



CHRONIC ILLNESS AND AGING

SECTION 4. CANCER AS A CHRONIC LIFE THREATENING CONDITION

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Although chronic illnesses in older adults have predictable psychological and social impacts, the specific characteristics of any disease influence the adaptive challenge it presents. To be effective the social work role, interventions, and service delivery models need to be designed and developed to take account of the particular characteristics of an illness and its affect on patients, families, and communities. Such defining characteristics for the biopsychosocial assessment and interventions include, for example:

- ◆ The disease prevalence and life threat
- ◆ The disease and treatment trajectory over time
- ◆ The effects and side effects of required treatments
- ◆ The impact on patient functioning in all domains
- ◆ Societal attitudes to the disease
- ◆ Implications for care coordination.

Presented here is the example of cancer, a disease that has high prevalence in older adults, is life threatening, is increasingly becoming chronic (but may have periods of remission and exacerbation), often requires decision making about the use of complex high technology treatments. Both cancer and its treatment have a broad range of impacts on patient functioning, and only recently has it been viewed as a disease that should be treated in older adults. The use of care coordination models with older adults with cancer is just emerging and has included primarily interdisciplinary team care, patient and caregiver education and support, and care/system navigator programs to improve access and continuity for multiple populations.

Epidemiology: Cancer and Age

Prevalence Overview

- ◆ In the United States, almost 60% of new cancers and 70% of deaths from cancer occur in adults over the age of 65 (NCI, 2005)

The burden of cancer is considerable in older adults and as the population ages it will continue to grow. Based on cancer incidence rates and U.S. census department population projections the number of cancer patients 65 years and older will double over the next 30 years and in those 85 years and older it is expected to increase four fold from 2000 to 2050 (Edwards et al., 2002).

The Changing Trajectory of Cancer as a Disease

- ◆ Early detection and improved treatments for many different types of cancer have changed our understanding of this group of illnesses from that of a single disease that was often uniformly fatal in a matter of weeks or months to that of a variety of diseases, some of which are curable, almost all of which are treatable.

For many individuals long-term disease-free survival is now possible (IOM, 2006). In the past two decades the 5-year survival rate for the 15 most common cancers has increased from 43% to 64% for men and from 57% to 64% for women (Jemal et al., 2007). With survivors living longer, often with more than one chronic condition, some types of treatable cancer can be seen less as a terminal disease and more as a manageable chronic condition. This new trajectory is especially important for older populations to learn about as they may have perceived a cancer diagnosis as a death sentence given their early life experiences prior to the current advances in cancer control. Despite advances, cancer does remain a group of diseases that represent both acute life-threatening illnesses and serious chronic conditions (Maramaldi & Lee, 2006).

Impact of Cancer on Older Adults

- ◆ Older people bear a disproportionate cancer burden in the United States.

As a result, cancer is now classified as a disease of older adults (Cohen, 2003; Deimling, Kahana, Bosmon, & Schaefer, 2002; Ershler, 2003).

- 1) They are at higher risk of a diagnosis of most cancers. Cancer rates are 10 times higher for people age 65 and older.
- 2) They have a higher rate of cancer deaths.
- 3) They are more likely to have concomitant health problems associated with advancing age.

- 4) Sixty percent of cancer survivors are over the age of 65. Even if diagnosed at an earlier age, they are now living as survivors into their older years. Approximately 14% of the 10.5 million estimated cancer survivors were diagnosed over 20 years ago. That often means they are living with the late effects of treatments that were more radical and more toxic than the treatments of today (IOM, 2007b).

- ◆ The most common sites of cancer differ in men and women.

The five most commonly diagnosed cancers in women age 65 and older are cancer of the lung, breast, colon, rectum, and pancreas. In older men the five most common cancer sites are lungs, prostate, colon, rectum, and pancreas (Maramaldi & Lee, 2006; Sacks & Abraham, 2003).

- ◆ Median ages of cancer patients at diagnosis are above 65 for most types of cancer.

Table 1 shows the median ages of patients at diagnosis for both sexes. With the exception of non-Hodgkin's lymphoma (NHL), the median age in men for these common cancer sites is uniformly above the age of 65, and in some cases above 70 years. For women the situation is similar.

Table I. Median Age of Cancer Patients at Diagnosis, 2000-2003

Cancer site	Men		Women	
	Median Age	Number	Median Age	Number
Breast	67	1,720	61	212,920
Colon	71	49,220	75	57,460
Corpus uteri	--	--	63	41,200
Leukemia	66	20,000	68	15,070
Lung	70	92,700	71	81,770
NHL*	64	30,680	69	28,190
Ovary	--	--	63	20,180
Pancreas	70	17,150	74	16,580
Prostate	68	230,110	--	--
Rectum	66	23,580	70	18,350
Stomach	70	13,400	74	8,880
Bladder	72	44,690	74	16,730
Total		523,350		517,330

* NHL = non-Hodgkin's lymphoma. Source: Adapted by R. Yancik from American Cancer Society (ACS) Facts and Figures, 2006; National Cancer Institute (NCI) SEER program Data, 2000-2003. Presented by R. Yancik, 2007. The U.S. Demographic Imperative: Implications for Oncology Practice, in *Cancer in Elderly People Workshop Proceedings*, Institute of Medicine. National Academies Press: Washington DC.

- ◆ The proportion of cancers in all sites in the 65 and older population is 56%. As shown in Figure 1, for several tumor types the proportions are even higher.

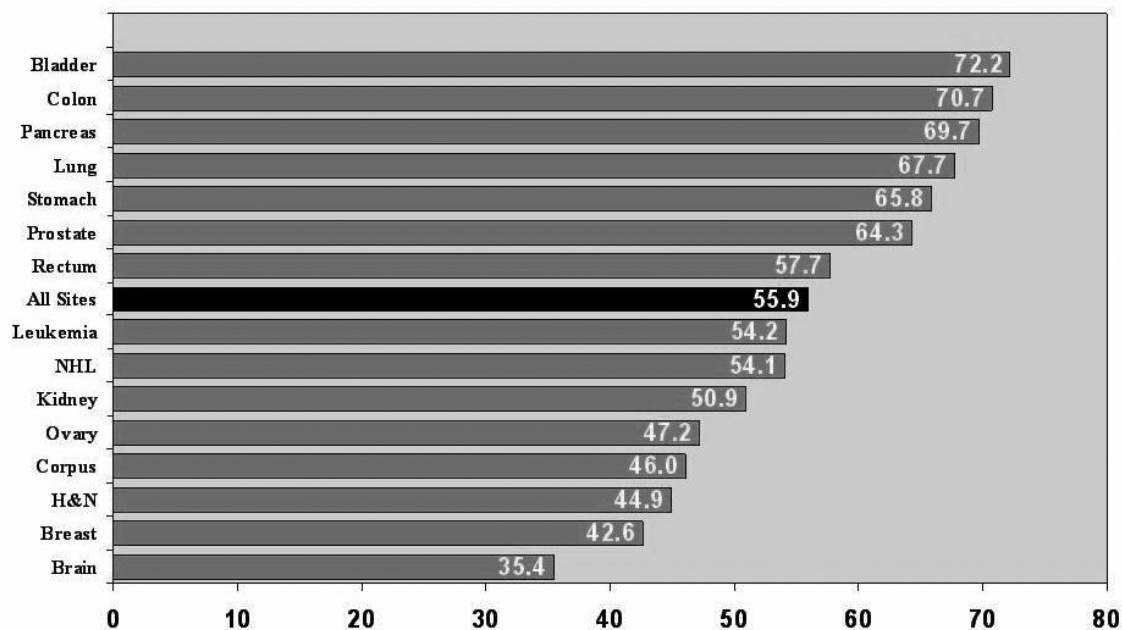


Figure 1. Proportions of tumors in patients 65 and older. Source: Adapted by Yancik from NCI Seer Program Data, 2000-2003 (Yancik, 2007). The U.S. Demographic Imperative: Implications for Oncology Practice, in *Cancer in Elderly People Workshop Proceedings*, Institute of Medicine. National Academies Press: Washington DC.

