

REPORT ON
Cancer & Aging

THE NEW JERSEY TASK
FORCE ON CANCER
AND AGING

TO

THE NEW JERSEY
COMMISSION ON
CANCER RESEARCH

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EXECUTIVE SUMMARY

The United States and the State of New Jersey face a rapidly aging population that will challenge existing health care resources within 25 years. Older adults are more physically and financially vulnerable than the general population and they may have limited access to medical care because of health, social or income restrictions. It has been clearly documented that aging increases the risk for cancer; consequently it is anticipated that cancer rates will experience a significant increase.¹ Additional diseases (co-morbidities) are also more common in older adults and exacerbate the complexity of meeting healthcare and financial needs. Moreover, there is evidence of inconsistency in cancer screening recommendations and the quality of cancer treatment for older adults.

The aging population in New Jersey provides unique challenges to cancer prevention, detection and treatment. New Jersey has a more diverse and complex population distribution than many other states; consequently the burden to the State is likely to create a more substantial crisis than in the rest of the nation. Many compelling issues must be addressed to reduce the escalating personal and financial burdens of cancer incidence and mortality in the State. More than 60% of all cancer diagnoses are made in people over age 65; more than 70% of all cancer deaths occur in this population. Overall incidence for cancer among older adults in New Jersey is slightly higher than national averages.

According to the 2000 Census, the State of New Jersey had more than 1.1 million residents (13.2% of the population) over the age of 65 years. As life expectancy increases, projections for future growth estimate that nearly 20% of the state's population will reach that milestone by 2030. Some critical points to consider include:

- Cancer survival is lower overall for older adults when compared to all other groups.
- While cancer death rates have been decreasing over time in younger people, they have remained level among older adults.
- Despite considerable documentation of the problem, little is known about the exact relationship between cancer and aging. Initial basic research points to a direct connection between the aging process and cancer development. It is important that these studies be expanded to provide an understanding of the specific mechanisms that cause cancer, and increase it's propensity in older people.
- An understanding of the physiologic, immunologic, pharmacologic and psychosocial differences between older adults and younger persons with cancer is also essential to provide comprehensive, coordinated and effective cancer and geriatric care.
- Few medical practitioners are well trained or educated about the specific problems of the older adult with cancer. The need for well prepared geriatric oncology specialists will become even more critical.
- As a general observation, older adults are less likely to be screened for breast, colon, and skin cancers, and are more likely to receive incomplete diagnostic work ups.
- More aggressive medical interventions are often not offered to older patients and their pain and other cancer related symptoms may not be treated appropriately.
- Older adults are less likely to be referred to cancer centers or oncology specialists and their participation in clinical trials is low.²
- Fragmentation of care can be especially detrimental to the older cancer patient. Extensive coordination among primary care providers and oncology specialists will be required to deliver comprehensive care.

1 Day JC. US Bureau of the Census. 1996 Population projections of the united states by age, sex, race, and hispanic origin: 1995 to 2050. *Current Population Reports*, P25-1130. Washington, DC: Bureau of the Census; 1996.

2 Lewis JH, Kilgore ML, Goldman DP, et al. Participation of patients 65 years of age or older in cancer clinical trials *Journal of Clinical Oncology* 2003;21(7):11382-1389.

- While other existing medical conditions (co-morbidities) can render cancer treatment more complex and are more common in those over 65 years, some older individuals may be less able to care for themselves, understand the options available, or comply with the demands of treatments completely.
- Complex psychosocial and cognitive issues as well as lack of family support may make decision-making, care-giving and support services more difficult, and the need for comprehensive services more compelling.
- The State will experience a dramatic expansion of the need for supportive care services including referral services, home care, transportation, respite care, palliative care and hospice for older patients with cancer.

The New Jersey Commission on Cancer Research (NJCCR) Task Force on Cancer and Aging was convened to address the major public health concern related to cancer prevention, detection and care for individuals over age 65, and to raise awareness of the challenge to public health that this issue presents. Many compelling issues must be addressed in our aging population to reduce the escalating personal and financial burdens of cancer in the State. This report provides information, recommendations and the urgent call to key policy makers and stakeholders in New Jersey to take the necessary steps today to avert a crisis in the future. A substantial infusion of robust new resources, coordination and leadership will be required to meet these dramatically escalating needs.

SUMMARY OF RECOMMENDATIONS

The Cancer and Aging Task Force proposes that the State of New Jersey take the lead in creating initiatives to:

- I. Stimulate Geriatric Oncology research throughout New Jersey.**
- II. Intensify statewide planning to deal with the growing burden of cancer resulting from the aging of the population.**
- III. Expand educational opportunities in geriatric oncology for all health providers.**
- IV. Increase supportive care services for older adults with cancer.**

New Jersey can become a national model for bold and innovative approaches to cancer prevention, detection and care for the older adult through the collaboration of State agencies and departments, statewide research, education and training institutions, medical providers, the legislature, social service agencies, and the citizens of New Jersey. The Task Force urges that these groups become the driving force to accomplish these goals.

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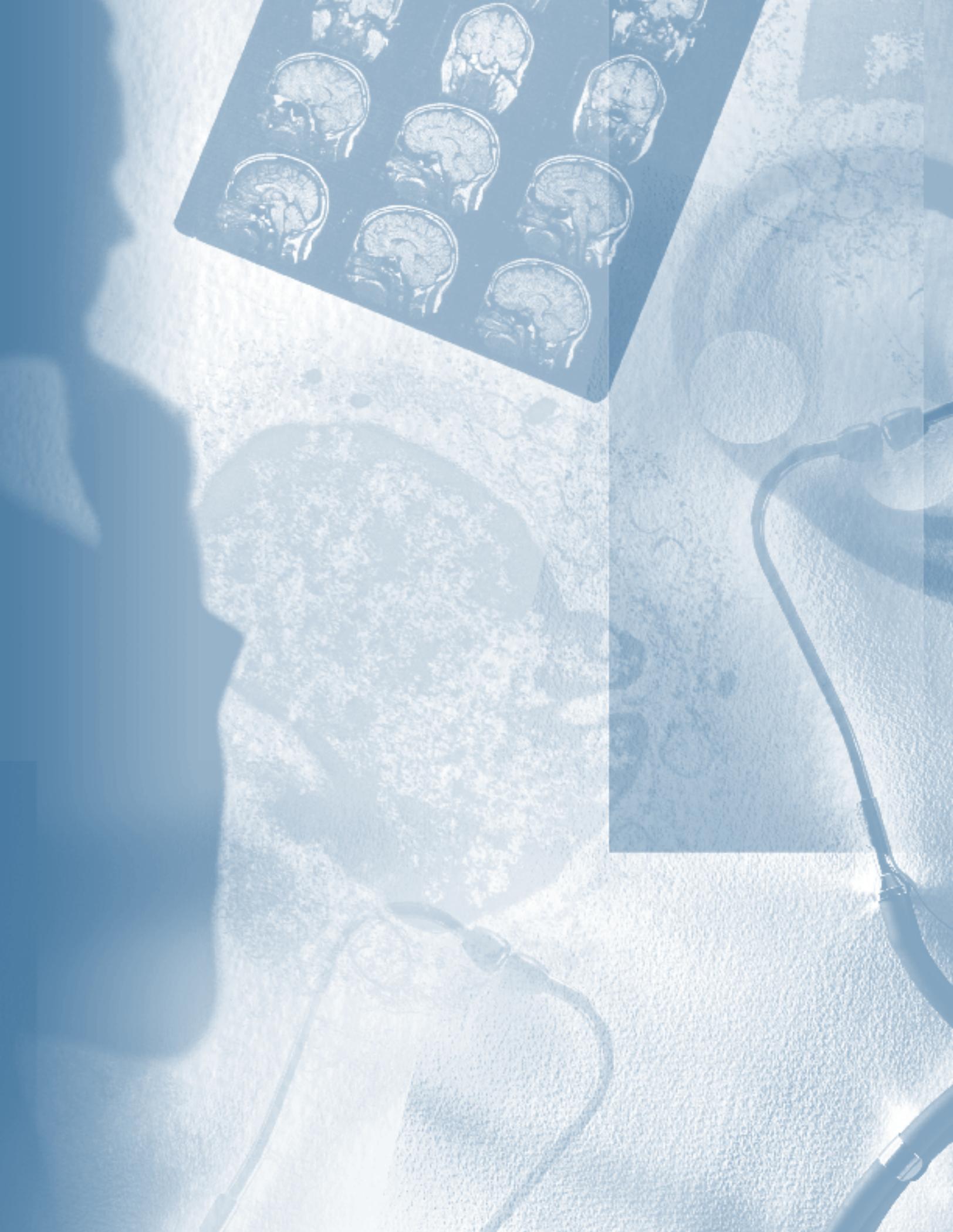
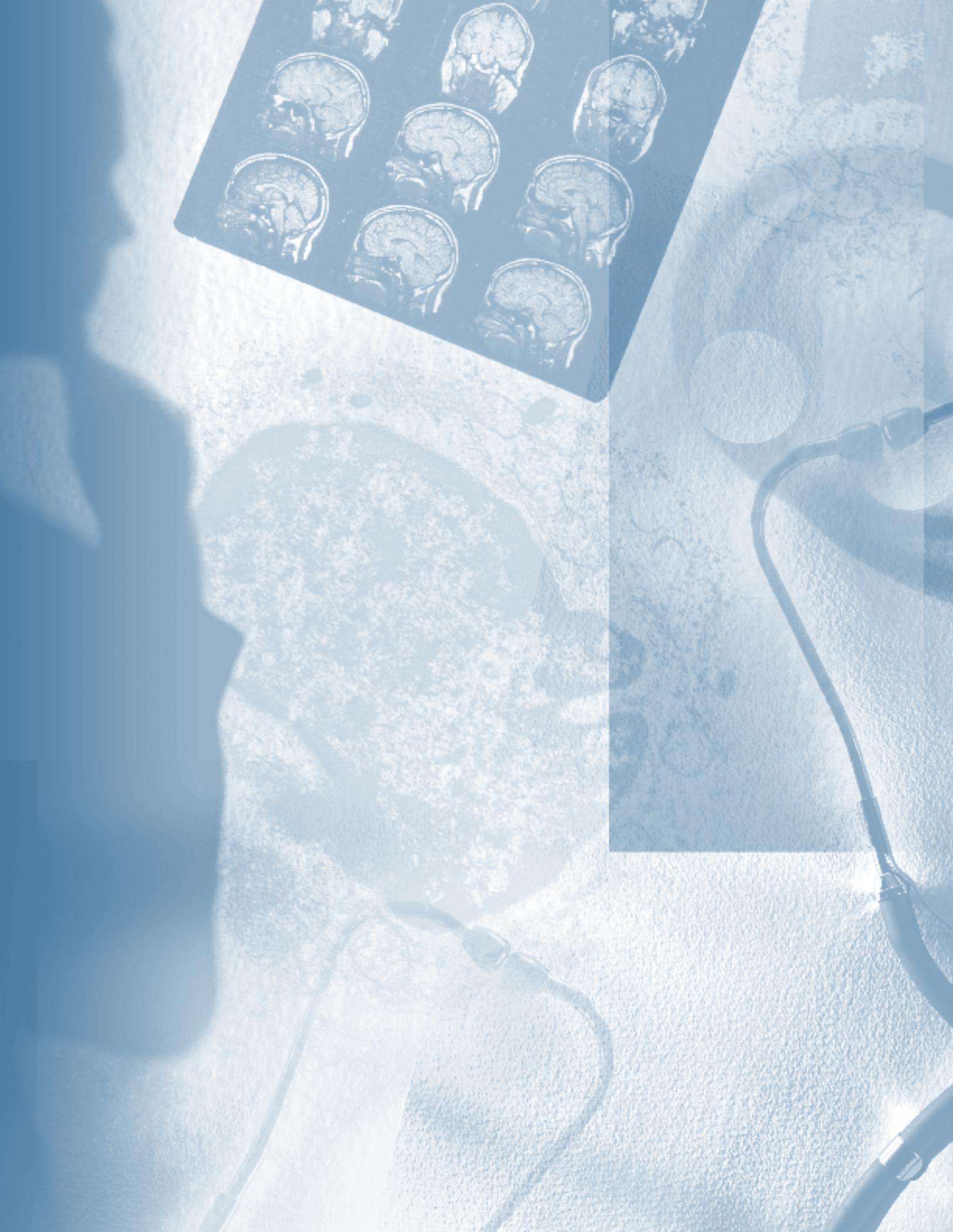


