's desire for life-sustaining treatment (Hooper, Vaughan, Tennant & Perz, 1996). Depression often is not easy to assess in those with cancer, but identification and treatment is essential. Co-morbid illnesses can complicate treatment and may lead to poor compliance with treatment recommendations and less than desirable outcomes.

Individuals with a prior history of depression have worse survival changes than would be expected from cancer alone (Stommel, Given & Given, 2002). Although a number of theories have been posed, the reason for this link is not yet known.

It is important to remember that seniors are often dealing with a variety of challenges even prior to a diagnosis of cancer. These challenges may include relocation, decreased income, loss of family/friends, multiple medical problems, multiple medications, decreased function and possible cognitive changes. The interplay of the multiple factors requires a variety of skills and knowledge to address the biology of aging, mental health needs and cancer care.

The importance of recognition of depression and appropriate intervention is crucial. Seniors with depression respond best to a combination of medication and psychotherapeutic and psychosocial interventions. Choice of antidepressant medication is made by taking into consideration the target symptoms, drug-drug interaction and potential side effects. Supportive psychotherapy and cognitive behaviour therapy are beneficial, especially when used in combination with antidepressant therapy.

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PRACTICE TIPS: UNDERSTANDING DEPRESSION

- Depression is a biological illness affecting thoughts, feelings, behaviour and physical health.
- The average rate of depression for seniors with cancer is approximately 25%.
- Symptoms of cancer often mimic those of depression.
- Although tools and guidelines are available, asking the senior if they still enjoy what previously gave them pleasure can assist in determining if the individual is depressed.
- Frequently seniors do not express sadness but rather irritability.
- Sustained suicidal thoughts are not normal and should be taken seriously.
- Depression is treatable!

UNDERSTANDING SEVERE AND PERSISTENT MENTAL ILLNESS

Ngairé Abernethy, BSW, RSW & Darlene Henry, RPN, RN

What is Severe and Persistent Mental Illness?

Mental disorders contribute more to the global burden of disease than all cancers combined (Stewart, D. et al, undated). Caring relationships, a place to call home, a supportive community, and work and leisure all contribute to mental health. Mental health is also about learning the coping skills necessary to deal with life's ups and downs in the best way possible.

In the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV), mental disorders are conceptualized as “a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e. impairment in one or more important areas of functioning) or with a significantly increased risk of suffering, death, pain, disability, or an important loss of freedom” (American Psychiatric Association, 1994). This syndrome or pattern must not merely be an accepted and culturally sanctioned response to a particular event (e.g., the death of a loved one). The syndrome may present as adjustment disorder, major depression, delirium, dementia, substance abuse, or other disorders. Severe and persistent mental illness is a serious disturbance in thoughts, feelings and perceptions that is severe enough to significantly affect daily functioning.

Some of the more debilitating mental illnesses affecting Canadians include (Mood Disorders Society of Canada, 2006):

- **Schizophrenia:** Seeing, smelling or hearing things that aren't there or holding firm beliefs that make no sense to anyone else. The lifetime incidence of schizophrenia in Canada is 1%.
- **Depression:** Intense feelings of sadness and worthlessness and a loss of interest in life.
- **Bi-polar disorder:** Cycles of feeling intensely happy and invincible followed by depression. The lifetime incidence of bi-polar disorder in Canada is 1%.
- **Anxiety disorders:** Panic attacks, phobias, obsessions or post traumatic stress disorder. The group of Canadians with the highest hospitalization for anxiety disorders are those 65 and over. Twelve percent of Canadians experience an anxiety disorder at some point in their lifetime.
- **Eating disorders:** Anorexia (not eating), or bulimia (eating too much and then vomiting).
- **Borderline personality disorder:** Severe difficulty with relationships, placing oneself in danger, making bad decisions. This type of disorder is most often a result of a history of child abuse, abandonment or neglect.

Seniors Living with Mental Illness

At any given time, approximately 20% of Canadian seniors are living with a mental illness (Kirby & Keon, 2004). People with mental illness spent more time in hospital and are less likely to follow

through on their treatment plans. The group with the highest suicide rate in Canada is men over 80 years of age (31 per 100,000). Two percent of seniors reported suicidal thoughts in the last 12 months (Kirby & Keon, 2004).

Older adults living with severe and persistent mental illness may have been long estranged from, or have distant relationships with their families. They may reside in alternate care settings such as psychiatric institutions, personal care homes or group residence settings. They may also be living in the community but with intensive formal community supports.

What are the Implications of Severe and Persistent Mental Illness for Seniors with Cancer?

Individuals living with mental illness are often a marginalized group within our society. Financial concerns, poor nutrition, inadequate housing, below average employment and education, increased use of addictive substances such as tobacco and alcohol or illicit drugs, along with the effects of long term use of psychotropic medications all contribute to increased risk of developing a cancer. These same factors also contribute to difficulty in diagnosing cancer in this population.

It is important to assess any senior's support network, but especially those living with mental illness. The relationship between the person diagnosed with cancer and their caregivers will be unique in every case, and the degree with which they should be involved in care and treatment decisions will also vary. While they may be technically "staff" or provided through formal networks, these care providers often have a longstanding and meaningful emotional connection with the person with mental illness, and the senior may look to them for support as well as hands-on assistance while going through cancer treatments. The issues of appropriate caregiving boundaries may become very complex in these situations.

In addition to the informal relationships which develop, many people living with chronic mental illness have designated substitute decision-makers, assigned either by themselves through the legal system, or under mental health legislation. It is essential to determine who the legal decision-maker is for a person living with mental illness, especially with regards to consent to treatment. Even when there is a substitute decision-maker, the person living with mental illness and those they identify as their supports should participate in treatment decision-making as much as they are able.

The information needs of an older adult with cancer who is also living with mental illness may be different than those of other seniors diagnosed with cancer. There is no doubt that cancer patients receive more complex information now than in the past. Some research has studied the impact on outcomes but little research addresses the specific needs of the seriously mentally ill. If the information provided causes an exacerbation in psychiatric symptoms, it will not be as helpful to the cancer patient, and may even be detrimental. A senior person living with mental illness and their support network should be consulted about the level of information to be shared. Information should be appropriate to the person's education level, literacy and comprehension. The "tailoring" of information may complicate the issues of informed consent and decision-making for these people.