- ◆ Age-adjusted cancer incidence and death rates show that rates are significantly higher among older adults than among younger ones.

Figure 2 shows age-adjusted incidence and death rates for all cancer sites combined. The age-adjusted incidence per 100,000 population is 10 times greater for individuals 65 and older compared to the rate for younger persons. And, in all cancer sites age-adjusted death rates are 17 times greater for this age than for those aged less than 65. This is important because for many years health care researchers/providers believed that older people did not die of cancer. The presumption was that they would die from other co-morbid diseases and that cancer progressed more slowly than those diseases did. Therefore, both screening and treatment were often not recommended. As people began to live longer, however, it became clear that they can live long enough to die from cancer, and over the past decade new guidelines have been developed such that more screening and treatment now occurs in older people.

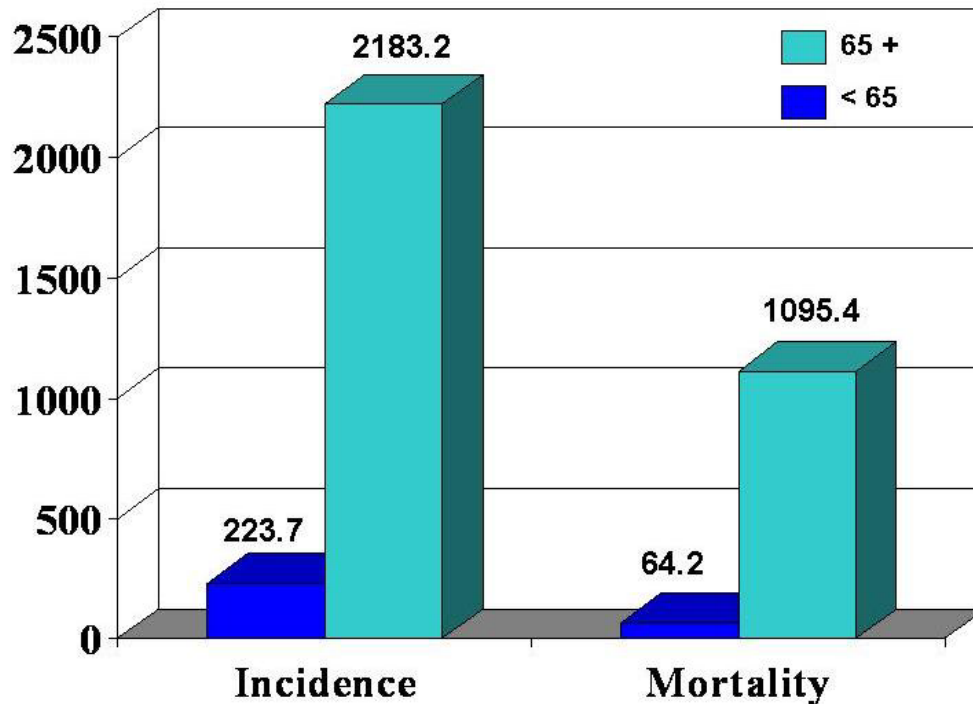


Figure 2. Age-adjusted incidence and death rates, all cancers.

Source: Adapted by Yancik from NCI SEER Program Data 2000-2003. Presented by R. Yancik, (2007). *The U.S. Demographic Imperative: Implications for Oncology Practice*, in *Cancer in Elderly People Workshop Proceedings*, Institute of Medicine. National Academies Press: Washington DC.

Factors Affecting the Impact of Cancers in Older Age

- ◆ Little is known about cancer in older adults.

It is important to recognize that despite the high incidence of cancer in older adults little is known about the intersection of cancer and aging (Marimaldi & Lee, 2006). Interaction between these two specialty areas, gerontology and oncology, has been quite limited. In a June 2001 a workshop convened by the National Institute on Aging and the National Cancer Institute (NCI) expert participants acknowledged that geriatric and cancer research have developed separately with little interaction. A cross-institute initiative was subsequently implemented with the goal of bringing aging and cancer research together. In 2006, an Institute of Medicine workshop on Cancer in Elderly People presented information documenting gradual improvements in survival of older people with cancer, although such improvements lag far behind those made in pediatric oncology, until recently another age group for which cancer was insufficiently studied (IOM, 2007b). Yet, older cancer patients still do not receive the appropriate standard of care, in spite of near universal health coverage of this population under Medicare.

Specifically, older patients continue to be underrepresented in clinical trials. Referrals to hospice occur late in the course of this illness. Because of the outpatient locus of most cancer treatment and the increasing complexity of care over longer periods of time, an increasingly high burden falls on the families who care for older adults (IOM, 2007b).

- ◆ Cancer treatment is arduous and generally requires some combination of surgery, radiation, or chemotherapy for months, sometimes years.

Even when treatment is completed and no cancer remains, there are frequently permanent, and serious residua of cancer and/or of chemotherapy, radiation, hormone therapy, surgery, and other treatments. These can permanently impair cardiac, neurological, kidney, lung, and other body functioning, necessitating ongoing monitoring of cancer survivors' health. Cancer survivors report a broad range of functional limitations as well as mental health problems, such as depression and anxiety disorders. Regardless of age, an individual with a cancer history must be diligently monitored for recurrence of a previous cancer or the occurrence of a new form of cancer.

Older cancer patients may require a longer period of rehabilitation from treatment and experience more severe or longer-lasting treatment side effects. There may be setbacks after initial treatment. Restoration to pre-illness functioning may not be possible. The same physiological processes that slow down the progression of cancer in older adults may also delay the recovery process (Balducci & Yates, 2000).

Critical Challenges of Cancer to the Older Adult Population

Three critical challenges for older adults with cancer are concurrent diseases with the cancer diagnosis, the lack of a workforce trained to treat older adults with cancer, and the increasing need for family caregivers for older adults.

First Challenge: Cancer and Co-morbidities:

- ◆ *Common co-morbidities:* With aging, physiological changes and susceptibility to geriatric syndromes (incontinence and falls, among others) increase, as do chronic disease, susceptibility to infections, and other co-morbidities.

The major diseases and conditions common to older persons include heart-related conditions, diabetes, hypertension, chronic obstructive pulmonary diseases (COPD), cerebrovascular diseases, urinary tract problems, and subcategories of each of these. Using these conditions, one study of breast cancer patients found that the number of co-morbidities ranged from 0-13 per patient and that the numbers increased with age. (Yancik et al., 2007, as cited in Institute of Medicine, 2007b).

- ◆ *Interaction of cancer and co-morbidities:* Research is just beginning to assess and treat the interaction of many co-occurring conditions and diseases of older adults.

Co-occurring conditions limit the ability to determine prognosis, minimize treatment options, and increase the risk of death from multiple causes. Co-morbidity is frequently assessed in the context of an index disease (e.g., a newly diagnosed cancer). Some researchers/practitioners have suggested that focusing only on the index disease is insufficiently comprehensive to be used in a primary care setting. Alternatively, they encourage an approach that would define co-morbidity as the total burden of biological dysfunction. A recent article that contributes to developing the research structure in this area proposes that co-morbidity be assessed in a way parallel to the World Health Organization's (WHO, n.d.) International Classification of Functioning, Disability, and Health. Functioning of each system is assessed on a continuum from high-functioning, protective zones to early subclinical changes, to overt disease of increasing severity, to end-stage disease. It does not rely solely on clinically diagnosed diseases and explores the full range of performance in each system (positive and negative) instead of measuring only negative aspects.