Table of Contents

	Page
Acknowledgements	ii
Executive Summary	iii
Summary of Recommendations	iv
Task Force Membership	v
Introduction	1
Part 1 The Scope of the Problem	3
Part 2 Research on Cancer and Aging	11
Part 3 Provider Education and Training	15
Part 4 Issues in Prevention, Detection and Care	21
Part 5 Facing the Challenge	29
Resources in New Jersey	35



Introduction

Cancer is not a single disease but a family of diseases that can emerge in many forms. Regardless of type, cancers progress in distinct stages, often over long periods of time. Cancer is much more common in older adults and brings with it a complex array of specific needs that require accelerated education, research, responsive policy and advocacy for dedicated resources and changes in the delivery of health care.

In 2001, the National Institute on Aging (NIA) and the National Cancer Institute (NCI) sponsored a national consensus conference on *Cancer Burden for Persons 65 Years and Older* that called for the mobilization of scientists and health providers to address the gaps in knowledge for older adults with cancer. In response to these findings, the NJCCR, joined forces with the Meridian Health System, Saint Barnabas Health Care System and the University of Medicine and Dentistry of New Jersey – School of Public Health, Office of Public Health Practice in 2002 to sponsor a pioneering conference aimed at addressing these problems at a state level. As a result of this extremely successful conference, the NJCCR created the *New Jersey Task Force on Cancer and Aging* to develop and discuss potential strategies to encourage research on cancer and aging, and enhance cancer services for the elderly in the State of New Jersey.

The charge of the NJCCR Task Force on Cancer and Aging was to conduct an assessment to identify existing resources and major gaps in knowledge, care or resources including the use of information and data from governmental and private organizations, and to establish priorities and specific strategies to address the complex needs of the older adult with cancer.

This report summarizes the results of the Task Force efforts. The report identifies the current status of efforts to address this healthcare issue and the ongoing challenges to avert the potential for a major public health crisis relative to cancer and aging. It highlights significant gaps in research, education, screening and treatment that exist when addressing cancer in the older adults. It reviews the demographic implications for New Jersey, with its large population of older residents and describes how the disease poses an increasingly significant burden on the health care system. As the size of the older population escalates, that burden will intensify.

The mission of the Task Force is defined as:

To acknowledge and seek ways to ameliorate the specific and unique burden of cancer on older adults and improve quality of life through identified action steps to reduce or eliminate these gaps.



Part 1

The Scope of the Problem

According to the American Cancer Society (ACS), the incidence of all cancers combined is ten times greater for those over the age of 65. These older cancer patients are also 16 times more likely to die as a result of their cancer than younger patients. With longer life expectancy the number of people who are over the age of 65 is expected to almost double by 2030, to 70 million people (ACS). The population of those age 85 or older is expected to reach 9.6 million. Given the considerable size of the population, the escalating cost of health care and the expanding impact of those becoming eligible for Medicare, the outcome according to Dr. Harmon Eyre, the Chief Medical Officer of the ACS, is the "perfect storm."³

A large segment of the population, known as "baby boomers" will begin to reach age 65 in about eight years. At that time, 76 million people in the United States will be facing retirement and senior citizenship. Experts have predicted that mid-life will extend well beyond the traditional age of 65 years and older adults are likely to enjoy good health into old age. The expanding demographic shift will create an unprecedented demand on hospital admissions, the health care workforce and many health care services. Medicare spending will increase sharply with the shift from private financing of care to the public sector.⁴

Table 1: Estimated Percentage of the Population Ages 65+ and 85+ Years of Age in New Jersey and the United States: 2000, 2015 and 2030

	2000		2015		2030	
	65+ Years	85+ Years	65+ Years	85+ Years	65+ Years	85+ Years
New Jersey	13.2	1.6	15.0	2.4	20.0	3.0
United States	12.4	1.5	14.5	2.1	19.7	2.6

Source: US Census 2000

New Jersey's Cancer Rates for Older Adults

Age is the greatest risk factor for cancer. According to Cancer Epidemiology Services (CES) of the New Jersey Department of Health and Senior Services, approximately 64% percent of the men and 58% of the women diagnosed each year with cancer in New Jersey will be over 65 years of age.⁵ Almost 70% of cancer deaths occur in adults over 65 years of age. Incidence and mortality rates for older men are significantly higher than for women. Overall incidence for cancer among older adults in New Jersey is slightly higher than national averages. Colorectal, prostate, lung and breast cancers are most common in older adults and account for 72% of all cancers diagnosed in this age group.⁶

3 Older, E. Cancer Boom. Momentum Autumn 2006
4 http://www.iftf.org/docs/SR-812_Boomers.pdf, p. 3
5 http://www.state.nj.us/health/cancer/cancer_older_adults.pdf
6 http://www.state.nj.us/health/cancer/cancer_older_adults.pdf, p. 2

Table 2: Observed Cancer Site Incidence and Mortality Rates for Females and Males 65 and older in New Jersey

	2002				2003			
	Female		Male		Female		Male	
	Incidence	Mortality	Incidence	Mortality	Incidence	Mortality	Incidence	Mortality
Breast	420.3	131.3	N/A	N/A	397.5	133.6	N/A	N/A
Colon/Rectal	290.9	111.0	403.5	162.0	267.2	116.8	374.5	161.2
Lung	292.9	226.8	476.2	388.5	284.3	232.9	459.5	401.3
Prostate	N/A	N/A	1,157.4	192.0	N/A	N/A	925.5	196.2

Incidence data provided by SEER Program. Incidence and mortality rates calculated by the National Cancer Institute using SEER*Stat. Incidence and death rates are per 100,000 population per year, and are age-adjusted to the 2000 U.S. standard population. Death data are provided by the National Vital Statistics System.

New Jersey's Aging Population

In New Jersey more than 1.1 million residents (13.2% of the population) were over age 65 years at the 2000 census. Projections for future growth estimate that nearly 20% of the state's population, or 2.4 million people, will be over the age of 65 by 2030 (NJ Dept. of Labor). New Jersey's aging population is more diverse and has a larger proportion of minorities than most other states. Almost 80% of New Jersey's seniors are non-Hispanic whites; other demographics include:

- Slightly less than 10% are African American
- About 7% are Hispanic
- And 3.7% are Asian/Pacific Islanders

The percentage of minorities is expected to increase substantially in the future. More than seven percent of those over 65 years live below poverty. According to the 2003 National Health and Interview Survey, 24% of those over the age of 65 have only Medicare coverage. The state's population also includes a large number of frail, elderly persons over the age of 85 years who often have complex needs that are different from other population subgroups.⁷

Cancer deaths for men over 65 years are almost 21 times higher than for those under 65 years. Women over 65 years of age are almost 14 times more likely to die from cancer than females under age 65 years. Survival rates for older women in New Jersey are poorer than for other age categories. There is less difference in the survival rates for older men, although black men over 75 years still have lower rates.⁸

7 New Jersey Dept. of Labor population projections are available online at <http://www.wnjp.in.net/OneStopCareerCenter/LaborMarketInformation/Imi03/>

8 "Cancer Survival in New Jersey 1979-1997" Cancer Epidemiology Services, New Jersey Department of Health and Senior Services, pg. 20.

Table 3: Estimated Number of New Cases of Cancer for New Jersey Residents 65+ Years of Age, with 95% Confidence Intervals: 2005 and 2010

Year	Males	Females	Total
2005	14,784 (13942, 15688)	12,849 (12110, 13639)	27,633 (26052, 29327)
2010	15,065 (13884, 16365)	13,168 (12205, 14217)	28,233 (26089, 30582)

Source: NJ Cancer Epidemiology Services

The Burden of Cancer

The cost burden of cancer to society is difficult to determine. Indeed, health care costs alone do not provide an accurate portrait of the burden of cancer because of the host of complex medical, social and economic factors. While it is hard to quantify the burden of cancer on society as a whole, it becomes even more difficult to determine the portion of that burden attributable to cancer among the aging population. This is partly because older persons often have other diseases, or co-morbid conditions, that complicate and intensify the costs of their cancer. For example, it might be impossible to isolate the purpose and consequently assign the costs of tests; i.e., a chest X-ray ordered to check for infection for an older adult with Chronic Obstructive Pulmonary Disease who also has cancer.