Although people living with severe mental illness may have frequent contact with community-based mental health services, they may be isolated from medical care. For all individuals diagnosed with

cancer, the stage of the disease at initial presentation is a critically important variable in determining the overall prognosis for survival. The inability to communicate effectively with health care providers will impact both detection and treatment. For those living with mental illness, some sources of poor communication include delusions, disorganized speech, affect that is incongruent with the nature of the physical complaints, or difficulties in developing a relationship with care providers.

Symptoms of paranoia, hallucinations and delusions may be challenging for clinicians who are not experienced in working with mental illness. Some of the negative symptoms associated with mental illness such as apathy, lack of motivation, lack of insight, poor judgment and difficulty with long-term planning may impede a patient's abilities to comprehend health care information, integrate change, and follow through on treatment protocols. There also may be barriers to early detection or treatment related to a cancer patient's personal history. For example, screening and treatment for gynecological or breast cancer may be particularly challenging for a person with history of sexual abuse.

The model of cancer care delivery in most jurisdictions in Canada involves travel for consultation with a tertiary care cancer centre to determine treatment options. Some treatments are available close to a cancer patient's community of residence, but others require travel to obtain treatment or consultation. Radiation therapy, for example, is often five to six weeks of outpatient treatment, demanding that the patient either travel daily or remain in the treatment community until the treatments are complete. While this is an issue for all patients with cancer, it is especially significant to older adults with co-morbid mental illness. A person who is reliant on formal community supports may have difficulty making appropriate travel and accommodation arrangements to participate in the treatment. There may be added costs associated with having escorts accompany them on their travel. Travel and the stress of unfamiliar environments may exacerbate psychiatric symptoms and cause harm. Thus the very choice of realistic treatment options becomes an issue for people living with mental illness.

Treatment decisions are made taking into account a patient's performance status prior to diagnosis. Physicians also take into account the patient's quality of life both before and after treatments, and how this will be influenced by the treatment protocol. It is important that the older person with mental illness is consulted about how they define their quality of life, rather than having health care professionals make assumptions based on perceptions or biases related to the mental illness and/or aging. Treatments for cancer are often rigorous and have an effect on a patient's daily functioning, at least in the short term and especially for older patients. Many older people living with severe and persistent mental illness are already compromised in their day to day functioning and may have difficulty completing their treatment regimen. There is a risk that patients with mental illness may be under-treated if assumptions are made about their ability to tolerate the treatments. Inability to complete treatments will influence survival and also have an impact on the emotional response to the diagnosis.

Much has been written about the effect of positive outlook on the outcome for treatment of cancer. Psychosocial supports are designed to help increase a person's coping skills and enhance a positive attitude. An older person living with mental illness may have extra challenges in participating in

supports such as structured support groups, especially if they have paranoid ideation. The stigma associated with mental illness coupled with the stigma associated with old age may create barriers for access to such supports.

Strategies to Help Seniors with Severe and Persistent Mental Illness Access Cancer Care:

- Consider the person's ability to navigate the complex system and make decisions regarding their treatment. This capacity may be impacted by many factors including cognitive impairment, knowledge deficits, concurrent medical or psychiatric conditions, fear or stress.
- Pay attention to the literacy level and comprehension of information, and when indicated, identify an advocate to help the client navigate the system.
- Provide the client with a primary contact person on the treatment team with appropriate Releases of Information authorized between support persons.
- Ensure that clients are aware of information sources such as help lines and the Canadian Cancer Society.

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PRACTICE TIPS: UNDERSTANDING SEVERE AND PERSISTENT MENTAL ILLNESS

- A thorough psychosocial assessment is important when providing support to cancer patients with co-morbid mental illness.
- Factors such as the patient's coping skills, informal and formal supports, and their understanding of the cancer diagnosis should inform the development of an individualized treatment plan.
- The goal of care should be to maintain optimum functioning, recognizing the burden of treatment on day to day functioning.
- Care plans should respect the individual needs of the person living with mental illness and ensure appropriate supports are in place during treatment.
- Health care providers should assess the capacity of the person with mental illness and include them in decision-making as much as they are able. Health care providers should also include those formal or informal supports identified by the patient as significant in the decision-making process.
- Seniors with mental illness who have been diagnosed with cancer experience the stigma associated with both aging and mental illness. Care providers can reduce this stigma and provide optimum care by recognizing the special concerns of this unique population.

SECTION FOUR: CHALLENGING ISSUES

Caregiver Burden

Heather Neilson-Clayton, MSW, RSW

Drug Costs and Travel Issues

Ngairé Abernethy, BSW, RSW & Darlene Henry, RPN, RN

Elder Abuse

Brigitte Wagner, MSW, RSW

Self Care for Care Providers

Mary L. S. Vachon, RN, PhD

CAREGIVER BURDEN

Heather Neilson-Clayton, MSW, RSW

Who are the Informal Care Providers?

Seniors make up the majority of the population of people living with cancer in Canada (Public Health Agency of Canada, 2007; Sellick & Edwardson, 2007). Coupled with a trend towards longer survival, a greater proportion of our population will, as a result, become informal caregivers (Glajchen, 2004; Pitceathly & Maguire, 2003). Furthermore, the burden of caring for seniors with cancer may be compounded, as informal caregivers may be managing multiple roles and responsibilities or, of more concern, coping with their own personal vulnerabilities.

Informal caregivers may be elderly as well and they may also have co-morbidities. Elderly caregivers may be frail and have limited stamina to provide care in the home setting. Being elderly magnifies caregivers' vulnerabilities and compounds any physical, psychological, social and economic burdens. In some cases, high levels of stress in elderly spousal caregivers have been identified as risk factors for death (Houts, Nezu, Nezu & Bucher, 1996; Northouse, Templin & Mood, 2001).

Informal caregivers who are adult children can be already stretched to the limit with family and work responsibilities (Grunfeld, Glossop, McDowell & Danbrook, 1997). Caregivers who are employed, middle-aged adult children reported the highest levels of depressive symptoms compared to other caregivers (Given et al., 2004). According to Vanderwerker et al. (2005), many caregivers of advanced cancer patients either meet the criteria for, or are being treated for psychiatric problems. Cuellar and Butts (1999) found rural women caregivers may report having poorer health than the older adult for whom they are caring.

Research emphasizes the interrelationship between the informal caregiver and patient, in that patients' and informal caregivers' quality of life are interdependent (Mellon, Northouse & Weiss, 2006; Given et al., 2004; Grunfeld et al., 2004). Thus, it is imperative that health care professionals understand and address the needs of informal caregivers (European Oncology Nursing Society, 2007). Health care professionals can help to alleviate the negative aspects of caregiving through early assessment and by offering emotional support and assistance with problem solving (Grunfeld et al., 2004; Scherbring, 2002; Haley, 2003; McMillan et al., 2006; Mellon, 2002). In so doing, health care professionals would augment family strengths and resources, thereby promoting family quality of life (Mellon, 2002). In short, they would be helping families to cope.