Both researchers and practitioners are advocating greater attention to the research interface of aging and cancer treatment. Further they recommend stronger ties between geriatric medicine and medical oncology to meet the current and future needs of the older age segment of the population (IOM, 2007b; Maramaldi & Lee, 2006).

Second Challenge: The Uninformed Workforce

- ◆ The lack of an educated workforce with sufficient understanding of the impact and effects of cancer in older adults is a major challenge.

For example, when deciding what screening and treatment to offer geriatric patients, professionals still focus on the particular age of the individual rather than considering their functional level, co-occurring conditions, and symptoms. Until recently individuals over 70 years of age were routinely restricted from participation in clinical trials because it was believed that none could tolerate aggressive treatments or would live long enough to benefit from them. In fact, older adults are quite heterogeneous in relation to their physical condition, depending upon their functional status, co-morbidities, and symptoms. Therefore, specific age is not sufficient to rule in or out many treatments. Their limited representation in clinical trials makes it difficult to predict older adults' reaction to newer treatments. What are the potential risks in terms of morbidity and mortality, and what are the potential benefits in relation to longer active life time? Many patients ask this question. Often older adults are not offered screening and treatment that would improve their survival and quality of life, and conversely, they may receive treatments in the advanced stages of an illness that

are futile and prolong suffering (IOM, 2007b). Providing a better informed workforce that understands how to assess strengths and protective factors as well as co-morbidities and that appreciates the continuing expansion of active life time in older adults is a current challenge.

Ageism and stereotyping of older adults as “having lived long enough” or being unable to tolerate the burden of treatment, or no longer needing cancer screening because they will die of another disease before the cancer reaches a fatal stage are attitudes that also contribute to the failure to meet the correct standard of care for older adults in many situations. Contrary to earlier notions that older adults would not die of their cancer illness, but would die of organ failure first, current data document a high mortality rate from cancer among this age group.

Third Challenge: Understanding the Family and Community Role as Caregivers

- ◆ *Developments in health care have shifted the focus of care to the family/community.*

The trend in U.S. health care towards “de-hospitalization,” in combination with advances in cancer treatment makes it possible for many elderly cancer patients to be managed on an outpatient basis and remain in the community while in treatment.

Diagnostic testing, surgical treatments, complex chemotherapies, and radiation treatments previously performed on an inpatient basis are increasingly administered in physicians offices or outpatient treatment facilities.

We have not often thought of cancer as a long-term caregiving situation in comparison with, for example, the care of patients with dementia. However, with medical advances the disease progression can now extend over many years resulting in increasing needs for family care. Consider the length of time from initial diagnosis through therapy, potential progression, possible recurrence, perhaps even a second cancer, and then palliative and end-of-life care. With a second cancer or late recurrence, family members report already being involved for 4.6 years on average. (Cannuscio et al., 2002; Hayman et al., 2001). So, caregiving can go on for a considerable period of time, and as survival time lengthens to 15 or 20 years, caregiving also stretches out for many years.

- ◆ *Economic value of family caregiving:* Family care across diseases makes a major economic contribution to health care.

In 2004, calculated at \$9.92 per hour, the value of family care was estimated to be \$306 billion dollars (Hayman et al., 2001; Rabow, Hauser, & Adams, 2004). This is substantially more than we are currently spending on nursing home care or other professional services provided in home care. It is a major contribution and a major resource to the health-care system.

- ◆ *Family involvement:* Family are involved in different ways at different stages of the disease process.

Families play different roles in helping patients at different stages of the illness process and have varying abilities and skills for fulfilling these roles. Different judgments and different expectations of families occur during diagnostic phases, treatment phases, maintenance phases, rehabilitation phases, recurrence and metastasis, and palliative care at the end of life. The range of tasks they may have to fulfill in caring for the patient with cancer is quite broad and demands considerable skill and knowledge. These tasks include:

- a. medication dispensing and monitoring
- b. symptom management
- c. monitoring of side effects and adverse events
- d. meal preparation and nutritional balance
- e. care decisions and problem solving
- f. skin care and infection control
- g. management of highly technical equipment
- h. management of medical procedures such as catheters and wound care
- i. bill paying
- j. transportation and errands
- k. advocacy with health professionals and within the health care system.

The general roles and functions assumed by informal caregivers are shown in Table 2.

Table 2. Health-Related Responsibilities Assumed by Informal Caregivers

Role	Function	Examples
Companion	Provide emotional support	Discuss ongoing life challenges, troubleshoot problems, facilitate and participate in leisure activities
Coach	Encourage patient self-care activities	Prompt patient's engagement in health care, encourage lifestyle (diet, exercise) and treatment adherence
Homemaker	Manage household activities	Inventory, purchase food and medications, prepare meals
Scheduler	Arrange medical care	Schedule tests, procedures, and services
Driver	Facilitate transportation	Provide transportation to medical appointments and emergency hospital visits
Patient extender	Facilitate provider understanding	Attend appointments; clarify and expand on patient history, symptoms, concerns; introduce topics to provider
Technical interpreter	Facilitate patient understanding	Clarify providers' explanations, technical terms, record and remember discussions with providers
Decision maker	Make medical decisions	Select among treatment alternatives; decide among settings of care
Coordinator	Coordinate care across providers and settings	Ensure flow of information among providers
Financial manager	Handle financial issues	Resolve issues relating to insurance claims secondary coverage, co-pays, and benefit limits
Health provider	Deliver medical care	Administer medications, operate equipment
Attendant	Provide task assistance	Hands-on personal care task assistance
Monitor	Assess health status	Ensure that changes in health status are noted and properly addressed

Source: (Wolff, 2007, see Institute of Medicine, 2008, p. 252.
<http://www.iom.edu/?ID=53452>

- ◆ Caregiver stress in cancer is related to the relationship with the patient, the caregiver's own health status, and specifics of each situation.
 - a. Relationship to patient: Adult children caregivers experience distress and anxiety related to role change (from taking care to giving care) and task overload with multiple role demands from their work and family life. Older spouses, on the other hand suffer from role changes in the relationship, the loss of support, and anticipation of future loss and change.
 - b. Caregiver illness and depression: Disabilities and health and mental health conditions of caregivers affect their caregiving capacity
 - c. Specifics of the caregiving situation: Research shows that it is not so much the amount of physical care that is the stress; it is the transitioning from more care to less care or less to more. Also the number and severity of the patient's symptoms create varying stress for the caregiver, especially the management of pain and fatigue. The experience of caring for a person with advanced disease and terminal illness is a time of high stress for everyone involved (Greenberg, Seltzer, & Brewer, 2006).
- ◆ *Research findings on patient and caregiver stress:* Studies show that about one third of caregivers of cancer patients are highly stressed and one third are clinically depressed.

Importantly, studies show that caregiver stress can be very high up to 18 months after care is completed. Caregivers describe being distressed by fear of the future, worrying about the patient's death, problems of managing pain and fatigue, and in older adult spouses, feeling the absence of respite assistance. They are also distressed by conflicts with the patient and inconsistency among providers, by the hours of care, and the level of vigilance required (Cameron, Franche, Cheung, & Stewart, 2002; Greenberg et al., 2006; Rabow et al., 2004; Schulz, Tompkins, Wood, & Decker, 1987).