Any attempt to calculate the cost burden of cancer specifically for the aging population is likely to be underestimated.⁹ It is known that the current cost estimate for cancer in New Jersey exceeds \$5.8 billion annually. Based on the demographics of the population and the anticipated growth of the oldest cohort, it is possible to estimate that the cost in dollars for dealing with cancer in older adults will be at least \$6.3 billion annually by 2030.

Co-morbidities

Older adult cancer patients are likely to have concurrent and previous illnesses that make cancer prevention, detection and care more difficult. Co-morbidities often result in physical, social and cognitive impairment that lead to greater complexity in diagnosis and treatment. These conditions further influence the quality of care and the degree of supportive care required. As a result, the older cancer patient often requires a larger and more costly array of services. Models that focus decision-making on evidence-based information are lacking, creating a considerable gap in providing comprehensive, advanced care.

⁹ Yancik R, Ries LA. Aging and cancer in America: demographics and epidemiologic perspectives. *Hematology and Oncology Clinics of North America* 2000;14:17-23.

Myths and Biases about Cancer in the Older Adult

Older adults are frequently the victims of ageism, often defined as the grouping of people over the age of 65 into a category typified by negative beliefs and attitudes without consideration of individual capabilities or needs.¹⁰ Ageism takes many forms and discrimination may take place related to housing, exclusion from social networks and medical care.¹¹ Older individuals are frequently viewed as too frail or unlikely candidates for certain types of cancer treatments and protocols despite evidence to the contrary. Although older cancer patients are a large population, they are often inappropriately excluded from cancer screening, clinical trials, and cancer treatment due to the perception that they cannot tolerate more aggressive procedures.¹²

Psychosocial Concerns

As individuals age, some may experience a number of new or exacerbated psychosocial problems and an increased need for financial, living or emotional support. Mental function, including selective attention, verbal fluency, complex spatial skills and logical analysis may decline with increasing age. Hearing and vision loss can contribute to reduced cognitive functioning. A diagnosis of cancer can worsen these conditions and reduce levels of independence and capacity for self-support.¹³ However, it is important that such changes are not assumed, but documented specifically in each case. Under these circumstances, good communication and informed decision-making regarding cancer treatment may become compromised. Studies also indicate that older adults who participate in decisions concerning their care have positive adjustments to their diagnosis and better coping skills than younger counterparts.¹⁴ How well older adults cope with cancer can be positively affected by having the ability to make their own choices and determining their own directions.¹⁵

10 Busse, I. Viewpoint: Prejudice and gerontology. *The Gerontologist* 1968; 8:66.

11 Alliance for Aging Research. *Ageism: how health care fails the elderly*. Washington, DC. 2004. Also available online at www.agingresearch.org/brochures/ageism/ageism_booklet_final.pdf.

12 Turner NJ, Haward RA, Mulley GP et al. [Cancer in old age—Is it inadequately investigated and treated?](#) *BMJ* 1999 (31 July); 319: 309–312.

13 Seeman TE, Berkman LF, Kohout F, et al. Intercommunity variations in the association between social ties and mortality in the elderly: A comparative analysis of three communities. *Ann Epidemiol* 1993;3:325–335.

14 Colussi, AM, Mazzer, L., Candotto, D, "The elderly cancer patient: A nursing perspective," *Crit. Rev. Onco. Hemat.* 2001: 39 (3) 235-245.

15 Thome' B, Gunnars, B., Dykes, AK., Ingalill, R., "Experiences of Older People Living with Cancer," *Cancer Nursing*, Vol. 26, No. 2, 2003, 85-95.

Lack of Supportive Care

Studies indicate that poor social support, limited access to transportation and impaired cognition all lead to delays in cancer diagnosis and inadequate treatment.¹⁶ Individual circumstances dictate the level of supportive services needed, but in general, the more frail a person becomes, the more care and support services are required. Common supportive services needed by older cancer patients may include:

- Nutrition
- Wellness services
- Home care services
- Palliative care management
- Transportation
- Care assessment
- Care coordination
- Monitoring
- Caregiver support
- Respite care services
- Hospice

Income Level

Nationwide, about 3.4 million persons over the age of 65 years (10.1%) and 7.7% for New Jersey lived below the poverty level in 2001. The median income of older persons in 2001 in the United States was \$14,152.¹⁷ All racial and ethnic minority groups in New Jersey (1999) were reported to have higher poverty rates than non-Hispanic whites. The poverty rate for Asian and Pacific Islanders was only slightly higher than the (non-Hispanic) white population. The poverty rates for non-Hispanic blacks, for American Indians and Alaska Natives, and Hispanics and Latinos were considerably higher.

Living in poverty brings special challenges, including substandard living arrangements, limited transportation and a general lack of access to care. These challenges contribute to a decrease in probability of cancer screening, and if diagnosed, the prospect of lacking access to high quality and comprehensive care. Individuals living on low incomes:

- Have limited access to adequate specialized treatment centers
- Lack insurance to offset care costs
- Must rely on family members who may not have the time or income resources to care for the patient

16 Goodwin JS, Samet JM, Hunt WC. Determinants of survival in older cancer patients. *Journal of the National Cancer Institute* 1996. 88(15):1031-38.

17 Department of Health and Human Services, Administration on Aging. *Income and Poverty among the Elderly*. Washington, DC: DHHS. 2003. Online at http://www.aoa.gov/press/did_you_know/2003/april_pf.asp.

Disparities in Cancer Care for Older Ethnic Minorities

The United States Census Bureau projects increasing diversity in older populations. Older ethnic minorities are growing at a ratio of two to three times faster than the whole population of older adults. Minorities are projected to represent more than 25% of the older adults by the year 2030.¹⁸

Table 4: Overall Percentage of Population Projections for Persons 65 and Older, 75 and Older, and 85 and Older, within Race Categories

	Census 2000			Projection 2010			Projection 2050		
	65+	75+	85+	65+	75+	85+	65+	75+	85+
<i>White</i>	13.7	6.7	1.7	14.4	6.8	2.1	21.9	12.5	5.2
<i>Black</i>	8.1	3.4	0.9	8.6	3.5	1.0	14.2	6.9	2.6
<i>Other races</i>	7.2	2.7	0.6	8.7	3.5	0.9	15.0	7.9	3.1
<i>Hispanic</i>	6.0	2.4	.6	6.9	3.0	.8	14.3	8.0	3.4

Source: US Census 2000

Recent research has shown that for all cancer sites combined, black men have a 25% higher cancer incidence and 43% higher mortality rate than do white men. In women, blacks have lower incidence rates than do white females for all cancer sites combined, and yet they have 20% higher mortality rate.¹⁹ Furthermore, data demonstrate significant additional burdens for older minorities. Cancer staging, treatment outcomes and survival tend to be poorer in older ethnic minorities when compared to white counterparts.²⁰

Ethnic minorities face particular challenges when dealing with cancer. Often these individuals are coping with profound barriers and obstacles as well as competing priorities due to cultural, educational or poverty issues. Cultural differences among older ethnic minorities can create communication and behavioral barriers with providers that can influence the levels of care offered. In addition, health literacy and language competency issues may be more common in some minorities and those with low socioeconomic status and can limit participation and compliance in medical decision making. Some of cultural barriers requiring special attention and resources include:

- Attitudes about suffering and pain management
- Fatalism and misperceptions about cancer
- Significant mistrust of the health care system
- Lack of financial resources for transportation, home care, and medical costs

18 American Psychological Association; <http://www.apa.org/pi/aging/practitioners/demographic.html>

19 Jemal, A. et al. Cancer Statistics, 2004. *CA Cancer J Clin* 2004; 54:8-29

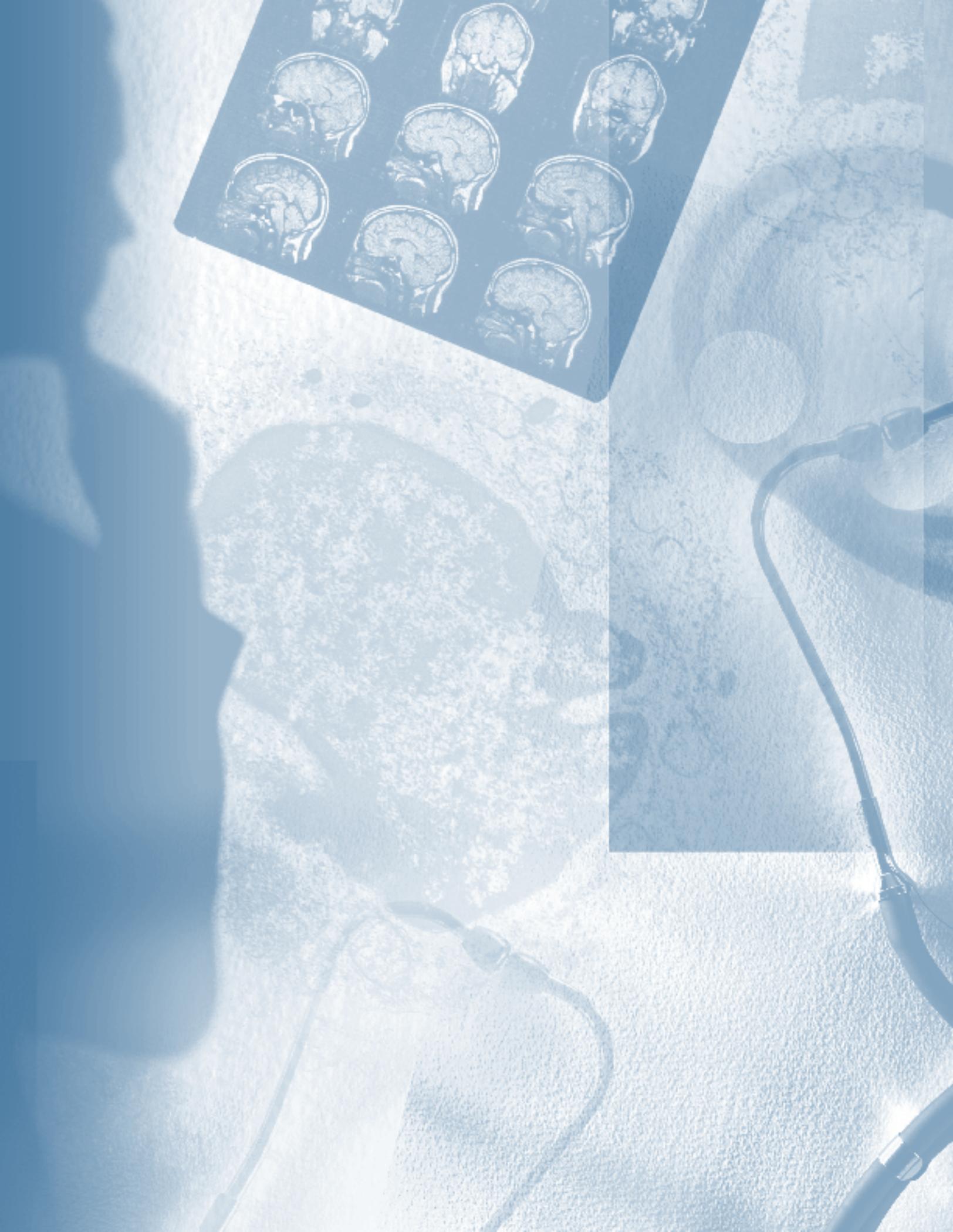
20 Jemal, A. et al. Cancer Statistics, 2004. *CA Cancer J Clin* 2004; 54:8-29

