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Editor: Kathleen Neville, Ph.D., RN

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The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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Addressing Cancer Among Older Adults in New Jersey

by
Stasia S. Burger, MS, CTR
Cancer Epidemiology Services
New Jersey Department of
Health & Senior Services

In New Jersey and nationally, over half of all newly diagnosed cancers occur in adults age 65 and older. In New Jersey, 64% of men and 58% of women who are newly diagnosed with cancer are age 65 and older; therefore this age group bears the greatest burden of cancer. To address this problem, the New Jersey Department of Health and Senior Services developed a report titled, "*Cancer Among Older Adults in New Jersey, 1994-1998"*. This report is designed to examine the incidences and trends of cancer among New Jersey's older adults from 1979 through 1998 with special attention to the years 1994 through 1998.

IN THIS ISSUE

The number and proportion of older adults (age 65 and older) in the U.S. population are increasing dramatically. According to the U.S. Census (2000), 34.9 million people or 12.4 percent of the U.S. population are older adults. By 2030, the proportion of older adults is expected to be 20 percent of the entire U.S. population. Currently, in New Jersey, the proportion is even higher; about 13.2 percent or 1.1 million people are age 65 and older. Those age 85 and older are the fastest growing segment of this population.

Cancer is a group of more than 100 different diseases primarily affecting older adults. Due to the anticipated future growth in the number and proportion of older adults (in the U.S. and New Jersey) and because of substantial increases in life expectancy, the proportion of all cancers in this population is likely to increase.

Cancer among older adults presents special challenges. Older adults often comprise a more physically and financially vulnerable population, although there is a broad variation in health and economic status. Older adults may have limited access to medical care due to health, social, or income restrictions. Some may therefore receive sub-optimal quantity or quality of medical care. Co-existing health conditions, or co-morbidities, create special clinical challenges. However, the evidence is growing that effective treatment strategies leading to improved clinical outcomes in older adults with cancer are possible.

The *Cancer Among Older Adults* report analyzes three older adult age groups: the "young old", age 65-74, the "older old", age 75-84, and the "oldest old", age 85 and older. Age-specific incidence and mortality rates by gender and race are presented for cancers common in these three age groups. Stage at diagnosis is reported for cancers for which techniques for early detection are available and recommended. Some New Jersey comparisons with national cancer rates in the aging population are also presented.

Both incidence and mortality rates for total cancer have been higher for each successive age group in New Jersey. In recent years, incidence rates in the oldest old (age 85 and older) have converged toward the older old (age 75-84) for both men and women. Declining prostate and colorectal cancer rates may explain this trend among the oldest men, and declining uterine and colorectal cancer rates may be responsible for the trend among the oldest women. Incidence and mortality rates vary greatly by gender among older adults. Incidence rates for older men are higher than rates for older women, especially for men age 75 and older. Mortality rates for older men are also higher than rates for older women and share a similar pattern over time.

An early stage at diagnosis is important for predicting a good prognosis and successful treatment of many cancers at any age. A favorable pattern for stage at diagnosis shows a higher proportion of cancer diagnosed as *in situ* or localized. Among older adults in New Jersey, favorable patterns for stage at diagnosis are seen for female breast cancer, prostate cancer and melanoma of the skin, which may be the result of effective screening. Less favorable patterns for stage at diagnosis are seen for cervical, colorectal and

oropharyngeal cancers. Better screening efforts among older adults and their physicians may increase the detection of these cancers at an earlier stage.

Also in this report, cancer incidence and mortality rates for older adults in New Jersey and the U.S. are compared by site, gender, and race for the time period 1994 through 1998. New Jersey incidence rates for men and women age 65 and older are generally higher than those for the total U.S. However, lower incidence rates are seen for leukemia, multiple myeloma and oropharyngeal cancers compared with the U.S. Lower overall mortality rates are seen among older black men in New Jersey compared with the U.S. Some lower mortality rates are also seen in New Jersey with lung, cervical, uterine, multiple myeloma and pancreatic cancers for various age groups, genders and races compared with the U.S.

With the rising number and proportion of older adults with cancer in New Jersey anticipated in the future, attention should be given to interventions that will decrease the burden of cancer among adults. There are many needs and opportunities for research to understand the issues of early diagnosis, treatment and support of older adults with cancer. For example, research should address the variation in incidence patterns by age, gender and race such as black males age 75 and older having the highest cancer rates. Early detection research needs to investigate the finding that later stage oral cancers among older adults possibly indicates the need for increased screening by dentists or that later stage cervical cancer among older women possibly indicates the need to change screening age recommendations. Such research could lead to improvement in screening and decreased cancer incidence. Data from the New Jersey State Cancer Registry (NJSCR) may provide researchers with important tools to address these issues.