Caregiving Issues for Informal Care Providers

With health care services being restructured and more cancer patients dying outside of hospitals (Burge, Lawson & Johnston, 2003) the reliance on informal (family) caregivers to support patients with terminal illness at home is growing (Crosato & Leipert, 2006; Glajchen, 2004; Haley, 2003; Pitceathly & Maguire, 2003; Hayman et al., 2001; Houts et al., 1996). Informal caregivers play a vital role in cancer patients' quality of life throughout the course of their illness (Mellon, Northouse & Weiss, 2006; Northouse, Templin & Mood, 2001). While cancer patients seem satisfied with this informal support (Sellick & Edwardson, 2007), informal caregivers' experiences may be

quite different. Given little or no formal training, families are increasingly assuming primary caregiver roles and responsibilities, assisting patients with activities related to everyday tasks and medical procedures (Glajchen, 2004; Braun, Mikulincer, Rydall, Walsh & Rodin, 2007; Fast, Keating, Otfinowski & Derksen, 2004; Given et al., 2004). These roles and responsibilities can take considerable time each day and may continue for many months.

Cancer and its treatment have a major influence on informal caregivers (Braun et al., 2007; Given et al., 2004) who are charged with providing support in situations where the state of their loved ones' health may vary from stable to acutely ill and, eventually, death. Informal caregivers may be unprepared to provide necessary care to their loved ones and can feel burdened by this responsibility (Hayley, 2003; Braun et al., 2007; MetLife Mature Market Institute, 2004; Scherbring, 2002). Informal caregiver burden has the potential to be two-fold: first, it can negatively affect the caregiver; and second, it has direct implications for the quality of life of the cancer patient (Mellon et al., 2006; Northouse et al., 2001; Scherbring, 2002; Haley, 2003; Haley, LaMonde, Han, Narramore & Schonwebber, 2001; Schultz & Beach, 1999).

Over the long term, providing care to individuals living with cancer may result in a reduced quality of life for informal caregivers (Glajchen et al., 2005; Valdimarsdóttir, Helgason, Fürst, Adolfsson & Steineck, 2001) who can become physically, psychologically, socially and economically burdened (Haley, 2003, Given et al., 2004; Grunfeld et al., 2004; Scherbring, 2002; Doorenbros, 2007). With respect to physical health, informal caregivers may be adversely affected by the giving of care and may let their own medical needs go unattended (Braun et al., 2007; Haley et al., 2001; Sharpe, Butow, Smith, McConnell & Clarke, 2005; Kurtz, Kurtz, Given & Given, 2004; Cuellar & Butts, 1999). Informal caregivers may also experience psychological (emotional) distress (Piceathly & Maguire, 2003; Given et al., 2004; Dumont et al., 2006; Vanderwerker, Laff, Kadan-Lottick, McColl & Prigerson, 2005), may lose sleep (Carter, 2002, 2003, 2005, 2006; Carter & Chang, 2000) and can be at high risk for depression (Braun et al., 2007; Given et al., 2004; Grunfeld et al., 2004; Scherbring, 2002; Haley et al., 2001; Valdimarsdóttir et al., 2001; Doorenbos et al., 2007; Carter & Chang, 2000). In addition, informal caregivers report negative social consequences such as social isolation (Houts et al., 1984) and a sense of interpersonal loss (Haley, 2003). Finally, informal caregivers can experience economic loss associated with caregiving as a result of out-of-pocket expenses and time away from work (Hayman et al., 2001; Haley, 2003; Houts et al., 1984; Longo, Fitch, Deber & Williams, 2006). For example, Longo et al. (2007) note that 36% of informal caregivers lost one-third of their working days in any given month.

Furthermore, compared to their urban neighbors, families in rural settings (i.e., both patients and caregivers) have fewer formal resources upon which they can depend (Bédard, Koivuranta & Stuckey, 2004). Informal caregivers in rural settings in Canada tend to be women, commonly daughters, who provide 80-90% of care for people greater than 65 years of age (Fast, Keating, Otfinowski & Derksen, 2004; Bédard et al., 2004). There also may be greater costs associated with being a caregiver in a rural setting, especially if the caregiver is a woman (Crosato & Leipert, 2006).

The implications of providing long distance caregiving to cancer patients have not been examined to any great extent in the literature. However, research on the provision of care to non-cancer patients

suggests that long distance caregiving plays a role in increasing caregiver burden (“Miles to Go”, 2004; Collins, Holt, Moore & Bledsoe, 2003) and may have a negative effect on the patient’s quality of life (Collins et al., 2003). While these findings cannot be directly generalized to cancer, they may offer some insight to the challenges cancer patients and their caregivers face.

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KEY POINTS: CAREGIVER BURDEN

- With cancer patients living into their senior years, an increasingly greater proportion of family members will become informal caregivers.
- The responsibility for providing care to people living with cancer primarily falls to informal caregivers.
- As a result of their caregiving role, informal caregivers may experience a decline in their physical health, as well as emotional distress and depression, sleep loss, social isolation and economic loss.
- In the case of seniors living with cancer, informal caregivers may be elderly themselves and/or ill, or they may be adult children already overwhelmed with family and work responsibilities.
- Spousal caregivers of older patients may be particularly vulnerable to the negative effects of care giving because of their own old age, poor health, and willingness to suffer in order to care for their partner.
- Health care professionals must recognize that the wellbeing of informal caregivers is key to ensuring cancer patients' quality of life.
- Health care providers are in a position to improve caregivers' wellbeing by providing appropriate information and education and ensuring caregivers have access to emotional and practical support services.

DRUG COSTS AND TRAVEL ISSUES

Ngaira Abernethy, BSW, RSW & Darlene Henry, RPN, RN

Research suggests that a sizable minority of cancer patients find the burden of out-of-pocket costs to be significant or unmanageable, even in a health care environment where much of the care falls within the public funding envelope (Longo, Fitch, Deber & Williams, 2006). Drug costs and travel issues are two significant factors that can limit an older adult's ability to access care.

Drug Costs

Drug costs are a source of particular concern for many seniors. With advances in cancer drug treatments, many drugs are now available to cancer patients outside of cancer centres. However, most of these drugs are very expensive and may not be covered under provincial Pharmacare programs or private insurance programs. The cost must be borne by the cancer patient.

