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**ABSTRACT OF THE DISSERTATION**  
**THE INSTITUTE OF MEDICINE'S 2001 REPORT ON PALLIATIVE CANCER**  
**CARE AS AN INSTRUMENT OF INNOVATION IN PALLIATIVE ONCOLOGY**  
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This dissertation assesses the effectiveness of the 2001 Institute of Medicine (IOM) report on palliative cancer care at inducing innovations in cancer research and practice among key organizational stakeholders in the health care system, including those concerned with cancer research and the provision of health care. The IOM report on cancer palliation was written by the National Cancer Policy Board, a diverse group consisting of prominent scientists, health care providers, third party payors, social scientists, patient advocates and others who have an interest in the development of cancer research, practice, and financing. Between 1997 and 2005 the Board published reports on cancer prevention, control, diagnosis, treatment, and palliation, until it was reorganized as the National Cancer Policy Forum.

The authors of the 2001 IOM report on cancer palliation found that patients who are dying of cancer usually face an enormous burden of physical discomfort, lost functionality, and psychological stress, as well as a strong possibility of economic hardship. The authors made ten recommendations, summarized into five program areas

that address the need to improve research, practice, and reimbursement for palliative, supportive, and end-of-life care, and to improve the quality of educational materials oriented toward the patients with advanced cancer and their loved ones. Taken together these recommendations represent a complex organizational innovation, which the Board sought to induce by publishing the report.

This dissertation presents a case study of induced diffusion of innovation, by policy entrepreneurship within an epistemic community. The analysis includes review of documents, content analysis of relevant parts of the National Cancer Institute research program from 1998 – 2005 and professional journals from 1994 – 2004, and semi-structured interviews with key informants. The findings show that although the report's recommendations were sound its impact was limited by entrenched cultures at NCI and among professional groups.

## **ACKNOWLEDGEMENT AND DEDICATION**

This work is dedicated to every human being who has ever experienced symptomatic cancer and to my father, Stephen M. Hanson, MD who said "I'm a doctor. I help people!" (Summer, 1976), and to every physician who has agreed and lived that agreement.

This work would have been impossible without the wisdom of my advisor Professor Dona Schneider who with kindness brought humor to things that are not really funny, and my wife Sallie Gordon, whose patience, flexibility, and hard work at keeping things together for this project kept us in New Jersey and me working on this project.

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## CHAPTER 1. INTRODUCTION

This thesis is a policy analysis based on a case study. It evaluates the effectiveness of the 2001 Institute of Medicine (IOM) report, *Improving Palliative Care for Cancer* (Foley & Gelband), at redirecting palliative cancer care at the institutional level. The IOM report on cancer palliation recommends specific changes in the ways that palliative care for cancer is researched, practiced, and paid for by organized stakeholders within the health care system. A full assessment of the impact of the effectiveness of the IOM report would require completely addressing the areas of research, practice and finance. This thesis focuses on the first two areas, evaluating how the recommendations for research and practice in the IOM report were implemented and how they diffused throughout the health care system from a perspective of policy innovation.

The policy entrepreneurs in an epistemic community guide how that community performs its particular function. In this case, the National Cancer Institute (NCI), and through it the 39 comprehensive cancer centers and 21 cancer centers, set and finance a detailed research agenda which has been the single largest component of the National Institutes of Health (NIH) program since the end of World War II. Professional organizations defend the interests of each professional group and guide the practice of their particular professions through policy statements, symposia, professional journals and other communications. These organizations include the American Society of Clinical Oncology (ASCO) among oncologists, the Oncology Nursing Society (ONS) among oncology nurses, and the Association of Oncology Social Work (AOSW) among oncology social workers. In addition the American Cancer Society (ACS), a non-governmental organization, is named as a provider of public-oriented information about

cancer and publishes the journal *Cancer Practice* for an audience of health care providers. The National Association of Health Underwriters (NAHU) plays a similar role among private health insurance providers. Medicare and Medicaid provide health coverage to elderly Americans and certain groups of poor Americans. Medicare does this through a federal program while Medicaid funds programs in each state. All of these public sector programs were coordinated by the Health Care Finance Administration, which was reorganized as the Centers for Medicare and Medicaid Services in 2001. These stakeholders were named in the IOM report on Cancer Palliation. Each publishes a website and one or more journals.

Within diffusion of innovation theory, stakeholders advocate changes in technological and organizational practices. Policy entrepreneurs act as change agents in the policy arena. A comprehensive examination of the effectiveness of IOM as a change agent via the 2001 report on cancer palliation would determine what changes occurred during the deliberations for the 2001 IOM report on cancer palliation, how each organization sought to implement the applicable recommendations after publication, and whether the 2001 IOM report on cancer palliation is still accepted by the organizations as a basis for the evolution of palliative cancer care.

As this thesis is limited to IOM's recommendations for research and practice, it is logical to begin with an examination of innovation behavior at NCI and the comprehensive cancer centers. From the perspective of diffusion of innovations, a number of factors are examined for each innovation. These factors include: 1) the characteristics of each proposed innovation, 2) the characteristics of each stakeholder and the change agent and 3) the characteristics of the environment in which each functions.

These factors help explain why innovations are accepted or rejected, and once accepted why innovations are continued or discontinued.

The validity of the general systems approach to diffusion of innovations is assessed qualitatively. Specifically, the characteristics of NCI, the comprehensive cancer centers, and professional organizations, the IOM recommendations directed to them, and the environments in which they function are assessed qualitatively as predictors of acceptance and continued acceptance, through content analysis, document review and interviews with key informants. Documents, other data and key informants are drawn from NCI, as well as where applicable and possible, from professional organizations. Key informant interviews were used.

### **Burden of Cancer**

Cancer is the second leading cause of death in the United States and an notable burden on the health care system. The American Cancer Society estimates that in 2003, 8.9 million people in the United States were diagnosed with cancer (2003). The NIH estimate for 2002 was that cancer cost Americans \$60.9 billion in treatment expenses and \$15.5 billion in lost productivity due to cancer morbidity (as cited in American Cancer Society, 2003). The NCI estimated that in 2002, 4.7% of all medical expenditures in the United States were for cancer treatment (2003). Although new estimates show that cancer deaths dropped slightly between 1990 and 2000, cancer is expected to overtake heart disease as the leading cause of death in the United States (National Center for Health Statistics, 2003).

In the Twentieth Century, medical science was able to increase survival time with many cancers, and achieve cure with a few. Longer survival times mean that many cancer

patients suffer with advanced cancer and the side effects of treatment for extended periods. Palliative care is health care that supports cancer patients' quality of life by relieving physical symptoms and addressing psycho-social and spiritual issues. Despite broad agreement about what palliative care should be, there are substantial gaps in practice, including poor coordination of care, inadequate training in palliative care, economic barriers, and insufficient practice standards, among others. Most cancer patients will have symptomatic cancer at some point. In a 1998 *Journal of Clinical Oncology* special article, the ASCO estimated that 50% of those diagnosed with cancer die of cancer. It follows that more than half of those diagnosed must face symptomatic cancer. The ACS estimated that in 2003 there were 1.3 million new cases and 556,500 deaths from cancer in the United States (2003).

### **Recommendations of the IOM Report on Palliative Care for Cancer**

The 2001 IOM report on cancer palliation makes measurable recommendations for the mobilization of stakeholders to improve palliative care. The authors of the IOM report on palliative care recommend changes in palliative care practice, research and financing (Foley & Gelband (Eds.), 2001, pp. 50 – 53). The recommendations broadly address 1) the creation of centers of excellence in symptom control and palliative care within the comprehensive cancer centers, 2) improved reimbursement, 3) improved patient-oriented informative materials, 4) development of practice guidelines and quality indicators, and 5) institutionalization of an approach to palliative care within NCI. These are dealt with at length in the literature review.

## **Research Questions and Hypotheses**

This research seeks to determine how the 2001 IOM report on cancer palliation guided research in palliative cancer care and practice. Each of the following research questions addresses what changes occurred during the deliberations, how each organization sought to implement the applicable recommendations after publication, and if the report is still accepted by the organizations as a basis for further evolution of palliative care. For each question, the factors contributing to acceptance decisions, continuation decisions, and reinvention are addressed.

### ***First Research Question – How did the 2001 IOM report on cancer palliation impact research in palliative cancer care?***

The 2001 IOM report on cancer palliation recommended programmatic and organizational changes within the comprehensive cancer centers and organizational changes within NCI and the comprehensive cancer centers to incorporate palliative care into the research agenda for cancer. This first research question is addressed through four hypotheses:

***Hypothesis 1.*** NCI conducted state of the science conferences and published proceedings on palliative care and symptom control that resulted in a clear and prominent research agenda that is followed by NCI and the comprehensive cancer centers.

***Hypothesis 2.*** Examination of the NCI intramural and extramural budgets will show that NCI has shifted emphasis in funding to prioritize palliative care and symptom management. Indicators of palliative care and symptom management will show S-curves when graphed by year through the pre-deliberative (1994-1996), deliberative (1997-2001), and post-deliberative (2002-2005) periods, indicating adoption of the report's



recommendations through the theory of diffusion of innovations. Adoption is expected to begin to increase early in the deliberative period because of increased public attention to the issues raised in the 2001 IOM report on cancer palliation. Research-based adoption curves should lead adoption curves in professional journals by one or two years as new research findings get translated into journal articles.

***Hypothesis 3.*** NCI amended its guidelines to create centers of excellence in palliative care and symptom management and to require that comprehensive cancer centers engage in palliative care and symptom control as a condition of NCI recognition.

***Hypothesis 4.*** Examination of the NCI extramural budgets will show that the cancer centers and comprehensive cancer centers have reorganized to incorporate palliative care and symptom control into their research agenda. Indicators of palliative care and symptom management will show S-curves when graphed by year through the pre-deliberative (1994-1996), deliberative (1997-2001), and post-deliberative (2002-2005) periods, indicating adoption of the report's recommendations through the theory of diffusion of innovations. Adoption is expected to begin to increase early in the deliberative period because of increased public attention to the issues raised in the 2001 IOM report on cancer palliation and that research-based adoption curves will lead adoption curves in professional journals by one or two years as new research findings get published.

***Second Research Question – How did the 2001 IOM report on cancer palliation impact the practice of palliative cancer care?***

Articles published by professional organizations all of which publish articles intended to guide the practice of oncology, oncology nursing, and oncology social work

follow predictable and often similar patterns. Although the ACS publishes articles intended to guide the practice of cancer care as well, these articles are beyond the scope of this evaluation, because while scholarly, these articles are not published by the professional organizations themselves and do not represent positions taken by the organized professional stakeholders that this research question addresses. This second research question will be addressed through hypotheses 5 and 6:

***Hypothesis 5.*** Examination of the websites of the professional organizations of oncologists, oncology nurses, and oncology social workers will show that these organizations developed best practices in accordance with the state of the science and with their professional interests.

***Hypothesis 6.*** Professional journals published an increasing proportion of articles on palliative care and symptom management during the study period (1994-2005). The articles reflect increased interest and attention to qualitative research, attention to psychological symptoms and patient participation in decision making. Indicators of palliative care and symptom management will show S-curves when graphed by year through the pre-deliberative (1994-1996), deliberative (1997-2000), and post-deliberative (2001-2005) periods, indicating adoption of the report's recommendations. A lag period of one or two years behind research-based adoption curves is expected as increased palliative care research gets published.

## **Conclusion**

The above hypotheses permit an assessment of the extent to which the principal stakeholders named in the 2001 IOM report on cancer palliation substantially adopted the research and practice recommendations of that report. Within the theory of deliberative

process, stakeholders work together to negotiate common meanings, values, and intentions by pragmatically addressing real and potential conflicts within the context of power relations. The findings of this thesis suggest what type of efficacy IOM had as an agent of medical innovations in the field of oncology.

Chapter 2 reviews the literature on diffusion of innovations as the theoretical framework from which to examine the research questions, and discusses the roles and interests of each of the stakeholder groups in that context. It also addresses the early development of palliative cancer care, the state of the art before gaps in palliative care came to the attention of IOM, the basis for IOM intervention, and finally how IOM responded to gaps in palliative care and what the principal findings were. Chapter 3 addresses key findings and recommendations in the 2001 IOM report on cancer palliation, which form the basis for operationalization of variables. Chapter 4 discusses the methodology for answering the research questions and the individual hypotheses.

Chapter 5 addresses Hypotheses 1 and 2, providing a qualitative discussion of the formal institutionalization of palliation and symptom management research followed by a quantitative assessment of changes in the funding priority given to palliation and symptom management research. Chapter 6 addresses Hypotheses 3 and 4, first describing institutional changes in the Cancer Center Program, and then addressing proportional changes in funding levels for palliation and symptom management research at the cancer centers. Chapter 7 explores professional organizations' websites in order to qualitatively assess development of best practices as called for in Hypothesis 5, after which it addresses changes in editorial policy as called for in Hypothesis 6. Chapter 8 reviews conclusions to be drawn from this work.

## **CHAPTER 2. THEORETICAL BASIS FOR THIS CASE STUDY**

This chapter establishes the theoretical framework for assessing the impact of the 2001 report on cancer palliation on the interested stakeholders' conduct of the research and practice of palliative care for cancer. IOM's mission to hold the health care system accountable for the social consequences of health care requires that IOM boards, fora, and committees act as change agents in the context of the theory of diffusion of innovations. The National Cancer Policy Board (NCPB) played this role between 1997 and late 2005 at its reorganization as the National Cancer Policy Forum, by bringing together a broad base of expertise including researchers, practitioners, third-party payors, medical ethicists, patient advocates, epidemiologists and others, to deliberate on the nature of problems in the treatment and management of cancer, and to suggest solutions.

To develop the theoretical framework, this chapter reviews the literature on diffusion of innovations, highlighting organizational innovations, change agents, policy innovations, epistemic communities as change agents, and the role of networks. It is argued that the IOM, the National Academies in general, and the NCPB in particular act as epistemic communities, which by definition use knowledge creation as a form of power. As such, they act as policy entrepreneurs. Epistemic communities and other policy entrepreneurs are change agents that seek to induce organizational changes at the societal level through deliberative process. This means that both must reconcile evidence with the values and interests of concerned stakeholders. It is argued that those values and interests can create inertia, which contributes to maintenance of the status quo despite unaddressed negative consequences, such as the irony of increased burden of morbidity from cancer resulting from improvements in survival times for many cancer sites. It is

further argued that epistemic communities, like other policy entrepreneurs, can address this type of inertia through the creation of dual networks, which IOM does. Essentially, through the 2001 IOM report on cancer palliation, the NCPB addressed a concern in the management of cancer that has been outside the traditional cancer program of the United States. This case study seeks to appraise its success.

### **Classical Theory of Diffusion of Innovations**

Diffusion of innovations refers to the flow of innovations through a population of actors through space and over time in the context of social networks, which provide communication channels and the regulation of social controls. Diffusion of innovations is generally seen as a communications problem. The model includes four elements: an innovation, communication of same, time over which the communication occurs and a social system or structure through which the innovation reaches potential adopters (Katz, Levin, & Hamilton, 1963; Rogers, 1962, 2003).

### ***Brief History of the Field of Innovation Diffusion***

Tarde (1903) is widely credited with laying the philosophical or sociological groundwork for diffusion of innovations theory (Katz et al, 1963; Kinnunen, 1996; Rogers, 1962, 2003; Wejnert, 2002). As a sociologist of the Nineteenth Century, Tarde sought general explanations of human behavior (Kinnunen; Rogers, 2003). In order to explain why inventions spread from a geographical origin, Tarde proposed that on an individual level, “beliefs and desires or motives” are imitated or rejected through logical laws and extra logical influences (Kinnunen, p. 433). Through logical laws inventions that are too simple or complex are rejected by potential adopters. Through extra-logical influences, adoption, in the present terminology, spreads from a single point or

individual, from people of superior social status to their inferiors, and from those influenced by fashion to those influenced by custom, i.e. from modern to pre-modern. The S-curve, which is a theoretically normally distributed cumulative relative frequency curve representing the proportion of a social unit that adopts an innovation, is attributed to Tarde by Rogers (1962, 2003) and Kinnunen. Modern diffusion of innovation studies define potential adopters as individuals, but also as groups, organizations, national polities, or any other social unit (Katz et al, 1963; Rogers, 2003; Wejnert 2002) that might adopt, reject, or reinvent an innovation (Rogers, 2003).

Diffusion of innovations research has existed as a paradigm for about sixty years. Rogers (2003) and Wejnert (2002) trace the origins of diffusion research to mid-Twentieth Century rural sociology. Rogers (2003) credits the Ryan and Gross study of the diffusion of hybrid corn among Iowa farmers (1943) as the first true diffusion of innovations study. Diffusion research declined in rural sociology by the end of the 1950s in the United States and by the end of the 1960s in the rest of the world. However by the early 1960s diffusion research had become firmly established in a number of disciplines including anthropology, education research, industrial research and medical sociology (Rogers, 1962). In a review of the diffusion of innovations in service organization literature Greenhalgh, Robert, MacFarlane, Bate, and Kyriakidou (2004) classify rural sociology, medical sociology, communication studies, and marketing research as early diffusion research. Early diffusion studies focus on the individual as the unit of adoption (Rogers, 2003; Wejnert, 2002), but later studies and review articles of firms' innovation decisions, particularly those that involve organizational innovations (Alange, Jacobsson, & Jarnehammar, 1998), and policy innovations (Bennett, 1991; Berry & Berry, 1992;

Mintrom, 1997; Mintrom & Vergari, 1998; Volden, 2002; Wejnert, 2005; Welch, 1980), involve diffusion at a societal scale. Wejnert (2002) distinguishes among individual actors, small collective actors, such as groups of firms, organizations, and friendship groups on the one hand, and large collective actors, such as nations, states, social movements that act on a societal scale. Some studies of policy innovation on a global scale address the role of epistemic communities in creating international regimes (Adler & Haas, 1992; Hasenclever, Mayer, & Rittberger, 1996; Jasanoff, 1997; Salter & Jones, 2005). None of the studies found addressed epistemic communities and diffusion of policy innovations solely at the national level.

### ***General Systems Models***

Modeling of diffusion of innovations was done extensively using general systems theory. Hagerstrand's (1967) systems approach begins with a conceptualization, i.e., a network of social communications (Brown, 1981). The general systems approach used in classical diffusion studies models three phenomena: the S-curve, the *neighborhood effect* and the *hierarchy effect* (Brown, p. 21). The S-curve is defined as a normally distributed cumulative relative frequency curve showing the time of adoption for all potential adopters (Brown; Rogers, 1962, 2003). The neighborhood effect accounts for the relative ease of communicating information that is relevant to adoption decisions across shorter distances (Brown; Wejnert, 2002). It is operationalized as a gravity model where the mutual attraction of the population centers of a region is offset by a distance decay function (Brown). In this model the likelihood of interaction-communication is calibrated to the probability of adoption. Wejnert (2002) adds that geographically close areas are likely to share similar characteristics. The hierarchy effect reflects the tendency for

adoption to occur earlier in larger urban areas than in smaller urban areas due to greater communication opportunities in larger cities and greater social density.

***Relevant Characteristics from the General Diffusion of Innovations Model***

Innovations refer to a knowledge base. Wejnert (2002) defines innovations as ideas about “abstract ideas and concepts, technical information, and actual practices” (p. 297). Wejnert’s (2002) definition is useful because it is broad. Katz et al (1963) and Rogers (2003) are narrower, but use a miscellaneous category at the end of their descriptive lists.

***Social Networks.*** Decisions to adopt or reject an innovation occur through social networks, allowing information to flow through communication channels (Rogers, 2003). Social systems are groups of interrelated units that engage in problem-solving behavior in order to realize a common goal (Rogers 1962, 2003). Social networks may be related through interpersonal relationships, i.e. strong ties, or formal relationships, i.e. weak ties (Granovetter, 1973). Networks may be interpersonal or organizational, such as labor unions and medical associations (Wejnert, 2002). West, Barron, Dowsett, and Newton (1999) offer density, centralization, and centrality as network variables.

Dense networks have large numbers of redundant links so that information flows reliably, which increases the level of group solidarity, i.e. shared norms, values, and expectations, however cohesiveness tends to reduce the amount of new information that such networks can absorb (West et al, 1999). Members of cohesive networks, such as professions tend to share social characteristics such as age, education, and social class, which affirm identity and legitimacy (West et al; Wejnert, 2002).



Centralization refers to the degree of hierarchy that exists in a network (West et al, 1999; Wejnert, 2002). Horizontal ties refer to peer relationships and vertical ties refer to relations of authority. Highly centralized networks with high degrees of stratification apply coercive authority to their members to achieve conformity, which results in homogeneity and higher adoption rates and more efficient flows of information. Such networks advise members on new developments, and publicize their deliberations and the opinions of experts, in addition to coercive regulation through implicit and explicit rewards and punishment (Wejnert, 2002).

Centrality refers to the location of individuals in networks. Actor information centrality is positively related with the proportion of information links that flow through the actor, and is negatively related to the number of alternative intermediaries (West et al, 1999). West et al implicitly view power within networks as a combination of position within a hierarchy and information centrality. Information flows through formal communications, such as written material, and through personal contact (Wejnert, 2002).

***Potential Adopters.*** Potential adopters may be individuals, small collective actors, or large collective actors. Small collective actors include firms or networks of firms, organizations, friendship networks and family groups, while large collective actors include nations, states, social movements (Wejnert 2002) as well as epistemic, i.e. knowledge-based, communities (Adler & Haas, 1992). Collective actors are social networks in their own right (Alange et al, 1998; Wejnert, 2002). Structural equivalence, determined in part by economic factors involving control of resources, cultural factors such as history, and common interests and approaches, provides the basis of group identity for collective actors (Wejnert, 2002).

***Adoption Decisions.*** Typically innovations are perceived as new by potential adopters (Rogers, 1962, 2003). Adoption decisions are based on perceived risk and potential benefits (Alange et al, 1998; Mintrom, 1997; Rogers, 1962, 2003; Wejnert, 2002). These consequences are direct and intended, or indirect, unintended and risk-based (Rogers, 2003; Wejnert, 2002). Social consequences involve the creation of externalities (Wejnert, 2002). Public consequences impact on a societal level and are typically brought about by large collective actors. Uncertainty and perception of risk decrease the likelihood that innovations will be adopted (Rogers, 2003; Wejnert, 2002). Wejnert (2002) adds that formal communications decrease uncertainty about public consequences. High status actors are more likely to support innovations that are modest in nature, while peripheral actors are more likely than most to support radical innovations (Wejnert, 2002), which contributes to inertia. Adoption may be in whole or in part--reinvention-- and may be subsequently discontinued based on perceived consequences (Rogers, 2003; Wejnert, 2002). Alange et al (1998) describe innovation as continuous reinvention.

Decisions to continue an innovation are based on actual consequences as well as the inertia that results from subjective attachment to inefficient innovation decisions due to the tacit nature of knowledge and the path dependency of adoption decisions (Alange et al, 1998). According to this argument, adoption decisions are based on existing technological and organizational bases, i.e. previous adoption decisions, and built on a knowledge base that exists within individual members of firms. Alange et al suggest national systems of innovation to stimulate efficient innovations and discontinuation of inefficient previous innovations or *exnovation*. Wejnert asserts that lack of economic resources may impede adoption (2002), citing the case of adoption of democracy (2005).

Change agents influence clients' adoption decisions along prescribed lines (Rogers, 2003). National networks, as change agents can induce desirable organizational innovations by bridging gaps in adoption of desirable organizational innovations, through dual networks that link firms and national networks through individuals belonging to both, i.e. strong ties (Alange et al, 1998). Wejnert (2002) discusses personal networks of alumni from elite schools who network as chief executives of firms as dual networks.

*Discussion.* Innovation decisions are made by individuals, but through those decisions social networks may be mobilized, and through that mobilization social networks may induce diffusion of innovations. The study of innovation decisions must be contextualized within the social networks that provide the communication opportunities and social regulation. Networks may be dense, having a relatively high number of active contacts among members, or not. Networks may be highly regulated, centralized and hierarchical emphasizing vertical ties, or loosely regulated emphasizing horizontal ties. Centralized networks tend to be homogenous, cohesive, and able to impose innovations as well as encourage them. Actors may be central in networks, having claim to status, power, and prestige, or peripheral. High status networks and individual actors exercise economic or political power, but also may lay claim to specialized knowledge, which is considered to be legitimate in larger networks or society in general. Innovation decisions are adopted through information, collective decisions, and authoritative decrees or in the case of science, declarations. Formal communications in science and related fields bridge gaps in networks that prevent information flows through social networks.

Power, through high status, economic power, and scientific knowledge can impose decisions to accept, reject, reinvent, or discontinue an innovation. Wejnert (2002)

asserts that high status networks can impose innovations on lower status actors. Wejnert further asserts that high status networks are less likely to adopt innovations perceived as radical. Thus high status networks tend to be conservative in their innovation decisions and more able to impose that conservatism on related networks of lower status.

### **Policy Innovations and Policy Entrepreneurs**

Policy entrepreneurs act as change agents in the context of policy innovations. Their role is to overcome perceived inertia in policy issues. Mintrom (1997) discusses this relationship and establishes the attributes of policy entrepreneurs. Policy innovations are *policy ideas* (Mintrom, p.739). For Mintrom policy entrepreneurs induce policy innovations by identifying policy problems, engaging in endogenous and exogenous networking in policy circles, framing debates, and building coalitions. Rogers (2003) establishes seven roles of change agents. These roles include 1) establishing the need for change, i.e. convincing potential adopters; 2) establishing credibility of the change agent; 3) diagnosing problems; 4) creating an intention on the part of clients to change; 5) translating that intention into action; 6) stabilizing adoption to avoid discontinuation; and 7) ending the relationship when the change is successfully implemented (pp. 369-370).