Studies have documented a variety of emotional consequences of caregiving for the older cancer patient, including increased levels of depression and anxiety, helplessness hopelessness, emotional exhaustion, low morale, distress, feelings of isolation, guilt, and anger. The emotional distress centers around helplessness, loss of control, insecurity about the course of illness, and the fear of losing the family member. The physical, psychological, and economic impact of caregiving is substantial (Hauser & Kramer, 2004). Schultz and colleagues (2001) showed that older spousal caregivers had a mortality risk that was 63% higher than non caregiver controls and had an increased number of physical symptoms. Patients and caregivers also have an impact on each other. Patients who lose their caregiver have higher mortality rates and caregivers have

more chronic illnesses and increased mortality when they become bereaved (Hauser & Kramer, 2004; Schulz & Beach, 1999; Schulz et al., 2001)

An overview of current research on the stresses of older adult cancer patients reported few studies that also included the specifics on impairments among relatives of older cancer patients; however, the authors highlighted the following (Kotkamp-Mothes, Slawinsky, Hindermann, & Strauss, 2005):

- 1) Age-related impairments in the healthy partner add considerable stress and limit their caregiving capacity.
 - 2) A cancer diagnosis disrupts continuity of relationships and requires change in future plans.
 - 3) Older adults have already experienced losses that may increase their fear of loss.
 - 4) The older caregiver is stressed by the physical demands of caregiving.
 - 5) Positive experiences of caregiving are reported to include an increase in self-esteem, the experience of competence, positive feedback from patients and other social partners, existential factors, and improved family relationships (Koop & Strang, 2003; Nijboer, Tempelaar, Sanderman, Triemstra, & van den Bos, 1998).
- ◆ *Caregiver interventions:* Interventions are not as well developed for families caring for members with cancer as they are for members with other diseases, such as dementia.

Interventions have been slower to be developed for families caring for members with cancer than for those caring for members with dementia, where the cognitive impairment creates disruptive behaviors and an obvious urgent and demanding role for caregivers. Another difference is that in families with cancer patients, changes in role and in daily activities start immediately after identification of the cancer, whereas changes in cognitively impaired patients develop gradually. Diagnostic procedures and treatments for cancer can be arduous and have multiple reactions and side effects. The predominant responses of relatives of cancer patients are reported to be anxiety and unassertiveness, depressive reactions, hopelessness, feelings of guilt and psychosomatic symptoms such as sleep disorder, gastrointestinal disorders, headache, and fatigue (Raveis, 2007).

Families are rarely included in the development of a care plan with cancer patients, and they are often given very little guidance, counseling or direction about what to do and the range of expectations. Emerging interventions are aimed at improving the direction and communication between the physician and other members of the interdisciplinary team through family conferencing (Rabow et al., 2004). Psychoeducation, coping skills training, and multidisciplinary interventions have

shown some effectiveness with families of older cancer patients with advanced illness. (Greenberg et al., 2006; McMillan et al., 2006; Rummans et al., 2008).

Social Work Role in Response to Biopsychosocial Needs: Screening and Assessment

- ◆ Psychological and social problems are accentuated in persons with cancer.

Older adults bring strengths of life experience and established coping patterns to the event of a cancer diagnosis. While social workers validate and build on these strengths, they must also recognize the special needs of older adults with cancer. They may require different kinds of help with understanding and processing the diagnosis and complex treatment options offered to them. Explaining the opportunities for remission and the risks of complications from the treatment itself can create difficult decision challenges. Age cohort and cultural differences complicate understanding of the situation. The functional level of elderly people may be impaired by the total burden of chronic conditions they have been living with in addition to a cancer illness. The treatments may be more difficult for their bodies to accommodate. Emotionally they may be exhausted by recent losses of family and peers and their own functional challenges. As a consequence the elder's social network is often strained and unable to provide the physical and emotional support they need for cancer treatment. The major caregiving challenges for families of older adults are described above.

Both psychological and social problems are accentuated with cancer because of the arduous treatment procedures used to achieve control or cure of the disease, including multiple surgeries, radiation, and a broad range of chemotherapies. These problems are also exacerbated by late effects of treatment and the long period of surveillance to detect recurrence or metastasis.

Psychosocial health needs vary by the type of cancer, the time since diagnosis, degree of functional and role impairment, the amount of pain and discomfort, and the prognosis. Physical stresses include degree of impairment and disability related to disease or treatment, fatigue, and pain. Psychological distress can include depression, anxiety, guilt, loss of control, anger, sadness, confusion, and fear. Patients may experience mood disturbances, fear of recurrence, and concerns about body image.

Relational concerns of patients include distress about the impact their illness is having on their family, their role changes within family relationships, and changes in sexual function and intimacy. They may have feelings of isolation, loneliness, and diminished self-esteem. Older adults are found to have special vulnerability to loss of self-esteem related to functional impairments and loss of autonomy. As noted previously their combined burden of chronic illnesses in addition to cancer may be quite high. Because of the rigorous treatments, side effects of treatments, fears of

recurrence, and constant monitoring, families and support networks can experience severe strain over time.

Patients also experience spiritual and existential concerns. While cancer in many situations can be managed as a chronic illness today, it is life-threatening and older adults may have experienced the deaths of other from this disease. Therefore, they confront fears of death and a dying process that includes uncomfortable symptoms and pain. They may ponder the meaning of their illness, their suffering, their relationship to God, and their possible death.

Socially patients are stressed by the arduous treatment procedures used to achieve control or cure of the disease. The long period of treatment and rehabilitation and continuing surveillance can also exhaust insurance and require significant out-of-pocket expenses. It may cause the loss of employment for patients or severely impede functioning and imperil family finances.

Obstacles to managing psychosocial stressors include lack of information, insufficient logistical resources, lack of transportation, strained social support, and inattention and lack of support from the health care system. Established approaches to informing and educating patients and caregivers may not be effective with older adults. Specifically they may not have access to internet resources of other cohorts, or be able to process information given in group format. Their understanding of the potential effectiveness of current treatments may be outdated and based on earlier life experiences.

Table 3 presents seven domains of biopsychosocial health needs assessed by social workers and the psychosocial health services social workers use to meet these needs for cancer patients and their families. The domains include:

- ◆ Understanding illness, treatments and services
- ◆ Coping with emotions surrounding the illness and treatment
- ◆ Managing illness and health
- ◆ Behavioral change to minimize disease impact
- ◆ Material and logistical resource needs
- ◆ Managing disruptions in work, school, and family life
- ◆ Financial assistance

Table 3. Biopsychosocial Health Needs of Older Cancer Patients and Services Needed