We need to develop effective screening policies and treatments guidelines for older adults, which take into account competing health problems. Additional research needs include cancer mortality rate disparities among races, e.g. in relation to application of, or access to specialized treatments. Research can also address co-morbidities and treatments, practice guidelines for screening and treatments, the role of palliation, as well as the economic and social implications of the increased burden of cancer.

Participating in the Cancer and Aging: A Call to Action conference is an important step in addressing the commitment New Jersey continues to have in the war against cancer. The energy and enthusiasm generated by the meeting provided the spark to change the way in which older adults are viewed, served and cared for in New Jersey.

For this report, New Jersey cancer incidence data were provided by the New Jersey State Cancer Registry. U.S. cancer incidence data were provided by the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. Cancer mortality data were provided by the National Centers for Health Statistics (NCHS) through the National Vital Statistics System, which covers the entire United States. This report is available in its entirety from the New Jersey State

Dept. of Health's Cancer Epidemiology Services and is also available on the web at http://www.state.nj.us/health/cancer/statistics.htm.

Cancer and Aging: A Call to Action
OVERVIEW

by

Barbara Rabinowitz, PhD
Director for Oncology Services
Meridian Health System

How gratifying to watch a room full of professionals representing multiple health care domains come together around the right topic for the right reasons and in the right spirit. Following, you will find a summary of the uniformly excellent presentations with which attendees of the Cancer and Aging: A Call to Action conference were delighted and educated. But first let me share a few words about what this means to us in New Jersey.

As one might hope, attendance at this two-day conference covered many specialties including medical oncology, geriatrics, radiation oncology, social work, nursing, epidemiology and others. These specialists found much about this robust conference to enhance their understanding of the interface between senior status, co-morbidities, cancer and their specialties. The audience welcomed the opportunity to review our current understanding of how the needs of the geriatric cancer population may be different form younger counterparts facing similar diagnoses and treatment, and how they often may be the same. The attendees seemed deeply committed to expanding their understanding of the senior cancer patients. However, it was also evident, and the speakers took the attendees through each domain, that we have learned little to date empirically regarding the screening and treatment nuances that should be guided by broad range of factors impacting the more elderly cancer patient. It seems clear that the scientific community has failed to engage the older cancer patient in clinical trials, thereby leaving us with less scientifically generated guidelines on which to base screening, treatment and rehabilitation decisions. While we decry the paltry number of adult cancer patients who enter clinical trials, the number of older patients on trial pale even in comparison to that. Presenters noted that the next challenge for healthcare is to better involve our senior patients in clinical trials that will help answer questions that will positively impact their care. We must work to understand the myths and misinformation that provide barriers to seniors involving them in research, and even possibly, to health care providers offering seniors the opportunity to participate in trials. I do not believe it is just a matter of promoting the benefits of trials. Without understanding and addressing the barriers, there is an insidious back pull against trials involvement and we will remain impoverished.

The presenters sounded a hopeful note, as they, almost to a person, congratulated New Jersey for taking a position on the topic of cancer and aging. They were enthusiastic and noted that optimism that they experienced in seeing this topic step up for its more than due attention here in New Jersey, noting how few states have begun to address these issues. And they were quick to note that the position that New Jersey has taken has real merit, and was given added thrust with the announcement at the conference by Assistant Commissioner for

Health and Senior Services, Dr. Eddy Brusnitz, of a Cancer and Aging Grant Request for Applications. Now the ball is in the court of the New Jersey research community to begin this quest to better understand the special needs of our senior cancer patients. And so we begin.

Cancer and Aging: A Call to Action
October 4-5, 2002
CONFERENCE HIGHLIGHTS

by

Denyse Adler, MA
President
The Adler Group

Exploring what is known and unknown about the unique aspects of cancer in the older adult was the challenge to a number of nationally recognized authorities presenting to the New Jersey healthcare community. Despite the significantly accelerating numbers of older adults with cancer, and the reality that more than one half of all new cancer diagnoses are found in this population, little special attention has been paid to meeting their unique and complex needs. Conference participants shared persistent concerns about the lack of research focus and dissemination of information, frustrations relative to minimal or diminishing resources, and the urgency imposed by the scope of the rapidly growing population to be served. The conference, chaired by Drs. William A. Lerner, and David J. Sharon, was sponsored by the New Jersey Commission on Cancer Research (NJCCR), Meridian Health System and Saint Barnabas Health System, with administrative support from the UMDNJ-School of Public Health.

Some of the specific issues that make cancer in the older population such a challenge include:

- Increased and complex co-morbidities
- Myths and biases regarding the ability of older adults to tolerate treatment and their interests and concerns
- Ethical and compliance issues in treatment decisions and clinical trial participation
- Lack of age-appropriate prevention, screening and surveillance protocols
- The psychosocial impact of disease, treatment and vulnerability in the aging
- Special concerns regarding palliative care including pain and symptom control
- Differentiating among “older and younger” seniors
- Disparities in access to care among minorities and individuals with limited fixed resources
- The disproportionate burden cancer represents for older citizens, including costs, a dearth of specially prepared professionals and facilities, and research funding.