- Dependency upon children for all care-giving and support; or lack of any family support
- Limited primary care, medical specialists, home care, and support services in poorer urban regions

In New Jersey, the concentration of older minorities varies significantly by county. Bergen, Essex, Hudson, and Union have the largest percentage of older minorities with more than 50% over age 60 years. In addition, certain ethnic minorities are represented at much higher rates in some counties than others. For example, Hudson county has the largest number of Hispanics and Essex the largest concentration of Non-Hispanic Blacks.²¹

Such diversity will bring increased challenges to the health care system in general and will require allocation of resources to those communities with special populations. The demands on many locally-based health care services will increase as these numbers accelerate in the future. Culturally competent and appropriate care will be critically needed. A focus on enhancing community programs will be required to assure effective education, services and resources.

21 http://www.state.nj.us/health/senior/documents/strategic_plan/strategic_plan.pdf, July, 2007



Part 2

Research on Cancer and Aging

Trends in Research Funding

In light of the rapidly accelerating age of the population and the high costs associated with cancer screening, detection and care, the increasingly scarce funding for research on cancer and aging presents a serious challenge. The National Institutes of Health (NIH) funding for the National Cancer Institute is expected to continue to decline further restricting the ability to assess the impact of aging on the health care system. Despite past efforts by the New Jersey Commission on Cancer Research (NJCCR) to stimulate studies on geriatric oncology by directing research funds to this area, New Jersey has only a handful of basic studies focusing on aging and its role in cancer formation.

Without a cadre of scientists focusing on aging, progress will be hindered by a lack of knowledge about causation and effective methodologies to address cancer in the older adult.

The Need for Advanced Research on Cancer and Aging

Research in cancer and aging is especially important. The relationship behind the high cancer rates and the aging population has not yet been fully explained. Age-related molecular factors represent an important avenue to explore including:

- Increased cell breakdown
- Susceptibility to cell damage
- Longer exposure to carcinogens and free radicals
- Poor immune status and response
- Altered DNA repair function
- Changes in cell regulation affecting cell death
- Changes effecting cell proliferation

Expanded resources to fund basic research are essential to attempt to reduce the incidence, morbidity and mortality associated with the rapidly aging U.S. population. Understanding the escalating cancer rates among older adults may provide insights into how cancer occurs in general. In recent years, New Jersey has been a pioneer in addressing the role of cancer and aging by organizing resources and creating a statewide, integrated agenda to promote research for both the basic and behavioral sciences. Many significant resources in the State focus primarily on cancer and/or on aging. Some of these agencies/organizations include:

- New Jersey Commission on Cancer Research
- Cancer Epidemiology Services, New Jersey Department of Health and Senior Services
- The Cancer Institute of New Jersey (CINJ)

The availability of funding often drives scientific focus, as research cannot proceed without resources. The scarcity of funding for cancer and aging has severely restricted both national and state efforts to move forward in understanding and addressing cancer in the aging.

- Rutgers, The State University of New Jersey
 - Institute for Health, Health Care Policy and Aging Research, New Brunswick, NJ
 - Center for State Health Policy, New Brunswick
- Geriatric Oncology Program at Hackensack University Medical Center
- University of Medicine and Dentistry of New Jersey (UMDNJ)
 - New Jersey Institute for Successful Aging at the UMDNJ-School of Osteopathic Medicine, Stratford, NJ
 - The Geriatric Psychiatry Training Program at the Robert Wood Johnson Medical School, New Brunswick, NJ
 - Comprehensive Services on Aging (COPSA) at the University Behavioral Healthcare Center, Piscataway, NJ

Participation of Older Adults in Clinical Research

Despite the large representation of older adults among cancer patients, this group represents the smallest percentage of enrollees in clinical trials.²² A number of studies have documented this phenomenon. In New Jersey, recent NJCCR surveys measuring older adult enrollment in cancer clinical trials indicate lower recruitment rates when compared to those less than 65 years, but data limitations exist for this population.^{23, 24}

Some of the factors identified as responsible for low representation in clinical trials among older adults include:

- Stringent enrollment criteria
- Bias and myths about the ability to tolerate aggressive treatment
- Logistical barriers
- Mistrust of care providers
- Misperception about clinical trials

The latter issue may be especially relevant for ethnic minorities.²⁵ The lack of participation of older subjects in clinical research serves to further limit the ability to understand how cancer affects those over the age of 65 differently. It also hinders the ability of physicians to acquire evidence-based knowledge of the interactions of co-morbid conditions and cancer treatments, which are quite common among older populations. To address these issues, national groups such as the Geriatric Oncology Consortium (GOC) have sought to develop trials to examine the specific needs of older, specifically frail elderly cancer patients.²⁶ Medicare has also developed a policy to cover the routine costs for older adults to enroll in clinical trials.

22 Trimble EL, Carter CL, Cain D, et al. Representation of older patients in cancer treatment trials. *Cancer* 1994;74:2208–2214.

23 Henry-Tooke N, Schneider D, Hill AM. *Minority Participation in Cancer Clinical Trials in New Jersey*. Poster presented at the Annual Retreat on Cancer Research in New Jersey Princeton, NJ. April 2005.

24 Hanson, C., Schneider D, Hill AM, 2005 Cancer Clinical Trial Participation Rates for New Jersey, unpublished, June, 2007.

25 Lewis, MJ, Hill, AM, Merced M., & Greenberg A, "Perceptions & Barriers to Participation in Cancer Clinical Trials Among African Americans and Hispanics," Annual Retreat on Cancer Research in New Jersey, Plenary Presentations, May 2002

26 <http://www.thegoc.org/index.html>

However, more aggressive steps to increase enrollment of older adults in cancer clinical trials will be required including forward thinking policy development, expanded education aimed at researchers, health care providers, and older adults themselves and adjustments to address logistical obstacles.

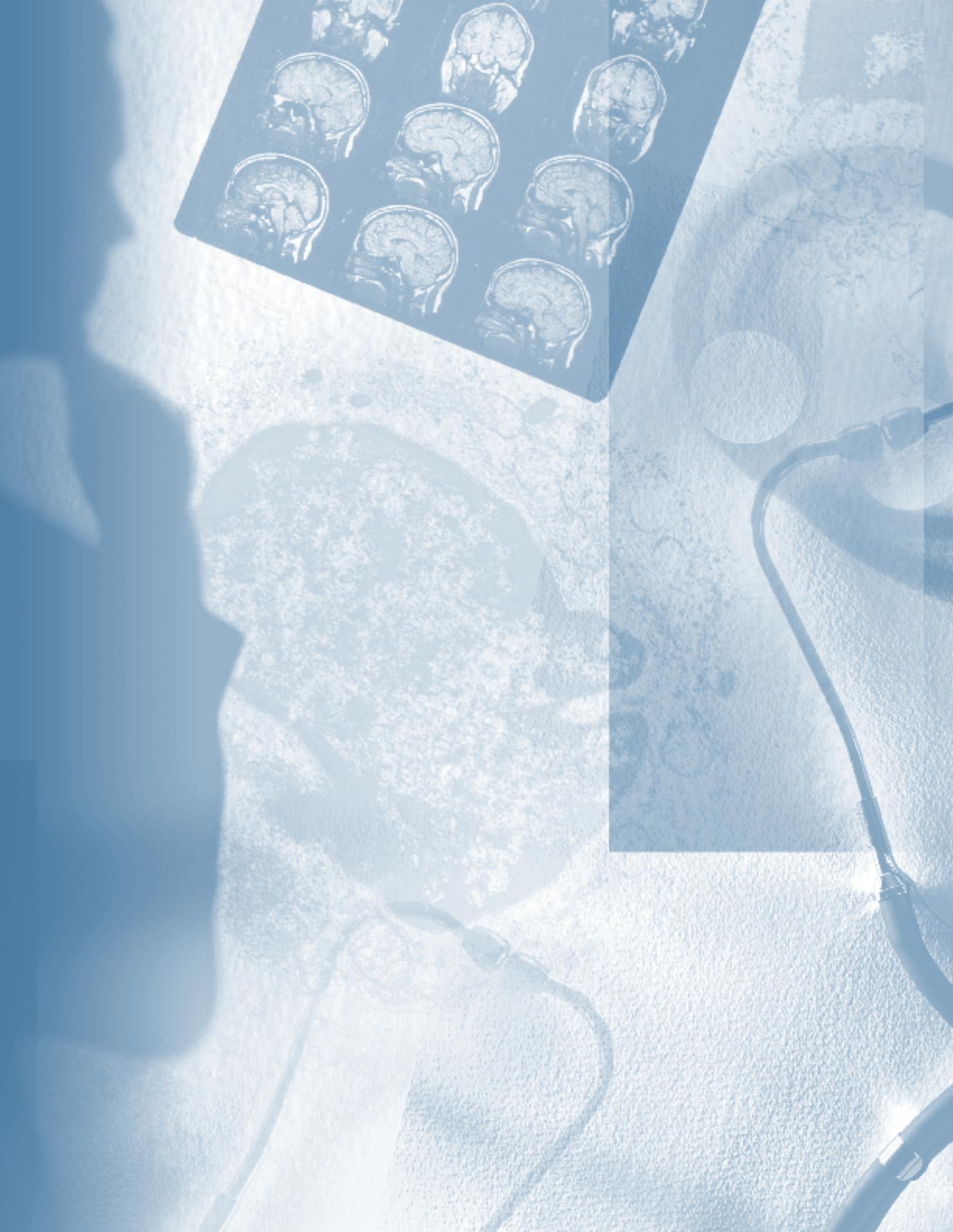
Data Sources and Surveillance

National organizations dealing with cancer research, including the National Institutes of Health, and the Centers for Medicare and Medicaid Services, have cited the need to create uniform standards for reporting health data, including cancer data.²⁷ Significant efforts have been made to improve data standards through programs like the NCI's Surveillance, Epidemiology and End Results (SEER) program, an authoritative source of information on cancer incidence and survival in the United States. The SEER data are now linked to the Centers for Medicare and Medicaid Services (CMS) and are available to researchers. Because New Jersey's Cancer Registry is part of SEER, the State is well positioned to take advantage of this important database linkage.

