A Special Report of the New Jersey Commission on Cancer Research

Cancer and Aging: A Call to Action

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Dear Colleagues:

As you may know, the *Cancer and Aging: A Call to Action* conference was held on October 4 & 5, 2002 at the Westin Hotel in Princeton, NJ. We are pleased to share the outcome of this exhilarating and inspiring conference that addressed the unique aspects of cancer in the older adult; what we know and what we don't know. Nationally recognized authorities highlighted the special and complex needs of this underserved population, including such issues as: the economics of cancer among the aging, co-morbidities, treatment options, screening interventions and clinical trials, among other topics.

Participants also shared pressing concerns about the absence of research focus and dissemination of information. Frustrations over minimal or diminishing resources were voiced and the urgency imposed by the scope of the rapidly growing population to be served was given unmistakable expression.

The deliberations of the conference produced a consensus on the importance of a collaborative and coordinated approach to this population. It is our hope that the proposed *New Jersey Cancer and Aging Task Force*, properly funded and under the aegis of the New Jersey Commission on Cancer Research, will be able to get to work immediately. There is every reason to believe that the energy and enthusiasm generated by the conference will provide the spark to change the way in which older adults are viewed, cared for and served. Given the urgency of the issues, there is little time to waste.

We are grateful to the sponsors and benefactors who made this pioneering conference possible. We hope that you, whether you attended the conference or not, will become involved in the collaborative effort to move New Jersey forward with exciting and innovative approaches to the special and complex needs of older adults with cancer. We look forward to working with you to achieve these goals.

Sincerely,

William A. Lerner, M.D.
Co-Chair

David J. Sharon, M.D.
Co-Chair

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Cancer and Aging: A Call to Action

SCOPE OF THE PROBLEM

Despite the significantly accelerating numbers of older adults, 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. The aging population presents specific and compelling challenges to the healthcare community.

It is no longer rational to relegate the "elderly" to second class status in research, healthcare delivery and focused resources:

- More than 35 million people in the United States (1.1 million in New Jersey) are over age 65; approximately 13% of the population.
- With the exponential growth of the population and extended life expectancy, this figure will accelerate; by 2030 one in five Americans will be age 65 and older.
- In addition, more effective healthcare has ensured that more individuals are surviving to the"oldest of the old" category; by 2030 it is anticipated that more than 8.5 million people will be age 85 and older.

Moreover, the rate of cancer in the older population is disproportionately high. In New Jersey, 64% of men newly diagnosed with cancer are age 65 and older; for women, 58% of the newly diagnosed are 65 and older. Both incidence and mortality are higher for each successive age group.

Presenters identified some crucial concerns, which include:

MYTHS AND MISCONCEPTIONS

Myths and bias' abound about the aging, including their"inability to tolerate" aggressive treatment, and the view of older adults as a homogeneous group who don't want information, are often depressed, unable to make decisions, and are more willing to easily accept death. It is a disservice to refer to all patients over age 65 as one generic group. As might be expected, there are significant differences in the more than thirty years which might follow, and it is imperative that distinctions be drawn between "young old" and "old old," as well as between those functioning actively and those with limited functional status – at any age.

Educational programs are necessary to provide information and to acknowledge the extent to which lack of science-based evidence and information have resulted in the exclusion of older patients in clinical trials, new treatment modalities, or decision-making roles. Gerontology must be integrated into the training programs of all health professionals and broad public education undertaken.

COMORBIDITIES & TREATMENT DECISIONS

It is well documented that comorbidity elevates the risk of death among cancer patients and that age increases the risks of comorbid conditions. While the incidence of comorbidity and increased vulnerability may affect some older adults, many are healthy and able to support more aggressive treatment regimens. Tolerance to treatment and potential benefits are impacted by the presence of complicating conditions, as well as age and attitude.

Although comorbidity 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 evaluate the benefits versus the risks of treatment for each individual. Treatment decisions should be evidence-based and data driven. Patient's goals and quality of life assessment should also be considered.

Aging patients may have different physical responses to disease and treatment than younger patients. These differences may include gastro-intestinal function, skin changes, dehydration, renal function and drug distribution. Tools also exist to assist the healthcare practitioner ask appropriate questions and assess the patient's goals and interests. Such questions should include:

- 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?