Deliberative practitioners attempt to resolve social conflict and uncertainty by exploring evidence and the values, goals and interests of interested parties taking into account relations of economic and political power (Forester, 1989; Hajer & Wagenaar, 2003). Policy entrepreneurs, consistent with deliberative theory, impact policy deliberations by framing debates on terms that advance their particular agendas but are also consistent with politically accepted values and understandings of the policy-making community (Mintrom, 1997). They may guide politically relevant assumptions by

bringing in expert opinion and learning from the experiences of similar entities. However, the health care system in the United States is largely fragmented (Institute of Medicine, 2001), and privately funded (Anderson & Hussey, 2001). Thus, exogenous networking may not play the same role in inducing policy innovations in the US health care system as it does in other areas of policy.

### **Epistemic Communities and Policy Innovation**

Epistemic communities use knowledge as power (Adler & Haas, 1992). In his discussion of planning theory, Forester (1989, pp. 29-30) suggests five mechanisms by which information may be so used. Planners may use information *technically*, using data to do standard analyses. From this perspective information is considered neutral and its application is dictated by rote methodologies. From an *incrementalist* perspective information serves social needs, which are equated with the needs of organizations. From the *liberal-advocacy* perspective information serves the needs of particular groups within society which are seen as paramount. From a *structuralist* perspective, information serves the needs of the state by protecting current relations of power. From a *progressive* perspective, information is used to balance the needs of powerful interests with the interests of other groups.

Epistemic communities are policy entrepreneurs and engage in policy innovation through deliberative process. They include networks of knowledge-based experts who frame political controversies, define state interests, and establish knowledge-based standards, through which they exercise power by controlling knowledge and defining information, and thus the parameters of policy debate (Adler & Haas, 1992; Haas, 1992).

## **The Institute of Medicine as an Epistemic Community and Policy Entrepreneur**

The IOM is one of the four National Academies of Science created by acts of Congress or executive order. In addition to the IOM, the National Academy of Sciences (NAS) includes the National Research Council (NRC), and the National Academy of Engineering (NAE). The National Academies are an epistemic community and network that embodies a vision of science as independent and un beholden to influences from outside of the scientific community. They are self-regulating and self-funded, which allows them to act as independent consultants on matters of science, medicine and engineering to the Federal Government, other polities, private groups and the public (Cochrane, 1978). Guston (2000) refers to the NAS as “the principal honorific society for scientists” (p. 161). Cochrane traces the origins of this vision to royal societies and national academies of Enlightenment Europe, in which the best minds of the realm would receive increased standing in society and patronage in exchange for solving the scientific and technological problems of the state. However, the vision is of independent science that strongly contrasts with government-initiated science such as the program of the NIH and particularly the NCI, which for the last 70 years has spent massive amounts of federal funds to eradicate and manage cancer (Patterson, 1987; Proctor, 1995; Rettig, 1977; Strickland, 1972).

### ***The Institute of Medicine (IOM)***

IOM was founded in 1970, in the midst of a profound reevaluation of medical and health policy in the United States. Berkowitz’s central thesis (1998) is that IOM survived the last three decades of the Twentieth Century as a semi-independent policy institution under the supervision of the NAS by providing politically independent health policy

analysis, which has helped to integrate social issues into the field and humanize the practice of medicine and public health. “The Institute would speak out about, not for, medicine” (Berkowitz, p. 40). The NAS Council reviews IOM reports but those reports are released under IOM authority. One quarter of IOM’s membership comes from fields other than medicine and health. Its interests include both the practice of medicine and health-related social issues. As an epistemic community, IOM evaluates issues in medicine and public health from a health policy perspective.

IOM has had to negotiate its survival in the face of political power. It survived by being policy relevant and politically neutral (Berkowitz, 1988). In the early 1970s and again in 1984, under the Reagan Administration, IOM survived attempts to reduce it to the status of an honorary organization by moving its operations to the NRC and reorganizing the remainder within NAS. IOM adapted to the Clinton Administration, with which it could have aligned itself extensively on health, by maintaining its independence. It involved itself neither with Congress nor the Administration on the question of reforming the health care system in 1993-4, and survived the Republican capture of both houses of Congress and the election of George W. Bush as President, into the Twenty-First Century.

IOM reports generally convey an articulated single message. They are funded by government agencies and private foundations. Since the 1990s, IOM reports are either addressed to the general public and to government, or, in the case of the report on palliative cancer care, are addressed to elements of the medical profession (Berkowitz, 1998). Through these reports IOM disseminates its findings and guides policy discussions, framing the discussions and recommending actions by the actors it deems

appropriate, whether they are the public, health and public health professions, or government (Berkowitz).

### ***Cancer and Curative Cancer Treatment***

The early part of the Twentieth Century witnessed improvements in medicine and public health that allowed control of many communicable diseases that had afflicted the people of the United States since first European settlement (Starr, 1982). Control of infectious disease shifted the causes of mortality toward chronic disease, especially heart attack, cancer and stroke. By the end of the century, Proctor (1995) noted that cancer incidence was increasing and cancer mortality was stable. In 2001 Lynn and O'Mara observed that due to longer survival times many cancer patients no longer die of cancer.

Historically, cancer research focused on cure rather than palliation, driven to a great extent by federal support of medical research through the NIH, especially the NCI (Rettig, 1977; Starr, 1982) and increased dramatically when President Nixon declared war on cancer in 1971 (Proctor, 1995; Rettig, 1977). Through this effort chemotherapy was developed, surgery and radiation therapy were improved (Hewitt & Simone (Eds.), 1999; Rettig, 1977) and much was learned about prevention (Lynn & O'Mara, 2001; Proctor, 1995). Only recently has there been a decline in cancer mortality (Wingo, Ries, Rosenberg, Miller, & Edwards, 1998), and after 1995 those rates stabilized (Edwards, et al. 2002; Jemal, et al. 2004).

### ***Longer Survival with Symptomatic Cancer***

Evidence that life with cancer extended by aggressive treatment does not meet the needs of all cancer patients may be found in the success of the hospice movement in the



United States after about 1970 (Kohut & Kohut, 1984; Stoddard, 1978; Torrens, 1985). The hospice movement is a grassroots movement that responded to what had become isolated and prolonged death due to cancer treatment technologies. A quarter of a century later the IOM published a report on gaps in health care at the end of life (Field & Cassel, (Eds.), 1997). That study grew out of a concern to identify and limit futile treatment but the project evolved into an assessment of what constitutes effective treatment at the end of life, dying as “both a biological process and a psychological and social experience that occurs in a cultural context” (Field & Cassel (Eds.), 1997, p. 46). Lynn & O’Mara (2001) tie extended life for cancer patients to increased suffering, which makes the difficulty of dying with cancer an unintended consequence of partially effective curative treatment. The hospice literature and Field and Cassel point to inertia in the development of cancer care.

***Improving Palliative Care for Cancer (Foley & Gelband (Eds.), 2001)***

The 2001 IOM report on cancer palliation, like other IOM reports, makes broad recommendations on issues of health policy affecting organized stakeholders and the general public. As part of the National Academies of Science, the IOM consults the Federal Government, other polities, private stakeholders, and the general public in issues that concern the practice of medicine and more generally, the provision of health care, as well as public health in the United States and elsewhere. Under the National Academies model, IOM deliberations and IOM reports are intended to represent the considered opinion of the most reputable experts available to address specific issues within health care and public health (Berkowitz, 1998). The 2001 IOM report on cancer palliation was

written through the efforts of the NCPB, which was organized by IOM and the National Research Council in 1997.

Between 1997 and the end of 2005 the NCPB published 28 consensus reports, proceedings summaries, non-technical summaries, and reports directed to the general public. For the most part these reports addressed issues of central importance to the cancer research agenda that crystallized at NCI after World War II, i.e. cause, prevention, control, diagnosis, and curative treatment (Rettig, 1977, p. 45). However, the work of the NCPB is notable because it has added cancer palliation to the United States national agenda on cancer. The 2001 IOM report on cancer palliation not only brought attention to the need for improved cancer palliation but is also remarkable in three other respects (Foley & Gelband, 2001b). First, the authors redefine palliative care as supportive care for cancer at all stages of its progression from diagnosis to death rather than simply as care given to patients for whom efforts to eradicate or slow the progress of the disease have been abandoned. Second, the authors advocate a broad approach which encompasses the total needs of the patient, including adequate management of physical symptoms and attention to psycho-social care of patients and their families, especially at the end of life. Third, the authors advocate informed patient participation in decision making and sensitivity to and accommodation of patient preferences. A short article in the online NCI magazine *Benchmarks* (Hightower & Vaughn, 2003) acknowledges IOM's role in changing the accepted definition of palliative care to begin at diagnosis and include a psycho-social component. In that article Hightower and Vaughn note that a content analysis of NCI publications having to do with palliative care revealed that most addressed symptom management during treatment but relatively little had been written

about palliation at the end of life or bereavement. Hightower and Vaughn call for increased development of educational materials to inform patient participation in decision making.

Taken as a whole, the 2001 IOM report on cancer palliation adds a phenomenological dimension of patient satisfaction and empowerment to the science of managing cancer. In so doing the NCPB fills the IOM's role of impartial arbiter of broad health policy issues as described in Berkowitz (1998), which is reviewed more fully below. The themes of patient satisfaction and participation in decision making are found in NCPB reporting and elsewhere in IOM reports. In 1997 the IOM Committee on Care at the End of Life issued a report (Field & Cassel, (Eds.)) addressing broad gaps in the handling of death by the health care system and a lack of public confidence in the health care system to treat patients humanely as death approaches. Field and Cassel suggest the requirements of an effective palliative care system. End-of-life care should be accepted as "integral and important" to health care and should be sensitive to patient and family needs and preferences, i.e. the "culture, values, resources, and other characteristics" of patients, their families and loved ones (p. 22). In 1999 the NCPB published a report on quality of care for cancer (Hewitt & Simone, (Eds.)). The authors of that report briefly discuss end-of-life care, but more importantly raise customer satisfaction as a factor in quality of care. The themes of patient satisfaction and control are developed more fully in the IOM Committee on Quality of Health Care in America report *Crossing the Quality Chasm* (Institute of Medicine, 2001), which was published in the same year as the 2001 report on cancer palliation. This report calls for customization of safe, evidence-based

health care to meet patients' needs and values, with the informed patient ultimately in control of health care decisions (p.8).

At the beginning of the preface of *Improving Palliative Care for Cancer*, Foley (2001) articulates the NCPB's rationale for safe, effective, evidence-based, and patient-centered palliative care for patients with advanced cancer:

It is innately human to comfort and provide care to those suffering from cancer, particularly those close to death. Yet what seems self-evident at an individual, personal level has, by and large, not guided policy at the level of institutions in this country. There is no argument that palliative care should be integrated into cancer care from diagnosis to death. But significant barriers – attitudinal, behavioral, economic, educational, and legal – still limit access to care for a large proportion of those dying of cancer, and in spite of tremendous scientific opportunities for medical progress against all the major symptoms associated with cancer and cancer death, public research institutions have not responded. In accepting a single-minded focus on research toward cure, we have inadvertently devalued the critical need to care for and support patients with advanced disease, and their families. (p. ix)

By issuing these reports, IOM bodies have indicated that their considered opinion drawn from experts in the context of health policy, whose biases balance each other, from all relevant fields of expertise, is that patient satisfaction and expression of informed patient preferences in health care both generally and at the end of life, are desirable. The same may be said of cancer palliation at all stages of the natural history of the disease in all of its forms. These developments represent a paradigm shift in medical and health care science of enormous proportions.

The medical model traditionally emphasizes treating disease not people (Proctor, 1995; Rettig, 1977; Starr, 1982). As we have seen, the hospice care movement arose in response to gaps created by this orientation. Both advocates (Quill & Battin, (Eds.), 2004) and opponents (Foley & Hendin, (Eds.), 2002) of assisted suicide/dying recognize the role of effective palliative care in reducing demand for assisted suicide/dying.

### **The State of Palliative Care of Cancer before the IOM Report**

Kuhn (1996) wrote that “led by a new paradigm, scientists adopt new instruments and look in new places.” (p. 111) Against this backdrop it is not remarkable that the authors of the 2001 cancer palliation report should find the field of cancer palliation to be underdeveloped and feel the need to call for its development through research and the development of quality indicators, as recommended in the Executive Summary (Foley and Gelband, 2001a). Valid measurement of the quality of palliation is meaningless if it does not refer to patient satisfaction. Teno (2001, p. 117), one of the report’s authors, states: “Medical records can document treatments received and whether physicians state that they discussed treatment decisions with patients and/or their families. Even though this can be useful information, *a consumer perspective* [italics added] on communication, decisionmaking, coordination, and other domains is important when assessing the quality of care of the dying.” The authors of the 2001 IOM report on cancer palliation define palliative care according to the contemporary World Health Organization (WHO) definition as the “active total care of patients whose disease is not responsive to curative treatment,” but add, again in agreement with WHO, that “many aspects of palliative care are also applicable earlier in treatment,” and further recommend that palliative care begin at diagnosis (Foley and Gelband, 2001b, p. 10). In the paragraph just cited, the authors add that palliative care addresses control of physical symptoms and complications of treatment, psycho-social care of patient and family, as well as communication, decision making, and care of the dying.

Palliative care for cancer is not a new concept. In the mid 1980s, Billings edited a guide to palliative care for advanced cancer patients (1985). He addresses pain control,

with a social psychological component, as well as many of the symptoms addressed in the 2001 IOM report on cancer palliation and includes a chapter on psycho-social issues, including spiritual matters and bereavement.

One chapter discusses limits on how to treat patients with advanced cancer appropriately, including at the end of life (Cassem, 1985). Cassem warns against both neglect--under treatment--and overzealous treatment--over treatment--of advanced cancer. Advanced cancer is defined here as cancer that is no longer reversible. Three broad principles are offered to guide treatment decisions. The first is that all symptoms which can be relieved should be, and physicians should recommend those treatments. The second is that patients have the right to refuse treatment. The third is that ineffective treatment should be discontinued. Cassem recommends on balance, that patients be given the basis to make informed decisions and that those decisions be respected. The exception is when patients are incompetent by reason of delirium, dementia, or coma, in which case family members should be consulted.

There is evidence that this standard for cancer treatment has not been effectively practiced. Zussman (1997) argues that although physicians generally believe that patients and their families should be consulted about important medical decisions, cancer patients are only consulted on about a fifth of decisions to terminate care, while their families are consulted only slightly more.

### **The IOM, the National Cancer Policy Board and Cancer Palliation**

From 1997 until the end of 2005 the NCPB brought together experts from a range of disciplines in order to guide developments in cancer care, research and funding, from a broad perspective. Most of the reports published by the NCPB addressed the concerns

that have made up the core of US research policy since NCI's founding in 1937, namely cause, prevention, control, diagnosis, and curative treatment (Rettig, 1977, p. 45). Yet, the NCPB's work is most remarkable because it may have broadened what is regarded as salient in cancer research to include palliative care, quality of life and access issues.

### ***Prevention, Control, Diagnosis, and Treatment Reports***

The NCPB's reports addressed cancer broadly but in practice over the eight years that it functioned some clear directions are notable. Prevention studies, including the NCPB's first published report, focused on tobacco use (National Cancer Policy Board, 1998, 1999) because tobacco is the single carcinogen most linked with death in the United States. These policy reports are 44 and 19 pages in length respectively, and address the role of government in reducing tobacco use. In addition, control and diagnosis reports emphasized breast cancer, and treatment reports emphasized the process of getting new agents to market but also discussed the volume-outcome relationship.

Among the NCPB's reports that address control and diagnosis, breast cancer figures prominently, especially breast cancer imaging. In 1999 The NCPB undertook an appraisal of possibilities for the improvement of early breast cancer detection, which resulted in two reports. The first (Newman, 2000) was a white paper that summarized the proceedings of a workshop that reviewed new breast cancer detection technologies. The second report (Nass, Henderson, & Lashof, (Eds.), 2001), which was detailed and book length (288 pages) addressed issues of development and diffusion of innovations in breast cancer detection technologies. This second report was re-released as a non-technical white paper (Patlack, Nass, Henderson, and Lashof (Eds.), 2001) the same year. In 2005 a report was published (Joy, Penhoet, & Petitti, (Eds.)) that broadly and systematically

addressed the need for improvements in breast cancer screening, at book length (376 pages). The findings of this report were disseminated through an activity sponsored by the Breast Cancer Foundation and the ACS, among others, the results of which were published shortly thereafter (Herdman & Norton, (Eds.), 2005). The Nass and Ball (Eds.) report (2005) on imaging standards for breast cancer detection rounds out the NCPB's effort on breast cancer control and diagnosis.

Breast cancer received by far more attention than any other issue of control and diagnosis. In 2005 the NCPB published a report (Pignone, Russell, & Wagner, (Eds.)) that addresses discrepancies in economic models used to predict colorectal cancer. The report is a 30 page white paper followed by several long appendices summarizing a workshop. Other NCPB reports that address control and diagnosis do so generally. Curry, Byers, and Hewitt, (Eds.) (2003) address cancer prevention and early detection from a perspective of encouraging and empowering healthy behaviors, surveillance, early detection, and state regulation of health risks, especially tobacco. The findings of this report were presented at a forum with cooperation by IOM, NCI, and ACS, the proceedings of which are published (Herdman & Lichtenfeld, (Eds.), 2004). Nass and Stillman, (Eds.) (2003) review the state of biomedical science and recommend changes in NCI, NIH and other federal funding of cancer research.

The NCPB's writing on cancer treatment consists of three reports, all short. Two of these address the development of new anti-cancer agents for adults and children, both of which were published in 2005, the NCPB's last year of operation. After reviewing the science and history of developing anti cancer pharmaceuticals and other agents, Newhouse, Mendelsohn, Gelband and Herdman (2005) address challenges to



coordination and scientific barriers faced by NCI and the Food and Drug Administration (FDA) in the creation and approval of new agents. Adamson, Weiner, Simone, and Gelband, (Eds.) address the clinical need for separate therapeutic agents for children with cancer and recommend public sector involvement to offset a weak market for the development of such agents (2005). In a 42-page white paper length report that addresses treatment and was written under the auspices of the NCPB and the NRC, Hewitt and Pettiti (Eds.) conclude that the volume-outcome relationship, which involves better outcomes at institutions where technically difficult procedures are performed frequently rather than infrequently, applies to rare cancer sites (2001). This report was the result of a workshop called to review the existing literature, the proceedings of which were also published (Hewitt, 2000).

### ***Access to Care***

In addition to the foregoing the NCPB produced a white paper and a short book that addressed patient access to clinical trials. The white paper (Gelband, 1999) presented a description of the current system by which cancer clinical trials were conducted. The book (Aaron & Gelband, (Eds.), 2000) makes recommendations for removing barriers to access to clinical trials by Medicare recipients mostly through regulation by the Health Care Finance Administration, which was responsible for Medicare and Medicaid regulation at the time.

### ***Quality of Care Assessment***

Hewitt and Simone edited two reports that address quality of care generally (1999) and its measurement (2000). The 1999 report entitled *Ensuring Quality Cancer*

*Care*, defines quality of care and discusses barriers to it. The 2000 report addresses its measurement. In the face of a lack of recognized benchmarks of quality, progress, and success in cancer treatment, as well as non-standard and retrospective data gathering, and issues pertaining to patient privacy and confidentiality, this report included recommendations to standardize definition and operationalization of indicators of quality, data collection, and data manipulation.

### ***Reports that Address Palliative Care, Quality of Care, and Access to Care***

In historical context, *Improving Palliative Care for Cancer* (Foley & Gelband, (Eds.), 2001) must be seen as the defining step in the NCPB's work on quality of life issues in cancer. The 2001 palliative cancer care report builds on four previous IOM reports, two of which it cites in its statement of purpose. This section addresses these two reports, which serve as background for the report on palliative care. The palliative cancer report cites *Ensuring Quality Cancer Care* (Hewitt & Simone (Eds.), 1999) and another IOM report, *Approaching Death: Improving Care at the End of Life* (Field & Cassel (Eds.), 1997). In addition the 2001 report on cancer palliation adopts the systematic approach recommended in *Crossing the Quality Chasm* (Institute of Medicine, 2001) and reflects the concern for underserved populations, especially racial and ethnic minorities expressed in *The Unequal Burden of Cancer* (Haynes & Smedley, (Eds.), 1999).

***Approaching Death: Improving Care at the End of Life* (Field & Cassel (Eds.), 1997).** This IOM report on dying defines both hospice care and palliation (Field & Cassel (Eds.), 1997). Hospice care provides advice and supportive services for the dying, as well as to their friends and family. These services may be provided in the home, hospital, nursing home, or in a dedicated facility. Palliative care is care that “seeks to prevent,

relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure.” (Field & Cassel (Eds.), 1997, p. 31) Palliative care is not restricted to those who are dying or have foregone life prolonging treatment, such as hospice patients, because it supports quality of life and enables patients to withstand potentially life-saving treatments with difficult side effects, such as chemotherapy.

After publication of the 1997 IOM report on death in America the National Institute of Nursing Research (NINR) became the locus of end-of-life care research within NIH. Field & Cassel (1997) called for the development of a research agenda to “define and implement priorities” for developing end-of-life care within NIH and other national agencies (p.12). NINR was not mentioned specifically as a target of that recommendation. However, by 2001 NINR was recognized as a particularly important locus of end-of-life care research activity within NIH, and the authors of the 2001 IOM report on cancer palliation (Foley & Gelband, 2001b, p.52) were at pains to recommend collaboration within that locus in NCI end-of-life research, but not as an exclusive vehicle for NCI end-of-life care research. The 2004 NIH consensus statement on end-of-life care recognizes NINR as the earliest primary NIH member institute in the field of end-of-life care.

*Ensuring Quality Cancer Care (Hewitt & Simone (Eds.), 1999).* This report addresses cancer prevention, control, diagnosis, treatment, and palliation. It asserts correctly that, as with other chronic diseases, there is no national cancer care program in the United States, and health care providers, insurers and cancer centers operate as they see best. The result is an inefficient and fragmented cancer care system which frequently denies needed services to cancer patients and their families.

The authors of the cancer palliation report justify its writing, in part, on the basis of the National Cancer Policy Board recommendation to “Ensure quality of care at the end of life, in particular, the management of cancer-related pain and timely referral to palliative and hospice care,” which they quote (Hewitt & Simone (Eds.), 1999, p. 7, Foley & Gelband (Eds.), 2001, p. 12). Studies to identify non-financial barriers to care are called for (Hewitt & Simone (Eds.), 1999).

This report asserts that often those fighting cancer suffer unnecessary pain and that their treatment preferences are ignored by providers, despite the presence of practice guidelines (Hewitt & Simone (Eds.), 1999). Quality of care defined negatively is the absence of over use, under use, and misuse of medical care. Defined positively it is technically competent care, based on good communication, shared decision making, and cultural sensitivity. Quality measures should be a basis of accountability.

The report defines both palliative care and end-of-life care (Hewitt & Simone (Eds.), 1999). The purpose of palliative care is to improve quality of life for cancer survivors through all stages of treatment. The report sets a clear standard for quality of life:

“For a person with cancer, maintenance of quality of life requires, *at a minimum*, [italics added] relief from pain and other distressing symptoms; relief from anxiety and depression, including the fear of pain; and a sense of security that assistance will be readily available if needed” (Hewitt & Simone (Eds.), 1999, p.25).

Adequate end-of-life care requires adequate palliation, i.e. effective control of physical and psychological symptoms and social support. In addition, it requires counseling on the risks and potential benefits of life extending treatment, respite and bereavement support, advance care planning, and spiritual support as the individual faces the existential crisis

of dying. Treatment goals shift from “the quality of life to the quality of life and symptom relief.” (Hewitt & Simone (Eds.), 1999, p.26)

*Improving Palliative Care for Cancer (Foley & Gelband, (Eds.), 2001).* At the time that the 2001 report on cancer palliation was published, the National Cancer Policy Board was composed of prominent scientists, health care providers, public health practitioners, patient advocates, social scientists, and others. Rockefeller University President Arnold J. Levine was chairman of the NCPB. The vice chairs included a medical director of a prominent cancer institute, Joseph Simone, a prominent patient advocate, Ellen Stoval, and Director of Research and Evaluation for Kaiser Permanente, Diana Pettiti. The rest of the NCPB was made up of leading physicians in oncology, Kathleen Foley, John Mendelsohn and Monica Morrow, an ACS nursing professor, Sandra Million Underwood, biologists, Cecil B. Pickett and Thomas Kelley, epidemiologists, Tim Byers, Vivien W. Chen and Nancy Mueller, medical ethicists, Normal Daniels and Pilar Ossorio; patient advocates, John Seffrin (ACS), Frances Visco, and Susan Weiner, an economist, Mark McClellan, a health policy professor, Susan Curry; and health insurance leader, William McGuire. This NCPB broadly represented the relevant interests in a policy deliberation about palliative cancer care, and in so doing fulfilled the mission of the IOM.

The 2001 report on cancer palliation begins by making five claims: 1) that roughly half of the million or so people diagnosed with cancer in the United States, every year will eventually die of the disease; 2) that a growing health policy consensus exists that cancer palliation, although less important than diagnosis and treatment, should not be neglected simply because efforts at curative treatment are ongoing; 3) that most patients

with advanced disease do not receive adequate symptom control because the need is not recognized sufficiently; 4) that a very large proportion of medical expenditures is spent on patients at the end of life, even though these expenditures fail to meet the needs of dying patients and their families; and 5) that the gaps in palliative and end-of-life care are due to institutional and economic barriers, lack of information about the potential for better care, inadequate education and training of health care providers, and “minuscule” (p.10) public sector financing of research. As noted above, the authors define palliative care as supportive care for cancer at all stages of its progression, which encompasses the total needs of the patient, including adequate management of physical symptoms and attention to psycho-social care of patients and their families, especially at the end of life, as well as informed patient participation in decision making and sensitivity to and accommodation of patient preferences. The rest of the report’s first chapter identifies barriers to quality palliative care for cancer and presents the NCPB’s recommendations.