However, the lack of uniform standards among other databases limits the ability of researchers to evaluate programs and analyze cancer trends as they relate to aging.²⁸ Consequently, the several data sources with valuable potential to study geriatric oncology are not accessible to epidemiologists for use in a meaningful study design.

27 <http://www.hhs.gov/healthit/federalprojectlist.html> and <http://www.iom.edu/focuson.asp?id=8089>.

28 Swan J, Wingo P, Clive R, et al. Cancer surveillance in the U.S.: Can we have a national system? *Cancer* 1998;83(7):1282-121.



Part 3

Provider Education and Training

A focus on education across the spectrum of health professionals, paraprofessionals and the community will be required to assure sensitivity to the complexity of problems associated with cancer and older adults. In addition, this education will help to assure the expansion of resources and services that will be required with the accelerated size of the older population.

Education for Physicians

Oncology is a changing discipline as improved treatment and survivorship move from the acute care setting to a chronic disease mode. Practicing oncologists with little formal training in geriatrics, and geriatricians with limited knowledge of oncology and the complexity it presents, will be responsible for care of a rapidly accelerating group of patients.

Consequently, the need to incorporate geriatrics in oncology training and likewise, a focus on oncology in geriatric training will become increasingly important in the future. Less than 10% of US medical schools require a course in geriatrics. While over 90% claimed to integrate geriatrics into their curricula, only a few offer combined geriatric oncology courses.²⁹

National efforts to address these gaps have been spearheaded by the American Society of Clinical Oncology (ASCO) and the John A. Hartford Foundation, and have resulted in a number of major US universities developing geriatric oncology fellowship programs.

Given the limited resources for health care overall, primary care physicians will be pressed to take an expanded role in geriatric cancer care. Consequently additional training, particularly relative to assessment and symptom management, may improve overall care management and keep costs lower.

Oncology training is well represented at all UMDNJ campuses. However, geriatric training varies among schools, and in general, opportunities for training in geriatric oncology are very limited. The UMDNJ-School of Osteopathic Medicine (SOM), through the Institute for Successful Aging, includes geriatrics across their curriculum, and an option for students to explore oncology. However, a lack of fellowships for geriatric oncology specifically and the lack of qualified senior research faculty who can provide such an education represent real barriers to medical schools seeking to address these issues.

The role of primary care physicians in geriatric cancer care will expand and additional training, particularly around assessment and symptom management, may improve overall care management and keep costs lower.

29 Eleazar GP, Doshi R, Wieland D, et al. Geriatric content in medical school curricula: results of a national survey. *Journal of the American Geriatrics Society* 2005; 53(1):136-140.

While hospital-based programs, such as the new Geriatric Oncology Program at Hackensack University Medical Center, have increased in recent years, specialty training at medical schools and continuing medical education programs for palliative care are limited and increased attention to this specific issue is important.

Continuing Medical Education (CME) in geriatric oncology has also emerged as a high priority nationally. The American Society of Clinical Oncology (ASCO) and the Geriatric Oncology Consortium (GOC) are actively supporting CME programs in Geriatric Oncology. GOC provides patient education programs, regional education meetings and access to clinical trials results to further knowledge in the field of geriatric oncology.³⁰ However, there is little evidence of this training in New Jersey.

Education for Nurses

As the cancer burden expands in the future, the need for more oncology nursing specialists, in general, and more advanced geriatric oncology nurse practitioners specifically, will increase. Yet, few of the 2.2 million registered nurses in the nation have received education in geriatric oncology care as part of their nursing curriculum.³¹ There is some indication that this situation is changing. The Schools of Nursing that offer baccalaureate degrees now incorporate a range of training opportunities from a single course to a semester directed toward oncology care. Many programs also offer gerontology in their curriculum under the umbrella of a life continuum approach. However, efforts to integrate geriatrics with oncology are still lacking.

Oncology nurses are key partners in patient assessment, chemotherapy delivery, symptom control, education and counseling, psychosocial and quality of life enhancement, follow-up and survivorship, and end of life care.³² They carry significant responsibility for patient care and this trend will increase in the future.³³ For these reasons, the need to support training opportunities for advanced nurse practitioners, clinical nurse specialists and research nurses in geriatric oncology is critical, and will accelerate in the future. Fortunately, there has been growing recognition by an increasing number of schools of nursing, including many in New Jersey, that a dual track in gerontology and oncology for advanced nurse practitioners is important. However, schools have yet to formally adopt a geriatric oncology advanced nursing practitioner certification, a step that would assure such integration.

Continuing nursing education in geriatric oncology and palliation is also necessary. Schools of Nursing, academic centers such as the Cancer Institute of New Jersey and non-profit groups like the American Cancer Society should

30 <http://www.thegoc.org/>.

31 www.aacn.nche.edu/Education/Hartford/pdf/ImprintArticle05.pdf.

32 McCorkle R., Strumpf, NE, Nuamah IF, et al. A specialized home care intervention improves survival among older post-surgical cancer patients. *J Am Geriatr Soc.* 2000;48:1707-1713.

33 <http://ezinearticles.com/?Future-of-Baby-Boomer-Health-Care&id=230689>

be encouraged to expand continuing education on programs focusing on the older adult with cancer.

Education for Social Workers

Social workers play an important role in the care of patients and family members faced with a diagnosis of cancer. Oncology social workers are involved in addressing the psychosocial impact of cancer including assessment, case management, patient and family counseling, discharge planning, education, and linking patients to resources and services. Given future projections, the need for trained oncology social workers to handle the increasing presence of older adults will expand rapidly in the coming decade. The National Institute on Aging has projected that more than 60,000 social workers with special training in geriatrics will be needed by 2010.³⁴ Expansion of education programs for masters prepared social workers and integration of geriatrics and oncology in baccalaureate programs will be important if the demands for trained social workers are to be met.

The Association of Oncology Social Workers (AOSW) has a certification program in place for Licensed Oncology Social Workers (LOSW) that offers a comprehensive program in oncology including education, clinical practice, administration and research. A sub-specialization in palliative care and end of life is possible. However, few courses offer geriatric oncology.

National organizations including the National Association of Social Workers (NASW) and the AOSW promote educational programs on aging, end of life issues and cancer through their conferences, online education modules and specialty practice sections.³⁵ Continuing education for social workers in oncology and gerontology are offered at schools and institutions throughout the state but few programs focus on integrating the two disciplines.

Education for Pharmacists

Pharmacists play a critical role in dispensing and providing information on drugs. Older adults consume 30 to 40% of all prescriptions, yet comprise only 13% of the US population.³⁶ Few schools of pharmacy require students to take courses in geriatrics or offer a clinical clerkship in gerontology. The Institute of Medicine and others have identified drug overuse, interactions and other medication errors as a significant problem for older adults.³⁷

34 Halpain MC, Harris MJ, McClure FS, et al. Training in geriatric mental health: needs and strategies. *Psychiatric Services* 1999;50(Sept):1205-1208.

35 The Association of Oncology Social Workers has also focused upon palliation and end of life issues in their programs. Other groups including the Association for Gerontology Education in Social Work (AGE-SW) and the Council on Social Work Education (CSWE) have a focused agenda that provides "leadership and assistance to social work educational programs and professionals in order to advocate for the integration of gerontological content in undergraduate and graduate social work education; to promote the teaching of gerontology to all social workers; and to develop short and long-term perspectives in relevant curricular developments." <http://www.agesocialwork.org/about.html>.

36 Clancy TR. Medication error prevention: progress of initiatives. *JONA'S Healthcare Law, Ethics, and Regulation* 2004;6(1):3-12.

37 Clancy TR. Medication error prevention: progress of initiatives. *JONA'S Healthcare Law, Ethics, and Regulation* 2004;6(1):3-12.

As a result of these findings, the American Geriatrics Society in collaboration with the American Society of Consultant Pharmacists (ASCP), called for a geriatric focus to current core pharmacy curriculum including didactic and clinical experiences in pharmacy schools across the country. In response to the need to provide post-graduate specialization, the Commission for Certification in Geriatric Pharmacy has been formed and certification of geriatric pharmacists has been initiated. Only about 700 of the 200,000 pharmacists in the United States have this designation.³⁸

The American Society of Health-System Pharmacists accredits residency programs in oncology for pharmacists. Programs train pharmacists in the management of oncology drug delivery to cancer patients usually in health care settings. However, few licensed pharmacists have had any geriatric oncology education. The need to expand opportunities for combined training will become a major necessity in the future.

Education For Other Allied Health Professionals and Paraprofessionals

Comprehensive cancer care for older adults involves a whole host of allied health professionals, including radiation technologists, respiratory technicians, physical and occupational therapists, patient navigators, nursing aides, emergency medical technicians, home care workers, and administrative personnel, among others. All of these dedicated individuals play a considerable role in promoting the health and quality of life of older adults with cancer. Consequently, a focus on their understanding of the complex issues would make a significant contribution. Many of these groups are currently in short supply and the need for well trained and competent healthcare professionals and paraprofessionals will escalate with the growing older population.