The complexities of addressing the specific needs of this population prompted the participants to recommend the immediate development of a collaborative *New Jersey Cancer and Aging Task Force* which would coordinate with ongoing efforts in the state directed at the older adult, as well as cancer-focused programs. Typically, problems associated with aging represent little space in medical school and health professional curricula and often attract only minimal attention in clinical training. This has permitted the present dilemma; too little evidence based data, a dearth of research on drug and treatment impact on the older adult, and

the proliferation of myths that impede a reasoned and appropriate approach to comprehensive treatment of this population.

- Myths and misconceptions abound about the aging, including their "inability to tolerate" aggressive treatment, the view of older adults a homogeneous group who don't want information, are often depressed, unable to make decisions, and more willing to easily accept death. A consensus was achieved about the importance of education to eradicate such inaccurate views.

- While the incidence of co-morbidity and increased vulnerability may affect some older adults, many are healthy and able to support more aggressive treatment regimens. It is understood that co-morbidity may impose additional risks and decreased life expectancy, none of these conditions should restrict consideration of appropriate treatment approaches unilaterally. Assessment tools are available to assess the benefits versus the risks of treatment of each individual. Treatment decisions should be based on evidence-based data, as well as the patient's goals and quality of life assessment.

- The impact of age on tumor growth, progression and natural history of the disease is not well understood. While it is clear that older adults can tolerate treatments that had earlier been considered too rigorous and debilitating, research is lacking in defining exactly how older patients metabolize drugs and respond to new treatment modalities. Medications generally have a longer half-life in the elderly and little information is available to direct the clinician in this regard. The disease itself may have a different natural history or trajectory in the older adult, and differential responses may include gastro-intestinal function, skin changes, dehydration, renal function and drug distribution. Patient's must respond to such questions as:

- How do you value physical capability and what is most important to you

- Who do you want to make medical decisions if you cannot

- What are your specific instructions in the event you cannot share communicate your decisions

The controversy surrounding screening and surveillance for all populations is exacerbated in the older adult. With the lack of randomized trials focused specifically on the older adult, it is difficult to define an appropriate screening protocol, especially with the differential comorbidities and physical capabilities encompassed by the 30-40 years generally labeled "elderly." Some national organizations place an upper limit on recommended screening; others leave this question to the analysis of the practitioner.

- Psychosocial distress in cancer was defined as "an unpleasant emotional experience of a psychological, social and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fear to disabling problems such as depression, anxiety,

panic, social isolation and spiritual crisis." Decisions about the course of treatment, or its termination must be controlled by the patient's goals. These generally include control of symptoms, assurance of a central role in future care plans, and support from family and professionals.

Depression is a co-morbidity that is poorly recognized and often under treated. Patients often experience significant grief reactions and this also plays a role in treatment response.

Screening of this population should include cognitive deficits, social support, nutrition and medication induced responses.

- The economics of cancer are imposing; in 2001 more than $156 billion was spent on cancer, and this is estimated to increase as the population ages. Existing workforce shortages will become exacerbated as the need escalates for physicians, nurses, support services and surrogate caregivers, while Medicare and Medicaid spending, already considered to be growing uncontrollably will have to expand. A dearth of healthcare providers with special training in geriatric care and expertise in adapting treatment modalities will significantly limit the quality of care for the expanding population of older adults.

- Palliative care is a philosophy of care that incorporates the management of physical, emotional, social and spiritual suffering, and which should be initiated at the outset of the diagnosis. The visibility of Palliative Care has increased significantly in recent years, but may not be applied equivalently in older adults who might not have functioning primary care givers in the home, or may be reluctant to accurately report distress.

- The intense competition for research funding has constrained the initiation of new studies relative to the biology of cancer and aging, and clinical treatment directed to the older patient. Participation in clinical trials has been limited as a result of misconceptions on the part of both physicians and patients/families: stringent eligibility criteria, coexisting medical conditions, costs and logistical barriers. Some of the areas to be explored include: the natural history and biology of cancers of the aging, differential physiologic changes, age related factors which might contributing to tumor growth, and strategies which might more effectively address aging the cancer.

It is hoped that the energy and enthusiasm generated by the meeting will provide the spark to change the way in which older adults are viewed, served and cared for. The reality was clear: this is about all of us – each one of us and the patients we serve will be, sooner or later, in this population – and time is flying.

State of New Jersey
Commission on Cancer Research
28 West State Street, RM 505
PO Box 360
Trenton, NJ 08625-0360

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