The balance of the report addresses economics, definition and measurement of quality, the difficulties in serving special populations, and the state of contemporary clinical practice guidelines, research, and the education and expertise of health care providers. In Chapter 2, Lynn and O’Mara (2001) discuss market failures and gaps in the assessment of cost and value. In Chapter 3, Teno (2001) discusses five dimensions of quality of care at the end--last year--of life, including: symptom management, patient satisfaction, shared decision making, coordination of care, and continuity of care. In Chapter 4, Kesselheim (2001) explores the quality and availability of contemporary cancer-related information geared toward the end of life and oriented toward patients and family members. In Chapter 5, Payne (2001) discusses issues of quality and access to

palliative care among African-Americans and other vulnerable groups. In Chapter 6, Hilden, Himmelstein, Freyer, Friebert, and Kane (2001) discuss pediatric cancer palliation as a special case. In Chapter 7, Holland and Chertov (2001) discuss contemporary practice guidelines for the management of physical and psychological symptoms in the dying. In Chapter 8, Cleeland (2001) reviews epidemiological, social behavioral, health services, and symptom research literature. In Chapter 9, Gelband (2001) reviews studies that address the quality of preparation and expertise of oncologists, oncology nurses, and oncology social workers.

***NCPB Sequelae to Improving Palliative Care for Cancer (Foley & Gelband, 2001)***

Between publication of the 2001 report on cancer palliation and the reorganization of the NCPB into the National Cancer Policy Forum, several NCPB reports were published. In 2003, *Describing Death in America: What We Need to Know* (Lunney, Foley, Smith, & Gelband) was published as follow up to Field and Cassel (1997) and addresses issues of measurement and accountability in end-of-life care, which are raised strongly in Foley and Gelband (2001). In 2003 simplified versions of the 2001 report on cancer palliation were published in English (Institute of Medicine & National Research Council, 2003b) and Spanish (Institute of Medicine & National Research Council, 2003a) for the public. Reports were also written about pediatric palliative care (Hewitt, Weiner, & Simone, 2003), a clear priority in Foley and Gelband, and psychosocial issues in female breast cancer patients (Hewitt, Herdman, & Holland, 2004).

**Case Definition**

The IOM report on palliative cancer care (Foley & Gelband (Eds.), 2001) represents an attempt to induce policy innovations among cancer researchers, cancer

providers, and concerned third party payors, the first two of which are addressed in this thesis. Together these entities make up an epistemic community, and for the most part, represent epistemic communities that influence policy diffusion through deliberative processes by creating knowledge about issues that concern them.

The NCPB's report includes an analysis of gaps and a detailed list of recommendations, which challenge *de facto* priorities within the science of managing cancer that have prolonged the lives of cancer survivors but failed to reduce the difficulty of living with cancer. The gaps that the report identifies are products of inertia within the practice of cancer treatment, and an approach to health care that is entrenched in the paradigm of disease treatment and eradication. Thus, the report provides a useful case study of the impact of an epistemic community within the context of diffusion of national policy in medicine in the United States. The next chapter reviews the recommendations of the IOM Report in detail. The recommendations are then examined on the basis of their diffusion among the stakeholders in the remaining chapters of this thesis.



### **CHAPTER 3. IOM FINDINGS ON CANCER PALLIATION**

This chapter summarizes and reviews recommendations and supporting analyses from the 2001 IOM report on cancer palliation, providing a basis for document review, content analysis, and expert interviews which make up the methodology for conducting this case study. The first section establishes the case study's propositions by summarizing the NCPB's rationale for recommending changes in the research, practice, and funding of palliative oncology. The next section presents the specific recommendations the authors of the 2001 IOM report make for improving cancer palliation. The last section operationalizes definitions of units of analysis.

This chapter forms the basis for content analysis of the NCI research budget, comprehensive cancer center research budgets and professional journals of oncologists, oncology nurses and oncology social workers and document review of the NCI website and the websites of the professional organizations of oncologists, oncology nurses, and oncology social workers. Variables are defined, permitting evaluation of the effectiveness of the cancer palliation report, the product of an epistemic community in inducing organizational change among cancer research institutions and health care providers and related services to cancer patients, as prescribed by the NCPB in its role as change agent.

#### **Gaps in the Provision of Care of High Quality**

Overall and in a number of particulars, the IOM report strongly suggests that medicine and the health care system fail to meet the needs for palliation of most patients with advanced cancer so that there is inertia within the context of diffusion of innovations theory. The NCPB (Foley & Gelband, 2001b, pp. 13-14) identifies seven barriers to high quality palliative care for cancer in the United States, including: 1) separation of curative

and palliative care in the health care system, often due to reimbursement policies, which can force a dismal choice between fighting to live and accepting comfort; 2) inadequate training of health care providers in palliative cancer care; 3) inadequate standards of care and accountability where dying patients are concerned; 4) disparities in care resulting from inadequate care for African-Americans, other minorities, and vulnerable socioeconomic groups; 5) lack of public-oriented information resources regarding palliative and end-of-life care; 6) lack of quality of life and quality of care data for patients dying of cancer and other causes; and 7) inadequate investment by the public sector in end-of-life and palliative care research and training.

## **Background**

This section addresses the NCPB's construction of cancer palliation as a complex and problematic field within the research, practice, and financing of cancer treatment. Throughout the 2001 IOM report on cancer palliation, the authors address the problems of morbidity and lost functionality and their economic implications in the context of the fragmented, largely privately-funded health care system. Physical and psycho-social morbidity are defined, as are gaps in provider training, information for the public, access, and patient participation in decision making.

### ***The Cost of Treating the Very Sick***

Lynn and O'Mara (2001) argue that the health care system is often unable to adequately provide for patients and their families because of uncertainty and vagueness of many prognoses. Patients with advanced cancer and their families face enormous burdens not only of physical and emotional suffering but also financial hardship. Treatment of patients dying of cancer is expensive because the patients are generally

quite sick. From a perspective of palliation, Cleeland (2001) considers the distinction between the symptoms per se, experienced at the end of life, and those experienced by other advanced cancer patients to be artificial; however, he acknowledges that the severity of symptoms increases and *functional status* decreases as death approaches. These are differences of degree which suggest overlap. In addition to increased severity and decreased function, dying cancer patients and their families face the categorical difference of the spiritual and existential implications of death (Holland & Chertov, 2001). In short, *cost* becomes an increasing factor as cancer patients approach death because of their increasing morbidity, making *affordability* and *insurance coverage* a critical issue.

### ***Economic Determination of Access to Palliative Care***

Gaps in the health care system exacerbate morbidity for patients approaching death, although better measurement is needed. Lynn and O'Mara (2001) assert that the most useful services are under utilized because they are often not covered, while covered services are often over utilized. However, it is difficult to assess the real cost of treatment because the effects of palliative treatment on survival time are usually unclear and treated as negligible. However as patients approach death, daily treatment costs soar and with them the magnitude of errors resulting from effects on survival time that have been assumed away. By the same token, Lynn and O'Mara point out that the economic value of treatment is usually not measurable in survival terms and is largely unquantified. Lynn and O'Mara call for a "period of innovation" (p.90) in cancer palliation, in which Medicare prescription drug coverage, payment for hospice, nursing home care, long-term care, home care, and family home care are adjusted and compensation through capitated

and fee-for-service arrangements are rationalized, especially in the case of high-cost palliative care. This would require the development of many missing indicators. In short, there is no consensus about the costs and benefits of cancer palliation because, while it is possible to assess the effect of market forces on optimal use of health care services for palliative purposes, the effect of palliation on survival is assumed away at precisely the time when palliation costs and the distress that palliation is intended to relieve are at peak.

***Lack of Patient Participation in Decision making***

Another gap is the lack of patient participation in decisions regarding treatment, which impacts patient satisfaction. Patients should be included in making informed decisions that affect their hope for a cure, and not only as death approaches (Teno, 2001). Teno argues that there is strong institutional support for respect of patients' wishes in the extremity of the do-not-resuscitate decision, but less when death is less clearly imminent, often because physicians misunderstand patient preferences. Teno also argues that

Good care (1) is based on scientifically sound evidence, (2) incorporates informed patients' preferences, (3) provides access to appropriate multiple segments of the health care system including high-quality clinical trials, (4) coordinates services across multiple segments of the health care 'system,' and (5) is compassionate, attending to both the physical and psychological needs of the patient and family (p. 120).

Teno calls for development of valid indicators for measurement and accountability of treatment of physical symptoms, and development of quality indicators for treatment of anxiety and depression in patients with advanced disease.

### ***Inadequate Expertise in Palliative Care among Health Care Providers***

Generally the information base of cancer palliation was found to be underdeveloped. Physicians overall are not prepared by education or experience to provide quality palliative care (Gelband, 2001). Nurses spend more time with cancer patients and than do oncologists, but their effectiveness is largely unstudied, although there were two small studies in which nurses rate their preparation between 6 and 7 on a ten-point adequacy scale, but few rated their education excellent in nine dimensions of quality of care (Gelband). While nurses and social workers may be more effective at meeting the needs of cancer patients, more information is needed. Gelband asserts that there is evidence that palliative care and end-of-life care are under funded. Teno (2001) describes the 1999 National Cancer Policy Board mandate to develop quality indicators for cancer as unmet. Uncertainty about who is dying from cancer presents an economic stress to hospice providers because production costs are high in the first days of hospice care and much lower thereafter (Lynn & O'Mara, 2001). Teno notes that patients referred to as dying are usually days from death, at most.

### ***Control of Physical Symptoms***

The means to control physical symptoms exist, overall, but valid indicators of quality of care are insufficient. Part of the horror about cancer may be patients' frightening appearance, odors, and suffering and the tendency of patients to linger longer than with other chronic diseases (Lynn & O'Mara, 2001). Pain from advanced cancer can be severe and is greatly feared by the public. Patients whose pain is adequately managed tend to demand less of their care providers. At present there are adequate measures of pain, which can be controlled for 90% of cancer patients, so that the principal task of

measuring pain is to develop good measures of accountability (Teno, 2001). Other physical symptoms are less well measured and treated (Teno). Dyspnea, the inability to breathe properly, like pain is quite distressing and associated with approaching death. Unlike pain, dyspnea may be difficult to alleviate, often because of lung metastases (Teno), however there are a number of causes of dyspnea among cancer patients some of which are treatable (Holland and Chertkov, 2001). There are effective treatments for fatigue, nausea and vomiting, yet due to a lack of standards these symptoms were described as under treated (Holland and Chertkov). Holland and Chertkov call for the training of physicians in the use of restricted pain medications to avoid inadequate doses out of a misguided concern to avoid addiction at the end of life. Teno calls for measures of informed consent by patients sedated for pain. Holland and Chertov suggest that adequate clinical practice guidelines for symptom control could reduce the burden of secondary anxiety and depression.

### ***Psycho-social Palliation***

Cancer causes psychological distress including anxiety, depression, and an increased risk of suicide (Teno, 2001). Holland and Chertov (2001) argue that debilitating depression, anxiety, and delirium are under treated at the end of life. Measures, descriptive studies, and research on the treatment of anxiety and depression among seriously ill cancer patients are needed (Teno). Holland and Chertkov assert that there are no practice or training standards for psychological, social, existential, or spiritual care for oncologists, while mental health professionals and spiritual counselors are not included sufficiently in end-of-life care. Holland and Chertov recommend that oncologists should be trained in communication, particularly on the subject of breaking bad news of a

deteriorating prognosis. This training should come from within the discipline or from mental health professionals.

### ***Setting Standards***

Holland and Chertov (2001) recommend that clinical practice guidelines, which exist for hospitalized and ambulatory patients should be adapted to also address the needs of patients at the end of life. Teno (2001) calls upon NCI, the comprehensive cancer centers, Agency for Healthcare Research and Quality, Cooperative Oncology Groups, America Society of Clinical Oncology, and the Health Care Finance Administration to develop and implement quality indicators and to explore the “structure, process, and outcomes of care” (p.116) that will permit the healthcare system to adapt for the needs of cancer patients at the end of life. Cleeland (2001) concludes that, although feasible and improving, physical and psychiatric-affective symptoms research is under funded, has not attracted a desirable level of interest of investigators and research institutions, and has failed to generate the clinical trials necessary to take full advantage of the battery of research methods now available to develop methods that can manage physical and psychological symptoms in patients with advanced cancer.

### ***Education of Patients and Family Members***

Kesselheim (2001) concludes that a variety of materials are available through a number of media, but these materials fail to educate because of problems with the materials and because cancer patients and their families do not seek the information, often because they are reluctant to face the likelihood of approaching death. Holland and

Chertov recommend that educational materials for patients and their families reflect clinical practice guidelines for symptom management to relieve fear and confusion.

### *Access Issues*

The authors of the report recognize that some populations, particularly minorities and children are systematically under served because existing guidelines are not sensitive to their particular needs. Payne (2001) indicates that African-Americans are poorly served because of gaps in the health care system, and because of lack of knowledge of the availability of palliative care and cultural barriers on the part of African-Americans. Payne recommends establishing “palliative care units” (p. 157), increased training and funding of palliative care, and focus group research in vulnerable communities to assess the needs of patients and families, in the short term. In the long term, Payne calls for expanded research into the needs and preferences of minorities and other vulnerable populations and efforts from NCI and the comprehensive cancer centers to improve access for these populations. Hilden et al (2001) articulate pediatric cancer palliation as a special case due to the relative importance of cancer as a cause of death among children, the fact that childhood cancers are different from adult cancers, the special difficulty in predicting death in children, and the societal abhorrence of death among children that impacts institutions and family members alike. Hilden et al call for the development of educational materials for providers and families of children with cancer, inclusion of children in their treatment decisions, specialized protocols in pediatric palliative cancer care that emphasize continuity of care and symptom relief, with adequate regulation and reimbursement, and development of specialized quality of care indicators.



***IOM 2001 Recommendations for Improving Palliative Cancer Care***

In order to fill the gaps described above, the NCPB (Foley & Gelband, 2001b, pp. 50-53) made ten recommendations intended to improve the research, practice and financing of palliative cancer care. These ten recommendations are collapsed here into five program priorities. Each program priority involves the major stakeholders named in the report including: NCI, the comprehensive cancer centers, the Health Care Finance Administration / Centers for Medicare and Medicaid Services, private insurers represented by the National Association of Health Underwriters (NAHU), the professional organizations of oncologists, oncology nurses, and oncology social workers represented by the American Society of Clinical Oncology (ASCO), the Oncology Nursing Society (ONS), and the Association of Oncology Social Work (AOSW), respectively, as well as the American Cancer Society (ACS). Table 1 shows how each of these program areas applies to each stakeholder.

***Table 1. Matrix of Stakeholder Groups and IOM Recommendations***

Program Areas of IOM Recommendations	Stakeholder Groups					
	NCI	Comprehensive Cancer Centers	HFCA/CMS	Private Insurers (NAHU)	Professional Organizations (ASCO, ONS, AOSW)	Non-Governmental Organizations (ACS)
I Centers of Excellence within Comprehensive Cancer Centers	√	√	–	–	–	–
Improved Reimbursement	–	–	√	√	–	–
Patient Information	√	–	–	–	–	√
Development of Practice Guidelines and Quality Indicators	√	√	–	–	√	–
Institutionalization within NCI	√	–	–	–	–	–

***Centers of Excellence within Comprehensive Cancer Centers.*** Recommendation 1 calls upon NCI to designate comprehensive cancer centers and promising community centers as centers of excellence in symptom control and palliative care. These centers are to “play a central role as agents of national policy in advancing palliative care research and clinical practice, with initiatives that address many of the barriers identified in this report (p. 50).” The following specific recommendations under Recommendation 1 are taken verbatim from the report (pp. 50-51). They constitute a non-exclusive list of recommended activities for the proposed centers of excellence:

- \* *formal testing and evaluation of new and existing practice guidelines for palliative and end-of-life care;*
- \* *pilot testing “quality indicators” for assessing end-of-life care at the level of the patient and the institution;*
- \* *incorporating the best palliative care into NCI-sponsored clinical trials;*
- \* *innovating in the delivery of palliative and end-of-life care, including collaboration with local hospice organizations;*
- \* *disseminating information about how to improve end-of-life care, including collaboration with local hospice organizations;*
- \* *uncovering the determinants of disparities in access to care by minority populations that should be served by the center and developing specific programs and initiatives to increase access; these might include educational activities for health care providers and the community, setting up outreach programs, and so forth;*
- \* *providing clinical and research training fellowships in medical and surgical oncology in end-of-life care for adult and pediatric patients;*
- \* *creating faculty development programs in oncology, nursing and social work; and*
- \* *providing in-service training for local hospice staff in new palliative care techniques.*

Recommendation 2 calls upon NCI to require that comprehensive cancer centers participate in this area of research as a condition of recognition (p. 51).

***Improved Reimbursement.*** Because reimbursement practices and policies prevent optimized palliative care, the authors, under Recommendation 3, call for the Health Care Finance Administration to fund demonstration projects for service delivery

and reimbursement that integrate palliative care and potentially life-prolonging treatments throughout the course of disease. Private insurers, under Recommendation 4, are called upon to provide adequate compensation for end-of-life care (p.51). The needs of dying children and their parents to receive extended adequate communication are singled out for special mention as a problem for reimbursement. A full assessment of the success of the cancer palliation report at addressing this gap would require that this program area be addressed, but that assessment is beyond the scope of this thesis.

***Patient Information.*** Under Recommendation 5, the authors call upon NCI, the American Cancer Society, and other patient-oriented organizations including disease-specific groups, as well as insurance providers and pharmaceutical companies, to provide accurate, comprehensive, and reliable information about cancer palliation at all points in the course of the disease and survival by type and stage of cancer (p. 51). The information should be culturally relevant and suitable for special populations. Assessment of the success of the cancer palliation report at improving the quality of information available to the public is beyond the scope of this thesis.

***Development of Practice Guidelines and Quality Indicators.*** Management of physical and psychological symptoms is to be based (Recommendation 6, p. 52) on the best available practice guidelines, supported by professional bodies, funders, and insurance providers. The authors call for the creation of quality indicators for patient satisfaction, shared decision making, coordination of care, and continuity of care for accountability (p. 24). Recommendation 6 as it pertains to insurance providers is beyond the scope of this thesis.

Recommendation 7 calls for the creation of data systems sufficient to put palliative care and end-of-life care on a par with “other aspects of cancer treatment” (p. 52). The tasks for achieving Recommendation 7 reproduced below (p.52) verbatim, includes:

- \* *developing a core set of cancer care quality measures;*
- \* *increasing public and private support for cancer registries;*
- \* *supporting research and demonstration projects to identify new mechanisms to organize and finance collection of data for cancer care quality studies;*
- \* *supporting the development of new technologies, including computer-based patient record systems and intranet-based communications systems, to improve the availability, quality, and timeliness of clinical data relevant to assessing quality of cancer care;*
- \* *expanding support for training in health services research and other disciplines needed to measure quality of care;*
- \* *increasing support for health services research aimed toward improved quality of cancer care measures;*
- \* *developing models for linkage studies and the release of confidential data for research purposes that protect the confidentiality and privacy of health care information; and*
- \* *funding demonstration projects to assess the impact of quality monitoring programs within health care systems.*

Adoption of Recommendation 6 requires that professional organizations, NCI, and third party payors develop evidence-based guidelines to manage *physical* and *psycho-social* morbidity. An implied dimension is the development of indicators of *quality* and *accountability*, as well as *information systems* and *surveillance* to measure the effectiveness of palliative and supportive care, which addresses Recommendation 7.

***Institutionalization within NCI.*** NCI should convene State of the Science Meetings on palliative care and symptom control, under Recommendation 8; incorporate palliative care, symptom control, and end-of-life care into its research agenda, under Recommendation 9; and review membership on advisory bodies, under Recommendation 10 (pp. 52-3).

## **Discussion**

The authors of the 2001 IOM report on cancer palliation found that patients who are dying of cancer usually face an enormous burden of physical discomfort, lost functionality, and psychological stress, as well as a strong possibility of economic hardship. In this, patients at the end of life differ from other patients with advanced cancer mostly by degree. Patients with advanced cancer face a battery of physical symptoms and psychological stress that often leads to clinical psychological disorders, which become more serious as disease progresses. Patients dying of cancer face the additional burden of spiritual and existential questions, which they often have thrust upon them precipitously because their health care providers, care givers, and perhaps they themselves too often avoid facing the approach of death until that event is just days away. Patients with advanced cancer including the dying suffer preventably through systematic under utilization and over utilization of healthcare services, ineffective management by oncologists, nurses, and social workers, as well as lack of access and poorly coordinated care. Racial-ethnic minorities and children are especially vulnerable in this regard.

In order to address these gaps the authors of the 2001 IOM report on cancer palliation made ten recommendations to improve research, practice, and reimbursement for palliative, supportive, and end-of-life care, and to improve the quality of educational materials oriented toward the patients with advanced cancer and their loved ones. Taken together these recommendations represent a complex organizational innovation, which the NCPB sought to induce by publishing the report.

In conclusion, the theory of diffusion of innovations suggests reasonable explanations of how adoption patterns reflect the change agent's success at its role. The

NCPB, made up of central network members from a broad range of epistemic communities with a patient-focused mandate and broadness of approach that is the unique contribution of the IOM in US medicine at the national level, was uniquely qualified to call for the changes recommended in its 2001 report on cancer palliation.

## **CHAPTER 4. STUDY DESIGN, DATA AND METHODS**

This chapter describes the study design, data and methods used to evaluate research and practice stakeholder acceptance of and action on the recommendations advanced by the NCPB report on palliative care for cancer (Foley & Gelband, 2001). The study design is that of a single relevant case study. The theoretical framework is diffusion of innovations and policy entrepreneurship in the context of an epistemic community.

There are two research questions. The first addresses the national cancer research community's response to the recommendations directed to it. The second research question assesses the responses of professional organizations to recommendations regarding the development of guidelines and best practices for the provision of quality cancer palliation, end-of-life and supportive care. The analysis demonstrates the acceptance or rejection of changes proposed in the report by comparing organizational behaviors to the report's recommendations during three periods of time: the pre-deliberative period (1994-1996), the deliberative period (1997-2001), and the post-deliberative period (2002-2005).

Grounded theory based on Foley and Gelband (2001) was used to extract search terms or keywords for document review and content analysis. The keywords were used to search specific websites and to use search engines in order to guide document review. The same keywords were used in content analysis intended to search databases including the NCI research budget databases and professional journal databases, primarily for the development of adoption curves for NCI-funded research in palliative cancer care, and relevant publications in professional journals. Document review and expert interviews were also used to illustrate how adoption decisions were made by organizational

stakeholders in a historical sense. The concerns about validity and reliability for this study are first listed below, followed by the specific methods for addressing each research question and its related hypotheses.

### **Study Validity and Reliability**

This section addresses issues of validity and reliability in this case study design. Construct validity was established by addressing cancer research and treatment practices that attempt to address the broadest practicable extent of the NCPB's recommendations. Internal validity was established through theory-based predictions and pattern matching as well as an argument that addresses rival explanations. As this case study addresses a rare event, the results are not easily generalizable. Threats to reliability, therefore, are largely from the selective coding of the report's text.

### ***Construct Validity***

There are three problems of construct validity in the hypotheses. The first is that the hypotheses do not address third party payors or the development and distribution of informative materials for the general public. The second is that recommendation 7 addresses surveillance, computer-based information systems, and data storage and retrieval as general issues within cancer research and treatment. This makes the impact of recommendation 7 nearly impossible to assess. The third is that recommendation 10, addressing a review of membership on national advisory boards, is not addressed at all.

Broadly speaking, the six hypotheses of this thesis address adoption of the NCPB's recommendations in the areas of cancer research and treatment practice, but they do not address adoption of recommendations as they address third-party payors, or educational materials intended for the general public. This paper addresses activity



related to the development of the science of cancer palliation among cancer researchers and those who treat cancer rather than the extent or quality of cancer treatment that is provided and paid for by insurance providers. Conceptually, the economic constraints and concerns of insurance providers could very easily derail mass implementation of scientifically valid palliative treatments developed by cancer researchers and those who treat cancer. By the same token, because information geared for the general public was not addressed in these hypotheses there is no way to assess the quality of information that informs patients' informed participation in decision making. These limitations might be serious if the science of cancer palliation was not considered to be in its infancy when the NCPB took up cancer palliation. Since the focus of this research is the development of the science of cancer palliation, it seems reasonable that the case can be made without directly addressing the politics of personalities on advisory bodies suggested by recommendation 10.

The other issue of construct validity arises from general recommendations by the NCPB for the improvement of computer-based surveillance and data storage and retrieval within recommendation 7. Because this recommendation is aimed at cancer research and treatment in general it is not valid to suggest rejection if the search terms are not productive in connection with palliative care and symptom control. Conversely an increase in hits on these search terms not specific to palliative care and symptom control would not necessarily suggest adoption.

### ***Internal Validity***

The theoretical framework of this thesis has an explicit causal relationship. The NCPB as an epistemic community sought to induce a complex innovation with

organizational and technological components among a heterogeneous community of potential adopters. The two research questions address the impact of the report on cancer palliation research and palliative cancer care. It is generally hypothesized that adoption patterns will follow an S-curve with data broken down by year through clearly defined pre-deliberative, deliberative, and post-deliberative periods. This approach, which is typical of innovation diffusion research, depends on pattern matching.

However, one can also examine the face validity of the assumption that the 2001 report on cancer palliation could cause changes in cancer research and practice. To do this one must consider the likelihood that the NCPB would have the influence to elicit such changes. One must also consider the likelihood that another entity, unaffected by the NCPB, would have stimulated such changes. In the last chapter it was established that NCPB was made up of centrally placed experts in a broad range of fields. As a member body with IOM, *viz.* the medical and public health components of the National Academies, the NCPB is a highly prestigious national and scholarly body, whose focus is on the solution of medical problems from a health policy perspective. No other organization at the national level plays that role. It seems reasonable that if medical care practice did evolve along the lines prescribed by the NCPB's cancer palliation report, with good pattern matching the report may have had the effect desired by its authors. Seven expert interviews are used to augment internal validity based on pattern matching.