Part 4

Issues in Prevention, Detection and Care

A myriad of social, medical and economic issues affect the health care of the elderly in general. However, the complex needs and problems facing the older adult with cancer may be among the most challenging and difficult. Fragmentation of care can be overwhelming for all patients; it is especially daunting for the older adult cancer patient. A coordinated, multidisciplinary approach that embraces communication among oncology specialists and primary care providers, continual assessments of patient needs, and appropriate supportive services will promote a more seamless approach to care.³⁹ Specific concerns relative to care of the older patient include:

- Specific age-appropriate screening protocols
- Identification of an acceptable course of treatment
- Access to treatment in local venues
- Assistance to assure compliance with treatment protocols
- Attention to special communication needs
- Identification of special needs and obstacles, including concrete services such as transportation and home care
- Culturally competent care

Comprehensive Geriatric Assessments

Comprehensive geriatric assessment includes evaluation of the patient's physical, functional, psychosocial, nutritional, emotional and social status. When applied to the elderly, comprehensive geriatric assessments result in improved outcomes in geriatric care consisting of prolonged survival, increased functional status, decreased medication use, improved quality of life, and a decrease in the frequency of institutionalization.⁴⁰ If comprehensive geriatric assessments were implemented for all older patients with a diagnosis of cancer, improved quality of care and better outcomes should also be anticipated.⁴¹ Several models of oncology assessments for older adults are in development and nearing validation. Training oncologists, oncology nurse practitioners and other appropriate oncology providers in the use of such assessment tools is an important step towards this end. The assessment should be performed at each visit, which will allow the staff to determine whether a referral for palliation or home care is appropriate. A comprehensive geriatric assessment must include review and analysis of the role of co-morbid conditions, mental status and perception of quality of life issues. Steps to expand use of geriatric assessment tools are a high priority in assuring quality care for the older adult with cancer.

If comprehensive geriatric assessments were implemented for all older patients with a diagnosis of cancer, improved quality of care and better outcomes should also be anticipated.

39 Welch HG, Albertsen PC, Nease RF, et al. Estimating treatment benefits for the elderly: The effect of competing risks. *Annals of Internal Medicine* 1996;124:577-584.

40 Repetto L, Comandini D, "Cancer in the Elderly: Assessing Patients for Fitness" *Critical Review in Oncology/Hematology* 2000; 35:155-160.

41 Exterman M. Studies of comprehensive geriatric assessment in patients with cancer. *Cancer Control* 2003;10(6):463-68.

Cancer Prevention and Screening

Explicit cancer screening guidelines for older adults are lacking. Few studies have been conducted measuring cost/benefit of screening for older adults. Guidance from national organizations is often inconclusive; consequently practitioners may struggle to identify appropriate screening recommendations. The United States Preventive Services Task Force (USPSTF) uses evidence-based criteria for screening recommendations for older adults that are summarized below:

Colorectal Screening: The USPSTF strongly recommends that clinicians screen men and women 50 years of age or older for colorectal cancer. The USPSTF found fair to good evidence that several screening methods are effective in reducing mortality from colorectal cancer including: Fecal occult blood test (FOBT) every year; flexible sigmoidoscopy every 5 years; double-contrast barium enema every 5 years and colonoscopy every 10 years.

Breast Cancer Screening for Women: The USPSTF recommends screening mammography, with or without clinical breast examination (CBE), every 1-2 years for women aged 40 and older. While older women face a higher probability of developing and dying from breast cancer, they may have co-morbid conditions that limit their life expectancy reducing benefit from screening.⁴²

Prostate Cancer Screening: The USPSTF concludes that the evidence is insufficient to recommend for or against routine screening for prostate cancer using prostate specific antigen (PSA) testing or digital rectal examination (DRE). Other groups do recommend men over age 50 or high risk men over 45 years talk to their physician about the risks and benefits of screening with DRE and PSA for men.⁴³ However, men older than 70 and with co-morbid conditions are less likely to benefit from screening.⁴⁴

For these reasons, older individuals may not be screened adequately. Information from monitoring agencies such as HealthCare Quality Strategies (HQSI) and the Health Plan Employer Data and Information Set (HEDIS) for New Jersey indicate that older women have lower screening rates for breast and colon cancers.⁴⁵ Certain groups of older women including minorities, widows and those with low incomes are even less likely to be screened.⁴⁶ These low rates exist despite Medicare and Medicaid coverage for most cancer screenings. Innovative interventions aimed at improving this situation are needed.

42 U.S. Preventive Services Task Force. *Guide to Clinical Preventive Services*, Second Edition. Office of Disease Prevention and Health Promotion: Washington, DC. 1996.

43 http://www.cancer.org/docroot/ped/content/ped_2_3x_acs_cancer_detection_guidelines_36.asp, June 2007.

44 Harris RP, Lohr KN. Screening for prostate cancer: an update of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med* 2003;137:917-929.

45 Hiatt RA, Klabunde C, Breen N, et al. Cancer screening practices from National Health Interview Surveys: past, present, and future. *J Natl Cancer Inst* 2002;94(24):1837-46.

46 <http://www.cancernetwork.com/journals/primary/p9605a.htm>.

Barriers to Screening in Older Adults

Barriers to screening among older adults include:

- Lack of clear guidelines for physicians and for patients causing confusion on what is appropriate and necessary
- Perceived lack of insurance coverage (this may include misunderstanding of what is provided by Medicare, as well as uninsured or underinsured adults)
- Availability of screening facilities and resources
- Transportation
- Attitudes about the lack of options if cancer is diagnosed, the expectation that old age limits treatment options if diagnosed, an unwillingness to accept treatment if it is prescribed, and an expectation that cancer is a natural part of old age

Cancer Care Settings and Services

Home Care for the Older Adult with Cancer

Most cancer patients, even those who are frail, prefer to be treated in the home setting. This trend is expected to continue into the future. Patients and many healthcare professionals often do not understand the challenge of the transition from the hospital to the home setting. Planning this transition is critical to good home care and efforts to coordinate more seamless transfers are needed. Issues such as caregiver limitations, inadequate social support, family discord or the presence of young children and potential safety issues must be addressed.

Throughout home care, collaboration among all the providers will help to assure the best possible outcome for the patient and the family. Consistent follow-up is essential to evaluate the effectiveness of the home-based care plan.

Efforts to keep older adults in the community setting have expanded with strategies to improve assisted living arrangements and combine housing, personalized support services and health care. The New Jersey Department of Health and Senior Services offers supportive services and resources to provide comprehensive care and maintain the patient at home.

As pressures on home care services expand in the future, the need for additional trained personnel, resources and coordination of services will accelerate. Expansion of new monitoring technologies and use of computer assisted devices will also be important.

Finally, the need to bolster the pool of trained home health aides will become a paramount priority in the future as demands on these services expand. Increased funding and incentives to recruit home health aides as well as to offer higher wages must become a priority for government leaders.

Providing Cancer Services in Long Term Care and Assisted Living Facilities

There are many types of senior housing and care services. Some include: active adult communities; assisted living (AL); long term care facilities (LTC); and inpatient hospice. Older adults who are frail, lack family support or the resources to pay for private care may need to consider one of these residential options; however, the services provided by each of these facilities differ and each presents its own set of issues for cancer patients.

Older adults with cancer who do not require skilled medical care on a daily basis may find AL facilities to be a reasonable alternative to home care. As the need for complex cancer care develops, especially appropriate symptom management and palliation, careful assessment, more complex nursing care and therapeutic services will be required. Such services may not be available on a 24 hour basis in all AL settings. For those older individuals, long term care LTC facilities may be appropriate. Nutritional and interdisciplinary assessment /interventions, routine monitoring of symptoms and medication levels are generally provided in these settings.

Regardless of the residential settings, staff may not be fully trained or have extensive experience in oncology. Improved coordination of cancer services are required. For these reasons, expanded staff training in oncology and better coordination of cancer services may be needed in the future.

Palliative Care in Older Adults with Cancer

The goal of palliative care is to improve the quality of life of patients who have a serious or life-threatening disease. This goal is met by preventing or treating, as early as possible, the symptoms of the disease, side effects caused by treatment, and the related psychological, social, and spiritual problems. For older cancer patients, the need for appropriate palliative care is essential. However, studies indicate that such services are often poorly managed in older adults with cancer, especially for pain management, nutrition, and fatigue.^{47, 48} While some studies indicate that older adults with cancer often appear to cope with diagnosis and potential long term implications of this disease better than younger cancer patients, the need for services and special focus is essential.

Hospice and the Older Adult with Cancer

Hospice provides supportive rather than curative care and has been shown to improve symptom management and quality of life for patients at the end of life. Medicare and Medicaid Hospice Programs, geared toward the terminally ill, provide a number of vital services including professional nursing services through home health care services. Medicare incorporated a hospice benefit in 1982 for beneficiaries with a life expectancy of six months or less "if the disease runs its normal course." Medicaid also includes hospice care and may offer a more generous package of services.

47 Passero CL, McCaffery M. Pain in the critically ill. *Am J Nurs* 2002;102(1):59–60.

48 <http://www.ahcpr.gov/clinic/epcsums/canpainsum.htm>.

According to the National Hospice and Palliative Care Organization (NHPCO), four out of five hospice patients are over the age of 65, and one-third of all hospice patients are over the age of 85 (NHPCO 2006). Unfortunately, delays in obtaining hospice services may mean that fewer patients receive the benefits that hospice offers. Studies indicate that a third of patients served by hospice die within seven days or less of referral. Better supportive services and increased quality of life could be achieved through earlier enrollment, especially for older adults.⁴⁹

Pain Management

The prevalence of pain generally increases with the progression of a cancer diagnosis. Moderate to severe pain is reported by approximately 50% of the patients in the intermediate stages of the disease and by over 70% of patients with advanced cancer.⁵⁰ It is estimated that 1.1 million Americans experience cancer-related pain. More than twice as many people over age 60 report pain than younger people.⁵¹ Cultural beliefs about pain management must also be taken into account. Among the institutionalized elderly, persistent severe pain was found in almost half of those with a cancer diagnosis.⁵²

Coping with acute and persistent pain remains a critical concern for older adults with cancer. Misunderstandings abound about addiction, tolerance and dependence, the side effects of treatment interventions, and cultural and spiritual beliefs. Economics, the lack of Medicare reimbursement for oral outpatient medications, and the fragmentation of care in health care systems all contribute to ineffective treatment in this population. Although many myths have been identified, and assumptions proven inaccurate,^{53,54,55} they linger and contribute to the higher risk for the inadequate treatment of pain among this population.

A number of efforts have been initiated to address pain management which include the elderly. In 2000, the New Jersey Legislature passed laws that require health care facilities to assess, rate, and routinely monitor patients' pain and identifies minimal licensing requirements. In addition, HealthCare Quality Strategies currently identifies residents with pain as a quality indicator for nursing home residents. However, a considerable additional effort is needed to assure that pain management is enhanced for older cancer patients.

49 <http://www.nhpc.org/i4a/pages/Index.cfm?pageid=4210>.

50 Passero CL, McCaffery M. Pain in the critically ill. *Am J Nurs* 2002;102(1):59-60.

51 <http://www.ahcpr.gov/clinic/epcsums/canpainsum.htm>.