This issue poses particular problems for seniors who are diagnosed with cancer, as these individuals typically have left the paid workforce and may also have a fixed or limited income. For people under the age of 65 who had been receiving income security, the additional costs associated with a diagnosis of cancer would have been covered under most provincial income security programs. As soon as the same person turns 65, this coverage is no longer available and they must fund the out-of-pocket expenses themselves.

There are some strategies that health care providers can implement to make it easier for seniors to get the medications they require:

- Ensuring that clients are aware of insured benefits for medications and supplies either through provincial or private plans (public insurance or reimbursement plans for medications vary from province to province). Provincial Social Assistance supplements may be available for seniors in lower income brackets to help cover medical costs.
- Negotiating affordable payment schedules with pharmacies or other suppliers for payment of deductible amounts for insured benefits.
- Approaching local service groups for sponsorship, supplementary funding or fundraising activities for individual or program needs. Some pharmaceutical companies will offer compassionate funding when financial need is demonstrated.
- Seeking and maintaining an inventory of sources of compassionate funding payment schedules affordable to seniors.

Travel Issues

For people who live far from a regional cancer centre, travel is a significant concern. This issue may affect not only the senior with cancer, but their entire family and social support system. For example, if a senior with cancer has a spouse with other medical issues, the costs and challenges of arranging travel to access services is increased accordingly. If one or the other spouse cannot be left alone,

travel arrangements must accommodate this need for care. Family members may be available to assist to varying degrees, but this increases their own caregiving burden involving time away from work or their own family responsibilities. Seniors without spouses and/or family may have an even more difficult time making arrangements to access necessary services and medical treatments.

The model of cancer care delivery in most jurisdictions in Canada involves travel for an initial consultation with a tertiary care cancer centre to determine treatment options. Some of the proposed treatments may be available close to a cancer patient's community of residence, but others require travel to obtain treatment or consultation. Radiation therapy, for example, is often five to six weeks of outpatient treatment demanding that the patient either travel daily or remain in the treatment community until the treatments are complete. Travel to an urban centre presents significant challenges for many cancer patients and especially for seniors. Frequent trips are exhausting and the additional stresses of a strange environment, separation from family and social supports, navigating large buildings, parking, technology, etc., may be overwhelming. Seniors may decide not to pursue cancer treatments at all, rather than endure the rigors of the travel required.

Health care providers must be sensitive to this and other very pragmatic issues that can impact access to care for seniors and work creatively with them to ensure they are not prevented from receiving needed services. Some strategies to overcome barriers to transportation include:

- Scheduling appointments at the optimal time to meet the client's needs with consideration for long distance travel (e.g., avoid early mornings to reduce avoid overnight accommodation costs).
- Reducing travel costs by identifying opportunities to coordinate appointments for specialists, tests and clinics to minimize the number of long distance trips required.
- Arranging appointments when family or natural supports are available.
- Connecting seniors with available community supports such as the Canadian Cancer Society or senior service organizations that may have programs to facilitate affordable transportation.
- Coordinating car pools or group transportation when more than one client needs to commute from a remote geographic region.
- Providing an inventory of affordable accommodations close to the specialist's office or treatment centre.
- Hospital admission to accommodate tests or treatment may be indicated for identified clients with compromised physical health, poor mobility, limited supports or impaired cognition.

Additional strategies to overcome barriers to access can include:

- Being aware of the barriers that could impact the compliance or accessibility of treatment for elderly clients including poor mobility, illiteracy, lack of social or family supports, or limited finances.

- Exploring the affordability and local availability of various treatment options and helping the client or their supports to understand how to access lower cost alternatives as appropriate.
- Identifying a team member or alternate resource who can help clients who need assistance in completing the complex documentation often required to apply for and determine eligibility for benefits.

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KEY POINTS: DRUG COSTS AND TRAVEL ISSUES

- A sizeable minority of older cancer patients find the costs associated with cancer care unmanageable.
- Limited finances and poor mobility can impact the compliance or accessibility of treatment for elderly clients.
- Explore the affordability and local availability of various treatment options and help the client and their supports understand how to access lower cost alternatives.
- Ensure that clients are aware of insured benefits for medications and supplies either through provincial or private plans.
- Get creative in problem-solving around drug costs:
 - Negotiate pricing with pharmacies or other suppliers
 - Approach local service groups for sponsorship, supplementary funding or fundraising activities
 - Seek an inventory of sources of compassionate funding
- Find creative solutions for travel issues:
 - Schedule appointments to avoid the need for overnight accommodation
 - Minimize the number of long distance trips by coordinating appointments
 - Arrange appointments when family is available.
 - Connect seniors with available community supports.
 - Coordinate car pools or group transportation.
 - Provide an inventory of affordable accommodations close to treatment centres.

ELDER ABUSE

Brigitte Wagner, MSW, RSW

Why Talk About Elder Abuse in a Guide on Seniors With Cancer?

Research about the prevalence and incidence of elder abuse is challenging for several reasons. There has been controversy over definitions (Barker & Himchak, 2006) and it is often difficult to identify cases or recognize abuse when the older adult is not able to speak for her/himself. Canadian studies have produced some early data and it is generally recognized that this presents “the tip of the iceberg”. The National Elder Abuse Incidence Study in the US (NEAIS, 1998) noted that for every incidence of elder abuse reported, five are unreported.

- 1 in 12 (or 8%) of seniors in British Columbia have been financially abused in amounts averaging \$20,000 (Spencer, 1996).
- 4% of older Canadians suffered from one or more serious forms of abuse by a person close to them (Podnieks, Pillemer, Nicholson, Shillington & Frizzel, 1990).
- A more recent study in Quebec indicates that almost half of elder abuse situations occurred within a spousal relationship (Lithwick, Beaulieu, Gravel & Straka, 1999).

It is unknown whether seniors with cancer differ from their peers with respect to risk for elder abuse. Vulnerability increases with increased functional dependence. Health care providers need to remain vigilant for signs of abuse and intervene appropriately in this patient population as in all others.

What is Elder Abuse?

Elder abuse always constitutes an abuse of power and a violation of trust. Abuse is defined as a deliberate mistreatment of an adult that causes the adult:

- Physical, mental or emotional harm
- Damage to or loss of assets

Abuse can take many forms and be expressed by many different behaviours. In abusive situations, often more than one form of abuse occurs. The following are the most commonly recognized forms of abuse (BC Coalition to Eliminate Abuse of Seniors, 1998; National Clearinghouse on Family Violence, 1996).