A final issue of internal validity is to suggest a mechanism or mechanisms by which the report may have influenced its organized stakeholders. To address this we return to the seven roles of the change agent established in chapter two, which include 1) establishing the need for change, *i.e.* convincing potential adopters; 2) establishing

credibility of the change agent; 3) diagnosing problems; 4) creating an intention on the part of clients to change; 5) translating that intention into action; 6) stabilizing adoption to avoid discontinuation; and 7) ending the relationship when the change is successfully implemented. If the NCPB was able to establish the need for change but failed to convincingly define the problem then general search terms could be expected to be productive, but more specific search terms would not be because the stakeholders would address the problem along different lines. If the NCPB failed to create a real intention to change or the intention to change never got translated into action, even after establishing the need, we might expect to see initial adoption followed by discontinuation. If the adoption patterns follow the S-curve or an increasing trend line then discontinuation has been avoided. If the adoption patterns follow a flat line then the innovation has been rejected. The NCPB's role as change agent ended in late 2005 with its reorganization as the National Cancer Policy Forum. The type of influence that the NCPB had with the cancer palliation report on the targeted stakeholders, then, will be explained theoretically by the adoption patterns.

### ***External Validity***

This case is unique because of the scope of the innovation as well as the extent to which it is a radical departure from traditional practice of oncology research and practice. The NCPB, as a component of IOM, proposed coordinated innovations in all aspects of the health care system including research, practice, and funding of palliative care, in addition to which patient and family education and empowerment were systematically addressed. The proposed innovation addressed cancer palliation, which has not been a component of the US cancer program in place since the aftermath of World War II. As a

result there were found significant gaps in treatment of the dying in the United States, particularly those with cancer.

### ***Reliability***

The search terms or keywords to be used for Internet searches of specific websites and database searches of specific databases were selected *a priori* through selective coding of the cancer palliation report. While grounded theory is an involved process (see Strauss & Corbin, 1998), which begins with open coding, *viz.* discovering categories, and axial coding, *viz.* relating categories to each other, it is not appropriate for this study. Rather, selective coding, which depends on the work accomplished in previous phases, is the appropriate choice because the cancer palliation report provides clearly deliberate speech. The task of naming categories and relating to these was already done with clarity and consistency by competent bench and social scientists along lines that were relevant to their intentions. If this research included separate open and axial coding of the report's text some of that intentionality and overall reliability would be lost. Any loss to reliability, then, lies within the selective coding, which is unavoidable.

### **Research Question One**

The first research question addresses whether NCI and the comprehensive cancer centers have incorporated cancer palliation as a research priority. The entire record of NCI extramural funding, including the comprehensive cancer centers, is available beginning in 1998. Prior NCI extramural funding and the NCI intramural program funding are available from before 1994; however, these data sources are in summary format and therefore limited. Document review of the NCI and other NIH websites is supplemented with expert interviews to establish NCI supervisory practices that affect its

regulation of the comprehensive cancer centers, the thrust of relevant state of the science conferences as well as changes in the editorial policies of professional journals.

Expert interviews were conducted with authors of the 2001 IOM report on cancer palliation, Kathleen Foley (4/25/2007), Helen Gelband (4/25/2007) and Charles Cleeland (5/11/2007) to discuss findings for Hypotheses 1 – 4. These interviews focused on NCI efforts to establish a locus for palliative and end-of-life care and symptom management, increase funding of research that addresses these concerns, and establish centers of excellence within the cancer centers.

***Hypothesis 1 – NCI has conducted state of the science conferences and published proceedings on palliative care and symptom control resulting in a clear and prominent research agenda that is followed by NCI and the comprehensive cancer centers.***

This hypothesis addresses the overall institutional response of NCI to NCPB recommendations that palliative care and symptom control be formally and systematically incorporated into the NCI's work. There are two points to this hypothesis. The first is to determine whether NCI conducted state of the science research and what findings there were. The second point is to establish whether or not an institutional locus has been found at NCI for palliative care and symptom control, and if so to describe it.

***Data.*** The portions of the NCI and NIH websites which address state of the science findings were reviewed online. State of the science proceedings that address palliative care were reviewed online. Document review focused on communications relating to the portion of the NCI website that communicates information to health care providers and the general public, and the portions of the NCI website that communicate about the NCI organizational structure. A snowball sampling method was used to find

online documents that reveal a concrete organizational response to the problem of providing palliative care and symptom control that manifests through the organizational structure, budget, publications, and regulatory structures of NCI. Open-ended expert interviews supplement information from the NCI website.

*Analysis.* Document review established the relevant organizational structure at NCI, and priority as a function of budget growth, as well as the visibility of NCI's efforts in palliative care and symptom management. They suggest the priority of palliation and symptom management in the context of NCI's larger cancer program, including the amount of funding and overall integration with other priorities. These findings were corroborated by expert interviews with Andrea Denicoff who heads the NCI Palliative Care Working Group on 5/2/2007. Expert interviews were also attempted with NCI Office of Science Planning and Assessment Director Cheri Nichols and NCI Office of Cancer Survivorship Director, Julia Rowland. Dr. Nichols declined to be interviewed and Dr. Rowland did not return telephone calls or reply to e-mail messages.

Because of the existing locus in end-of-life care research within NINR, expert interviews were also attempted with NINR Director, Patricia Grady and Alexis Bakos, who was identified by Andrea Denicoff as the manager of the NINR end-of-life portfolio. Dr. Grady did not return phone calls or respond to e-mails. Dr. Bakos declined to be interviewed but gave permission to cite the information she sent in her e-mail (personal communication, 5/4/2007).

***Hypothesis 2 – NCI has shifted emphasis in funding to prioritize palliative care and symptom management.***

It is expected that indicators of palliative care and symptom management will show S-curves when graphed by year through the pre-deliberative (1994-1996), deliberative (1997-2000), and post-deliberative (2002-2005) periods, indicating adoption of the report's recommendations through the theory of diffusion of innovations. It is further expected that adoption will begin to increase early in the deliberative period because of increased public attention to the issues raised in the 2001 IOM report on cancer palliation and that research-based adoption curves will lead adoption curves in professional journals by one or two years as new research findings get translated into journal articles. These adoption curves should show statistically significant linear trends. Another outcome of interest is changes in trends with Fiscal Year 2002 as the change point. Statistically significant changes in trends in 2002 may indicate impacts of this IOM report on patterns of NCI funding.

Adoption curves were graphed as far as the data allowed between 1998 and 2005. The following indicators were used: proportion of projects compared to the overall NCI research agenda (extramural 1998-2005 and intramural 2000-2005), and the proportional amount funded compared to overall NCI direct spending on research (extramural only 1998-2005). Online databases were queried to identify records having to do with palliative care and symptom management through keywords or search terms identified below (in *italics*).

***Data and Limitations.*** Information about extramural research grants, including funded amounts, was available for fiscal years 1998 through 2005 through the NCI

Division of Extramural Activities (DEA) site on the NCI Funded Research Portfolio database (2006). For fiscal years 2000 through 2005 the International Cancer Research Portfolio (ICRP) database (2006) and the NCI Cancer Research Portfolio (CRP) database (2006) provided information about NCI extramural grants and intramural research projects. The International Cancer Portfolio Partners are governmental and non-governmental organizations in the United States and the United Kingdom that fund cancer research (2006). All three search engines allowed keyword searches of their databases. In addition, the ICRP and CRP databases can be searched using the Common Scientific Outline (CSO). Both the DEA and CRP databases were searched using NCI Special Interest Categories (SIC). Both CSO and SIC codes represent systematic classifications by qualified reviewers, and are considered to be more reliable than keyword searches of titles and abstracts.

The CSO includes six categories of biology, four categories of etiology, six categories of prevention, four categories of early detection, prognosis and diagnosis, three categories of scientific modeling, seven categories of treatment, none of which explicitly address supportive or palliative care, and nine categories of cancer control, survivorship, and outcomes research including end-of-life care, patient care and survivorship, and medical ethics. SIC codes include cancer survivorship, clinical trials for therapies, as well as hospice, nursing, mind/body research, pain but not other symptoms, palliative care, and rehabilitation. See the CRP site for a complete listing of CSO and SIC categories.

Databases were extracted from these three databases using predetermined keywords in the search engines of each database, making maximum use of the CSO and SIC codes. *Palliative care* was operationalized as *palliative care*, *end-of-life care*, and



*supportive care*. Symptom management was operationalized as *physical symptoms* management including *pain, dyspnea, nausea and vomiting or emesis, fatigue*, and *dementia*, and *psychological symptoms*, including *anxiety, depression, and delirium*. *Suicide/euthanasia* and *functionality* was searched as well because these terms have been linked in the literature closely with related issues in cancer palliation. *Oncology, oncologists, nursing, nurses, social work, and social workers* were searched as pairings of profession and professional groups in conjunction with palliative care, end-of-life care, and supportive care. For example the Boolean logic for the first pairing was (Oncology OR Oncologist) AND (Palliative Care OR End-of-Life Care OR Supportive Care). *Hospice care* was similarly paired as were *training programs, clinical trials, quality, accountability, indicators*. Accountability indicators were further divided into *patient satisfaction, shared decision making, coordination of care, and continuity of care*. These terms were also paired with the SIC term *palliative care* on the CRP database.

Records identified from each of these queries were saved as Microsoft Excel worksheets, imported into SPSS, and coded for the *database* on which the query was run, *keyword* as well as the following fields: project identifiers including *contract numbers* and *funding mechanisms, funded organization* (extramural) or *NCI division* (intramural), *principal investigator, project title, funding periods, year, and funded amount*. The entire extramural budget for 1998-2005 was extracted from the DEA database with *funded amounts*. Once all the queries were extracted, individual records for each grant and year were consolidated by aggregation. Sums were calculated for coding variables, each representing a unique combination of *project identifier, keyword, the database* from which it was identified, and the *project year*. The result was a database that identified

keywords, project information, and the databases on which the keywords were run for each year of each project.

Total research budgets for NCI were obtained from the NCI Fact Books (NCI, 1998-2005). This information allows the determination of the number and funded total of palliative care, end-of-life care, symptom management and supportive care research as absolute quantities and as proportions of NCI-funded research and NCI-funded comprehensive cancer center research activities. Total extramural budgets and the total number of projects were used as denominator data for the calculation of relative frequencies. Where there was no result from a clearly superior dataset on a given search term, Krippendorff's  $\alpha$  was calculated on all fruitful query results on that indicator. Appendix A provides a detailed account of how the data were extracted and aggregated across data sources. There are problems with missing data. Fellowships were excluded from the analysis because they are not covered well by the three online databases.

*Analysis.* Data for each search term or aggregate were graphed by year to show adoption curves. Budget amounts were adjusted to 2001 dollars to control for inflation. Two types of pattern in the data were of interest. The first pattern was that there would be a consistent trend in the data, either increasing indicating adoption, or negative to flat indicating rejection. Either would suggest a pattern coinciding with the NCPB's deliberation and continuing through the post-deliberative period. A non-parametric test, Chi trend, see Greenland (1998) and Mantel (1963), was used to establish statistical significance of the proportion of grants that fit into each research category identified in the selective coding of Foley and Gelband (2001) above. A parametric test, t scores from univariate regression using the proportion of extramural funding for each research

category from Foley and Gelband as the dependent variable and time as the independent variable, was used to establish statistical significance of trends in funding.

The second pattern of interest was a clear change point beginning in Fiscal Year 2002, which would indicate a change in funding levels that would coincide with publication of the 2001 IOM report on cancer palliation. A method used to assess the significance of changes in trend in Economics was considered (Cashin & McDermott, 2002; Watson, 1994), but discarded because the data lack face validity. Instead, change points at Fiscal Year 2002 were identified by visual inspection of graphs of adoption curves. These change points were described as *apparent*. Appendix A describes significance testing for this hypothesis in detail.

***Hypothesis 3 – NCI has amended its guidelines to require that comprehensive cancer centers engage in palliative care and symptom management as a condition of NCI recognition.***

This hypothesis addresses the contractual relationship between NCI and the comprehensive cancer centers and whether NCI has used its vertical ties, i.e. authority, to compel the comprehensive cancer centers to address palliative care and symptom management. The point of this section of this research project is first to determine whether or not NCI has made this formal requirement and then to determine, if so, what supplemental measures, or if not what alternative measures it may have taken. This is accomplished through expert interviews and document review.

***Data.*** Cancer Centers Branch guidelines for Cancer Center Support Grant (NCI Cancer Centers Branch, 2004) were reviewed. In addition, the cancer centers websites were searched for references to cancer palliation or symptom control. An expert

interview was conducted with NCI Cancer Centers Branch Chief, Linda Weiss on May 2, 2007 to discuss whether the Cancer Centers Branch has implemented recommendations of the 2001 IOM report on cancer palliation for the creation of centers of excellence in palliative care and symptom management through the cancer centers.

*Analysis.* Document review established the Cancer Center Branch's formal policy regarding whether or not palliative care and symptom management should be mandated to the comprehensive cancer centers, and what additional or alternative steps were taken to assure that these priorities were being addressed. The guidelines reviewed include the last grant guidelines written for the cancer centers before the reorganization of the NCPB at the end of 2005.

***Hypothesis 4 – The cancer centers and comprehensive cancer centers have reorganized to incorporate palliative care and symptom management into their research agenda.***

This hypothesis is based on analysis of NCI research funding for the comprehensive cancer centers taken individually and as a whole. It was expected that as a whole the comprehensive cancer centers would conduct an increasingly large proportion of cancer palliation and symptom management projects and show an overall trend toward increasing the proportion of NCI research projects named by each indicator and the funded total of those projects, between 1998 and 2005.

**Data.** The same dataset used to evaluate Hypothesis 2 was queried for all records where a cancer center, with and without comprehensive status, was identified as the *research institution*. See Appendix A for a full account of how this dataset was assembled.

*Analysis.* As with Hypothesis 2, adoption curves were used to evaluate trends and change points. Budget amounts were adjusted to 2001 dollars to control for inflation. The Mantel chi trend (1963) was used to establish statistical significance of the proportion of grants that fit into each research category identified in the selective coding of Foley and Gelband (2001) above. T scores from univariate regression using the proportion of extramural funding for each research category from Foley and Gelband as the dependent variable and time as the independent variable were used to establish statistical significance of trends in funding levels. Apparent change points at Fiscal Year 2002 were identified by visual inspection of graphs of adoption curves. Appendix A describes significance testing for this hypothesis in detail.

### **Research Question Two**

The second research question asks, “How did the 2001 IOM report on cancer palliation impact the practice of palliative cancer care?” Articles published by professional organizations, all of which publish articles intended to guide the practice of oncology, oncology nursing, and oncology social work, were used to describe practice patterns.

*Hypothesis 5 – Professional organizations developed best practices in accordance with the state of the science and their professional interests.*

Document review was used to test this hypothesis. Internet searches identified policy statements and statements regarding best practices. These position papers were discussed in Chapter 7 both in terms of subject matter, and extent of the general agreement or disagreement with the NCPB’s construction of palliative and supportive care and the priorities set forth in Foley and Gelband (2001) and NCI state of the science

statements. Expert interviews were attempted with people involved in the development of practice guidelines of the websites of the American Society of Clinical Oncology, the Oncology Nursing Society, and the Association of Oncology Social Work in late April and early May 2007. Of these only Linda Eaton (5/2/2007) of the Oncology Nursing Society was available to be interviewed.

**Data.** The principal data for Hypothesis 5 are the websites of the American Society of Clinical Oncology, the Oncology Nursing Society, and the Association of Oncology Social Work. The portions of these websites that present palliation-relevant policy statements and practice guidelines were reviewed and summarized.

**Analysis.** Grounded theory was used to evaluate both policy statements and interviews. Open coding was used to identify issues raised by these sources. The universe of issues raised by the document review and expert interviews was compared with the universe of issues raised in the 2001 IOM report on cancer palliation. Axial coding was used to develop relationships among the issues raised. Progress by the professional organizations in developing guidelines was discussed in the context of professional organizations' function within the health care system, and what that function implies for the collective orientation of oncologists, oncology nurses, and oncology social workers.

***Hypothesis 6 – Professional journals published an increasing number of articles on palliative care and symptom management during the study period (1994-2005).***

It is expected that the articles in professional journals will reflect increased interest and attention to qualitative research, psychological symptoms and patient participation in decision making relative to cancer care among the pre-deliberative (1994-1996), deliberative (1997-2000), and post-deliberative (2002-2005) periods. Overall

trends show increasing or decreasing interest in indicators identified in Hypothesis 2 throughout the deliberative and post-deliberative periods, while change points at 2002 show responses to publication of the 2001 report on palliative care for cancer.

***Data and Limitations.*** The principal data for addressing this hypothesis come from three clinical journals from the professional societies of oncologists, oncology nurses, and oncology social workers. Newsletters from these organizations were not reviewed. The clinical journals include:

From the American Society of Clinical Oncology

1. *Journal of Clinical Oncology* (first published 1983)

From the Oncology Nursing Society

2. *Clinical Journal of Oncology Nursing* (first published 1997)

From the Association of Oncology Social Work

3. *Journal of Psycho Social Oncology* (first published 1983).

PubMed (National Library of Medicine, 2006) searches of the *Clinical Journal of Oncology Nursing* and the *Journal of Clinical Oncology* were conducted using the indicators identified in Hypothesis 2. See Appendix B for a detailed accounting of the procedures for data extraction and significance testing. The reader is advised that there is lack of consistency in the format in which these articles are available. The *Journal of Psycho Social Oncology* is available as hard copy only until 2005 and the others are available in electronic format for every year they were published. The *Clinical Journal of Oncology Nursing* was first published in 1997. Mixed use of multiple search engines and hardcopy abstracts would have created serious problems with reliability. To maximize

reliability statistical analysis was only done with the *Clinical Journal of Oncology Nursing* and the *Journal of Clinical Oncology*.

**Analysis.** Adoption curves were created and evaluated using  $\chi^2_{\text{trend}}$ . These curves were visually inspected for change points at calendar year 2001. This cutoff is different from the Fiscal Year 2002 cutoffs used in Hypotheses 2 and 4 because the NCI fiscal year actually begins October first of the previous calendar year and the 2001 IOM report on cancer palliation was published in June when the NCI Fiscal Year 2002 budget could be expected to already have been largely in place.

To supplement the loss of information from the PubMed query results, query results for the *Clinical Journal of Oncology Nursing* and the *Journal of Clinical Oncology* as well as hardcopy abstracts of the *Journal of Psycho Social Oncology* were reviewed for content. These results were summarized in Chapter 7 before presentation of the statistical analysis. Expert interviews were attempted with editorial staff and officers of all three journals. The interview questions explored how the journals address issues of symptom management, and patient communication, how this editorial policy has evolved since 1997 and 2001, changes in the quantity and focus of articles on symptom management and patient communication, challenges created and responses to those challenges, and the impact of increased emphasis on psycho-social issues in oncology on the practice of oncology, oncology nursing, and oncology social work. Interviews were conducted with Rosemary Carroll-Johnson (5/3/2007) and Patricia Ganz (5/10/2007) regarding the evolution of editorial policies concerning cancer palliation and symptom management at the *Clinical Journal of Oncology Nursing* and the *Journal of Clinical Oncology*, respectively. An exemption from Rutgers IRB review for these interviews was



received March 20, 2007 on the grounds that the interviews do not constitute research on human subjects.

## **CHAPTER 5. NATIONAL CANCER INSTITUTE (NCI)**

This chapter presents the findings for the first two hypotheses, which address 1) institutionalization of palliative and end-of-life care and symptom management at NCI, and 2) trends within the portion of the NCI research portfolio dedicated to those concerns. The IOM Report (Recommendation 8) called for NCI to convene state of the science meetings in palliative care and symptom control, which would lead to a high-profile research agenda. It also called for NCI to establish an institutional locus or loci for palliative care, symptom control and end-of-life care (Recommendation 9). NIH held state of the science conferences in July, 2002 and December, 2004 on symptom management and end-of-life care, respectively. NCI developed an institutional locus for palliative and end-of-life care and symptom management in the form of a low-profile and informal working group, as well as some other more visible manifestations of effort within the Office of Cancer Survivorship and the online NCI Physician Data Query (PDQ) database. There were proportionate growth trends in the NCI research portfolio of palliative and end-of-life care and symptom management in terms of the total number of projects and share of the extramural budget. Taken together, this provides clear evidence that NCI has begun to institutionalize palliative care and symptom management, although growth in size of the research portfolio has been modest.

### **Hypothesis 1 – State of the Science Activity and Institutional Locus within NCI**

An NIH consensus conference on symptom management for cancer was held in the summer of 2002. NCI was a primary sponsor. The conference addressed symptom management along lines called for in the 2001 IOM report on cancer palliation. The agenda included descriptive analysis of specific identification of gaps in assessment and

measurement, recommendations for effective symptom management, and avoidance of barriers to care of high quality. However, the conference was limited to pain, fatigue, and depression, and did not address dyspnea, nausea, anxiety, or cognitive difficulties.

The conference participants (2002) recommended further research to conceptualize pain, fatigue, and depression with standardized measurement including individual diagnoses and assessment of incidence and prevalence, in order to address the needs of the general population and groups that face barriers to access. The proceedings included recommendations for treatment and called for clinical research to improve the science of managing pain, fatigue, and depression, including clinical trials. In the health care delivery policy arena, the proceedings also called for funding of symptom management research and research to identify barriers to care of high quality. In essence the conference participants echoed the concerns expressed by the authors of the 2001 IOM report on symptom management, however, on a shortened list of symptoms. The symptoms not addressed include important end-of-life concerns, in particular dyspnea and cognitive difficulties, which can be the results of lung and brain metastases, respectively.

The NIH consensus conference on end-of-life care was held late in 2004. The consensus statement is discussed here because Kathleen Foley suggested that it has a bearing on the success of the 2001 IOM report on cancer palliation (personal communication, 4/25/2007). However, its importance to this research must be qualified. NCI was only a cosponsor of the conference, although NINR was a primary sponsor. Recommendation 8 (Foley & Gelband, 2001b, p. 53) calls for an NCI-convened “State of the Science Meeting on palliative care and symptom control.” While NCI participated in

the 2004 consensus conference it did so quite modestly in comparison to the NCPB's recommendation because the conference was not an NCI initiative. This makes the 2004 consensus conference remarkable.

The 2004 consensus conference on end-of-life care is also remarkable in that its findings echo the state of end-of-life care at the time the 2001 IOM report on cancer palliation was published. Specifically, there were serious problems of measurement in end-of-life care. The conferees sought to define the transition to end-of-life and found a lack of clarity as to what constitutes end-of-life, palliation, and hospice care, which interferes with the development of science across the continuum from basic to bedside. One notable issue is the difficulty in determining that patients have moved to the end-of-life portion of the continuum of care. Outcomes are often not based in evidence. Interventions are untested and difficult to test because of problems with validation, including problems with interviewing and otherwise collecting data from the dying. This suggests that not only has NCI not moved into a central role, along with NINR, in developing end-of-life care, but that the field also remains underdeveloped.

### ***Cancer Control at NCI and the Cancer Centers Program***

Rettig (1977) traces the origins of cancer control and the cancer centers program at NCI. Since the 1960s the NCI cancer centers program has sought to bring together within and across institutions the means to coordinate basic and clinical or translational research in cancer diagnosis and treatment (NCI, 2007d; Rettig). From their beginning the cancer centers acted as change agents filling a historical gap between cutting edge cancer research institutions and private physicians (Rettig). At the beginning of the cancer centers that gap extended to medical schools, which taught little about oncology

because of the underdeveloped state of the science. Through the mandate of the 1971 National Cancer Act, cancer centers develop and disseminate applied techniques, but NCI cancer center grants do not support screening or treatment except to advance research priorities (NCI, 2007d; Rettig). One goal of the program has always been to maximize geographic coverage so that distance from state of the art dissemination facilities is equitable and minimal. The cancer centers develop techniques in cancer control, which addresses diagnosis, prevention, and treatment including rehabilitation and counseling for patients and their families.

Cancer control has its earliest roots in provisions of the original cancer act of 1937 (Rettig, 1977), which authorized cooperation between NCI and state health agencies for the “prevention, control, and eradication of cancer (p.50).” Before 1960, NCI conducted a program of direct aid to state and local health programs in order to provide cancer clinics, home nursing care, some follow up, lab work for the poor, statistical research, and education. Modest funding and the connection with health departments--not the better private or university-connected cancer research institutions--led to the program’s failure and transfer to the Public Health Service, where its decline continued until it was partially defunded in 1970. The cancer control program was returned to NCI by the National Cancer Act of 1971 (Rettig), which expanded it to allow inclusion of the best private and university institutions, with their connections to teaching hospitals, and focused it on translational research aimed at the “diagnosis, prevention, and treatment” (NCI, 2007c, p. 5). The mandate for NCI-supervised cancer control was expanded in 1978 to include rehabilitation and counseling (NCI, 2007e). That mandate was further expanded in 1985 to include research on rehabilitation and counseling for care givers and

continuing care, i.e. survivorship, for patients and their families (NCI, 2007e).

Legislation from 1993 calls for the development of psycho-social interventions geared toward quality of life (NCI, 2007e).

From as early as 1993, NCI was fully empowered by legislation to implement recommendations set forward in the 2001 IOM report on cancer palliation that pertain to it. The cancer centers exist for the purpose of major research institution-driven cancer control, which since 1993 includes psycho-social interventions, support of cancer survivors, and counseling of patients, their families, and health care providers.

The evolution of cancer control is really the story of successful research through which cancer was transformed from a death sentence to a long-term chronic disease with a significant burden of physical and psycho-social symptoms. The increasing role of the cancer centers as agents of cancer control has meant that the best of the cancer research infrastructure has been brought to bear on cancer control, which has increasingly become concerned with helping cancer patients and survivors to tolerate cancer and its aftermath.