52 Teno, JM, Weitzen S, Wetle T, et al. Persistent pain in nursing home residents. *JAMA* 2001;285(16):2081.

53 Passero CL, Reed B, McCaffery M. How aging affects pain management. *Am J Nurs* 1998;98(6):12-13.

54 McCaffery M. Understanding your patient's pain tolerance. *Nursing* 1999;29(12):17.

55 Passero CL, McCaffery M. The under treatment of pain. *Am J Nurs* 2001;101(11):62-65.

Nausea/Fatigue/Depression

Nausea, fatigue and depression are all common symptoms in cancer patients, both because of treatments or the disease itself. Older cancer patients appear to suffer from these side effects at levels similar to other patients. However, the problems may not be controlled as quickly or as well because of co-morbidity, frailty, fear of over-medication, and communication problems. Special attention by the health care team and family members to these problems is important.

Nutritional Support

Adequacy of nutritional support is always a difficult problem for cancer patients and becomes even more problematic with older cancer patients. Approximately 15% of community based persons over age 70 suffer from some degree of malnutrition.⁵⁶ With a diagnosis of cancer, the risks of malnourishment increase substantially and result in reduced efficacy of treatment and shorter survival. For example, cancer accounts for one half the cases of malnutrition in older institutionalized adults. Early interventions are possible to reduce the detrimental affects of this problem and should be pursued.

Transportation

According to the American Cancer Society, difficulties obtaining transportation for treatments and care represent a major obstacle to quality cancer care for older adults. New Jersey programs offer some transportation assistance but the availability of services differs significantly by region. Special efforts to enhance coordination and availability of these services are essential.

Caregivers of Older Adults with Cancer

Most cancer patients are cared for in the community by relatives or friends. As the population of older adults increases, and as they live longer with cancer as a chronic and/or terminal illness, the demand for supportive services will increase for patients as well as for caregivers. Planning for the increased demands for formal and informal services must be a high priority for policy makers, social service agencies, and the community.⁵⁷ Among the specific unmet needs of caregivers are:

- Information
- Access to and coordination of care
- Information regarding financial eligibility and assistance
- Transportation
- Bereavement services
- Respite care

It is often difficult for the care provider to balance work and family, resulting in considerable additional stress that can lead to illness, lost productivity

56 <http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijgg/vol1n1/malnutrition.xml>
57 Pandaya S. Caregiving in the United States. Public Policy Institute, AARP: Washington, DC, 2005. Available online at http://www.aarp.org/research/housing-mobility/caregiving/fs111_caregiving.html.

and wages, and family dysfunction among the caregivers. Existing programs of supportive services are used by approximately half of all caregivers. Caregivers also experience considerable economic and emotional strains including needing to take time off work without pay to care for their family member, increased costs for necessary services, and family conflict and disruptions.⁵⁸

A very small percentage (8%) of caregivers report ever using a service to temporarily relieve them of care giving duties, and even fewer claim to have ever enrolled their family member in an adult care facility or senior center program.⁵⁹ Caregivers' own health and well-being are also of concern with more than half reporting some level of emotional stress from care giving.

The New Jersey Department of Health and Senior Services has expanded informational resources, case management and respite care services in recent years for caregivers, but future demand will expand dramatically as populations grow and adequate support for those providing this care remains a major issue. For older adults who do not have caregivers on whom to rely, hired assistance such as Home Health Aids (HHA) or Geriatric Care Managers often become a necessary expense resulting in difficult financial choices. However, there is currently a significant shortage of such personnel.

58 Spector J and Tampi R. Caregiver depression. *Ann Long-Term Care* 2005;13(4):34-40.

59 Spector J and Tampi R. Caregiver depression. *Ann Long-Term Care* 2005;13(4):34-40.



Part 5

Facing the Challenge

In the face of a projected higher cancer burden among the aging population than national estimates, New Jersey must provide leadership in addressing the four critical issues related to cancer among the State's aging population.

It is suggested that many of the recommendations included in this report be reviewed for possible integration into the state's comprehensive cancer plan, especially as they relate to professional training, cancer prevention screening and improved palliation for the elderly. Collaboration with the Division of Aging and Community Services and other key stakeholders will be critical to this effort. It is essential that communication among oncology and geriatric communities is enhanced to assure a comprehensive and inclusive approach to the special needs of this population.

It is also strongly recommended that the New Jersey Commission on Cancer Research, the Cancer Institute of New Jersey and other research partners join together in addressing those critical issues involving cancer research and aging.

Recommendations

I. Stimulate Geriatric Oncology research throughout New Jersey

Provide grants to stimulate geriatric oncology research in New Jersey

Establish dedicated funding to award seed grants to investigators and multidisciplinary research projects through the New Jersey Commission on Cancer Research to stimulate fundamental, clinical and psychosocial research on cancer in older adults. The established grant mechanism and proven track record renders the NJCCR most appropriate to undertake such an effort. The funding would support innovative research and provide a core foundation for development of larger research programs that can compete nationally.

- Support competitive funding opportunities for geriatric oncology and cancer and aging for basic, epidemiology, clinical and psychosocial/nursing research studies.
- Provide research fellowships for promising students seeking to study cancer and aging.
- Create a multidisciplinary, multi-institutional advisory group on Geriatric Oncology Research to promote research on Cancer in Older Adults under the umbrella of the NJCCR.

Encourage leadership by New Jersey research institutions in Geriatric Oncology

New Jersey is well positioned to become a national leader in geriatric oncology research. Research institutions throughout the State should be encouraged to develop core strengths in geriatric oncology research, support collaboration among cancer and aging researchers, advance clinical trials and disseminate research findings related to geriatric oncology research.

- Sponsor a research roundtable that brings national and state leaders together to develop strategies to expand geriatric oncology research and training at NJ institutions.
- Support recruitment of faculty with expertise in cancer and aging.
- Increase support for NJ SEER Registry, Cancer Epidemiology Services, and BRFSS data bases and encourage data linkages with national databases.

Promote membership by New Jersey researchers, physicians and providers in national organizations that foster geriatric oncology research

Groups like the Geriatric Oncology Consortium (GOC) offer an opportunity for New Jersey clinicians to gain experience and leadership in a national program that seeks to advance research in cancer among older adults. Membership throughout New Jersey should be strongly encouraged.

- Promote membership and research affiliations in the Oncology Society of New Jersey, Oncology Nursing Society, New Jersey Chapters, Association of Oncology Social Workers, NJ Region, CINJ Oncology Group and other hospital systems.
- Sponsor interactive forums and educational sessions for physicians, nurses and cancer administrators on new developments in geriatric oncology research.

II. Intensify statewide planning to deal with the growing burden of cancer resulting from the aging of the population

Support oncology-based geriatric assessment in older cancer patient.

- Address the barriers to geriatric assessment including lack of time, understanding of tools, and access to follow-up interventions.
- Promote the integration of multidisciplinary assessment tools to identify and address specific needs of the older adult with cancer.
- Expand the role of nurse practitioners and other appropriate providers in undertaking geriatric assessments.
- Promote use of assessments at every patient visit to assure continued quality care.

Promote senior services aimed at wellness and improved outcomes in cancer

- Expand senior wellness education programs to include segments on cancer screening and prevention.
- Encourage cancer organizations and agencies throughout New Jersey to include prevention and screening services for older adults with cancer.

Assure quality of care for all older adults with cancer, especially minorities and the medically under-served

- Encourage development of age-sensitive educational materials and cancer specific information (large print, low literacy).
- Address common obstacles to access such as lack of transportation, limited resources, language barriers, risk of violence and health related services such as nutrition and self-care.
- Identify the frail elderly to providers to assure appropriate interventions and assistance.
- Increase sensitivity to common behavioral aspects of older adults including increased fears and feelings of vulnerability, fatalism, and reduction in mental sharpness, etc.

III. Expand educational opportunities in geriatric oncology for all health providers

Incorporate geriatric oncology curricula at UMDNJ and other academic centers in New Jersey for physicians, nurses, social workers, pharmacists and allied health professionals

- Support curricula change in medical, nursing, pharmacy and allied health education in geriatric oncology.
- Expand fellowship opportunities for physicians, nurses, social workers, pharmacists and other health care providers that integrate oncology and geriatrics.

Increase opportunities for continuing education in geriatric oncology throughout New Jersey

National groups including the American Society of Clinical Oncology and the Oncology Nursing Society (ONS) have recognized the need to improve current practice in treating older adults with cancer through continuing education programs. Continuing education curricula are available from these groups for use in hospitals, academic centers and specialty groups.

- Sponsor a major conference on Cancer and Aging every two years for physicians, nurses, social workers and allied health professionals.
- Support continuing education training on geriatric oncology with state academic institutions, professional associations, and hospitals.
- Increase awareness of cancer screening recommendations and the need for geriatric assessments for older adults with cancer for primary care physicians.

Promote education in palliation and hospice for all providers throughout New Jersey

- Initiate palliative care fellowships in New Jersey for physicians and nurses including support for a Geriatric Advanced Nurse Practitioner certification in New Jersey.
- Support continuing education in long term care facilities, assisted living and home care programs.
- Sponsor incentive based workshops, conferences and online training for all health professionals on a regular basis.