- **Financial abuse:** misusing the adult’s money and property; taking money, property or possessions by coercion; influencing the making of a will, the signing of a power of attorney or the sale of real property; cashing cheques without authorization; using bank accounts without the adult’s consent; refusing to properly account for common expenses; misusing a power of attorney or representation agreement.
- **Denial of civil rights:** censoring mail; invading or denying privacy; denying access to visitors; restricting the movement of an adult, or withholding information to which the adult is entitled.

- **Psychological or emotional abuse:** intimidation, isolation and exclusion from events, activities and decision-making; insults, degrading remarks designed to lower self-esteem; denial of emotional responsiveness and support (Stephens, 1996).
- **Physical abuse:** rough treatment and handling; acts of physical violence including slapping and pushing.
- **Sexual abuse:** any unwanted or exploitive sexual behaviour.
- **Medication abuse:** withholding medication the adult needs; giving too much medication often to keep the adult sedated or confused; using access to needed medications (e.g., pain medications) to coerce the adult.
- **Neglect:** any failure to provide necessary care and assistance, guidance or attention to an adult that causes serious physical, mental or emotional harm or significant loss or damage to the adult's assets. Neglect also includes self-neglect.

Why Do Older Adults Who Are Abused Often Not Disclose Their Experience?

Vulnerable adults who experience abuse or neglect are often reluctant to tell anyone or to talk about the abuse. Barriers to disclosing abuse include (Health Canada, 1994):

- **Hope that the abuse will stop or the abuser will change without intervention:** The older person experiences a sense of being to blame for or deserving of the abuse. The senior often hopes that by trying harder not to provoke the abuser, the abuse will stop.
- **Fear of reprisals:** Reprisals may involve loss of meaningful personal belongings. It may involve losing beloved pets or leaving them open to mistreatment. It may involve risk of personal injury, including having necessary medications withheld or being over-medicated.
- **Fear of abandonment:** Older persons often worry about leaving their homes and being institutionalized, a concern that may be reinforced by an abusive relative and used as a threat. Fear of being shunned by the rest of the family or being denied access to other family members (e.g., grandchildren) may be a real concern.
- **Hopelessness and isolation:** A fear of not being believed, a sense of shame and a lack of trust that things could change is a common experience for persons in abusive relationships. Low self-esteem and depression are often part of the feeling that nothing can change.
- **Values and beliefs:** Many older adults feel that it is inappropriate to discuss family problems with outsiders as this may damage the reputation of the family. If the abuser is a close family member, an adult child for example, the abused person may not want him or her criticized or punished. Older generations may also fear the involvement of authorities or government services.

- **Functional or communication difficulties:** Language or cultural differences can make it difficult to speak directly to an older person. Older immigrants for example may depend on younger relatives to translate. Physical or mental disability may affect communication as well.
- **Lack of awareness and information:** Lack of awareness of personal rights or lack of information about support and community services can be a barrier to disclosing abuse.

How Do Abusers Justify Their Behaviour?

People who are abusive commonly use several strategies to deny, justify or rationalize their behaviours. This denial can influence those who have a responsibility to intervene. Objectivity and judgment may be influenced, preventing appropriate actions to provide effective care. Awareness of the strategies used to neutralize or obscure abuse helps maintain objectivity when assessing a situation. Neutralization strategies (Tomita, 1990; McKenzie, 1997) include:

- **Denying responsibility:** The abuser says the act was an accident or caused by stress, alcohol or another reason. The person victimized may even assume responsibility and blame her/himself.
- **Denying injury:** The abuser maintains that the mistreatment did not cause significant pain or injury (e.g., medical treatment was not required or wealth will be inherited anyway and the person does not need those assets or income). The abuse or neglect is portrayed as normal perhaps due to the victim's isolation and lack of counteracting feedback from others.
- **Blaming the victim:** The abuser blames the victim, saying he/she is the wrongdoer or is a burden deserving of the abuse, neglect, exploitation, banishment or punishment.
- **Condemning people who would intervene:** The abuser blames critics, investigators and care providers or threatens legal or other action.
- **Appealing to higher loyalties:** The victim may deny the abuse due to lifelong or personal values (e.g., family problems are private), or loyalty to the abuser, (e.g., being the good parent, spouse, patient or resident). The abuser appeals to the victim's loyalty or love, asking him/her not to tell.
- **The defence of necessity:** The abuse is described as a necessary act to prevent a bigger problem or for safety (e.g., physical or medical restraints, locking in a room).
- **The metaphor of the ledger:** The abuser suggests that it is permissible to indulge in an unethical/illegal act if he/she has been "good" and has a sufficient "supply" of good behaviours to their credit. For example, the daughter is abusing her parents emotionally and financially but she is the only family member helping with the house cleaning or providing rides to appointments.

What Should Care Providers Do?

Seniors receiving cancer care may live in abusive situations which are a barrier to effective treatment. Missed appointments, despite available funds to pay for transportation, may be due to many issues but may also be a sign of financial abuse. Fear, anxiety or extreme passivity may be

a response to a new cancer diagnosis but may also be a sign of emotional abuse. Injuries such as bruises and burns may be accidental or associated with adverse treatment effects but could also represent physical abuse. Trauma suffered because of sexual abuse may get in the way of physical exams.

If a senior discloses abuse, he or she may talk about not wanting to annoy or anger their caregiver, may express a tentative desire to live somewhere else but the family not being able to afford it. It is important to listen empathetically, provide opportunities for private conversation and wherever possible encourage a consult with counselling staff. Never directly confront a suspected abuser or encourage disclosure while the abuser is present – the senior may not be safe when they leave the clinic to go home.

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KEY POINTS: ELDER ABUSE

- Living in an abusive relationship may be a significant barrier to accessing and optimally benefiting from cancer treatment. At least 4% of older Canadians have experienced one or more serious forms of abuse. Abusers may be spouses, adult children or close friends.
- Abuse always constitutes an abuse of power and a violation of trust. It means a deliberate mistreatment of an adult that causes the adult:
 - Physical, mental or emotional harm
 - Damage to or loss of assets
- In abusive situations, often more than one form of abuse occurs:
 - Psychological or emotional abuse
 - Physical and sexual abuse
 - Medication abuse
 - Financial abuse
- Why are abuse victims reluctant to ask for help?
 - Hope that the abuse will stop or the abuser will change
 - Fear of reprisals
 - Fear of not being believed
 - Communication difficulties
 - Shame and embarrassment
- Implications for care providers: If there is any indication of potential abuse or if the senior discloses abuse, listen empathetically, provide opportunities for private conversations, refer to patient family counselling or consult with an experienced counsellor. Never confront the suspected abuser or encourage disclosure while the abuser is present. The senior may not be safe once they leave the clinic.