### ***NCI Institutional Locus for Palliative and End-of-Life Care and Symptom Management***

Shortly after publication of the 2001 IOM report on cancer palliation a working group to address palliative and end-of-life care and symptom management was formed at NCI. The existence of the working group was established based on an expert interview with Andrea Denicoff, who coordinates the working group from within the Cancer Therapy Evaluation Program (personal communication, 5/2/2007). The working group was established in 2001 shortly after publication of the 2001 IOM report on cancer palliation. An unpublished slide presentation created by this working group (n.d.) establishes that the working group was created in direct response to Recommendation 9

of the 2001 IOM report on cancer palliation. This working group was intended to be interdisciplinary and to span NCI divisions and offices in order to coordinate NCI's activities in order to meet the mandate embodied in Recommendations 8 and 9. The approach creates multiple loci in the NCI Divisions of Cancer Treatment and Diagnosis, Cancer Prevention, and Cancer Control and Population Studies.

The history of NCI's Palliative Care Working Group is told through two slide presentations obtained from Andrea Denicoff (personal communication, 5/2/2007). The first is material for a presentation to the NCI director in September of 2003 on the NCI response to the 2001 IOM report on cancer palliation (NCI Palliative Care Working Group, 2003). The second presentation describes NCI research, training, and education efforts to improve cancer palliation and was made to the International Union Against Cancer (UICC) World Cancer Congress in July of 2006 (NCI Palliative Care Working Group, 2006).

The first presentation (NCI Palliative Care Working Group, 2003) applies the 2001 IOM report on cancer palliation redefinition by defining it as 1) intended to improve quality of life by attempting to relieve physical, psychological, social, and spiritual distress; 2) relevant to the entire continuum of cancer care from diagnosis to the end of life; and 3) to be coordinated with curative *anti-tumor* therapy. The presentation takes note of the redefinition of palliative care by the World Health Organization in October, 2002. Palliative care now spans five periods beginning with diagnosis and including initial treatment, survivorship, recurrence or progression, and end-of-life. It follows from this that the NCPB has successfully established the need to change the definition of palliative care within NCI.

The workload of palliative care research at NCI was divided among the Division of Cancer Prevention, the Division of Cancer Control and Population Studies, including the Office of Cancer Survivorship, and the Division of Cancer Treatment and Diagnosis, including the Office of Cancer Complementary and Alternative Medicine (NCI Palliative Care Working Group, 2003). The pages regarding Working group positions taken about the definition of palliative care and the distribution of work within NCI were identical in both slide presentations (2003, 2006).

The Division of Cancer Prevention was responsible for symptom management and supportive care research from diagnosis to the beginning of the survivorship period and from recurrence to the end-of-life (NCI Palliative Care Working Group, 2003). The 2003 presentation to the Director cites clinical trials under the Community Clinical Oncology Program (CCOP) and other projects as evidence of its activities in symptom management and supportive care. According to the slide presentation, 41 CCOP clinical trials were conducted addressing pain, menopausal symptoms, anemia and fatigue, nutrition, cognitive difficulties, depression and diminished quality of life, nausea, oral and gastrointestinal difficulties. This list does not include dyspnea or anxiety. That list of symptom concerns was unchanged according to the 2006 NCI presentation to the International Union Against Cancer Congress (NCI Palliative Care Working Group). The current Division of Cancer Prevention website lists 71 CCOP clinical trials in supportive care and symptom management (2007). The 2007 list does not include menopausal symptoms or gastrointestinal difficulties but does include anxiety, hair loss, and lymphedema or swelling. The presentation does not disaggregate the clinical trials to a particular research topic. In addition, 31 other grants in palliative care at the Division of



Cancer Prevention were added by Fiscal Year 2002 to the 30 that were funded in Fiscal Year 2000. Most of these grants in both years were directed at patients undergoing curative therapy.

The Division of Cancer Control and Population Studies portfolio in palliative care research consisted of three elements (NCI Palliative Care Working Group, 2003), including the Office of Cancer Survivorship, the Behavioral Research Program and the Applied Research Program. In Fiscal Year 2002, 49 grants were added to 41 Year 2000 grants, more than doubling the number of the Office of Cancer Survivorship grants to 90. In both years one in eight grants addressed the needs of pediatric survivors. Under the Behavioral Research Program grants and contracts were awarded in communication and information research, behavioral research, and research geared toward management and coordination of palliative care. Under the Applied Research Program grants were awarded that focus on patterns of care at the end of life, developing quality indicators, improvements in palliative care for patients with advanced lung and colorectal cancer, development of quality measures through outcomes research, translational research, and health services, and economic studies.

The Division of Cancer Treatment and Diagnosis portfolio in palliative care research consisted of 29 quality of life clinical trials (NCI Palliative Care Working Group, 2003). The Office of Complementary and Alternative Medicine portfolio included requests for applications in end-of-life care in cancer and HIV/AIDS, cancer center research in complementary and alternative medicine, and other projects.

The second slide presentation (NCI Palliative Care Working Group, 2006) to the International Union Against Cancer Congress presented the same symptom management

agenda as the report to the Director's Office (NCI Palliative Care Working Group, 2003). In addition, the 2006 presentation addressed shared decision making, disparities, behavioral research, and communication, as well as quality assessment, researcher and clinician training, and provider education.

The working group is a dual network as defined by Alange et al (1998). The working group publishes a summary of its activities online (2006a). That summary identifies individuals from the three NCI divisions named above and NCI's Office of the Director. The list includes 18 members. The Division of Cancer Control and Population Studies is represented by Office of Cancer Survivorship Director, Julia Rowland, and representatives of the Patient-Centered Communication Initiative, Health Communications and Informatics, the Applied Research Program, and Health Communications and Informatics. The Division of Cancer Prevention is represented by Ann O'Mara, who manages that division's Symptom Management Portfolio. The Division of Cancer Treatment and Diagnosis is represented by Andrea Denicoff, a senior investigator of that program and Jeff White, who is Director of the Office of Cancer Complementary and Alternative Medicine. The Office of the Director has nine representatives including Lenora Johnson who is Director of the Office of Communications and Education, Rick Marrow who is Director of the Office of Cancer Content Management within Lenora Johnson's office, Carolyn Strete who is Chief of the Cancer Training Branch, and six others. Individuals were identified from the Working Group's website (2006a) and verified in the NCI Fact Book for 2006. In the interview with Andrea Denicoff (personal communication, 5/27/2007) it was established that the working group was created as a direct result of publication of the 2001 IOM report on

cancer palliation for the purpose of implementing Recommendation 9, which addressed institutionalization at NCI.

Ann O'Mara, one of the report's authors, stated that the report was used effectively as a justification for program announcements shortly after publication (personal communication, 5/2/2007). Seventy-four current initiatives sponsored by working group members as part of their work in palliative care and symptom management are listed on the webpage entitled Funding Opportunities in Symptom Management and Palliative Care Research (NCI, 2007b). There were 19 symptom management program announcements addressing pain (6), lymphedema (1), oral complications (5), sleep issues (2) and symptom clusters (2), and mental health, including suicide prevention (3). There were also two program announcements in self management of chronic disease and one in care giving for chronic disease. End-of-life was represented by a single program announcement. There were five program announcements addressing career development, three of which addressed social work. Quality research was represented by 11 program announcements including decision making (5) and dissemination research (2), and outcomes research (4). Other program announcements addressed aging and cancer (2), biobehavioral research (8), complementary and alternative medicine (7), economic studies (1), ethics (3), health disparities (5), information technology and intervention delivery (3), physical activity and obesity (2), and spirituality as a social and cultural dimension (3).

Taken as a whole it is clear that there was an immediate and affirmative response to Recommendations 8 and 9. Roughly a year after the 2002 state of the science conference on symptom management a report was made to the Office of the Director.

That report detailed evidence that within NCI, actors had accepted the redefinition of palliative care and much of the NCPB's definition of the problem as stated in the 2001 IOM report on Cancer Palliation. It is also clear that those actors at NCI had resolved to make the changes requested of them by the IOM report's authors, and were in fact translating that intention into a program with an increased portfolio of active research projects, and were justifying themselves to the NCI Director in terms of having done just that. This indicates successful initiation of the innovation, i.e., Recommendations 8 and 9 as defined by Rogers (2003). The battery of symptoms addressed was roughly unchanged by the 2006 presentation to the International Union Against Cancer Congress, which suggests that whatever reinvention there was did not affect the core research agenda proposed by the NCPB as it was adopted by the working group.

A core and quite visible locus of palliative care activity is found in the Office of Survivorship. According to an official history (NCI Office of Cancer Survivorship, 2007b), The Office of Cancer Survivorship began its work in 1996, near the end of the pre-deliberative period. Its work addresses physical symptom management, psycho-social issues, and economic impacts of cancer and treatment, with an interest in quality of life, functional status, and access issues. The reader is reminded that the NCPB defines palliative care as "active total care" (Foley and Gelband, 2001b, p. 10) of patients approaching the end of life whose treatment objectives have shifted from curative care to supportive care, adding that much of palliative care is applicable to patients at all points from diagnosis through the abandonment of curative treatment and beyond. On the Office of Cancer Survivorship website, NCI defines a cancer survivor as anyone who has had cancer "from the time of diagnosis, through the balance of his or her life," adding that

“family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition” (2007c). Alange et al (1998) refer to innovation as a process of continual reinvention. Nowhere in an analysis of palliative care is this truer than in the case of survivorship. The 2001 IOM report on cancer palliation extended the validity of cancer palliation to all stages of the disease from diagnosis to death. This strengthened the development of cancer survivorship as a research concern at NCI.

NCI has clearly made palliative care and symptom management part of an overall agenda of cancer control. NCI published *The NCI Strategic Plan for Leading the Nation to Eliminate the Suffering and Death due to Cancer* in January, 2006. The plan includes a vision--“A nation free from the suffering and death due to cancer by 2015 with dramatic reductions in cancer incidence” (inside cover)--and a mission statement--“Reduce the burden and eliminate the adverse outcomes of cancer by leading an integrated effort to advance fundamental knowledge about cancer across a dynamic continuum of discovery, development, and delivery” (inside cover). The document is important because it describes the state of institutional thinking at NCI on palliative care and symptom management at the end of the study period, i.e., the end of the year 2005.

This strategic plan addresses the traditional US cancer program, including causation, prevention, diagnosis and curative treatment, i.e. the elements of cancer control that were recognized before 1978. The report also discusses addressing barriers in access to cancer care of high quality. In addition, rehabilitation and counseling, which were mandated in 1978, are discussed as are development of psycho-social interventions geared toward quality of life interventions, which were mandated in 1993. The report

addresses socio-cultural and economic factors that influence quality of care, the experiences of survivors, and disparities among vulnerable populations, in addition to environmental and behavioral factors. Quality of life among patients, survivors and their families is also discussed.

The improvement of quality of cancer care and improvement of quality of life are the last two of seven strategic objectives in the strategic plan, respectively. In order to improve quality of care the plan calls for the development of measures of quality and interventions to achieve these, including the development of information systems. It also calls explicitly for the translation of symptom management and palliative care research into interventions for patients--survivors--including again, explicitly, at the end of life (p.59). The plan explicitly recognizes psychological and social components to quality of life and calls for research to support these. It is reasonable to conclude that NCI officially included not only incorporation of palliative care and symptom management into its research agenda, but many of the other NCPB recommendations, including those impacting quality, accountability, and measurement. Specific examples of institutionalization include entries on the NCI PDQ site, funding of four extramural centers of excellence in patient communication and an Office of Cancer Survivorship within the Division of Cancer Control and Population Sciences. The Office of Cancer Survivorship was established in Fiscal Year 1996, five years before publication of the 2001 IOM report on cancer palliation.

***NCI PDQ Practice Guidelines for Symptom Management and End-of-Life Care***

The NCI website ([www.cancer.gov](http://www.cancer.gov)) provides information to cancer patients and health care providers by type of cancer, clinical trials, and selected cancer topics. The

links in these categories access NCI's PDQ database, which provides peer-reviewed summaries on a variety of topics including palliative and end-of-life care and symptom management to health care providers and the public. The information contained in this web presentation is relevant to palliative and end-of-life care and symptom management. It addresses NCI compliance with the NCPB's Recommendation 5 of the 2001 IOM Report on cancer palliation. Recommendation 5 is concerned with improving patient-oriented material, which is beyond the scope of this thesis. The health care provider information in this web presentation constitutes practice guidelines and is reviewed here from that perspective. As practice guidelines, these articles reflect NCI policy. Inclusion of palliative and end-of-life care guidelines and symptom management guidelines in this web presentation reflect institutional acceptance of the NCPB's recommendations.

The NCI web presentation includes a page entitled *Coping with Cancer*. That page begins with links to articles on fatigue and pain, which are followed by links to articles on *Other Complications/Side Effects*, i.e. other physical symptoms, *Nutritional Concerns*, and *Emotional Concerns*, i.e. psychological symptoms. These pages include PDQ articles on pain and fatigue, as well as nausea and vomiting, cognitive disorders and delirium. There are no links of any kind to dyspnea resources. But there are PDQ articles on anxiety and depression. There is also a PDQ entry on spirituality under the emotional issues heading. In other words, through peer-reviewed summaries, the NCI addresses all of the physical and psychological symptoms addressed in the 2001 IOM report on cancer palliation, except dyspnea. In addition, there are a number of symptoms and side effects of cancer not discussed in the report including cardiopulmonary issues, fevers sweats and hot flashes, gastrointestinal issues, lymphedema or swelling, sexual and reproductive

issues, sleep disorders, sequelae in pediatric cases, and others, that have PDQ entries. Additional PDQ entries addressing psycho-social issues include normal adjustment, i.e. sub-clinical psychological distress, post-traumatic stress disorder, substance abuse, and coordination of care issues. Another PDQ entry discusses loss, grief, and bereavement among its end-of-life links. Beyond this, psycho-social components to physical symptoms in the case of pain, fatigue, nausea, and cognitive disorders are recognized.

The NCI web presentation *Coping with Cancer* (2007a) demonstrates NCI institutionalization of palliative and end-of-life care and symptom management by providing peer-reviewed practice guidelines for health care providers. This web presentation addresses the breadth of the program proposed in the 2001 IOM report on cancer palliation, with the exception of dyspnea. In addition, the NCI web presentation addresses a number of issues not discussed in the report. The topics covered include severe end-of-life concerns, mostly covered in the report, less severe issues such as nutrition, and management of side effects of treatment. Spirituality and management of bereavement, two key concerns of the report, have PDQ entries. As reflections of NCI policy, these practice guidelines show that NCI has explicitly integrated the program set forth by the report's authors, expanded it, and integrated it with other concerns.

## **Hypothesis 2 – Trends in NCI-Funded Research**

The extent to which NCI shifted emphasis in funding to prioritize palliative care and symptom management was examined using project and budget data. The budget data do not cover intramural projects, although the project data do. However, only 2% (98) of the projects that are relevant to the measures of palliative care and related research are intramural projects. In addition to these 98 intramural studies, budget data are missing or



partially missing for seven of 4,472 extramural projects. Please see Appendix A for an accounting of missing data.

### *General Measures*

Taken together general measures of palliative care and allied research areas changed little. This is due to the adoption curve for palliative care research, which made up nearly all of these projects. Proportions of both the number of NCI palliative care projects and the NCI extramural budget spent by those projects, and supportive care show no significant trends. Only the proportion of end-of-life care research increased significantly (0.06% to 0.21% of budget,  $p=.001$  and 0.10% to 0.27% of projects,  $p=.006$ ).

**Figure 1. Adoption Curves – Proportion of the NCI Extramural Budget Invested in Palliative and Related Types of Care**

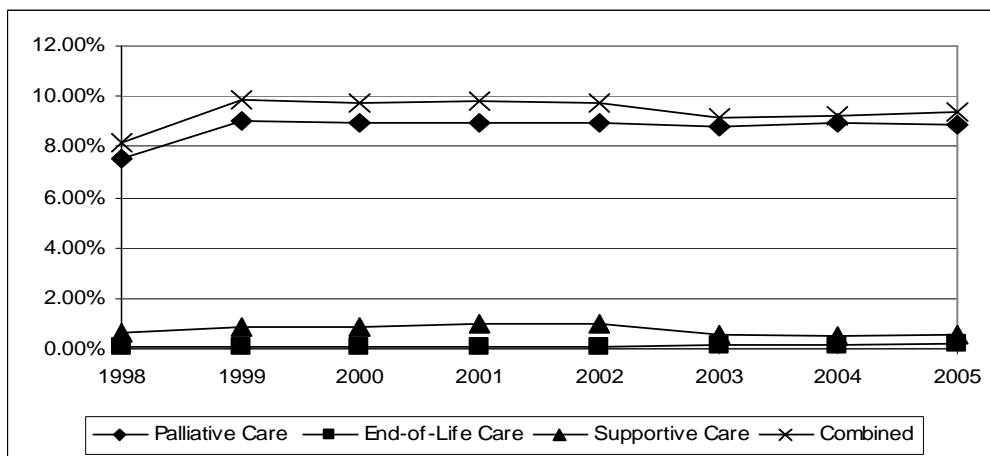
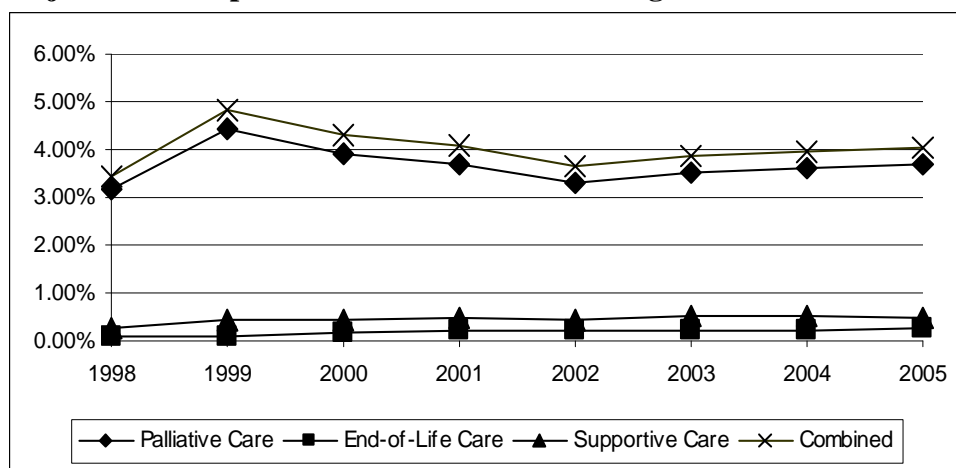


Figure 1 shows the overall pattern between Fiscal Year 1998 and Fiscal Year 2005. There was an increase in the proportion of NCI extramural spending early in the deliberative period for palliative care (from 7.6% in 1998 to 9.0% in 1999). As a budget priority palliative care remained stable after 1999 until 2005 (8.9%). As an extramural spending priority palliative care remained stable after 2002, but supportive care declined

from 1.0% to 0.5% of the NCI extramural budget. The overall result is that these allied research concerns declined slightly after publication of that report. End-of-life care as a research priority increased more or less steadily between 1998 and 2005, but was tiny by comparison to palliative care as a research priority at NCI with a significant trend ( $p=.001$ ), but as an NCI extramural research budget priority end-of-life care research remains minuscule (0.1% 1998-2004, and 0.2% in 2005). Figure 2 shows apparent positive change points for palliative care and all three research terms combined at 2002. Growth following the change points is sustained.

**Figure 2. Adoption Curves – NCI-Funded Palliative Care and Related Projects as a Proportion of the NCI Research Agenda**

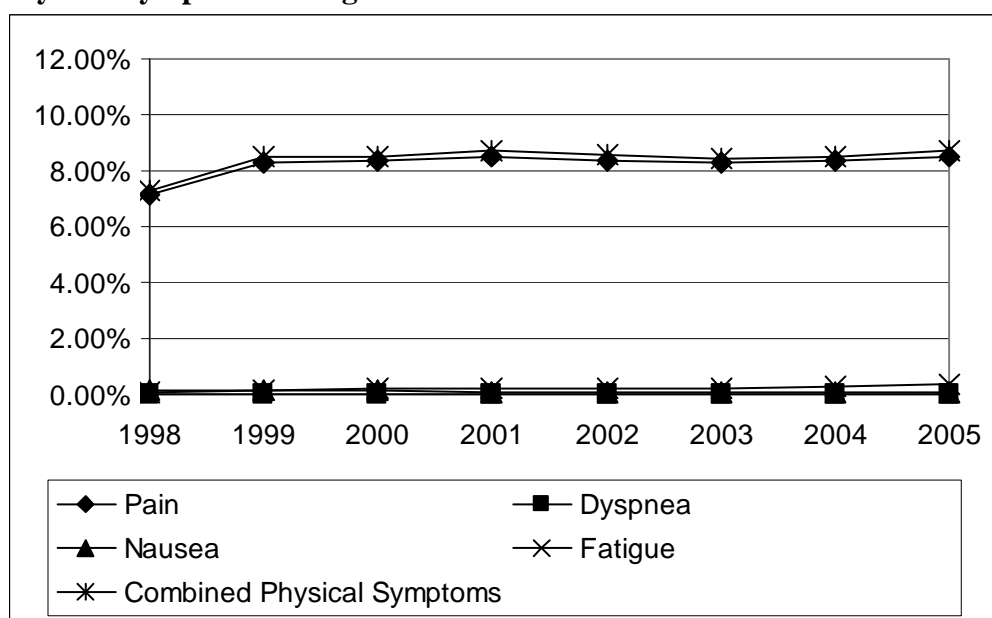


### *Physical Symptoms*

The story of NCI-funded physical symptoms research, as shown in Figure 3, is essentially about pain research. Pain research, named as a concern in the 2002 consensus statement, accounted for 96% of physical symptoms projects and 98% of physical symptoms research dollars in Fiscal Year 1998 and 90% of physical symptoms projects and 98% of physical symptoms research dollars in Fiscal Year 2005. While the relative number of pain research projects increased as a proportion of physical symptom research,

the relative size of the combined budget of projects that named pain as an issue changed little. The NCI investment in pain research and physical symptoms research generally did not change significantly as a proportion of the overall NCI extramural budget. However, dyspnea research and fatigue research increased significantly, while nausea research decreased significantly. No research projects named dyspnea as an issue in 1998. The NCI did not begin to fund extramural dyspnea research until 2000. Dyspnea research

**Figure 3. Adoption Curves – Proportion of the NCI Extramural Budget Invested in Physical Symptom Management**



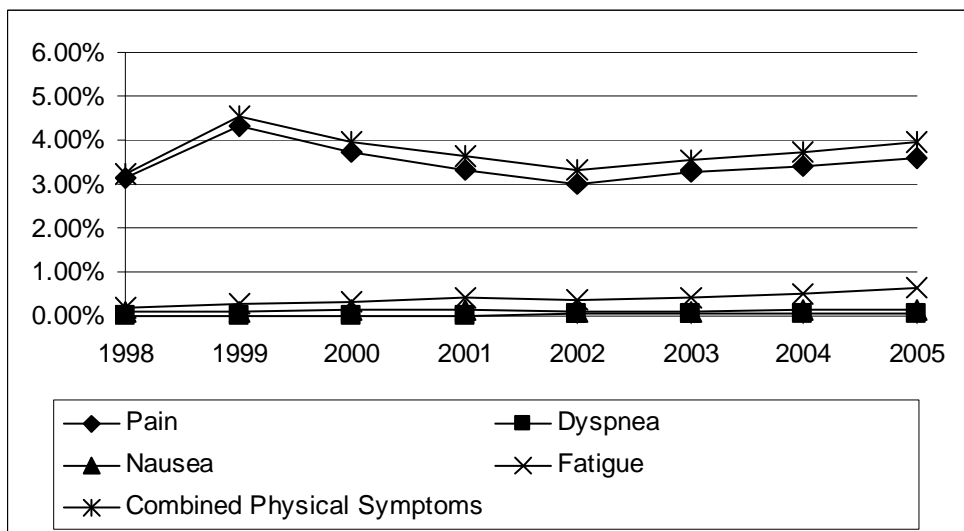
peaked in 2002 at 0.03% of the NCI extramural budget, which is the last year that the NCPB's findings were still unknown. After 2002 dyspnea research has represented 0.02% of the NCI extramural budget in every year. The overall trend is increasing for the proportion of funding ( $p=.003$ ) and the relative number of projects ( $p=.047$ ). However, dyspnea, described as difficult but not impossible to treat effectively in the 2001 report on cancer palliation, was not addressed in the 2002 consensus statement yet is an important issue at the end of life according to Charles Cleeland (personal communication,

5/11/2007), and has received minuscule funding levels from NCI, which declined after publication of the 2001 IOM report on cancer palliation.

Research projects that named fatigue as an issue quadrupled as a proportion of the NCI extramural budget between 1998 and 2005 from 0.09% to 0.38% ( $p=.001$ ) and increased more than six-fold from 0.16% to 0.51% ( $p<.001$ ). Fatigue was named as a research priority in the 2002 consensus statement. Research projects that name nausea as an issue decreased as a proportion of NCI extramural spending from 0.14% of NCI extramural spending to a low of 0.05% in 2002, before recovering to 0.09%. Although the overall trend is decreasing ( $p=.005$ ), 2002 represents an apparent change point in NCI extramural spending concerned with nausea, where the downward trend is reversed despite its exclusion from the 2002 consensus statement. The proportion of nausea-relevant projects funded by NCI did not decrease significantly.

There appears to be a trend toward relatively more projects concerned with dyspnea, nausea and fatigue compared to pain-related projects, but an increased number of projects seem to be competing for a portion of the NCI extramural budget dedicated to symptom management that is virtually unchanged. Figure 3 shows that extramural funding for symptom management generally and pain projects in particular increased early in the pre-deliberative period to just over 8% of the extramural budget in 1999 and remained stable through 2005. Figure 4 shows that the relative number of funded symptom management projects also increased in 1999, but then decreased through 2002, after which it recovered. Publication of Foley and Gelband (2001) coincides with an increased number of projects funded; however physical symptom management has not increased since publication of the report as a budget priority.