Needs	Health Services for Older Cancer Patients and Their Families
Information and education about illness, treatments, costs, health maintenance, and services available for patients and caregivers.	<ul style="list-style-type: none"> ▪ Provide continuous access to information and education about illness, treatments and their effects, costs, health, psychosocial and financial services. ▪ Provide decision support for patient and family who are considering options for treatment and care arrangements. ▪ Provide access to information about the impact of a cancer diagnosis in the context of pre-existing illnesses or health conditions.
Help in managing illness throughout its different phases.	<ul style="list-style-type: none"> ▪ Care coordination interventions to facilitate more appropriate delivery of services and assist with transitions in care. ▪ Comprehensive disease management and self-care programs. ▪ Interventions vary by type of cancer, phase of illness, time since diagnosis, degree of functional and role impairment, amount of pain, prognosis and available informal supports. ▪ Navigator programs to facilitate access by underserved populations.
Help in coping with emotions accompanying illness and treatment.	<ul style="list-style-type: none"> ▪ Community/peer support programs. ▪ Coaching/supportive counseling for patient and family. ▪ Pharmacological treatment for depression/anxiety coupled with psychotherapy. ▪ Pain and coping skills training for pain and discomfort.
Assistance changing behaviors to minimize impact of disease and manage side effects and late effects of treatments.	<ul style="list-style-type: none"> ▪ Health promotion interventions such as: <ul style="list-style-type: none"> Assessment/monitoring of key health behaviors such as diet, smoking, exercise Medication counseling Patient education on cancer related health risks, risk reduction interventions.
Material and logistical resources such as transportation, home care.	<ul style="list-style-type: none"> ▪ Provision of community and financial resources. ▪ Provide home care information for family caregivers. ▪ Help to provide and manage high tech care in the home.
Help in managing disruptions in work, activities, family life, and social network. Prepare for care transitions due to disease progression.	<ul style="list-style-type: none"> ▪ Ongoing Family/caregiver education and counseling. ▪ Assistance with activities of daily living (ADLs), and instrumental activities/chores (IADLS). ▪ Legal protections and services. ▪ Promote social network development and maintenance over time.
Financial advice and/or assistance. Managing and maintaining health insurance over time.	<ul style="list-style-type: none"> ▪ Assist with financial planning/counseling including management of bill paying. ▪ Insurance (e.g., health, disability) counseling/advocacy. ▪ Eligibility assessment for other benefits (SSI and SSDI). ▪ Supplemental financial grants. ▪ Ongoing assistance with major out of pocket expenses.

Source: Adapted from Institute of Medicine, (2007a) Cancer care for the whole patient: Meeting Psychosocial health needs p.68.

Social Work Role in Coordinated Care

- ◆ Services used to address biopsychosocial health needs include individual and group approaches as well as complex models of service delivery and coordinated care.

Fewer coordinated care approaches have been evaluated with cancer patients than with other diseases, and even fewer have focused explicitly on older adults with cancer. Until recently many questioned whether cancer patients' behaviors could have any impact on the progression of their illness. A recent IOM report challenged that assumption and recommended that more patient self-management approaches be used to lengthen and improve the quality of life of cancer patients as they are helped to access information and services in a more timely and effective way (IOM, 2007a). Care coordination approaches with some evidence base with cancer patients have included improving interdisciplinary communication; screening to identify patients with high distress and unmet needs; implementing case management, on-site collocation, and clinical integration of services (e.g., mental health and primary care); developing a broad range of information and education approaches that link patients with available services and teach problem-solving skills. After reviewing the evidence base for these models for cancer patients, the authors of the IOM consensus report adopted the following standard of care that they believed was warranted by the majority of study findings.

“All cancer care should ensure the provision of appropriate psychosocial health services by:

- ◆ Facilitating effective communication between patients and care providers.
- ◆ Identifying each patient's psychosocial health needs.
- ◆ Designing and implementing a plan that:
 - Links the patient with needed psychosocial services.
 - Coordinates biomedical and psychosocial care.
 - Engages and supports patients in managing their illness and health.
- ◆ Systematically following up on, reevaluating, and adjusting plans.”
(IOM, 2007a)

Psychosocial screening and patient navigator programs are two elements of care coordination that have particular importance to the social work role, although social work is involved in implementing almost all care models with this patient population. These programs present excellent opportunities for social workers to demonstrate their knowledge and skill base in assessment, communication, and problem solving in order to improve patient/family satisfaction, quality, and quantity of life within larger health

care systems. An example presented here is a model that is currently supported for study by both the National Cancer Institute and the American Cancer Society.

Psychosocial Screening

- ◆ A broad range of screening approaches to identify unmet psychosocial service needs have been described in the literature. Few, however, have been studied in clinical trials.

The available instruments cover a broad range of needs in multiple domains. More research is recommended to clarify reliable and valid measures with minimal patient/family burden (IOM, 2007a). No guidance currently exists to clarify which tools should be used for different types of patients seen in various clinical settings. Psychosocial screening instruments must address a broad range of problems patients encounter, beyond assessing for depression and anxiety (Wen & Gustafson, 2004). For example, one such approach recommended by National Comprehensive Centers Network (NCCN) and reported to be used by three cancer centers, includes both a distress thermometer and a problem list. The distress thermometer is a visual analogue scale displayed on a picture of a thermometer and used to screen for any type of psychological distress. Individuals are instructed to circle the number (from zero [no distress] to 10 [extreme distress]) that best describes their experience over the past week (NCCN, 2006). This assessment takes the patient less than a minute and the results are concordant with other more extensive and time consuming measures of psychological distress: e.g., the Brief Symptom Inventory (BSI) and the Hospital Anxiety and Depression Scale (HADS) (Jacobsen et al., 2005; Zabora, 1998). In guidelines issued by the NCCN, a 35-item Problem List provided on the same page as the thermometer covers a range of psychosocial problems (e.g., financial, emotional, work-related, spiritual, family, physical symptoms). The list does not include inquiries about behaviors that could interfere with illness management education such as smoking, alcohol or drug use, exercise, diet, or cognitive problems. Three cancer centers report having used this approach (Jacobsen & Ransom, 2007).

Care/System Navigators

- ◆ Use of care/system navigators, as well as individual patient advocates, is similar to case management and may also help link patients to needed psychosocial services.

These programs in cancer care were developed initially to help low-income patients participate in screening for the detection of cancer and to obtain diagnostic and treatment services when indicated. The concept and implementation of such programs has developed over the past decade (IOM, 2007a).

Initially, patient navigators were local community residents without professional credentials, but more recently nurses and social workers have filled the navigator role because of the complexity of cancer treatment approaches. Some of these programs include patient education and patient advocacy roles in addition to helping patients overcome barriers to receiving effective services (Dohan & Schrag, 2005).

Evidence to date for the effectiveness of patient navigator programs has documented their ability to accrue more patients for cancer screening. One of the few randomized trials of this type of program (Jandorf, Gutierrez, Lopez, Christie, & Itzkowitz, 2005) found that patient navigators increased the prevalence of screening for colorectal cancer. Other studies suggest that such programs increase screening rates and may increase the proportion of patients detected with early-stage disease (Dohan & Schrag, 2005). Patient navigators are found to increase patients' ability to overcome logistic and attitudinal barriers to obtaining screening. Their role in helping patients after diagnosis is less clear. A recent randomized trial evaluating the impact of a patient navigation program on follow-through with diagnosis among women with abnormal mammograms found that the intervention significantly increased the percentage of women achieving diagnostic resolution (Ell, Vourlekis, Lee, & Bin, 2007).

These programs appear to aid in engaging low-income patients to participate in cancer screening and diagnosis. Studies of their broader application in linking a diverse population to appropriate cancer services are currently receiving considerable research support. How they differ from more traditional case management functions remains uncertain. The American Cancer Society (ACS) and NCI have both launched major initiatives to implement and evaluate patient navigator programs. The ACS program places trained ACS staff in selected health care facilities to provide patients and families with personalized and reliable information about the disease, referral to ACS resources, and timely follow-up. NCI has launched a Patient Navigation Research Program to develop interventions to reduce the time required for delivery of the standard of care services in cancer diagnosis, and treatment after an abnormal finding. Patient navigators in this program will help patients and their families throughout the period of care by, for example, arranging various forms of financial support, scheduling transportation to appointments, and organizing child care during appointments. NCI and ACS are working together to develop evaluations of these programs.

Critique and Future Directions of System Responses to Cancer Patients' Psychosocial Needs

- ◆ A critique of the health systems response to cancer patients' psychosocial needs must include a call to action.