SELF CARE FOR CARE PROVIDERS

Mary L. S. Vachon, RN, PhD

The Experience of Caring for Seniors with Cancer

Health care providers who work with seniors with cancer may be specialists working in oncology settings with limited or extensive experience with seniors. They may be gerontological experts with limited or extensive experience with cancer. They may work in clinics, hospitals, the community, senior residences or long-term care. They may be providing acute care, chronic care management, and/or residential care. The setting may or may not be a more significant source of professional stressors than direct involvement with clients, patients and families. The client's experience of cancer may be a primary health problem or just one of many chronic health care issues. The senior living with cancer may be anywhere along the continuum of survivorship, from diagnosis, to receiving active treatment, to living disease-free, to experiencing a recurrence of cancer, living with cancer as a chronic illness or be in the palliative stage of illness. For many caregivers working in gerontology the primary focus is on wellness, despite the fact that clients may be living with a number of health and illness challenges (Futrell, Melillo & Devereaux, 2005).

Leppa (2004) suggests that long term care provides the "excitement" of what "real nursing" is all about. Caregivers working with seniors derive satisfaction from their work, patient care and relationships with colleagues (Engström, Ljunggren, Lindqvist & Carlsson, 2006). In one study, patient care or patient contact was the major source of satisfaction among oncologists, allied health personnel and support staff, even if their job didn't involve much patient contact. Oncology was felt to be a special environment, often because of longstanding relationships with patients. Having good relationships with patients, families and colleagues were the three top sources of satisfaction, being perceived to do the job well was fourth highest for all groups, and having variety in one's job was amongst the top for all groups (Grunfeld et al., 2000). Caregivers working with the dying found it rewarding to be able to help patients find meaning in suffering and dying (Kearney & Mount, 2000).

Like health care professionals in general, those who work with seniors with cancer are susceptible to a variety of factors that influence job stress and satisfaction. An understanding of these issues is critical for self care and quality service delivery.

What Is Known About Job Stress and Satisfaction in Canada?

Recent Canadian research found an increase in stress over the last decade (Higgins, Duxbury & Johnson, 2004) as well as a link between hours in work and role overload, burnout, and physical and mental health problems (Duxbury & Higgins, 2003). Nearly one-third of female Canadian nurses (31%) were classified as having high job strain compared with 26% of all employed women. Job strain was related to fair or poor physical and mental health and to lengthy absences from work for health related reasons (Shields & Wilkins, 2006).

In a study of burnout, job stress and job satisfaction in cancer care workers in Ontario, the prevalence of symptoms related to burnout were higher in physicians than in allied health professionals or support staff. More than half of physicians reported emotional exhaustion compared with about one-third of allied health professionals and support staff. More than one in five physicians reported feelings of depersonalization compared with about one in 20 among other staff members.

About half of physicians and more than half of allied health professionals reported low feelings of accomplishment compared with about one-third of support staff (Grunfeld et al., 2000).

Specific acute work-related stressful experiences contribute to depression, and enduring structural occupational factors can contribute to psychological disorders (Tennant, 2001). The impact of depression on work performance has been estimated to be greater than that of chronic conditions such as arthritis, hypertension, back problems and diabetes (Gilmour & Patten, 2007). Since work is such an important facet of daily life for so many Canadians, the stress they experience at work is a key determinant of overall mental health (Statistics Canada, 1999).

Life is not all about work. In the Canadian Work-life Balance Study, a majority of participants were juggling the responsibility of caring for children, elderly relatives or both. Role overload is having too much to do in a given amount of time. Fifty-eight percent of the group had role overload (Canadian Council on Integrated Healthcare, 2002). Recent research indicates that unhealthy work environments and heavy workloads are associated with a variety of health problems (Duxbury & Higgins, 2003; CCIH, 2002). The direct costs of absenteeism in Canada due to high role overload were estimated to be approximately \$3 billion per year (Higgins et al., 2004). Work stress is not only related to the employee and employer. A recent study (Eaker, Sullivan, Kelly-Hayes, D’Agostino & Benjamin, 2007) found that men whose wives were upset by work were 2.7 times as likely to develop coronary heart disease.

Table 1 defines some concepts used to describe the experiences associated with the challenges of professional caregiving. Of these concepts, the best researched is burnout. Burnout has been found to be higher in females (Kash et al., 2000; Maslach, Schaufeli & Leiter, 2001; Cocco, Gatti, de Mendonca Lima & Camus, 2003). Religiosity (Maslach et al., 2001) and a Hardy Personality (a sense of commitment, control and challenge) (Kobasa, Maddi & Kahn, 1982) have been found to protect caregivers against burnout (Duquette, Kerouac Sandhu, Ducharme & Saulnier, 1995; Kash et al., 2000).

Table 1. Challenges of Professional Caregiving

Stress	<ul style="list-style-type: none"> • The strain that remains “in response to the failure to manage tensions well and to overcome stressors” (Antonovsky, 1979). • “There is increasing consensus around defining work-related stress in terms of the ‘interactions’ between employee and (exposure to hazards in) their work environment. Within this model stress can be said to be experienced when the demands from the work environment exceed the employee’s ability to cope with (or control) them” (European Agency for Safety and Health at Work, 2000).
Burnout	<ul style="list-style-type: none"> • A syndrome of responses involving increased feelings of emotional exhaustion, negative attitudes toward the recipients of one’s service (depersonalization), a tendency to evaluate oneself negatively with regard to one’s work, and a feeling of dissatisfaction with accomplishments on the job (Maslach, 1982). • The root cause of burnout lies in people’s need to believe that their life is meaningful, and that the things they do – and consequently they themselves – are important and significant (Pines, 1993).