**Figure 4. Adoption Curves – NCI-Funded Physical Symptom Management Projects as a Proportion of the NCI Research Agenda**



It appears that publication of the 2001 report on cancer palliation and the 2002 consensus statement coincide with increases in NCI-funded pain and fatigue research. While relative funding levels for pain research held steady, funding for fatigue research though minuscule increased four-fold. There is an apparent change point at 2002 for the proportion of pain research projects, while the proportion of fatigue projects continued an increasing trend after 2002. The deliberative process beginning in 1997 coincides with the first NCI dyspnea research of the study period. It is nearly impossible not to overstate the relative importance of dyspnea research, which is represented by between one and three projects in any given year in 2000 and after. Nausea research was declining as a funding priority until 2002, after which it rallied despite failure to mention it in the 2002 consensus statement. This may be due to the importance of effective treatments for nausea in the management of the side effects of chemotherapy and radiation therapy.

In any case, we should avoid overstating the apparent impact of the 2001 report and its institutional aftermath. Although there are some minor increasing trends and apparent increasing change points in funding and the number of projects, the overall

funding level of physical symptom research has not changed much after 1999, nor has the relative priority of the components pain, dyspnea, nausea, and fatigue changed appreciably. On the other hand, fatigue research appears to be established as a research priority and dyspnea research has begun, however humbly.

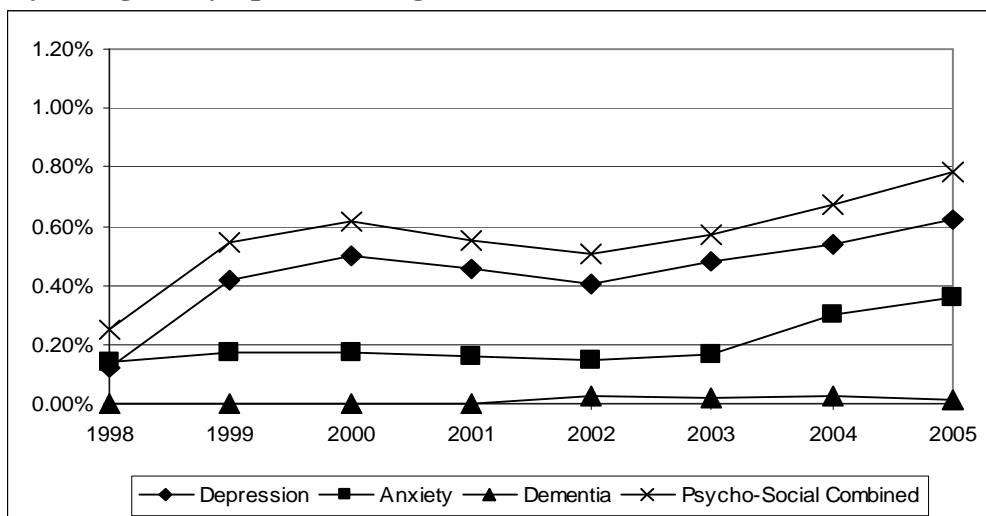
### *Psychological Symptoms*

Between Fiscal Year 1998 and Fiscal Year 2005, all psychological issues raised in the NCPB's report on cancer palliation received significantly increased attention from NCI. Research projects that name depression as a concern increased from 0.20% to 0.72% ( $p < .001$ ) of NCI-funded projects and from 0.12% to 0.62% (.018) of the extramural budget. Depression was named in the 2002 consensus statement as a target for further research. Research projects that name anxiety as a concern increased from 0.22% to 0.57% ( $p = .001$ ) of NCI-funded projects and from 0.14% to 0.36% ( $p = .027$ ) of the extramural budget despite exclusion of this issue from the 2002 consensus statement. Research projects that address dementia were not funded at all until 2000 and at less than 0.01% of the extramural budget until 2002, and represented 0.02% of the NCI extramural budget from 2002 until 2004 and 0.01% of the budget in 2005. The overall relative trend in funding is increasing ( $p = .046$ ), but the proportion of NCI-funded projects is not.

Figure 5 shows that during the pre-deliberative period, NCI extramural funding of projects that address psychological symptoms increased in the early part of the pre-deliberative period through 2000, but declined until Fiscal Year 2002, when the NCPB's report was published. The overall trend for funding of projects that address psychological symptoms is positive ( $p = .018$ ). After 2002, research that addresses psychological symptoms increased steadily. These increases were initially driven by increases in the

proportion of the budget that funds projects that address depression, while after 2003 research that addresses anxiety began to increase.

**Figure 5. Adoption Curves – Proportion of the NCI Extramural Budget Invested in Psychological Symptom Management**



The study period saw an increase in the extramural funding share of psychological research from 0.4% to 1.0% of the budget between 1998 and 2005. Both depression and anxiety research made impressive gains. Anxiety research does not seem to have suffered greatly from exclusion from the 2002 consensus statement, in light of funding increases between 2003 and 2005. Dementia research, like dyspnea research, became part of the NCI cancer program during the study period.

### ***Profession Development Projects***

The NCPB's report on cancer palliation called for development of the fields of oncology, oncology nursing, oncology social work, and hospice care. This section discusses palliative care projects that refer to oncology, nursing, social work, and hospice in their titles and abstracts and palliative care, end-of- life care or supportive care between Fiscal Years 1998 and 2005. See Appendix A. The growth in the numbers of

projects of these types did not show significant trends for the most part. Oncology and nursing did not show significant trends, either in the proportion of NCI projects or in the proportion of NCI extramural funding. Social work projects, never many, declined ( $p=.022$ ) from 0.04% of the extramural NCI budget in 1998 to 0.02% in 2005. The trend in the proportion of NCI projects was not significant.

**Figure 6. Adoption Curves – Proportion of the NCI Extramural Budget Invested in Profession Development Projects in Palliative Care**

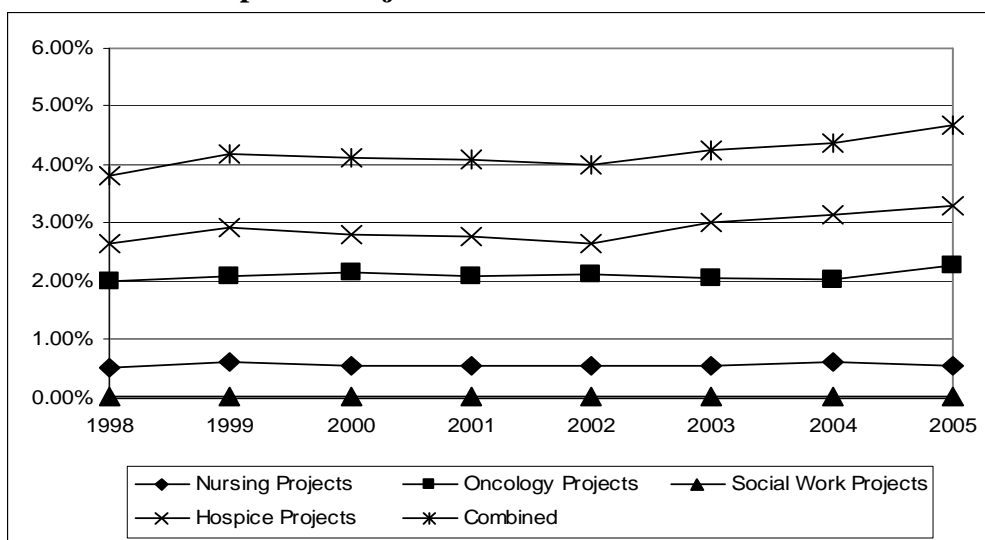
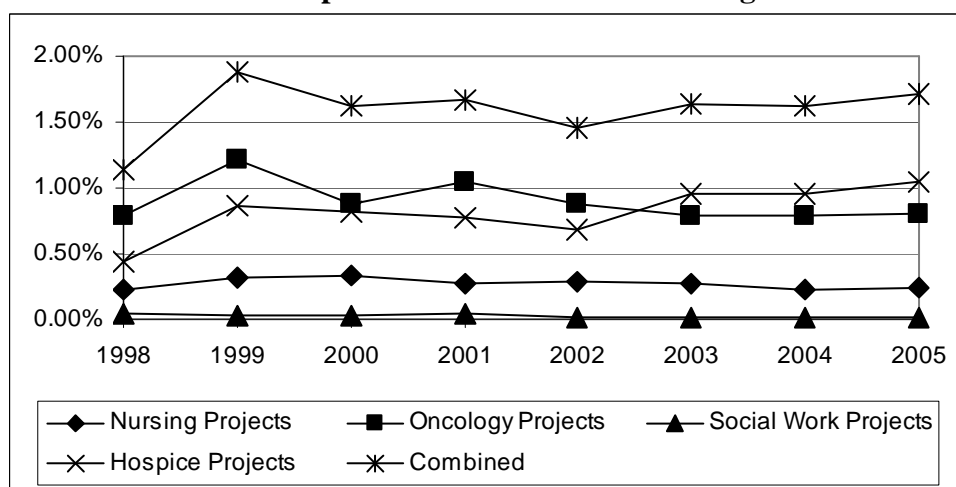


Figure 6 shows that when combined, these projects increased as a proportion of the NCI extramural budget between 1998 and 1999, declined slightly until 2000, and then began to increase. The 1998-1999 increase is attributable to increases in hospice and nursing projects. The 2002 apparent change point is due to a proportionate increase in hospice research. Between 2002 and 2003 the number of hospice research projects grew from 50 to 73, overtaking oncology research projects, which decreased from 65 to 60. Oncology research increased between 2004 and 2005. There is an apparent change point at 2002 in hospice research indicating coincidence with publication of Foley and Gelband (2001). That change point corresponds to the point where hospice research overtook



oncology research as a proportion of NCI-funded projects. The increase beginning in 2003 was due mostly to hospice research, not nursing research, and not oncology research until the end of the study period. See Figure 7 below.

**Figure 7. Adoption Curves – NCI-Funded Profession Development Projects in Palliative Care as a Proportion of the NCI Research Agenda**



It appears that research dealing with nursing interventions in palliative and end-of-life care responded quickly to the events that included the NCPB's deliberations. Hospice research may have been invigorated by publication of the 2001 IOM report on cancer palliation. Oncology research in this area was stimulated somewhat later for reasons that are not suggested by the palliative care deliberations but might coincide with the IOM publications on survivorship between 2003 and 2005. On the whole the growth in this area is modest. Between 1998 and 2005 this research grew from just less than four percent to just less than five percent of the NCI extramural research program.

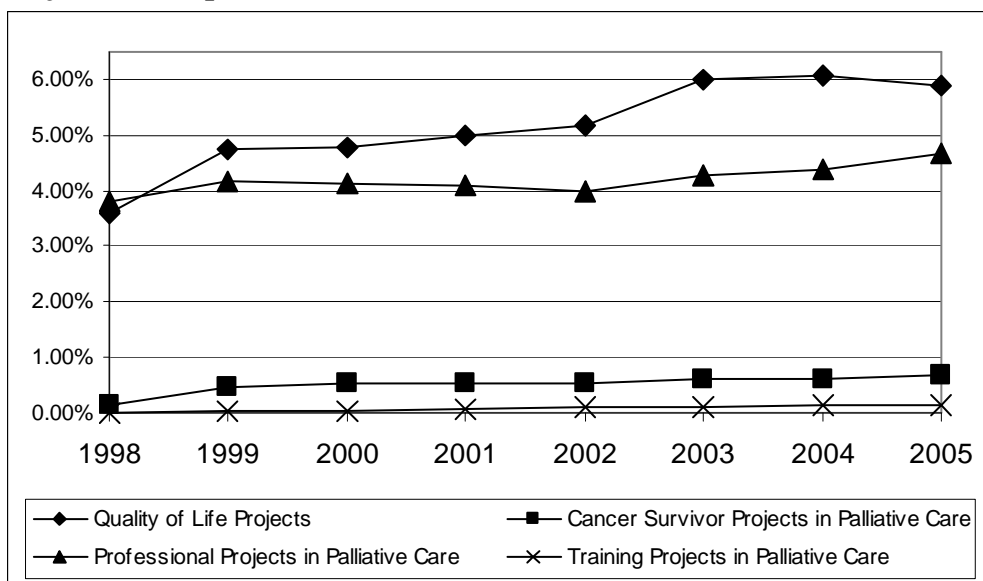
#### ***Four Measures of Emphasis on Palliative Care***

This section compares four indicators of institutional concern about palliative care and allied fields. *Quality of life* projects refer to the phrase "quality of life" in their titles or abstracts. This phrase captures the concerns of the authors of Foley and Gelband

(2001) to address quality in addition to length of life. *Cancer survivorship* refers to a CSO-recognized area of cancer research that is concerned with addressing the needs of cancer patients beyond the need to eradicate cancer. *Profession development* projects were described in the last section and did have a significant trend overall. *Training* projects and *clinical trials* refer to projects of this type in palliative care.

Projects referring to quality of life in their titles or abstracts increased significantly ( $p=.001$ ) from 1.90% of NCI-funded projects in Fiscal Year 1998 to 3.21% in Fiscal Year 2005. These projects also increased as a proportion of NCI extramural funding ( $p<.001$ ) from 3.61% of the budget in 1998 to 5.89% in 2005. Palliation cancer survivorship projects increased significantly from 0.22% of NCI-funded projects ( $p<.001$ ) in 1998 to 0.66% in 2005 and from 0.16% of extramural funding in 1998 to 0.52% in 2005 ( $p=.009$ ). Training projects increased both as a proportion of NCI-funded projects ( $p<.001$ ) and as a proportion of the extramural budget ( $p<.000$ ). No training projects in

**Figure 8. Adoption Curves – Proportion of NCI Extramural Budget Invested in Projects with Specific Relations to Palliative Care**



palliative care were funded by NCI in 1998. By 2005 training projects in palliative care accounted for 0.28% of NCI-funded projects and 0.08% of the extramural budget. No palliation clinical trials were conducted with NCI funding between 1998 and 2005.

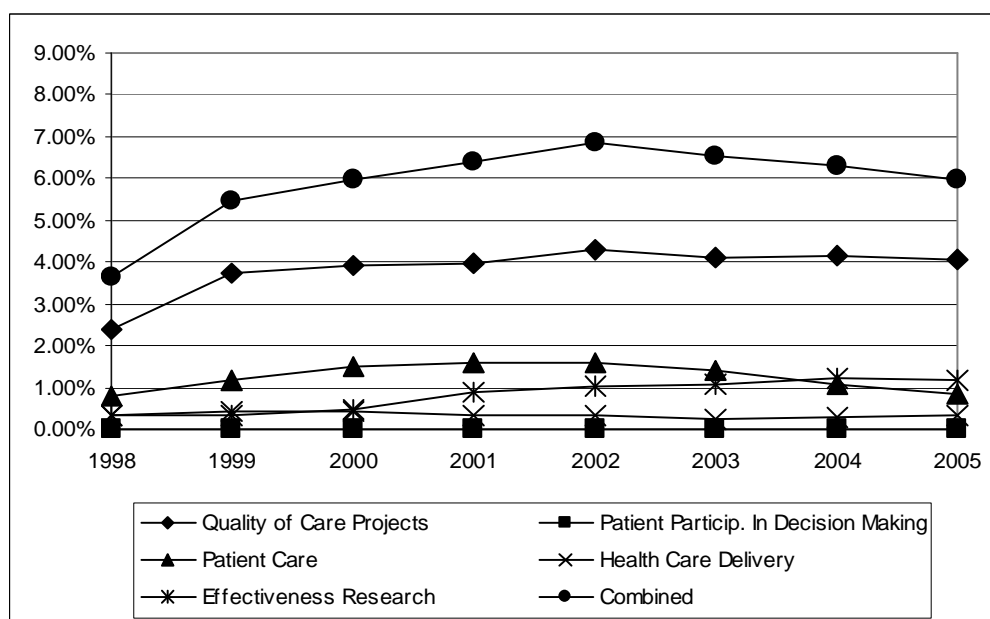
Figure 8 shows the proportion of the extramural budget for quality of life projects, palliation cancer survivorship projects, profession development projects, and training projects within palliative care. This graph shows that, except for clinical trials, all measures increased as a proportion of the budget early in the deliberative period, between 1998 and 1999. Cancer survivorship projects and palliation training projects in palliative care were stable between 1999 and 2004, although the number of projects that refer to quality of life in their titles and abstracts increased from 2002 to 2003, and remained stable thereafter. Profession development projects also had an apparent change point at Fiscal Year 2002 and remained stable at about 6.0% of the extramural budget thereafter, but up from less than four percent in 1998.

### ***Quality Research in Palliative Care***

This section discusses measures of quality discussed in the NCPB's report on cancer palliation. Indicators include quality of care, patient participation in decision making, patient care, patient satisfaction, coordination of care, health care delivery, and effectiveness research. All of these indicators refer only to palliative care projects. Of these indicators two, patient satisfaction and coordination of care are not represented by any NCI-funded projects between Fiscal Years 1998 and 2005. Patient participation in decision making is represented by a single project that was funded in 2001 and 2002. Projects within the CSO research category effectiveness research and the NCI special interest category palliative care increased significantly both as a proportion of NCI-

funded research projects ( $p < .000$ ) from 0.12% to 0.94% and as a proportion of the extramural budget ( $p < .000$ ) from 0.32% to 1.15%. Patient care research within palliative care increased significantly as a proportion of NCI-funded projects from 0.71% to 1.26%,

**Figure 9. Adoption Curves – Proportion of the NCI Extramural Budget Invested in Quality Assessment of Palliative Care**



but did not show a significant trend for the proportion of the extramural budget. Health care delivery within palliative care and quality of care research increased overall between 1998 and 2005 but without significant trends for the proportion of NCI-funded projects or the proportion of extramural funding.

Figure 9 shows that the proportion of NCI extramural funding dedicated to quality research for palliative care increased consistently from 1999 to 2002, when that trend was arrested and reversed, ironically coinciding with publication of the NCPB's report on cancer palliation. After the apparent change point in 2002--a maximum--only effectiveness research continued to increase. This must be a disappointment to the 2001 IOM cancer palliation report's authors, who called out clearly for quality and

accountability research and were echoed in the consensus statement of the following year. The NCPB continued to write on quality of care issues including the reports on pediatric survivorship issues in 2003 and breast cancer survivorship in 2004, cited above. A successor to the NCPB, the IOM's Committee on Cancer Survivorship: Improving Care and Quality of Life co-published a report on adult survivorship (Hewitt, Greenfield, & Stovall, Eds.) with the NCPB at the end of 2005.

### *General Trends*

Between Fiscal Year 1998 and 2005 the general trend for all projects identified in this content analysis was a significant increase in the proportion of all NCI-funded projects ( $p=.002$ ), but the trend in overall funding is not significant. Between 1998 and 1999 there was an increase in the proportion these projects represent of NCI-funded projects from 6.12% to 8.87% in conjunction with an increase in the proportion of the extramural budget from 13.3% to 16.3%, or roughly one-sixth of the extramural budget. After 1999 the proportion of NCI projects dropped to 8.19% in 2001, and began to recover after 2002 to 8.72% in 2005. The proportion of NCI projects that address palliative care or attempt to address it by referring to "quality of life" in their titles or abstracts increased by 0.5% of the number of NCI-funded projects, with an apparent change point at 2002. Funding of this research, however, is another story. After the initial proportionate increase in funding after 1999 the proportion of the NCI budget grew slowly from 16.3% in 1999 to a high of 17.0% in 2003. After 2003 the share of the budget was stable for a year (16.9% in 2004) and fell to 16.7% in 2005. In short there has been a modest increase in the proportion of NCI-funded projects, but that increase has not been accompanied by an increase in budget share.

This chapter has provided the chronology of cancer control at NCI from that agency's inception. It described the results of 2002 NIH consensus conference on symptom management for cancer and efforts to find an institutional locus for palliative and end-of-life care and symptom management. It also described the inclusion of these concerns in NCI program planning. Overall, the NCPB's concerns that an institutional locus for palliative and end-of-life care and symptom management should be located at NCI, an NIH consensus conference on palliative care and symptom management should be held, and a high profile research program at NCI should be initiated were addressed. The nature and scope of that research program was presented, along with NCI project and extramural budget data.

## **CHAPTER 6. RESULTS RELATED TO THE CANCER CENTERS AND COMPREHENSIVE CANCER CENTERS**

This chapter presents the findings for Hypotheses 3 and 4. Hypothesis 3 (Recommendations 1 and 2) addresses the development of centers of excellence in symptom management and palliative care and the requirement by the Cancer Centers Branch that the cancer centers develop programs in palliative care and symptom management as a condition of comprehensive status. Institutional developments within the cancer centers program are presented, along with the results from an expert interview with Cancer Centers Branch Chief, Linda Weiss (personal communication, 5/2/2007). Dr. Weiss establishes that neither recommendation was implemented and presents a brief rationale. Also presented are positions taken by the Cancer Centers Branch and the cancer center directors regarding palliative and end-of-life care, symptom management, and survivorship.

Hypothesis 4 addresses the evolution of the proportion of the NCI research portfolio in palliative and end-of-life care and symptom management. Results help define areas in which the cancer centers have provided leadership in the development of that portfolio. As a whole, this chapter documents the Cancer Centers Branch's rejection of Recommendations 1 and 2, but it also presents evidence of reinvention through incorporation of concerns presented in the 2001 IOM report on cancer palliation.

### **Hypothesis 3 – Institutional Development within the Cancer Centers Program**

NCI Guidelines from 2004 (NCI Cancer Centers Branch) list the Cancer Centers Branch policy regarding cancer center support grants and designation of cancer centers and comprehensive cancer centers. These guidelines may be assumed to be the most

recent because there are no later versions or updates published on the NCI website dated before December 31, 2005, as of March 1, 2007. Although the 2004 guidelines do not explicitly require research in palliative care or symptom management as a necessary condition for designation as a comprehensive cancer center, the concepts of palliative care and symptom management have been incorporated into the program of the Cancer Centers Branch on what appears to be an equivalent basis with other concerns within cancer control.

Cancer center support grants provide overall support for institutions with excellent cancer research programs that span a broad range of issues (NCI Cancer Centers Branch, 2004). As general support these grants may neither be applied to specific research programs, nor may they be used to subsidize services provided to patients or other institutions without payment unless those services are provided within the context of cutting edge research.

To make sense of this we must first understand the cancer center program. The mission of this program is to develop interventions to reduce cancer incidence, morbidity, and mortality through basic, applied, and translational research, as well as dissemination of state of the art interventions, and education of health care providers, patients and their families and the general public (NCI Cancer Centers Branch, 2004). In fact the program is described in the Guidance as a translational program. The cancer centers program addresses a broad spectrum of interventions including those aimed at prevention, early detection, treatment, and “palliation and support for survivors” (p.2). In other words, through the cancer centers program, cancer centers develop interventions that address a broad range of cancer control interests including palliation and symptom management,



including the psychological needs of cancer patients and survivors. The Guidance also calls for the development of interventions that improve access to services provided to minorities and other populations with problems of access to care, as called for in the 2001 IOM report on cancer palliation.

Cancer centers are chosen on the basis of their ability to bring together a broad range of scientific approaches to impact a broad range of cancer control interests. Cancer centers have scientific research programs that focus primarily on at least one, but possibly more than one of the following areas: basic research, clinical research, or population studies (NCI Cancer Centers Branch, 2004). Comprehensive cancer centers are expected to show emphasis in at least two of those areas and to demonstrate an ability to work across disciplines. The Guidance calls for cancer centers to “feature interactions across [their] research areas, and facilitate collaboration between laboratory, behavioral, epidemiologic, and clinical scientists, and between laboratory, clinical, and population science programs” (p. 4). However, the Guidance states that “no particular organizational configuration is mandated by these guidelines” (p. 4). Centers are expected to show breadth and depth of scientific interests that span laboratory, clinical, and cancer control addressing cancer risk, incidence, morbidity, and mortality. According to the Guidance cancer centers “should demonstrate grant support not only in epidemiology, but also in several other areas of primary prevention, early detection, health services, dissemination, palliation and survivorship research” (p.4). In other words, centers are not expected to necessarily contribute to the full range of concerns within cancer research, but should span research arenas and address a broad range of concerns falling somewhere within

prevention, treatment, and population studies that have incorporated palliative care and symptom management.

Comprehensive cancer centers must, in addition to the above, demonstrate the ability to conduct education and training of the public and health care providers and conduct outreach and community services. The Guidance calls for institutions that are considered as candidates for comprehensive status to describe degree programs and continuing education courses they provide in the disciplines of nursing, behavioral sciences and oncology including rehabilitation, pain management, and psycho-social services (NCI Cancer Centers Branch, 2004, p.32).

An expert interview was conducted with Cancer Centers Branch Chief, Linda Weiss (personal communication, 5/2/2007). In that interview it was confirmed that no formal centers of excellence have been established within the cancer centers program and that the Cancer Centers Branch does not require a research program in palliative and end-of-life care and symptom management as a condition of comprehensive status. The reason given for what amounts to categorical rejection of Recommendations 1 and 2 was that the Cancer Centers Program provides core infrastructural support to the cancer centers and is not an appropriate mechanism to attempt to implement an advocacy agenda. To use the Cancer Centers Program to create obligations would establish a precedent that would be contrary to the historical focus of that program, and thus unduly coerce institutions into developing away from their strength. However, palliative care, symptom management and cancer survivorship are recognized as part of the basis on which comprehensive status is determined. Although this amounts to categorical rejection of Recommendations 1 and 2, it does not establish that the institutional concerns in

Recommendation 1 and the research concerns in Recommendation 2 went entirely unaddressed. Such reinvention was not taken up in the interview with Linda Weiss, but is evaluated through the following document review.