SURVELLIANCE AND SCREENING

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.

It is appropriate to evaluate comorbidities in developing a screening and prevention protocol for older patients. For example, in some studies, women with severe comorbid conditions had uniformly higher mortality rates, and early diagnosis conferred no survival advantage with screening. Decisions relative to appropriate screening should attempt to answer the question, "Will the patient be more likely to die of the cancer, or with it?" Factors to assess include:

- An estimate of the patient's survival prospects including age, a functional assessment (possibly ADL) and comorbidities;
- The estimated benefits and risks of screening; controversy surrounds many accepted screening technologies such as mammography, Pap, and PSA among older adults; and
- The patient's attitude and wishes relative to aggressive screening and detection.

PSYCHOSOCIAL FACTORS

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. Factors to be considered include control of symptoms, assurance of a central role in future care plans and support from family and professionals.

Depression is a comorbidity that is poorly recognized and often undertreated. Patients may be experiencing significant grief reactions which can play a role in treatment response. Screening of this population should include cognitive deficits, social support, nutrition and medication induced responses.

PALLIATIVE CARE

Palliative care is a philosophy that incorporates the management of physical, emotional, social and spiritual suffering, and should be initiated at the outset of the diagnosis. All patients living with chronic, life-threatening or terminal illness can benefit from this approach, and consequently, it should be applied to the care of the older adult, whose need for support, symptom control and attention to emotional and spiritual concerns are exacerbated by illness.

While the visibility of palliative care has increased significantly in recent years, it 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. Pain and other symptoms are often severely underestimated and undertreated in the elderly, and may be especially problematic in some institutional settings.

Some of the factors that may inhibit the use of palliative care measures include:

- Misunderstanding about the term "palliative" and an incorrect sense that it means giving up;
- Fear of accepting pain or symptom management protocols amid myths about addiction;
- Limited expertise in the medical community, and aversion to complementary approaches;
- Financial or regulatory glitches; and
- An often "paternalistic" medical care system that discourages patient/family participation.

ECONOMICS OF CANCER AND THE ELDERLY

The economics of cancer are imposing; in 2001 more than $156 billion was spent on cancer, and this number is estimated to increase as the population ages. Existing workforce shortages will worsen as the need escalates for physicians, nurses, support services and surrogate caregivers. Medicare and Medicaid spending, already considered to be growing uncontrollably, will have to expand even further. 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.

Current reimbursement does not acknowledge the additional time often required to diagnose and treat multiple comorbidities. The lack of reimbursement for pharmaceutical treatments will limit access of older adults to adequate care. In addition, pressure is necessary to ensure that new, advanced technologies are reimbursed under the Medicare/Medicaid structure.

RESEARCH AND CLINICAL TRIALS

The intense competition for research funding has constrained the initiation of studies relative to the biology of cancer and aging, as well as screening, clinical treatment and the quality of life 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. Factors that may restrict participation include: stringent eligibility criteria, coexisting medical conditions, costs and logistical barriers. Some of the essential issues to be explored include:

- How the natural history of some cancers change with age;
- The physiologic changes in older persons that may impact treatment choices;
- Validation of geriatric functional and comorbidity scales in oncologic trials;
- Age-related factors which might contribute to tumor growth;
- Differential experience of similar tumors in older and younger populations;
- Appropriate surveillance and screening practices in the older adult;
- Elderly populations at high and low risk for cancers; and
- Quality of life concerns and support services forthe elderly.

CONCLUSIONS AND RECOMMENDATIONS: MOVING FORWARD

The consensus flowing from the conference was the immediate development of a *New Jersey Cancer and Aging Task Force*, to promote a statewide, comprehensive and flexible vehicle to identify priorities and design innovative implementation strategies to address the emerging and significant issues raised. The Task Force would include and collaborate with ongoing efforts in the state already directed at the older adult, as well as cancer-focused programs, to ensure a minimum of redundancy. Efforts to reduce the disparity of access to care among minority groups within the older adult community were identified as a high priority.