Job engagement	<ul style="list-style-type: none"> • The opposite of burnout. • Engagement is defined as a persistent, positive-affective-motivational state of fulfillment in employees that is characterized by vigor, dedication and absorption. • The individual's relationship with work involving: a sustainable workload, feelings of choice and control, appropriate recognition and reward, a supportive work community, fairness and justice and meaningful and valued work. • Engagement is also characterized by high levels of activation and pleasure (Maslach, Schaufeli & Leiter, 2001).
Compassion fatigue	<ul style="list-style-type: none"> • Compassion fatigue applies to those emotionally affected by the trauma of another (usually a client or family member) (Figley, 2002). • Most often this concept is associated with the "cost of caring" for others in emotional pain (Figley, 1982). • One form of burnout (Figley, 2002).
Compassion satisfaction	<ul style="list-style-type: none"> • The satisfaction derived from the work of helping others • Compassion satisfaction may be happiness with what one can do to make the world in which one lives a reflection of what one thinks it should be (Stamm, 2002).
<i>Source: adapted from Vachon & Sherwood, 2007</i>	
Moral distress	<ul style="list-style-type: none"> • Moral distress is the psychological disequilibrium, negative feeling state, and suffering experienced when nurses make a moral decision and then either do not or feel that they cannot follow through with the chosen action because of institutional constraints (Corley, 2002).

What Factors Contribute to Job Stress and Satisfaction?

Maslach, Schaufeli & Leiter (2001) reviewed the evidence for the major factors associated with burnout over the past three decades. These include: workload, control, reward, community, fairness and values. More recent research has found that emotion-work variables (e.g., requirement to display or suppress emotions on the job, requirements to be emotionally empathic) add to burnout scores, over and above job stressors (Maslach et al., 2001). Observations from the literature pertinent to several of these identified factors are presented below.

Sources of Job Stress and Job Satisfaction

1. **Workload:** Bedside, French-speaking, Quebec geriatric nurses were found to be more burned out than head nurses, assistant head nurses, team leaders or others; full-time staff perceived more stressors and were also more burned out; nurses working in nursing homes perceived more stressors than those working in hospitals (Duquette et al., 1995). A comparison of nurses working with the dying in community, hospice and acute care settings found that, for all groups, dealing with physical problems such as pain and symptom control was both the most frequent and most difficult problem (Copp & Dunn, 1993). Compared with staff in nursing homes, staff on acute geriatric wards, although experiencing only moderate burnout scores, had higher levels of burnout and stressful events at work particularly related to patients' behavioural disorders (Cocco et al., 2003). The lack of time in elder care put community nurses under considerable pressure (Weman & Fagerberg, 2006). A Swedish study found stressors in elder care included increased workload and difficulties in recruiting and retaining nurses (Engström, Ljunggren, Lindqvist & Carlsson, 2006).

2. **Control:** Staff who perceived more involvement in decision-making in their work had significantly fewer negative staff-resident interactions (Jenkins & Allen, 1998). Nurses in community and acute care settings reported difficulty when trying to advise physicians to use medications that are effective for pain and symptom control. Feelings of rejection and frustration were reported by nurses who felt their roles and knowledge were not valued (Copp & Dunn, 1993).
3. **Reward:** A study comparing the nature of nursing work in long-term care (LTC) facilities compared with that in intensive care units (ICU) found that work in the LTC environment is complex, demanding, and interesting as well as being different from, but not less satisfying than, nursing work in acute environments (Leppa, 2004).
4. **Community:** Conflict within teams is normal, but there is a need for staff to handle conflict constructively so that staff morale and the common goal of patient care are maintained and not eroded (Copp & Dunn, 1993). Community nurses found their work less stressful if their manager was a nurse who knew what the work of a community health nurse involved. They sometimes found it challenging to be a part of several different teams of caregivers caring for patients. Appreciation from their superiors and family members was a very important part of their work. There were challenges when there were communication issues between the senior and family members, or amongst family members. Nurses also found it difficult when family members “abandoned” seniors (Weman & Fagerberg, 2006). Administrative French-speaking Quebec nurses reported more work stressors than bedside nurses, but also perceived more work support; nurses on the day shift perceived more work support (Duquette et al., 1995). Nurses in acute care, as opposed to hospice or community nursing, both felt inadequate in providing support to colleagues and at the same time needed support themselves (Futrell, Melillo & Devereaux, 2005).

Staff who reported higher levels of personal accomplishment (i.e. lower levels of burnout on the personal accomplishment scale) had significantly more staff resident interactions in a residential home for older people (Jenkins & Allen, 1998).

5. **Values:** Attitudes of workers impact how care is implemented (Futrell et al., 2005). Chronic care management may alleviate older adults’ chronic health problems, reduce expenditures for their health care, and promote their satisfaction and quality of life (Hendrix & Wojciechowski, 2005). There can be conflicts between family members and caregivers re: decision-making with respect to when to pursue more aggressive care (Weman & Fagerberg, 2006).
6. **Emotion-work variables:** A study of the ethical and moral experiences of oncology nurses found that their care perspective focused on issues related to the moral principles of autonomy, beneficence, nonmaleficence, fidelity and truth-telling and revealed moral themes of suffering, secrets and struggle (O’Connor, 1996). Nurses practicing in oncology and medical surgical settings demonstrated a positive attitude about working with dying patients. Those who spent more time with terminally ill and dying patients reported more positive attitudes (Dunn, Otten & Stephens, 2005). Nurses in the community, acute care and hospice settings all reported

difficulty dealing with dying patients. They felt challenged if patients requested active treatment and did not seem to acknowledge that they were dying. They felt frustrated if patient's wishes were not respected, such as the wish to stop active care and pursue palliative care (Coop & Dunn, 1993). Caregivers dealing with patients who die, perhaps particularly those caregivers who have had long-term relationships with their clients, may experience feelings of grief, loss or chronic grief which must be addressed (Vachon, 2007).

Strategies for Dealing with Job Related Stress

Table 2 shows a variety of techniques that can be helpful in avoiding and dealing with job stress.

Table 2: Lifestyle Management Techniques

1. Recognize and monitor symptoms
2. Good nutrition
3. Meditation
4. Spiritual life
5. Grieving losses, personally and as a team
6. Decrease overtime work
7. Exercise: aerobic, yoga, qi gong, tai chi
8. Time in nature-walking, gardening
9. Music-singing, listening to music, playing an instrument
10. Energy work: reiki, healing touch, therapeutic touch
11. Maintain sense of humor
12. Balance work and home lives to allow sufficient "time off"
13. Go on a retreat
14. Have a good social support system-personally and professionally
15. Seek consultation if symptoms are severe
16. Discuss work-related stresses with others who share the same problems
17. Visit counterparts in other institutions; look for new solutions to problems (Vachon, 2006)
18. Remember that sometimes work-related problems can be solved, other times, leaving the work environment and taking the wisdom gained with one is a good solution.