A planning document was written from the proceedings of a meeting of cancer center directors in May 2006, for the purpose of establishing priorities for cancer research in support of the overall cancer control agenda of the Cancer Centers Branch (Cancer Center Directors Working Group, 2006). That report recognized the role of supportive care in the treatment of invasive cancer and as the end of life approaches. However, the directors' report strongly emphasized survivorship research as a key element of cancer control to the point of attaching the executive summary, including recommendations of the 2005 IOM report on cancer survivorship (Hewitt, Greenfield & Stovall). Survivorship research, as discussed by the cancer center directors addresses psychological and social factors, in addition to biological and physical ones, which impact patients' responses to cancer, treatment, and recovery. The directors recognized the needs of cancer survivors to deal with fatigue, depression, sexual problems not mentioned in the 2001 IOM report on cancer palliation, cognitive problems, and psycho-social function, which impacts education, marriage and employment. Other survivors' concerns include the increased risk of recurrence, treatment of the long-term secondary effects of curative treatment, and health behaviors such as diet, smoking, and exercise. The directors also discuss the need for effective pain management.

The directors' report refers to cancer palliation and supportive care within the continuum of issues relevant to cancer control. Symptom management issues are discussed largely, but not exclusively, as issues of survivorship. Pain management is

discussed as a concern in connection with treatment, and we should assume treatment at the end of life. Nausea was not addressed explicitly, but is an issue of supportive care in cancer treatment. Dyspnea was not addressed. Fatigue, depression, and cognitive problems were addressed as survivorship issues. Anxiety was discussed not at all. One of the general recommendations of the 2001 IOM report on cancer palliation was to treat the concerns of palliative care as valid from the time of diagnosis. It seems somewhat ironic that symptom management and psycho-social well-being are addressed among survivors, but there is little discussion of treatment at the end of life, including management of physical and psychological symptoms.

On paper at least, it is clear that cancer palliation, symptom management and psycho-social care have been incorporated into the work of the cancer centers if not the expectations that the Cancer Centers Branch has for the cancer centers. This provides a basis to assert some compliance with Recommendation 2 of the 2001 IOM report on cancer palliation, i.e. that research in palliative care and symptom control become a part of the cancer centers program even though these activities are not required outright of all comprehensive cancer centers. It bears repeating that no program component is absolutely required for recognition of comprehensive status.

#### **Hypothesis 4 – Trends in the Cancer Centers’ Research Portfolio**

Compliance with the NCPB’s Recommendation 1, which calls for the development of centers of excellence in palliative care symptom management within the cancer centers program, is somewhat more difficult to establish on paper than compliance with Recommendation 2. Recommendation 1 listed nine bulleted items, all of which were recommended activities but did not represent an exhaustive list in the NCPB’s estimation.

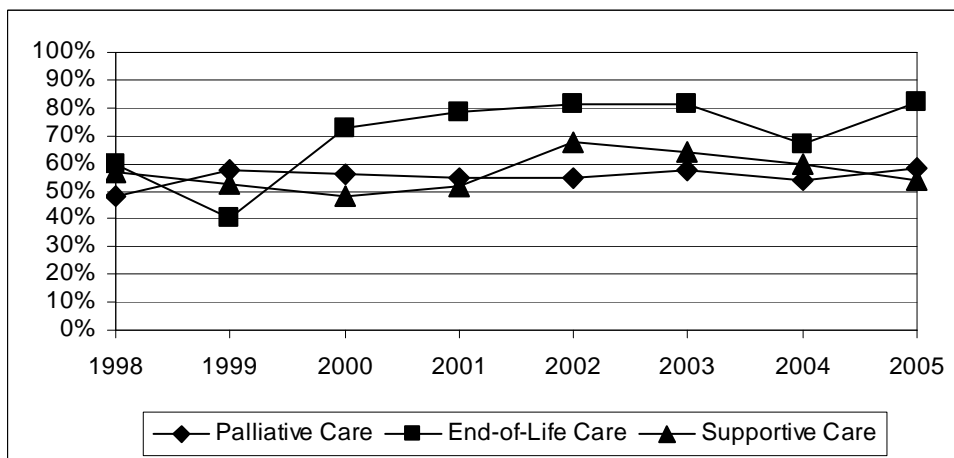
That list includes development of practice guidelines for palliative and end-of-life care, incorporation of palliative care into clinical trials and hospice interventions, improving palliative care and end-of-life care training for oncologists, nurses, and social workers, development of quality indicators, and addressing disparities and issues of access to care to vulnerable populations. However, by assessing trends in the growth of the cancer centers' research programs, i.e. the changes in the proportion of the budget made up by each activity, and by assessing trends in the proportion of NCI-funded projects, it is possible to measure the efforts of the cancer centers in each program area and the proportion of the burden carried by each. If the cancer centers are performing as the NCPB recommended then there will be significant growth in volume of research conducted in palliative and end-of-life care and symptom management, profession development and hospice research, and quality indicators, and the centers will have taken on a growing share of the projects in these areas that NCI funds.

### ***Palliative, End-of-Life and Allied Concerns***

The 2001 IOM report on cancer palliation recommends that the cancer centers formally test and evaluate practice guidelines for palliative care. If this has been the case it may be expected that the cancer centers have conducted a large and or growing proportion of palliative and end-of-life care research and that a large and or growing proportion of NCI funding to the cancer centers is for palliative and end-of-life research.

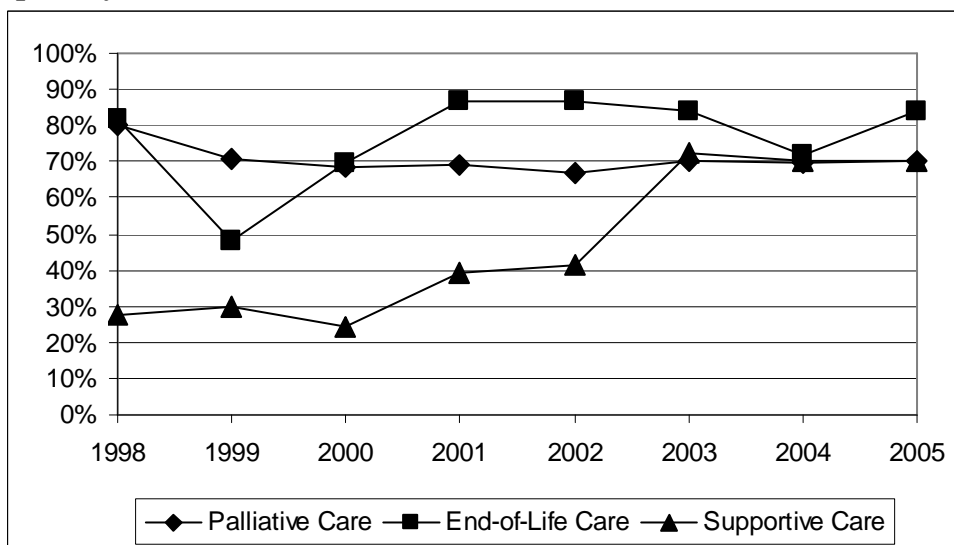
The cancer centers account for most palliative and related projects and most of NCI extramural research. Figure 10 shows that the cancer centers account for roughly 55% of palliative care research projects from Fiscal Year 1999 to Fiscal Year 2005 after a slight increase from 48% in 1998. After a one-year drop in their share of end-of-life

**Figure 10. Cancer Center Share of NCI Projects in Palliative and Related Types of Care**



research projects from roughly 57% of NCI-funded end-of-life research projects in 1998 to 40% in 1999, cancer centers conducted between 78% and 82% of NCI-funded end-of-life care research between 2001 and 2005 in every year except 2004 (67%). Between 1998 and 2005 the cancer centers' share of NCI-funded supportive care research projects varied between 50% and 58%. However, none of these trends in the proportion of cancer center projects was consistent enough to create a significant trend in these variables.

**Figure 11. Proportion of the Palliative Care Extramural NCI Budget Spent by the Cancer Centers**



The cancer centers produced most palliative care and supportive care research projects, but led in the area of end-of-life care research. Between 2001 and 2005 the cancer centers spent more than 80% of NCI extramural funds assigned to extramural end-of-life research. The proportion of extramural dollars spent declined from almost 80% in 1998 to 64% in 2002 and stabilized at between 70% and 71% thereafter, with an increasing trend over all ( $p < .001$ ). The proportion of supportive care research dollars spent by the cancer centers increased slowly before publication of the 2001 IOM report on cancer palliation from 28% to 41% but jumped to at least 70% each year thereafter for an overall increasing trend ( $p < .001$ ).

The proportion of spending by the cancer centers in palliative care research was flat at roughly 6% of cancer center-designated extramural funds in each year. On the other hand end-of-life care research, although quite small increased from 0.05% to 0.17% ( $p = .002$ ) and supportive care research increased from 0.18% to 0.38%. The reader is reminded that most NCI-funded end-of-life research does not appear in these searches, appearing instead as applied research in hospice development restricted by the SIC category palliative care.

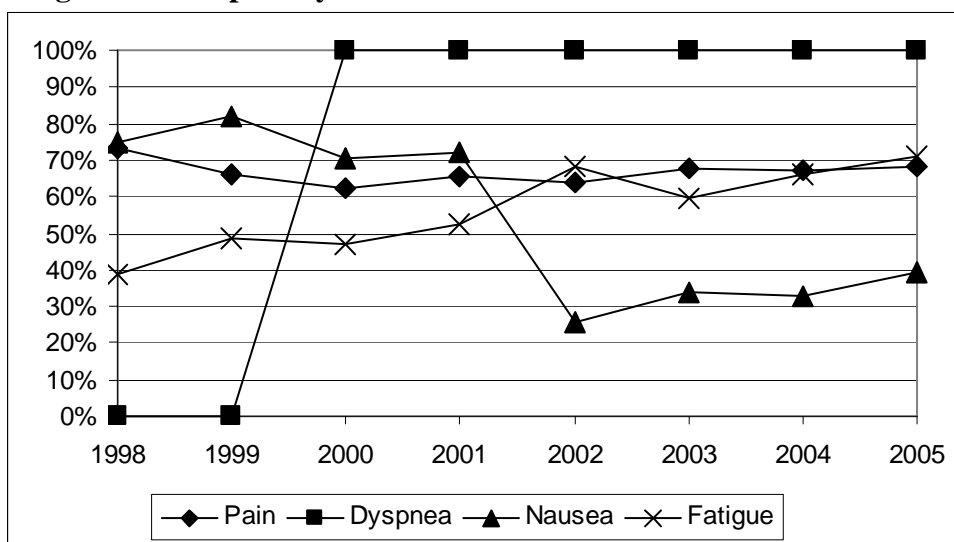
These trends show stability in the proportion of palliative care research conducted by the cancer centers, but there was significant growth in the cancer center share of end-of-life care and supportive care as research. These trends should not be over interpreted however, because supportive care was measured only by keyword searches, and the end-of-life term does not capture much of hospice research. However, it is notable that while supportive care research as measured here declined as an NCI research priority the cancer centers' share of supportive care research increased after 2002. Most of the research

funded by NCI in palliative care and end-of-life care is funded by the cancer centers. The cancer centers showed leadership in the area of end-of-life care, but NCI investment in end-of-life care research, excluding hospice research, was very small and has grown slowly.

### *Physical Symptoms*

The overall cancer centers' share of NCI-funded projects increased ( $p=.014$ ) from 48%, to 56% in 2002 and continued to increase to 60% in 2005. This increase was driven by a significant trend toward increased share of the extramural budget ( $p=.023$ ). NCI extramural funding of physical symptom management research at the cancer centers increased from 5.32% to 5.51% of the total cancer center's budget between 1998 and 2002. That proportion increased further to 5.94% in 2005.

**Figure 12. Proportion of the Physical Symptom Management Extramural NCI Budget Dollars Spent by the Cancer Centers**



Most of this increase is due to research in pain control, which the reader is reminded is the main component of NCI's extramural effort in symptom management. The cancer centers' share of NCI-funded pain projects increased ( $p=.009$ ) from 48% to



62% between 1998 and 2005. The cancer centers' share of the extramural budget for pain projects increased ( $p=.003$ ) from 5.21% to 5.80% during the same period. All dyspnea research, which began in 2000, conducted with NCI funding was conducted through the cancer centers, although the level of funding is low--never more than 0.02% of the extramural budget. However, this area of research has important end-of-life implications, i.e. lung metastases, which are discussed in Foley and Gelband (2001). Between 1998 and 2005, the cancer centers conducted between 20% and 45% of NCI-funded nausea research projects. There is no significant trend in the size of the cancer centers' share, although that share increased from 25% in 2002 to 38% in 2003. This is because, while funding levels for extramural nausea research declined overall, NCI funding of nausea research was unaffected. The proportion of the extramural budget spent on nausea research by the cancer centers decreased from 0.10% in 1998 to 0.01% in 2002, after which it recovered to 0.03% in 2005, giving it an apparent change point, but no significant trend. The cancer centers' share of NCI-funded fatigue projects increased ( $p=.003$ ) from 25% to 65% between 1998 and 2005. The cancer centers' share of the extramural budget for fatigue projects increased ( $p<.001$ ) from 0.03% to 0.27% during the same period.

It seems like an exaggeration to suggest that the cancer centers were at the head of a dramatic proliferation of symptom management research. The relative size of the NCI investment has increased little if at all and the relative importance of the components of such a program has not changed. Funding levels for pain, which makes up the lion's share of NCI-funded physical symptoms research, were largely unchanged by publication of the 2001 IOM report on cancer palliation and the 2002 NIH consensus statement,

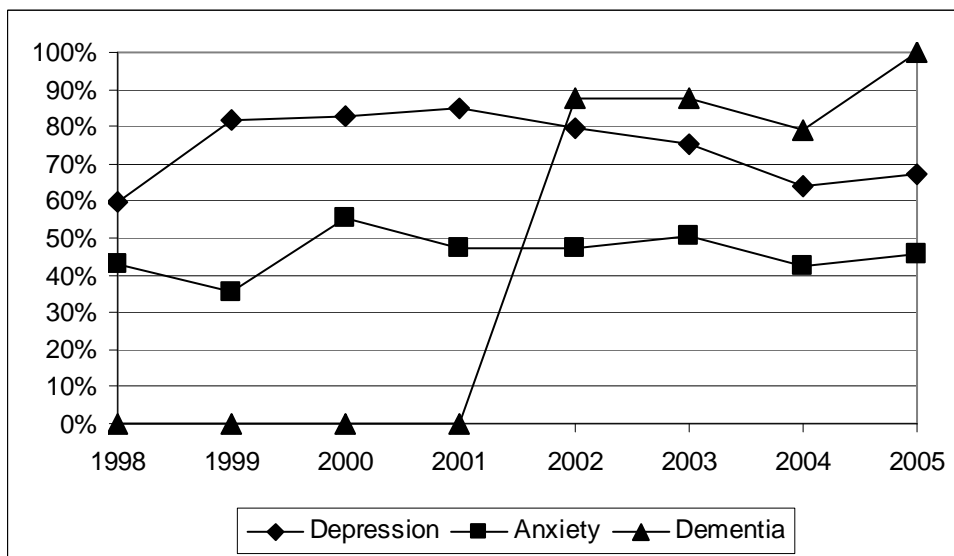
while funding levels for pain research at the cancer centers increased slightly. The proportion of NCI extramural pain research at the cancer centers, despite a fall from 73% to 66% from 1998 to 1999, increased overall ( $p=0.003$ ) to 68% in 2005. Most NCI-funded pain research was conducted at the cancer centers. All dyspnea research, less than 0.40% of NCI extramural research in every year it was conducted, was conducted at the cancer centers. Nausea research was nearly abandoned as a component of the cancer centers' budget (0.01%) by 2002, but recovered slightly by 2005. Fatigue research, clearly prioritized in the 2002 NIH consensus statement, increased nine-fold to 0.27% by 2005. However, it bears restating that many of the authors of the 2001 IOM report on cancer palliation argued that while, for the most part, the means to control physical symptoms exist, they are often under utilized. The notable exception was dyspnea, for which there is little that can be done in the case of lung metastases.

### *Psychological Symptoms*

The cancer centers' impact on research into depression, anxiety, and dementia is less clear than their impact on physical symptoms management. There are no significant trends between Fiscal Year 1998 and Fiscal Year 2005 in the proportions of these projects conducted by the cancer centers, nor are there clear change points at Fiscal Year 2002. Figure 16 should not be interpreted as having a change point at 2001 because no dementia research was funded by NCI until the following year.

The cancer centers' depression research represented 60% of all NCI-funded depression research in 1998. It jumped to 82% in 1999 and peaked in 2001 before declining to previous levels. The overall trend was negative ( $p<.001$ ). Without a significant trend, depression research accounted for between 0.32% and 0.42% of the

**Figure 13. Proportion of the Psychological Symptoms Management Extramural NCI Budget Spent by the Cancer Centers**



combined NCI contribution to the cancer centers' budgets between 1999 and 2005 after an increase from 0.07% in 1998. The cancer centers' budget for depression research may be described as stable in relation to the overall cancer centers' budget, however extramural NCI depression research grew disproportionately in other institutions.

The cancer centers' anxiety research represented 37% of all NCI-funded depression research in 1998 and 1999 and varied between 56% and 53% after that. The cancer centers did not play a disproportionately large role in this endeavor. This is notable because the 2002 NIH consensus report did not emphasize anxiety. However, the proportion of the NCI extramural budget trended higher ( $p=.014$ ), varying between 0.06% and 0.10% between 1998 and 2002, and increasing to 0.16% after that.

The NCI commitment to dementia research has been quite small--never more than six projects in any year for which there is data. However, starting in 2002 one cancer center began a two-year project in dementia research. In 2004 and 2005 there has been one dementia research project at the cancer centers. Extramural budget share varied

between 0.01% and 0.02%. However, most dementia research was conducted at the cancer centers (range = 79% - 100%).

Most depression research, which was targeted by the 2002 NIH consensus statement, was conducted at the cancer centers, but the share of other extramural institutions grew because of disproportionate growth among these. The cancer centers' share of anxiety research, which was not emphasized in the consensus statement, was stable but not disproportionately large. Most dementia research, which is a very small research priority in monetary terms, was conducted at the cancer centers.

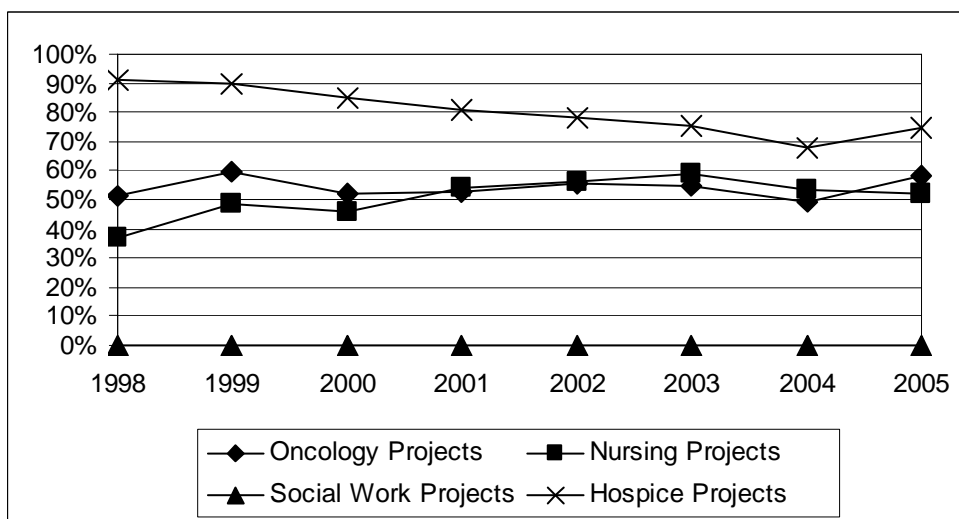
### ***Profession Development Projects and Training***

Between Fiscal Year 1998 and 2005 the proportion of oncology and nursing projects within palliative care conducted by the cancer centers did not have a significant trend. The cancer centers' share of palliative care projects within oncology varied between 49% and 60%. The cancer centers' share of palliative care projects within nursing varied between 33% and 57%. No social work research was done within palliative care between 1998 and 2005 by the cancer centers. The proportion of research in palliative oncology by the cancer centers was commensurate with levels of other types of research considered in this study, while proportion of palliative care research in nursing was, if anything disproportionately small, and non-existent in palliative care research in social work.

However, between 1998 and 2005, the cancer centers' share of hospice projects done by the cancer centers varied from 68% to 91%, although that share trended downward ( $p=.001$ ). That there is no significant trend in the proportion of extramural funds going to hospice research at the cancer centers is due to an apparent change point

reached at 2.44% of extramural funding in 2002, which coincides with publication of the NCPB's report on cancer palliation. In 2002 the proportionate decrease in extramural funding of hospice research within palliative care was arrested and reversed.

**Figure 14. Cancer Center Share of NCI Projects in Palliative Care Quality Measurement**



In 1998 there were no NCI-funded training projects in palliative care. In 1999 the cancer centers conducted five projects, which represented 71% of all NCI-funded training projects in palliative care. There is no significant trend in the proportion of palliative training projects conducted at the cancer centers. Although the proportion of extramural budget for these projects increased significantly ( $p < .001$ ) it was quite small, reaching 0.10% of the extramural budget in 2005. However, the reader is reminded that fellowships were excluded from the data because of poor coverage. No palliative care clinical trials were funded by NCI between 1998 and 2005, although the recommendations call for incorporation of principles of palliative care into clinical trials.

The positive change point suggests that the cancer centers may have attempted to increase their leadership in this area, as called for in Recommendation 1. The reader is

reminded that NCI hospice research increased over the study period with an inflection point at 2002, and that hospice research was the main thrust of end-of-life care documented by this budget analysis. The increase in hospice research at NCI and the cancer centers with positive apparent change points at 2002 suggest a direct response to mandates in Recommendations 1 and 8.

### *Quality Measures*

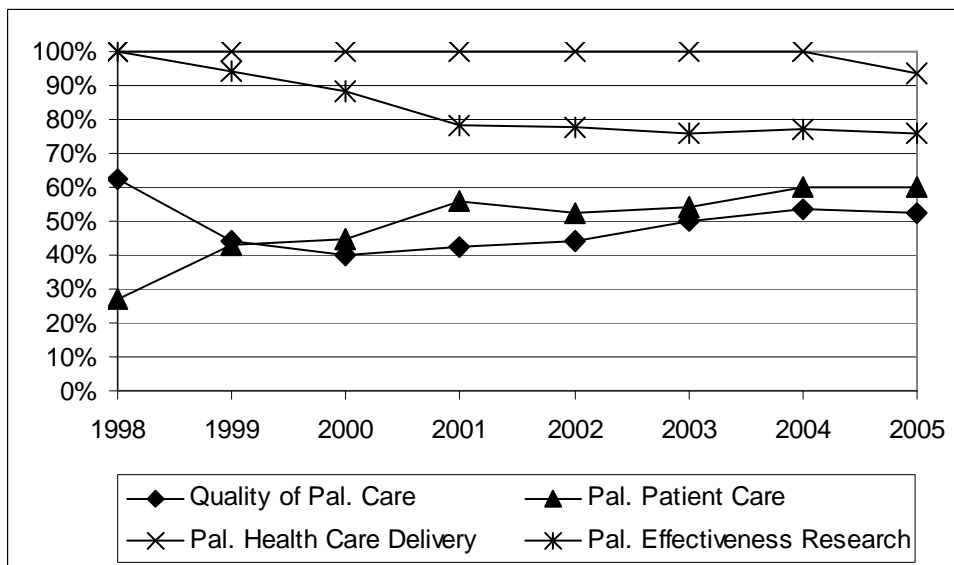
The proportions of quality of care research within palliative care research ( $p=.001$ ) conducted by the cancer centers increased significantly. During that time the proportion of the extramural budget for those projects increased significantly ( $p<.001$ ) from 1.49% to 2.14% of the cancer centers' NCI extramural research funding. Between 1998 and 2002 the cancer centers' share increased from 29% to 45% of projects and grew further to 50% by 2005. Cancer center research in this area grew toward proportionality with other categories of projects discussed in this study, but mostly before publication of Foley and Gelband (2001), stabilizing thereafter.

Patient care research at the cancer centers in palliative care did not show significant trends either in the proportion of the extramural budget allocated by NCI to the cancer centers for this purpose, or in the proportion of NCI funded research projects conducted by the cancer centers in this area. The cancer centers' share of these projects increased from 37% to 56% from 1998 to 2002, and having achieved rough parity, declined to 52% by 2005.

The single palliative care project in patient participation in decision making was conducted by a cancer center in 2001 and 2002. The lack of development of this field of quality research is striking in light of the importance of consultation with patients in the

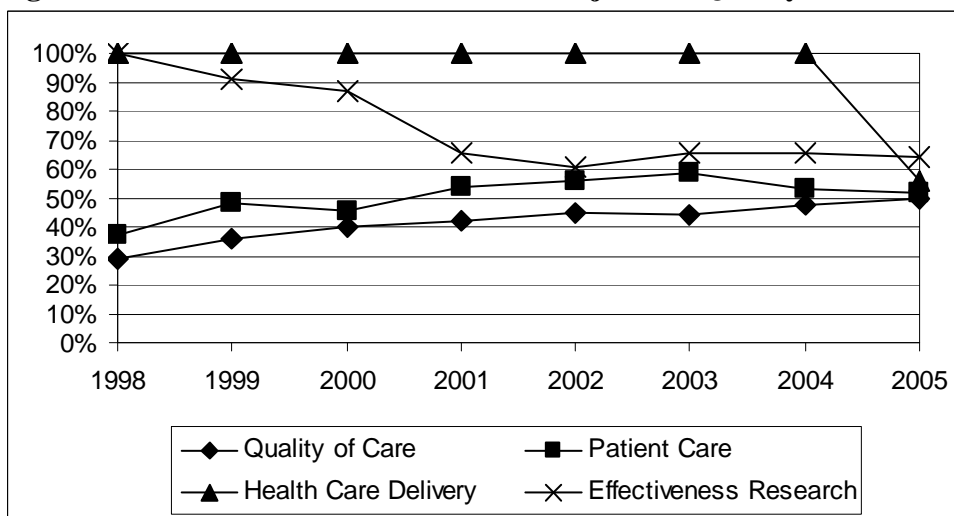
literature reviewed and at IOM. This represents a clear rejection of IOM concerns for development of quality indicators.