IV. Increase supportive care services for older adults with cancer

Enhance Home Care Services

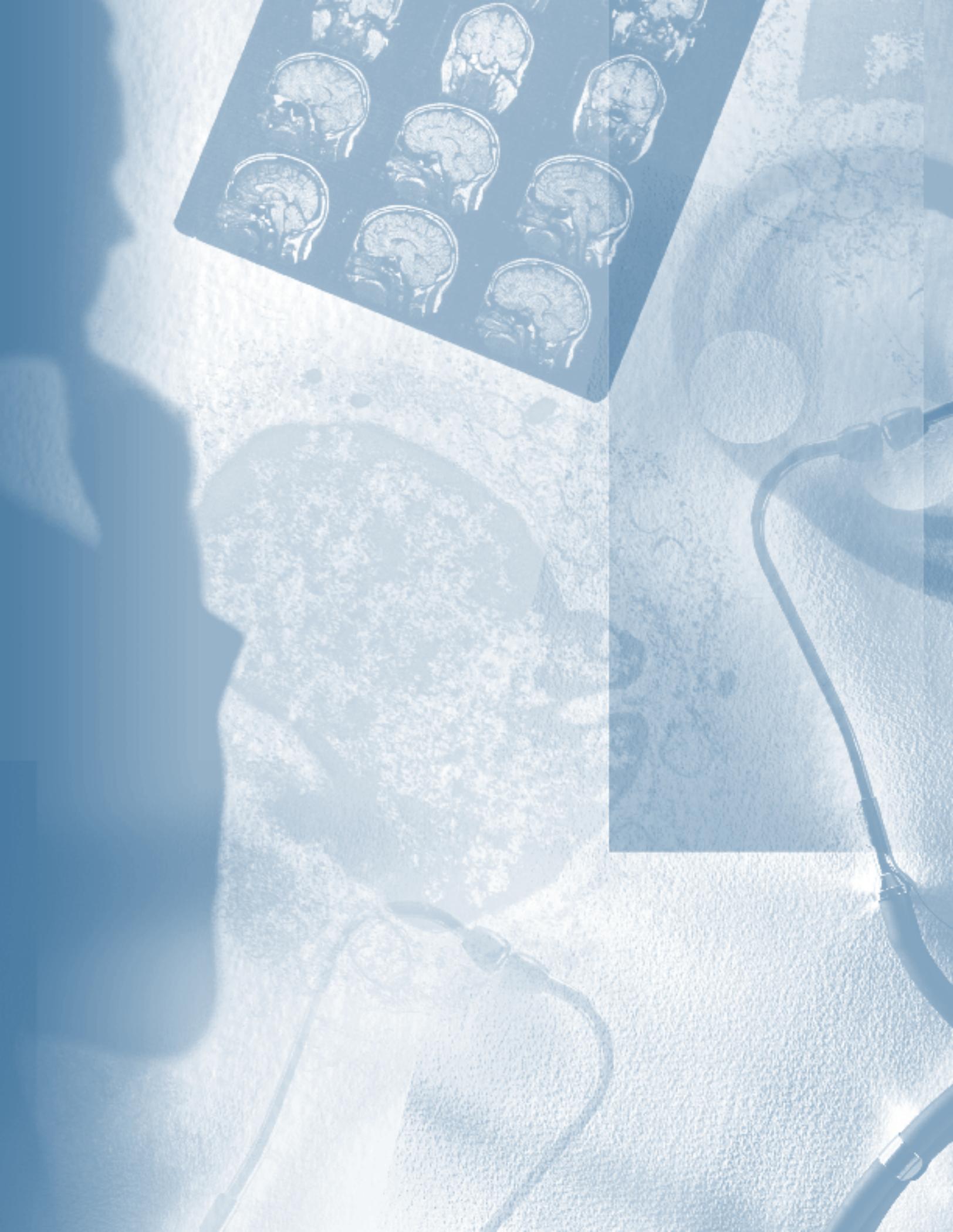
- Improve the transition from the hospital setting to home care.
- Encourage policies and programs that enhance reimbursement for palliative care in the home setting.
- Improve communication among providers and caregivers to assure comprehensive and coordinated compliance.

Support Symptom Management, Palliative Care and Hospice

- Strengthen pain management policies to assure access to appropriate medications.
- Improve reimbursement policies for palliative care services.
- Develop strategies to deal with the late entry of many patients into hospice programs.
- Continue to make practitioners aware of the importance of psychosocial, economic, and personal factors in affecting patient's well-being, and health outcomes.

Strengthen Caregiver Support Services

- Reduce the fragmentation of services through improved cancer care management and cancer navigator systems.
- Provide cancer specific caregiver training to assure compliance and quality of care.
- Expand respite care, counseling services and support groups to reduce stress and burnout in caregivers of older adults with cancer.
- Identify innovative strategies for the recruitment and training of Home Health Aides and Certified Nursing Assistants.
- Publicize currently available programs that support caregivers through mass distribution of the *Caregiver Best Practices in New Jersey* resource book from the New Jersey Department of Health and Senior Services.
- Disseminate information widely about the toll-free number of the ADRC/NJEASE to provide one-stop source of information about programs and services available to cancer patients and caregivers.



Resources In New Jersey

ADRC/NJEASE

The Aging and Disability Resource Connection which serves as the new single entry point, is a one step senior service delivery system for seniors and people 18 years and older with physical disabilities. Connections to many of the programs listed below can be obtained by calling this toll-free number **1-877-222-3737** or go online to www.adrcnj.gov.

The following programs are designed to assist eligible people to remain in the community.

Community Choice Program

This program works with seniors and people with disabilities in hospitals or nursing homes who want to return home.

Pre-Admission Screening (PAS)

People seeking help from Medicaid to pay for in-home and long-term care services need to meet both financial and medical eligibility standards. PAS conducts clinical assessments.

Information on resources and services for older adults with cancer can be found by calling ADRC/NJEASE toll-free at

1-877-222-3737

or go online at

www.adrcnj.gov

Long-Term Care Planning

A Guide to Community-Based Long Term Care in New Jersey

It is important to plan now for long-term care needs you may encounter as you age. This on-line guide can help you make the right choices now for a secure future.

<http://www.state.nj.us/health/senior/lcguide.shtml>

Adult Day Care

Adult Day Health Services

Adult Day Health Services provide a safe environment for the frail and elderly during the day when their caregivers are at work. Some health-related services are provided.

Alzheimer's Adult Day Services

This program partially subsidizes the purchase of adult day care services for persons with Alzheimer's disease or a related dementia.

Social Adult Day Care

This adult day care option is for individuals who do not need medical attention during the day, but may need supervision to ensure their safety and well-being.

Home and Community-Based Programs

Global Options (GO) Nursing Facility Transition (NFT)

GO NFT is a new program for nursing home residents wishing to return to the community. It allows eligible participants to hire qualified family members, friends or neighbors as service providers.

Community Care Program for the Elderly and Disabled (CCPED)

This program provides case management, home health, homemaker, medical day care, non-emergency medical transportation, respite care, social day care and prescribed drugs for eligible individuals living in the community.

Congregate Housing Services Program

This program provides supportive services to individuals who are elderly and disabled residing in selected subsidized housing facilities.

Adult Family Care

Adult Family Care is a community program in which up to three people receive room, board and other supportive health and social services in the home of another person. It is sometimes called adult foster care.

Assisted Living

Assisted Living is a Medicaid Waiver program that enables individuals, at risk of placement in a nursing facility and who meet certain income and resource requirements, to receive a broad array of supportive and health services by residing in an assisted living facility.

Assisted Living Programs in Subsidized Housing

This program funds personal care, nursing, pharmaceutical, dietary and social work services for individuals residing in publicly subsidized housing.

Caregiver Assistance Program (CAP)

CAP is a Medicaid program designed to supplement the assistance an individual receives from his/her natural support network of family, friends, and neighbors, as well as from community agencies and volunteer groups. It provides 13 in-home services for eligible individuals and provides consumer-directed services. The Client-Employed Provider service option allows a participant to work in collaboration with his/her Care Manager to employ his/her own provider and direct his/her own care.

Jersey Assistance for Community Caregiving (JACC)

JACC is very similar to CAP, however it serves individuals with slightly higher incomes. Based on the results of a clinical assessment, a Plan of Care (POC) is developed collaboratively by the participant and his/her Care Manager. All JACC participants receive Care Management services. In addition, the POC specifies other services to be delivered, which may

include:

- Respite Care
- Homemaker Services
- Environmental Accessibility Adaptations
- Personal Emergency Response Systems (PERS)
- Home-Delivered Meal Service
- Caregiver/Recipient Training
- Social Adult Day Care
- Adult Day Health Services
- Special Medical Equipment and Supplies
- Transportation
- Chore Services
- Attendant Care
- Home-Based Supportive Care

Statewide Respite Care Program

This program provides relief for unpaid caregivers by ensuring their loved ones are cared for while the caregiver takes personal time. This program includes a Caregiver Directed Option.

Disability Services

The Division of Disability Services in the New Jersey Department of Human Services is a single point of entry for all people seeking disability related information in New Jersey. For more information, call 1-888-285-3036 (toll free). The Division also has available a statewide directory that provides a comprehensive list of services and programs offered to New Jersey residents living and working with disabilities, *Resources 2006*.

Community Resources for People with Disabilities Waiver (CRPD)

The program is designed to provide services in addition to full Medicaid benefits to people who otherwise would be unable to live in the community and would probably have to move into a nursing home or other institution. Additional services included in the waiver are case management, environmental/vehicle modifications, community transitional services and personal emergency response systems (PERS). Up to 150 individuals enrolled in this waiver are also eligible to receive private duty nursing services.

Personal Care Assistant (PCA) Services

This is an optional benefit offered to New Jersey Medicaid beneficiaries who are experiencing some functional impairment and need a Personal Care Assistant to help them with some aspects of daily living; such as dressing or bathing. Recipients must have a doctor's order to receive this service, but they do not have to be permanently disabled. An estimated 16,000 people receive this service at any given time.

Personal Assistance Service Program (PASP)

PASP provides routine, non-medical assistance to adults with disabilities who are employed, involved in community volunteer work, or attending school. Personal assistants help with tasks such as light house keeping, bathing, dressing, preparing meals, shopping, driving, or using public transportation. The number of hours a person receives depends on individual need; up to 40 hours per week. This program differs from many other personal assistance services programs in that the people with disabilities direct their own services.

Personal Preference: New Jersey Cash and Counseling Demonstration Project

This initiative allows Medicaid recipients with disabilities who are eligible for Medicaid PCA services to direct their own care. Through use of a monthly cash allowance, participants work with a consultant to develop a cash management plan by which they decide the services needed and the individuals and/or agencies to hire to provide the identified services. The program requires greater consumer responsibility but offers participants greater control, flexibility, and choice.

Office of Ombudsman for the Institutionalized Elderly

The Ombudsman for the Elderly helps protect long-term healthcare facility residents aged 60 years or older from abuse, neglect or exploitation by conducting investigations and responding to complaints. Concerned persons can call 1-877-582-6995 or write to: The Ombudsman for the Institutionalized Elderly, PO Box 852, Trenton, NJ 08625-0852.

The Public Guardian for the Elderly

The Office of the Public Guardian is a State agency that makes legal, financial and healthcare decisions for individuals age 60 and older who have been determined by a Superior Court judge to be incapacitated. Call NJEASE to get connected (1-877-222-3737).

American Association of Retired Persons

AARP is a nonprofit, nonpartisan membership organization for people age 50 and over, dedicated to enhancing quality of life for all as one ages. AARP also provides a wide range of unique benefits, special products, and services for our members.

1-888-OUR-AARP (1-888-687-2277)

<http://www.aarp.org/>