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KEY POINTS: SELF CARE FOR CARE PROVIDERS

- Health care providers are susceptible to a variety of factors that influence job stress and satisfaction. An understanding of these issues is critical for self care and quality service delivery.
- Recent research suggests that job stress is increasing.
- Numerous factors contribute to both job stress and satisfaction, including workload, control, reward, community, values and emotion-work variables.
- Much is also known about a variety of techniques to avoid and manage job related stress.

PRACTICAL SUPPORT

Sheila Damore-Petingola, MSW, RSW

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This section will describe various programs and opportunities that may be helpful to clinicians, older adults and their family members when navigating the cancer care path. The health care provider whose speciality is neither oncology nor geriatrics may be unaware of the potential resources available for older adult cancer patients and their caregivers. This section is intended to provide an overview of programs and services that have been in existence for some time, as well as to encourage you, the reader, in your search for resources which might be listed under different titles in your community.

Comprehensive geriatric oncology programs are not common in Canada at the time of this writing; however, cancer care services are intended to provide for patients throughout the life cycle (infancy to old age). Accessing speciality programs for the patient and family becomes one of exploring and charting resources, which are neither equitable nor available throughout all parts of our nation.

This section will describe programs which are consistent and available throughout Canada. Programs and opportunities will be described from both the domains of oncology as well as geriatrics. Canadian website links and toll free telephone numbers are provided for quick reference. It is strongly recommended that providers, patients and families utilize the resource knowledge and advocacy skills of volunteers, health care professionals and the many others who work in a specific part of the care giving wheel. The importance of networking and connecting with community agencies, volunteers and health care providers cannot be overstated in accessing information, services and care. Although not specifically designed for older adults with a cancer diagnosis, it is important for health care providers to understand the programs and services that are available for all cancer patients and their families.

Cancer Programs

Breast Cancer

Peer-led support groups for women with breast cancer are available in some Canadian communities. These organizations provide information, emotional support and listings of support groups for people of all ages specific to breast cancer:

Canadian Breast Cancer Foundation (www.cbcbf.org)

Willow-Breast Cancer Support Canada (www.willow.org)

Canadian Breast Cancer Network (www.cbcn.ca)

Canadian Cancer Society

The following services are available from the Canadian Cancer Society (www.cancer.ca, toll free: 1-888-939-3333):

- The **Cancer Information Service** provides reliable cancer information anywhere in Canada from 9 am to 6 pm. Information specialists with health care backgrounds, who are knowledgeable about cancer and support services, provide information in a clear, sensitive and non-judgmental manner. This service does not advise or recommend care. Information is also available through the website, publications and the Canadian Cancer Encyclopedia (CCE).
- The **Community Services Directory** is an online directory that has over 4,000 cancer related services listed. This service is available directly through the internet (www.cancer.ca), by email or by contacting the toll free number and speaking with an Information Specialist. **Community Services** include Transportation, Peer Support and the Smokers' Helpline.
- **CancerConnection** is available to any adult with cancer. CancerConnection will match you up according to what is most important to you. It may be that you are looking for someone who had a treatment you are considering, or someone who had the side effects you are experiencing, or maybe you are looking for less cancer-specific criteria like someone who had young children at the time of their diagnosis. There is nothing quite like talking to someone who understands what you are going through because they have been there.
- **Coping with Cancer** provides an assortment of information (e.g., Living with Cancer; Managing Side Effects; Managing Stress; Nutrition During Treatment) available on the Canadian Cancer Society website. The Canadian Cancer Society may have information about support groups facilitated by volunteers, peers and professionals. Some support groups address a specific cancer, such as breast cancer support groups and prostate cancer support groups. Other support groups are designed to address issues that may be common to different types of cancer diagnoses.

Wellspring (www.wellspring.ca, toll-free: 1-877-499-9904)

Provides a wide range of cancer support programs and services, at no charge, to meet the emotional, social, psychological and informational needs of people living with cancer and those who care for them. Wellspring centres are non-institutional and non-residential. They are warm and supportive community efforts based on the needs of patients and their loved ones. Wellspring locations are found in different communities across Canada.

Palliative Care

Palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness, usually at an advanced stage. The Public Health Agency of Canada provides a Palliative Care Information Sheet for Seniors located at this website - http://www.hc-sc.gc.ca/seniors-aines//pubs/info_sheets/palliative_care/pall_e.htm. This information sheet answers some of the questions seniors frequently ask about palliative care (sometimes called hospice care). It also suggests where seniors can learn more about the services available.

Provincial Cancer Agencies

These government agencies have a direct relationship to the provincial health ministry of the province to ensure cancer care for residents. As such, contact with the cancer agency in your province may provide a first step toward connecting with caregivers and health care providers who have knowledge of the programs specific to residents of your province/territory and community.

Alberta Cancer Board
www.cancerboard.ab.ca

British Columbia Cancer Agency
www.bccancer.bc.ca

Cancer Care Manitoba
www.cancercare.mb.ca

Cancer Care Ontario
www.cancercare.on.ca

Cancer Care Nova Scotia
www.cancercare.ns.ca

New Brunswick Cancer Network
www.gnb.ca/0051/cancer/index-e.asp

Saskatchewan Cancer Agency
www.saskcancer.ca

Quebec Centre for Cancer Control / Direction de lutte contre le cancer
http://www.msss.gouv.qc.ca/sujets/prob_sante/cancer/index.php?lutte_contre_le_cancer

Prince Edward Island Cancer Treatment Centre
<http://www.cancercentre.pe.ca/>

Newfoundland Cancer Treatment and Research Foundation
www.nctrf.nf.ca

Yukon Health and Social Services
www.hss.gov.yk.ca

Northwest Territories Health and Social Services
www.hlthss.gov.nt.ca

Nunavut
www.itk.ca/health

Older Adult Programs

Cancer support groups for seniors may be available in some communities such as those described at the website in Lethbridge, Alberta where services are offered in partnership with the local chapter of the Canadian Cancer Society. A look at this website may stimulate thought about resources available in your community, www.lethseniors.com/groups.htm.

The following link provides a Psychosocial Resource Manual which describes models of care for older adults and identifies some programs and services throughout Canada, www.seniorsmentalhealth.ca/resourcemanuale.pdf.

Geriatric assessment programs may be available through your community hospital or health centre. Members of the geriatric assessment care team may collaborate with the oncology care providers to ensure continuity and comprehensive care.

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Promoting Seniors Mental Health In Cancer Care: A Guide for Front-line Providers