Defining action steps: Action steps from a recent IOM (year 2007a) consensus panel are listed under resources in the 10-point action plan noted below. The participants, including several social workers, expressed frustration with the lack of implementation

of previous reports and recommendations for integrating psychosocial and medical services that would improve quality of life of patient and family survivors of this complex disease and treatment process. Although people are able to live longer with this often chronic disease and in some situations are cured, they are struggling to cope with the challenges of later cancers, later affects of the treatments, and a health care system that is fragmented and often unresponsive to their human needs. The consensus panel report recommended a new standard for cancer care, a standard that incorporates acknowledgement, treatment, and management of psychosocial (social work) problems.

They identified a range of psychosocial needs of cancer patients from information about their therapies and the potential physical side effects, to treatment for depression, stress, or other mental and emotional conditions; assistance with daily activities that they can no longer perform independently; and assistance with transportation, prosthetics, medications, and other supplies they cannot afford or to which they do not have ready access. These specific needs encompassed seven domains of psychosocial need as presented above in Table 3.

Psychosocial health services are defined as “psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health” (p.6). The panel found that while cancer therapies save and prolong many lives, they and the tumors they target can exact a debilitating toll on patients’ mental and emotional well being and cause health problems that are not dealt with during oncology treatment.

Neglect of psychosocial services: Issues and evidence of system neglect of psychosocial services included the following:

- ▶ Twenty-eight percent of families affected by cancer say their doctors paid no attention to factors beyond direct medical care.
- ▶ A third of oncologists say they do not screen patients for psychological distress—and those who do often use unreliable methods.
- ▶ Only 3 of the world’s 20 leading cancer centers routinely screen all patients for psychological and social distress.
- ▶ Many of the recommendations that have been made over the years calling for more attention to the psychosocial concerns of cancer patients and their families have not been acted upon.
- ▶ Both cancer survivors and their caregivers report that their providers failed to understand their psychosocial needs and to recognize and adequately address depression and other symptoms of stress.
- ▶ Their providers also appeared to be unaware of available resources that could offer support; at least they did not make any referrals.

- ▶ Providers generally did not consider psychosocial support to be an integral part of quality care for the oncology patient.

Other barriers to addressing psychosocial care needs included the following:

- ▶ Insurance issues and other financial barriers
- ▶ Lack of awareness of community resources
- ▶ Social stigma associated with mental illness
- ▶ Inadequate psychosocial screening and assessment tools
- ▶ Limited access to psychosocial services
- ▶ Education and training of the health care workforce
- ▶ Shortages and misdistributions of health personnel
- ▶ Nature of the payment environment for providers

Future of Cancer Care: A Ten-Point Plan to Achieve Higher Care Standards

The IOM panel (2007a) participants developed a ten-point plan for how to achieve a higher standard of care:

- 1) Standard care should include a plan to link patients with psychosocial services, coordinate medical and psychosocial care, support patients in managing their illness, and conduct follow-up evaluations of patients to ensure that the plan is working.
- 2) Cancer doctors should make sure every one of their patients receives psychosocial care.
- 3) Patient education and advocacy groups should educate patients and families about the kinds of psychosocial care they should expect.
- 4) The NCI, the CMS, and the AHRQ should conduct large-scale demonstrations and evaluations of model psychosocial care programs.
- 5) Insurers – including Medicare/Medicaid – should “fully support” psychosocial health services.
- 6) NCI, CMS, and AHRQ should fund research on how best to evaluate psychosocial cancer care.
- 7) Medical groups, including licensing and accreditation boards, should require providers to be competent in delivering psychosocial health care.
- 8) The National Institutes of Health (NIH) should develop a standard language for describing psychosocial interventions in order to promote research and quality measurement.

- 9) Organizations funding cancer research should promote studies of how to improve psychosocial health care.
- 10) The NCI should make regular reports on progress in delivering psychosocial care to cancer patients.

Summary

Due to medical advances over the last four decades cancer has become a chronic, though still life threatening, illness for many individuals including older adults. While previously cancer often went untreated in elders since it was believed they would die of other conditions before their cancer advanced to end-stage, that is no longer a valid assumption according to mortality statistics. The social work role and function in cancer has therefore expanded and changed from helping people dealing with dying from their disease to a greater emphasis on helping individuals get appropriate treatment and live with a disease that in many situations can be controlled if not cured. The treatment of cancer in older adults is complex because of co-existing illnesses and conditions, the nature of the treatment, and individual frailty. There is also insufficient research on cancer treatment in older adults that can guide treatment decisions and predict outcomes. Older patient and family needs are often psychosocial in nature, requiring effective care coordination and supportive interventions to maintain an acceptable quality of life. As a consequence, there is a newly recognized need for the development of comprehensive disease management programs for older adults with cancer. Providers acknowledge that they have been slow to incorporate these approaches within the cancer protocols of treatment centers and hospitals. Social workers by virtue of their professional training and expertise are well positioned to use the findings from needs assessment and interventions with older adults to take leadership in developing social work care coordination models that can address the biopsychosocial needs of patients more fully. Specific ways social workers can address some of these needs include the following:

- 1) Be alert to and participate in the development of approaches such as Patient or Care Navigator programs, and advocate for their development in tandem with social work intervention strategies for coordination of care in health facilities and in nontraditional settings that may connect with underserved populations (e.g., churches, community centers, and libraries).
- 2) Develop better methods of screening for distress and unmet psychosocial needs of older adult cancer patients and their families including assessment of functional impairment, pain, depression and anxiety, and caregiver burden. This information may help to meet the new standard of care for psychosocial services to identify each individual's psychosocial health needs.

It may also contribute to the development of comprehensive care coordination programs.

- 3) Provide outreach to patients and families during transitions in care, as important psychosocial follow-up points to assure adaptation to the next illness phase. This would facilitate meeting the new standard of care for systematically following up on, reevaluating, and adjusting plans.
- 4) Identify barriers and impediments to education of older adults around the disease and its treatment. Facilitate the development of effective patient and family education and the availability of psychosocial support services within the institution and the community.
- 5) Assist with patient and family communication with the medical team around treatment and goals of care, facilitating a better understanding of the needs of older adults, including their religious, cultural, and cohort specific values and preferences. This addresses the new standard of care to coordinate biomedical and psychosocial care.

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- Zabora, J. (1998). Screening procedures for psychosocial distress. In J. Holland (Ed.), *Psycho-oncology* (pp. 653-661). New York: Oxford University Press.

Curriculum Resources



Suggested Readings:

- Loscalzo, M., & Brintzenhofeszoc, K. (1998). Brief crisis counseling. In J. Holland (Ed.), *Psycho-oncology* (pp. 662-675). New York: Oxford University Press.

This chapter presents the impact of cancer along the disease continuum of care for the patient. It is an excellent teaching tool for helping students to conceptualize how crises may differ at different points in the illness trajectory. The table containing a description of the meaning of these crises for the patient and for the family is particularly useful.

- Maramaldi, P., & Lee, J. (2006). Older adults with cancer. In B. Berkman (Ed.), *Handbook of social work in health and aging* (pp. 7-18). New York: Oxford University Press.

This chapter provides an overview of the most common cancers in older adults, their treatment, prognoses, and functional challenges for both the patient and the caregiver. It highlights the fact that older adults bear a disproportionate cancer burden in the U.S. Importantly the authors also outline the social work role in providing effective intervention.

- Yancik, R., Wesley, M., & Ries, L. (2001). Effect of age and comorbidity in postmenopausal breast cancer patients aged 55 years and older. *Journal of the American Medical Association*, 285(7), 885-892.