After consideration of several possible organizational structures including legislative, gubernatorial and the New Jersey Department of Health and Senior Services-created entities, it was agreed that the New Jersey Commission on Cancer Research, as a state agency with broad experience supporting advisory boards/task forces and a demonstrated commitment to these issues, was the most suited to sponsor the Task Force under its administrative umbrella. This is especially appropriate as the conference findings indicated a significant need for research in this area.

NEW JERSEY CANCER AND AGING TASK FORCE

MISSION

Assess the specific and unique burden of cancer on older adults in New Jersey and identify strategies to improve cancer care and quality of life through:

- Accelerated education;
- Research;
- Responsive policy and regulatory advances;
- Advocacy for dedicated resources and care; and
- Effective changes in the delivery of healthcare.

GOALS

- To assess and catalogue the existing resources in the state that deal with the elderly and cancer.
- To provide a thoughtful and studied assessment of future needs based on a rigorous review of projected demographics and trends in cancer and aging.
- To formulate recommendations for adequate and appropriate resources to meet those needs.

PARTICIPATION

A preliminary discussion of the appropriate partners for the Task Force identified a broad range of governmental and private agencies and citizen-based organizations. The members should represent:

- Healthcare professionals in oncology, geriatrics and related sub-specialties;
- State cancer control functions;
- Public health functions of screening and epidemiology;
- Senior services;
- Academic medicine and nursing;
- National organizations, including those directed to aging;
- Faith-based communities;
- Long-term and institutional care;
- Diverse ethnic and religious minorities; or
- Managed care and other third-party payers.

STRUCTURE

The Task Force should include 18-25 members, including the organizations and individuals representing the groups identified above. Appointments will be made by the New Jersey Commission on Cancer Research in cooperation with the key stakeholders in the field and will be based on qualifications, interests and commitment to the goals.

ACTION STEPS

- Create the Cancer and Aging Task Force and develop by-laws and timetable.
- Identify potential Task Force members and review credentials.
- Seek start-up funding for the Task Force from the Commission and other sources.
- Conduct a comprehensive needs assessment that identifies existing resources and major gaps. Information and data already developed by governmental and private organizations will be included.
- Establish priorities and specific strategies to address the complex needs of the older adult with cancer.

Some of the specific interventions may include:

- Promote research to elucidate cancer and the aging process with special emphasis on comorbidities, screening interventions, treatment practices, psychosocial support and QOL issues.
- Educate policy and regulatory authorities about the unique problems of the older adult with cancer.
- Provide information to clinical settings about the needs and concerns of geriatric oncology.
- Target expansion of clinical trials in the state to include older adults.
- Confront stereotypical attitudes toward aging that may impact screening and treatment decisions.
- Pursue inclusion of curricula about aging in educational settings.
- Market success stories.
- Promote implementation of special programs for: social support, respite care, rehabilitation and others, as well as interventions that target elderly care givers, children and grandchildren.
- Others to be determined.

The intentions of the workshop were effectively met and efforts to address the challenges of timely, appropriate, responsive and effective cancer care for the older adult in New Jersey have been set in motion. Only an inclusive, comprehensive and energetic response will assure accomplishment of the ambitious goals outlined.

SPECIAL ANNOUNCEMENTS

At its November 14, 2002 meeting, the New Jersey Commission on Cancer Research (NJCCR) approved a motion to create a New Jersey Task Force on Cancer and Aging under its administrative umbrella. It further recommended that Drs. David Sharon and William Lerner serve as acting Co-Chairs of the group to organize and guide it in its early stages. The Commission further charged the Task Force with the responsibility of providing a written report that includes an analysis of the impact of New Jersey's growing aging population on cancer care; the identification of significant gaps in research, prevention and control, treatment and palliative care; next steps that might be required to address these gaps; and any other recommendations that might be deemed important to the group.

The New Jersey Department of Health and Senior Services has provided funds to support research grants on cancer in the older adult through the NJCCR. In addition, a special report, Cancer Among Older Adults in New Jersey 1994-1998, is available from the Cancer Epidemiology Services, New Jersey Department of Health and Senior Services.

Report Editor

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