Because two thirds of all newly diagnosed female breast cancer patients are postmenopausal or over 55 years of age, it is an important cancer for health social workers to be informed about when they are involved with this age group. In fact the peak incidence occurs in women over the age of 70 years. The author uses cancer to illustrate how a chronic disease in older adults is often complicated by co-morbid conditions; limiting diagnostic tests and examinations and narrowing treatment choices for the “index” illness. The number and severity of co-morbid conditions increases over time and includes those such as hypertension, arthritis, high severity heart disease, previous malignancy, stroke/TIA, diabetes, and COPD. The authors advocate that aging and co-morbidity be incorporated into the mainstream of breast cancer clinical research and clinical trials in order to evaluate cancer treatment options for older women and develop more appropriate and evidence-based criteria for breast treatment decisions in this population.

- Raveis, V. (2007). The challenges and issues confronting family caregivers to elderly cancer patients. In S. Carmel, C. Morse, & F. Torres-Gil (Eds.), *Lessons on aging from three nations, Volume II: The art of caring for older adults* (pp. 85-97). Amityville, NY: Baywood Publishing.

This article is a comprehensive and evidence-based review of the many stresses on older caregivers of cancer patients. In great detail and with helpful examples and illustrations the author discusses the complex psychosocial challenges caregivers confront at diagnosis and

treatment and during survivorship. She thoroughly reviews the high costs of cancer caregiving including "...restrictions on occupational, social, and leisure activities; a loss of privacy; financial burdens; conflicts with well family members; physical strain; and chronic fatigue" (p. ?) that often result in adverse psychological and physical conditions. She also thoroughly explores the impact of the life stage on the caregiver including the spouse, but also older daughters. She joins the chorus of voices urging greater research and programmatic attention to understanding the multiple interconnected issues families encounter while caring for an elderly relative with cancer. Her detailed description of the factors affecting their experience provides a clear understanding of just how challenging it is to develop effective interventions.

- Kotkamp-Mothes, N., Slawinsky, D., Hindermann, S., & Strauss, B. (2005). Coping and psychological well being in families of elderly cancer patients. *Oncology Hematology, 55*, 213-229.

This article presents a thorough review of research findings and suggests directions for future studies on elderly cancer patients and the consequences of their disease for their partners and families. The authors are from Germany and extend their review to studies conducted in Europe, North America, and other continents. and European studies. Studies are reviewed as they relate to five different areas of family functioning: 1) the family and the etiology of the disease, 2) the family as a source of support, 3) the family as a second order patient, since family members are often more psychologically stressed than the patient, 4) cancer as a challenge for the family, and 5) intervention approaches and models to reduce family stress.

The review identifies some consistent findings across studies:

- the importance of social support, which can act as a buffer in diminishing the negative aspects of the disease for the patient
- the influence of negative support and conflict in the support system and the different coping preferences of older adults (religiosity, cognitive strategies, and optimism) compared to younger adults(problem-solving)
- the physical and psychological impairments of older adult caregivers
- the complex dynamics of the disease process and the way it impacts family
- the evidence of effectiveness of educational and support interventions.

The authors advocate for more longitudinal research studies with homogenous populations that could identify specific needs and burdens for different caregiving groups.

- Surbone, A., Kagawa-Singer, M., Terret, C., & Baider, L. (2007). The illness trajectory of elderly cancer patients across cultures: SIOG position paper. *Annals of Oncology, 18*, 633-638.

The authors review the "scanty" literature on the care of older cancer patients and explore the question of why they are less likely than younger patients to receive optimal medical, psychological, and spiritual treatment. Also, using literature from their research in medical oncology and their knowledge from anthropology and bioethics, the authors advocate for a broader understanding of the psychological and cultural factors contributing to the illness trajectory of elderly cancer patients. They raise questions about the social and existential meaning of cancer to older adults shaped by the strengths and experience they bring to this phase of their lives. Older patients confront ethical questions from society and professionals

about the appropriate use of health care resources for the elderly. These concerns may also influence how professionals treat them and the health options they give them. The authors encourage consideration of the roles of older adults through their life experiences as they are shaped by gender and their support networks, and how these roles are impacted by the disease. For example, the loss of interpersonal support from a partner of many decades may be particularly stressful to an older caregiver. How do older adults cope with cancer, how do they attain a sense of mastery and self-efficacy? How does culture shape their identity and view of the world, and how does culture interact with generational and cohort differences?

While older adults may approach illness and death with equanimity and acceptance as a natural course without social disengagement, the tendency in more industrialized countries is to devalue the elderly, creating experiences of social isolation and abandonment. This often occurs during episodes of serious illness. The goal of this literature review and analysis is to encourage research and practice that goes beyond a focus on physiological and psychological changes of aging and the pathophysiology of cancer in the elderly and to encourage study of the social and cultural aspects of aging that will promote more culturally competent care across the illness trajectory.



Case Study

Source: Les Gallo-Silver, MSW

Program Director

Associate Professor

Human Services Program

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Mr. Chu, a 67-year-old man born in China, emigrated to the United States 40 years ago. While fluent in English (although with a heavy accent) he is most comfortable speaking Cantonese. He has been married to his wife for 35 years, having met her in the U.S. Mrs. Chu, who is 12 years younger than her husband, is not fluent in English. They have three children, all now adults living out of the home: two married daughters ages 36 and 37, and an unmarried son age 28. Until recently Mr. Chu worked as a jeweler repairing jewelry and watches in a shop owned by his cousin. He presented with a profound loss of weight, coughing and having difficulty swallowing. Through an out-patient medical work-up, he was diagnosed with esophageal cancer. The social worker met the family on the medical visits at which the diagnosis and treatment were discussed. Their older daughter, a lawyer (recently a stay-at-home mother with her third child), acted as a translator and interpreter for her family. Mr. Chu refused the services of a hospital translator. The daughter and Mrs. Chu did not want the doctor to use the word cancer but agreed to the use of the word tumor. They family feared Mr. Chu would give up and die quickly if told he had cancer. The social worker explored this with the wife and daughter to gain an understanding of how the Chinese community copes with a diagnosis of cancer. The social worker also explored the family's previous experiences with cancer. Mrs. Chu indicated that her father died of lung cancer and that Mr. Chu's mother died of stomach cancer. Both died soon after their diagnosis but were treated with chemotherapy that made them very ill. Both were admitted to hospitals and neither was ever

discharged. Both died in a hospital. Mr. Chu's mother was treated in China; Mrs. Chu's father was treated in the U.S.

The health care team agreed to refer to Mr. Chu's illness as a tumor in his esophagus, but they indicated to the family that they were obligated to answer all of Mr. Chu's questions honestly and clearly. The social worker discussed with the health care team the cultural issues involved, the family history, and the family's concern about Mr. Chu giving up hope.

When Mr. Chu received his diagnosis, he seemed to understand he had cancer even though the word was not specifically used. Mr. Chu indicated he would refuse treatment and go home to die. He ordered his daughter to inform the immediate and extended family so they could visit him to say good-bye. His wife began to cry, and his daughter engaged Mr. Chu in what seemed to be a heated discussion. The health care team left the family with the social worker to sort through the information given and to assist Mr. Chu in planning and decision-making.

The social worker empathized with the daughter and in English she discussed her fears and anger about her father's refusal of treatment. It seemed that her mother agreed with Mr. Chu that there was no hope for him. In the family meeting, the social worker validated Mr. Chu's right not to seek treatment but indicated that it was important for Mr. Chu and his family to understand exactly what he was refusing. What ensued was a review of the patient education materials provided to Mr. Chu by the nurse on the health care team. During this intervention the social worker was able to help the family explore their fears as a unit but also evaluate the treatment outlined. In addition the social worker was able to point out the contrast between Mr. Chu's current situation and those of close family members regarding different types of cancer, different types of cancer treatment, and different ways of managing side effects. Mr. Chu agreed not to make a final decision until he spoke with his son and asked the social worker to meet with the son as well. The social worker reminded Mr. Chu that the doctor's were concerned about him and needed him to make a decision. The social worker was able to open up the dialogue about treatment without negating Mr. Chu's initial feelings. The social worker had Mr. Chu sign a HIPPA release form indicating who in the family the health care team could discuss his medical condition with.

Mr. Chu's son was a financial manager who indicated that he was not fluent in Cantonese like his sisters. He indicated his parents were upset that he moved out of the house before getting married. He was not surprised about his father's decision against treatment indicating that his father is very old fashioned and traditional. This was also an issue of contention between father and son, and they frequently argued about the son not following the father's ways and traditions. The social worker commented that it was interesting that Mr. Chu chose his son to help him. The social worker indicated that his father was making his decision based on his understanding of cancer and cancer treatment yet asks his son who is labeled as "too modern" to help him in this situation. The social worker wondered if Mr. Chu was still open to being treated if the information gathered by the son allayed his concerns.

The son then met with the nurse clinician, who reviewed the treatment protocol, which included chemotherapy, radiation, and ultimately surgery if the tumor size is reduced by the treatments. The social worker suggested that the son discuss all of this with his father and emphasize that this was a step-by-step process in which Mr. Chu could decide not to have further treatment at any point. It was agreed that the son would accompany his father to the next appointment with the doctor to review all of this and to determine what Mr. Chu would or would not accept as a next step. At this meeting, Mr. Chu agreed to begin the chemotherapy. He asked very specific questions about his prognosis, which the doctor answered. The son was far less uncomfortable about this information being discussed openly

than his mother or sister had been. The social worker pointed out that perhaps Mr. Chu had him involved in this process because he was more comfortable with what his father would describe as a "modern" discussion about cancer.

Mr. Chu struggled through his chemotherapy treatment and was challenged by side effects. The social worker remained involved and helped Mr. Chu find a comfortable way to ask for help from the health care team for his treatment side effects. Mr. Chu believed that making "a request" of the health care team was at best rude and at worst a challenge to their authority. The social worker helped Mr. Chu find the words he was comfortable using to ask questions which entailed reassuring Mr. Chu that the health care team was aware of his respect for them and his feelings of gratitude. The social worker met with the team to address these communication issues and how to reassure Mr. Chu that he was not being inappropriate.

The discussion of having a feeding tube placed in anticipation of the side effects of the radiation portion of Mr. Chu's treatment protocol was very distressing for the family and for him. Cooking and preparing food for Mr. Chu was a primary function for his wife that she felt was her contribution to helping Mr. Chu. Again, through the use of Mr. Chu's son, discussions were able to focus on this as a temporary measure. Other important roles for Mrs. Chu were identified, validated, and encouraged.

Recovery from the surgical removal of the tumor and a part of Mr. Chu's esophagus was complicated by issues of pain and pain management. Mr. Chu associated pain medication as an indication that the treatment did not work and that he was dying. His mother was given morphine to ease her pain before she died. The pain nurse explained the different medications and how they help the body recover by alleviating pain. The social worker suggested that Mr. Chu keep a diary to indicate how he felt when he was on pain medication, how he felt before taking it, and what he was doing during these times. Mr. Chu determined from his own diary that he felt better and more lively on the pain medication. The social worker pointed out how this did not match his fears that pain medication meant he was dying. He also determined that he could distract himself from his feelings of pain because he felt better when he saw or spoke to his grandchildren and could concentrate on brief games of Mahjong. Mr. Chu continued to have pain issues weeks after the surgery but was willing to use pain medication to obtain relief.

Mr. Chu continued to recover slowly and to adjust to the changes caused by his surgery. This had particular impact on eating and meals. Mrs. Chu "experimented" with what foods were comfortable for Mr. Chu to eat and digest. She now had to prepare frequent small meals, which she liked because she "could do more" for her husband. Mr. Chu is aware that his tumor could come back but has been able to enjoy his survivorship through being with family and friends.

Discussion questions:

- 1) Using Table 3, the biopsychosocial health needs and services required to address them, answer the following questions regarding this case:
Of the seven assessment areas outlined in Table 3, what information do you have for each?
Which of the seven areas were most prominent in the assessment and development of a treatment plan for the short term and for the long term with this family?
- 2) How was the family history of illness relevant to assessment of the family's understanding of the current illness?
- 3) How did the family's culture influence their decision-making process? How important was the son's, as contrasted to the wife's and the daughters', involvement

- in the father's decision-making process? What interventions did the social worker use to integrate the family's culture in the decision-making process?
- 4) What strengths does this family's culture evidence for adaptation to a cancer illness?
 - 5) What are the vulnerabilities of their cultural approach to adaptation to chronic or advanced cancer illness? What interventions might help them prepare for future adversities?
 - 6) Describe the various methods of education and information provided throughout the illness process.
 - 7) What was the social worker's role in providing emotional support to this family?
 - 8) Discuss other cases that present these types of issues of communication in your own practice setting and the intervention approaches that were used.

Care/patient navigation programs are care coordination approaches currently recommended for vulnerable populations of cancer patients.

- 1) How might such a program, implemented by a social worker, be developed to provide education and advocacy, link services, and reduce barriers to treatment and recovery for this older Asian patient and his family?
- 2) How might a patient/care navigation program be used with this family or others from this or a different cultural background?
- 3) Include longer term follow-up plans as well as psychosocial screening to identify vulnerable clients and to link services, education, and advocacy functions.



Web Resources

- ◆ **American Cancer Society (ACS):** www.cancer.org

ACS is a nationwide voluntary health organization that provides cancer resources for patients, families, and professionals on-line and in the community.

- ◆ **Association of Oncology Social Work (AOSW):** www.aosw.org

The AOSW is a non-profit, international organization dedicated to the enhancement of psychosocial services to people with cancer and their families. Created in 1984 by social workers interested in oncology and by existing national cancer organizations, AOSW is an expanding force of psychosocial oncology professionals. Educational resources for patients, families, and professionals are included in the Web site.

- ◆ **CancerCare:** www.cancercare.org

CancerCare is a nonprofit organization that provides free professional education and support services on-line and by telephone for anyone affected by cancer. Their booklets and PowerPoints for patients and families cover a broad range of topics and are instructive to professionals as well. They also provide workshops and educational teleconferences for professionals on different types of cancer, treatment, and a broad range of psychosocial aspects.

◆ **Susan G. Komen for the Cure:** www.komen.org

Komen, a grassroots network of survivors and activists, provides on-line information and resources for breast cancer survivors.

◆ **The Wellness Community (TWC):** www.thewellnesscommunity.org

TWC provides support groups, activities, and other resources on-line and in their many community sites.

◆ **Gilda's Club:** www.gildasclub.org

This nonprofit organization provides free meeting places nationwide where men, women, and children living with cancer, along with their families and friends, can join with others to build a personal network of social and emotional support as an integral part of cancer treatment. Gilda's Clubs offer support and networking groups, seminars, workshops, specialized children's programs, and social events in a nonresidential and home-like setting.

◆ **Nueva Vida:** <http://www.nueva-vida.org>

Nueva Vida's mission is to inform, support, and empower Latinas whose lives are affected by cancer.

◆ **National Cancer Institute Office of Cancer Survivorship (OCS):**
<http://cancercontrol.cancer.gov/ocs/>

OCS provides current information on survivorship research, resources, and publications.