**Figure 15. Proportion of the Palliative Care Quality Research Extramural NCI Budget Spent by the Cancer Centers**



Between 1998 and 2004, all NCI-funded palliative care health care delivery research was done at the cancer centers. In 2005, 44% of these projects were done outside the cancer centers. Despite this, the proportion of the extramural budget that funds these projects at the cancer centers increased from 0.28% to 0.32% from 2004 to 2005. It is

**Figure 16. Cancer Center Share of NCI Projects in Quality Measurement**



clear that the extramural projects conducted outside the cancer centers increased because the cancer centers' share of the extramural budget in this area remained over 90% in 2005. Between 2004 and 2005 the cancer centers moved from exclusivity to proportionality in this area in the number of projects but not budget share.

In 1998 all NCI-funded effectiveness research projects in palliative care was conducted at the cancer centers. By 2002 a low of 60% was reached, after which the cancer centers' share increased to 65% in 2003 and was stable thereafter. The trend in the cancer centers' share is significantly downward ( $p=.040$ ) as the cancer centers moved from exclusivity to a decreasing leadership role in 2002, which rallied thereafter. Cancer centers' funding for effectiveness research in palliative care increased significantly ( $p<.001$ ) as a proportion of the extramural budget from 0.32% in 1998 to 0.88% in 2005.

Looking at all measures of quality research in palliative care combined, trends in the cancer centers' share of projects of these types ( $p=.001$ ) and the extramural budget ( $p=.002$ ) were positive. The cancer centers' share of these projects increased from 35% in 1998 to 51% in 2002, achieving a bare majority, and was roughly stable after that. The share of these cancer center projects in the extramural budget increased from 2.19% in 1998 to 3.49% in 2002 and varied between 3.44% and 3.71% after that.

NCI Extramural research as a whole in quality of palliative care grew until publication of the 2001 IOM report on cancer palliation and declined after that. Spending as a proportion of cancer centers' research overall increased through 2002 and was stable after that. Within palliative care, quality of care ( $p<.001$ ) and effectiveness research ( $p<.001$ ) increased proportionately as components of the cancer centers' research program, but much more slowly after 2002. The only research project concerned with



patient participation in decision making, as defined in this research, was conducted at a cancer center, and until 2005 all of a handful of health care delivery research projects were conducted at cancer centers. In short the cancer centers have led a very modest effort to conduct quality research in palliative care.

## CHAPTER 7. PROFESSIONAL ORGANIZATIONS

This chapter presents the findings for Research Question 2 which addresses the extent to which professional organizations incorporated Recommendation 6 of the 2001 IOM report on cancer palliation. Recommendation 6 calls for the following:

Best available practice guidelines should dictate the standard of care for both physical and psychosocial symptoms. Care systems, payers, and standard-setting and accreditation bodies should strongly encourage their expedited development, validation, and use. Professional societies, particularly the American Society of Clinical Oncology, the Oncology Nursing Society, and the Society for Social Work Oncology, should encourage their members to facilitate the development and testing of guidelines and their eventual implementation, and should provide leadership and training for nonspecialists, who provide most of the care for cancer patients. (Foley & Gelband, 2001b, p. 52)

Hypothesis 5 calls for the examination of the websites of the professional organizations of oncologists, oncology nurses, and oncology social workers, i.e. the American Society of Clinical Oncology, the Oncology Nursing Society, and the Society for Social Work Oncology, respectively. This hypothesis predicts that such an examination would show that these organizations developed best practices in accordance with the state of the science and their professional interests.

Hypothesis 6 calls for the examination of professional journals between 1994 and 2005. It was expected that these journals published an increasing proportion of articles on palliative care and symptom management during the study period and that the articles reflect increased interest and attention to qualitative research, attention to psychological symptoms and patient participation in decision making. It was hypothesized that indicators of palliative care and symptom management would show S-curves when graphed by year through the pre-deliberative (1994-1996), deliberative (1997-2000), and post-deliberative (2001-2005) periods, indicating a concerted program for the

development of the scientific and professional basis for the development of practice guidelines. A lag period of one or two years behind research-based adoption curves was expected as increased palliative care research got published. Problems with availability of data made this lag period difficult to establish. Assertions of nurses and oncologists through expert interviews cast serious doubts on the ability of the NCPB or any body within the Institute of Medicine to impact the development of science within the professional organizations named.

### **Hypothesis 5 – Development of Professional Practice Guidelines**

This section explores practice guidelines set up by the professional organizations. It was expected that the professional organizations would have findings that reflect the impact of the 2001 IOM report and the professional interests of each group.

#### ***American Society of Clinical Oncology (ASCO)***

The ASCO website ([www.asco.org](http://www.asco.org)) includes supportive care guidelines for anti-emetic drugs, management of white cell, red cell and platelet levels, and the use of several protective therapies to address the side effects of chemotherapy and radiation therapy. All of these guidelines were either introduced or updated between 1999 and 2002. ASCO also posts a practice guideline statement for preserving fertility among cancer survivors published in 2006.

The practice guidelines described above seem minimal at best when compared to NCPB's call for the development of practice guidelines in Recommendation 6 by professional societies. However as discussed at the beginning of Chapter 5, the NCI website has PDQ articles for nearly all of the physical and psychological symptomatic concerns raised in the 2001 report on cancer palliation. The lone exception is dyspnea.

Pain, fatigue, nausea, and cognitive disorders are covered, as are anxiety and depression. There is an article on spirituality. A number of issues raised were not included in the 2001 IOM report on cancer palliation, including cardiopulmonary issues, fevers sweats and hot flashes, gastrointestinal issues, lymphedema or swelling, sexual and reproductive issues, sleep disorders, pediatric sequelae, and others. The articles are peer reviewed and include treatment guidelines. Clearly, for ASCO to have developed its own set of most or even many of these topics would have amounted to unnecessary duplication of effort with NCI.

ASCO published a policy regarding end-of-life care in 1998, already cited. That article affirms the primacy of the doctor-patient relationship; calls for effective communication with patients, or guardians in the case of children; recognizes the spiritual and psycho-social needs of patients and families; calls for optimization of healthcare quality; and commits ASCO to advocating for the removal of barriers to end-of-life care of high quality. The article further calls for improvement in the education of health care providers in the area of patient communication, supports the hospice model, and dismisses the debate about physician-assisted suicide as a result of gaps in end-of-life care. ASCO supports legislative initiatives in pain management research.

### ***Oncology Nursing Society (ONS)***

The ONS website ([www.ons.org](http://www.ons.org)) includes a clinical practice page primarily built around the concept of *nursing sensitive outcomes*. See the concept paper published on this website and authored by Given, Beck, Etland, Holmes Gobel, Lamkin, and Marsee (2003). This paper was published roughly two years after publication of the 2001 IOM report on cancer palliation. Given et al define nursing sensitive outcomes as patient

outcomes that are sensitive to nursing interventions. Their paper strongly echoes Foley and Gelband (2001) in a number of respects. Consequences of outcomes are discussed in terms of symptom experience, functional status, safety, psychological impact and economic costs. The purpose of publicly discussing nursing sensitive outcomes on the website is to create quality standards so that both quality and accountability can be measured, and vulnerable types of patients can be identified. Symptoms recognized in the 2001 IOM report on cancer palliation are addressed including pain, breathlessness or dyspnea, nausea and fatigue. In addition, Given et al recognize insomnia, constipation, anorexia, diarrhea, skin and mucous membrane problems, and neutropenia (p.6). Psychological distress issues mentioned in Foley and Gelband (2001), including anxiety and depression, are discussed as is spiritual distress (p.7). Spiritual distress is discussed in the 2001 IOM report on cancer palliation but not as the same class of issue as psychological symptoms. In addition, functional status is operationalized in detail to include: activities of daily living, instrumental activities of daily living, role function, activity tolerance, ability to carry out usual activities, and nutritional status (p.6). Given et al also define safety and economic impact as classes of outcomes. Safety outcomes are defined as having preventable negative impact, including infections, falls, skin ulcers, extravasation incidents and hypersensitive reactions (p. 7). Economic impacts include length of stay, unexpected readmissions, emergency visits, and costs, which are further broken down as out-of-pocket, per day costs, and per episode costs (p. 7).

The ONS approach to quality and accountability assessment for nursing is built on a conceptual framework that addresses the universe of issues raised in the 2001 IOM report on cancer palliation, and expands it from the literature, and from the experience

base of the organized community of oncology nurses to recognize as complete a definition of patient well-being as has been found anywhere in this research project.

Evidence-based summaries have been written for physical symptoms, including pain, dyspnea, nausea and vomiting, fatigue, as well as for mucositis, peripheral neuropathy, and problems sleeping. Summaries have also been written for functional status issues including nutrition and return to usual functioning. A summary on prevention of infections has been written. A depression summary has been written. Economic summaries were under contract. In addition the ONS website includes bibliographies on complementary and alternative therapies, nutrition, palliative care, patient education, and symptom management in general and in particular, including pain, dyspnea, and mucositis.

Even though many of the topics covered on the ONS webpage are addressed in the NCI PDQ web presentation, it seems that ONS leadership did not feel that the topics had been covered sufficiently to fill the need for nursing interventions. The ONS web presentation represents an attempt to reduce nursing interventions to an evidence-based state of development.

### ***Association of Oncology Social Work (AOSW)***

The AOSW website ([www.aosw.org](http://www.aosw.org)) includes a number of position papers on issues connected with psycho-social issues, which is described as central to the organization's mission in its mission statement. The 2001 AOSW standards of practice statement describe psycho-social services as the main contribution of oncology social work. These services consist of counseling at the individual, family, and group level, as

well as education, advocacy, discharge planning, case management and program development.

The AOSW website includes a joint position paper with ONS regarding end-of-life care. This statement was first approved by both organizations in October 1998 and revised in 2003. The statement calls for coordination among disciplines, use of therapies that are considered to be curative at the end of life if they improve quality of life, and development of the science of symptom management. Further the statement calls for recognition of the psycho-social needs of patients and their families, the reduction of palliative care to interventions, along with instruction in those interventions as part of nursing and social work curricula. The statement also calls for cultural competence of practitioners and good communication with patients and their families, as well as respect for advanced directives. This position paper calls for advocacy at the policy and institutional level. It is somewhat dated, predating the publication of the 2001 IOM report on cancer palliation.

The AOSW statement on euthanasia and assisted suicide does not categorically reject physician-assisted suicide, characterizing the decision to end one's life as a control issue that arises with the overwhelming changes at the end of life. This position paper also advocates assessment of the patient's psychological state and any unmet needs in the area of symptom management, whether physical or psychological. The paper also advocates effective communication among providers, patients, and their families, and assessment of the psychological and social environment. The paper addresses value conflicts that involve the social worker's values.

In addition to the foregoing, AOSW has issued a joint statement with the Association of Pediatric Oncology Social Work that defines family-centered care. The AOSW website also identifies special interest groups in AIDS, blood and marrow transplantation, children, complementary and alternative medicine, ambulatory care and fee for service, end-of-life care, pain and palliative care, spirituality, and issues of diversity.

### **Hypothesis 6 - Journal Review**

This section explores the development of the evidence base of each professional group. It was expected that the articles in professional journals would reflect increased interest and attention to qualitative research, psychological symptoms and patient participation in decision making relative to cancer care among the pre-deliberative (1994-1996), deliberative (1997-2000), and post-deliberative (2001-2005) periods. It was further expected that there would be a one or two-year lag behind research-based adoption curves as increased palliative care research gets translated into articles in professional journals. However, because the expansion of NCI funded research in palliative care and symptom management was quite limited, testing for this pattern in the data was not possible. Instead PubMed searches and a cursory review of article abstracts established journal content. Significance testing for patterns in journal content consists of evaluating Mantel trend scores where query hits are treated as cases; other articles are treated as controls. The number of years of publication after 1994 for the *Journal of Clinical Oncology (JCO)* or 1997 for the *Clinical Journal of Oncology Nursing (CJON)* is considered the exposure.



***Journal of Psycho-social Oncology (1994-2005)***

At the time the PubMed queries were made, 2005 was the only year in the study period of data available for this journal. Because the focus of social work is primarily patient-centered and concerned with the phenomenological, psychological and social issues, including patient preferences, relationships and economic well-being, the focus of this journal can be expected to be in line with the NCPB's recommendations from the 2001 report on cancer palliation throughout the study period. Overall, there is no apparent adoption of the NCPB's recommendations because *Journal of Psycho Social Oncology (JPSO)* entered the pre-deliberative period in apparent agreement with the NCPB's recommendations. Through the deliberative period the interest in palliative and end-of-life care and effective management of psychological distress, physical symptom management, and patient support continued to address a growing and increasingly more sophisticated knowledge base. In the post-deliberative period, emphasis seemed to shift

***Table 2. Main Topics Published in the Journal of Psycho Social Oncology 1994-2005***

1994-1996	1997-2000	2001-2005
Adjustment To Cancer	Adjustment To Cancer	Survivorship
Patient Control and Satisfaction Issues	Patient Control and Satisfaction Issues	Patient Control and Satisfaction Issues
Spirituality and Mind/Body	Spirituality	Adjustment To Cancer
Cultural Needs Of Vulnerable Populations	Symptom Management	Spirituality
Psychological Symptoms	Quality Of Life Issues	Symptom Management
Physical Symptoms	Support Groups	Quality Of Life Issues
Quality Of Life Issues	Vulnerable Populations	Support Groups
Relationships	Relationships	Vulnerable Populations
Economic Issues	Economic Issues	Relationships
Measurement	Measurement	Economic Issues
	End Of Life	Screening

somewhat to a new emphasis on survivorship at the expense of end-of-life care as a field of emphasis.

During the pre-deliberative period, between 1994 and 1996, *JPSO* addressed many of the issues raised in Foley and Gelband (2001), as a primary focus. Generally speaking these articles addressed dimensions of patients' well-being such as adjustment to cancer, patient control, communication with patients, patient satisfaction, compassion received from healthcare providers, spirituality, and the cultural needs of vulnerable populations. The mind/body connection was discussed. Difficulties faced by patients discussed by *JPSO* included: sub-clinical and more severe psychological conditions, physical symptom management needs and advocacy, hopelessness, quality of life, functional status, facing death, bereavement of loved ones, financial and other stress. Patient and family stress was discussed including marital relations, adjustment needs of parents and siblings, needs and means to support care givers, and interventions to boost patients' self image. The articles included reviews and analytic articles that used qualitative and quantitative methodologies. There are attempts to measure patient adjustment to cancer. Two central tendencies in the *JPSO* articles present themselves during the pre-deliberative period. First, oncology social workers from the perspective of the journal are primarily advocates for cancer patients and their families and care givers, and second, in broad terms the social work profession had already integrated the perspective on palliative cancer care presented by the NCPB in 2001.

During the deliberative period, between 1997 and 2000, the subject matter expanded and the sophistication of analyses increased. Examples of increased sophistication include discussions of scales for physical and psychological symptoms.

The dimensions of well-being and categories of difficulties faced by cancer patients and their families and care givers discussed above continued through the deliberative period. In addition *JPSO* articles addressed the role of exercise, sexual function and reproduction by cancer patients, the effects of age on older patients, and extensive discussion of the use of support groups, group therapy, and group education as an intervention. There was an increase in the number of articles that discuss minority issues, particularly in relation to spirituality and cultural preferences. In a broad sense, the universe of issues remained roughly the same as in the pre-deliberative period, but the knowledge-base seems to have increased, and the methods have become somewhat more sophisticated. As with the pre-deliberative period, most of the methodologies are qualitative, but there is a noticeable increase in the incorporation of quantitative methods.

During the post-deliberative period, *JPSO* articles seem to move away from the tendency to use quantitative methods for palliative care interventions. There is an increased interest in colorectal screening, which was the principle focus of a single issue, Vol. 19, Num. 3/4 (2001). This journal increasingly uses the language of survivorship, which it seems to adopt readily. The subject matter seems more or less consistent with previous periods. The most notable difference is that there is less attention to end-of-life issues, although spirituality is not deemphasized. However, fatalism among minority populations is discussed. For whatever reason there appears to be a transfer of interest from end-of-life issues to survivorship issues, without any diminishment of interest in patient advocacy or advocacy for effective supportive care.

***Clinical Journal of Oncology Nursing (1997-2005)***

The quantitative results of query hits for this journal were disappointing. The only significant trends that were apparent were a declining trend in comprehensive care articles ( $p=.045$ ) and an increasing trend in patient participation in decision making articles ( $p=.030$ ). Comprehensive care articles represented nearly half of *CJON* articles in 1998, and declined to 10% in 2001, after which the proportion of these articles increased, varying between 13% and 30% in subsequent years. The year 2001 is an apparent change point for this variable. Patient participation in decision making articles are represented by two (3%) *CJON* articles in 2000, but none of these articles were published in any other year between 1997 and 2002. After 2002 *CJON* published between one and five articles on patient participation in decision making per year (1%-6%). The positive findings are based on a very small number of query hits within a very small number of articles.

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***Table 3. Main Topics Published in the Clinical Journal of Oncology Nursing 1997-2005***

1994-1996	1997-2000	2001-2005
Not Yet in Publication	Symptom assessment Symptom management Patient education and communication Nutrition Role of nursing	Symptom assessment Symptom management Patient education and communication Patient decision making Nutrition Quality of life Role of nursing Evidence-based nursing

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The *CJON* did not begin to publish until 1997, the beginning of the deliberative period. The timing of the founding of this journal suggests an enthusiastic reception by organized oncology nurses to the discussion of gaps in palliative oncology. During the

deliberative period articles related to palliative and end-of-life care and symptom management addressed symptom assessment, management of symptoms for a number of conditions under particular circumstances. The journal also addressed the use of medications, side effects, patient education and communication, and nutrition. Other articles addressed issues of medical supervision of nurses and supervision by other nurses, as well as the role of nurses in symptom management. In other words the editors of *CJON* set about the business of educating readers in the science of palliative oncology nursing rather than debating its merits. One effect was to define and call attention to the role of nurses in providing supportive care, educating patients, and providing symptom management to cancer patients.

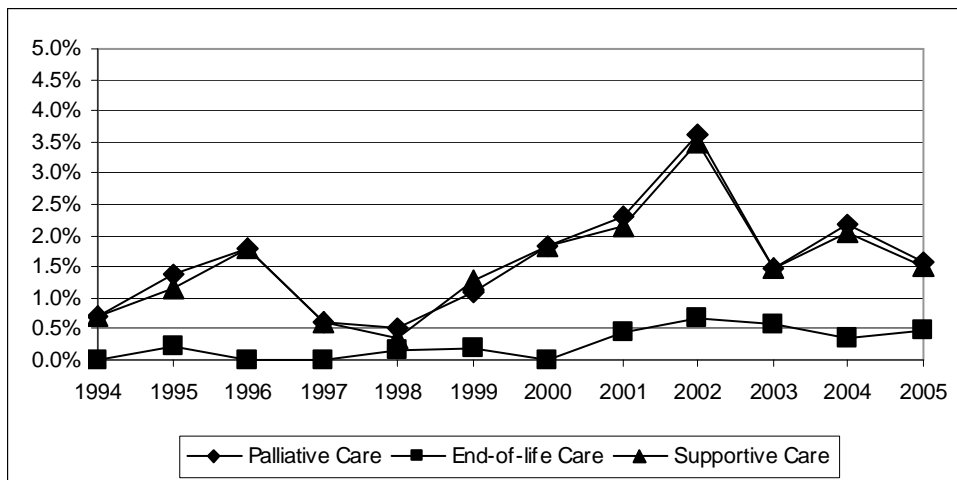
During the post-deliberative period, between 2001 and 2005, the variety of articles expanded to include patient participation in decision making, fertility as an issue in counseling and decision making, and economic considerations in cancer care. Depression was discussed clinically and on an interpersonal level. Humor was discussed. Also discussed were ethical considerations in the context of medical futility. Generally speaking the evolution of this subject matter shows that attention was paid to the NCPBs recommendations. However, for the most part these articles run somehow parallel to the recommendations, by doing the work of creating the knowledge base with which to manage cancer and establishing the role of nurses in that endeavor.

### ***Journal of Clinical Oncology (1994-2005)***

Palliative care and supportive care articles, depending on the year varied between 0% and 4% of *CJON* publications. End-of-life care articles never represented more than one percent of *CJON* articles in any given year. All three variables had significant

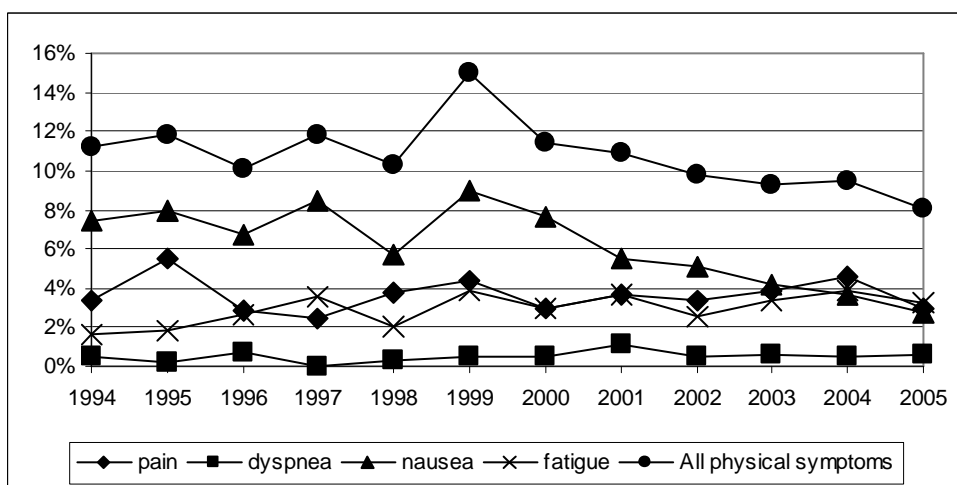
growing trends. Palliative care, end-of-life care, and supportive care had p values of .016, .006, and .016, respectively. Figure 17 shows that PubMed may have treated supportive care as a near synonym for palliative care. Figure 17 shows peaks for each variable in the pre-deliberative, viz. 1995 for end-of-life care and 1996 for palliative care and supportive

**Figure 17. *Journal of Clinical Oncology* Articles that Discuss Palliative Care and Allied Topics**



care. The proportion of articles about palliative and supportive care increased through the deliberative period, and did not peak until 2002, the year after publication of Foley and Gelband (2001). Articles about end-of-life care were more intermittent. There were a

**Figure 18. *Journal of Clinical Oncology* Articles that Discuss Physical Symptoms**



small number of articles on end of life care in 1998 and 1999, surrounded by 1997 and 2000, in which no articles were about end-of-life care. Articles on palliative care and supportive care declined in 2003, recovered in 2004, and declined again in 2005. It is difficult to conclude from this that a permanent change in publication policy has occurred.

Taken as a whole, *JCO* articles that discuss physical symptoms of some kind varied between 8% and roughly 15% between 1994 and 2005. They peaked in 1999 and began a long decline after that. There is no consistent trend throughout the study period, and the adoption curve is quite erratic before 1999. The adoption curve for articles on all physical symptoms closely coincides with the curve for nausea, which was significantly negative ( $p < .001$ ). Between 1999 and 2005 articles discussing nausea decreased proportionately by about two-thirds.

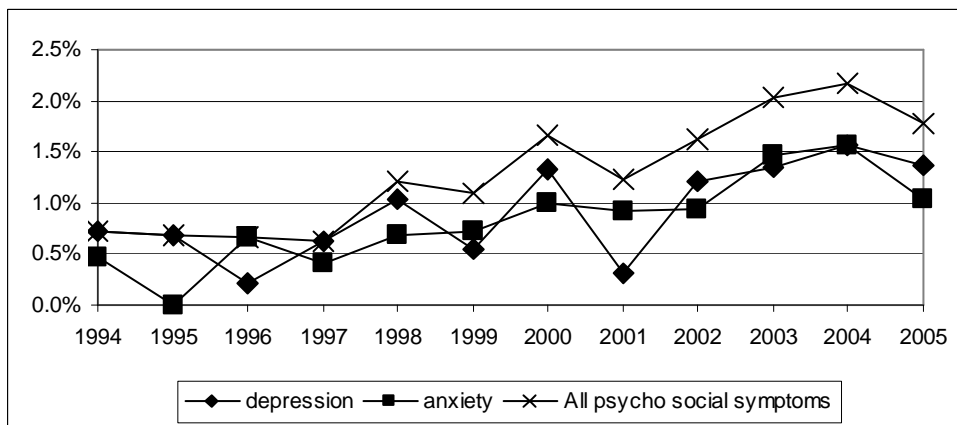
The adoption curve for pain articles did not have a significant trend over the study period, but it does show a small peak in 2001. The 2001 peak is dwarfed by others peaks in 1999 and 2004. The greatest spike in pain articles occurs in 1995, early in the pre-deliberative period. Fatigue articles showed an increasing trend ( $p = .029$ ) over the study period, with a low point in 1998. Dyspnea articles, never common, did not have a significant trend, but did peak in 1996 and again in 2001. Literally only a handful of articles were written about delirium--two each in 2002 and 2005.

### ***Psychological Symptoms***

The proportion of articles addressing psychological symptoms of all kinds increased more or less steadily over the study period ( $p < .001$ ). The combined curve for psychological symptoms peaked over 1.5% in 2000 and again at 2.2% in 2004 and

dropped in 2005 to less than 2.0%. The proportions of articles written about depression ( $p=.005$ ) and anxiety ( $p=.002$ ) also increased significantly but their curves are more

**Figure 19. *Journal of Clinical Oncology* Articles that Discuss Psychological Symptoms**



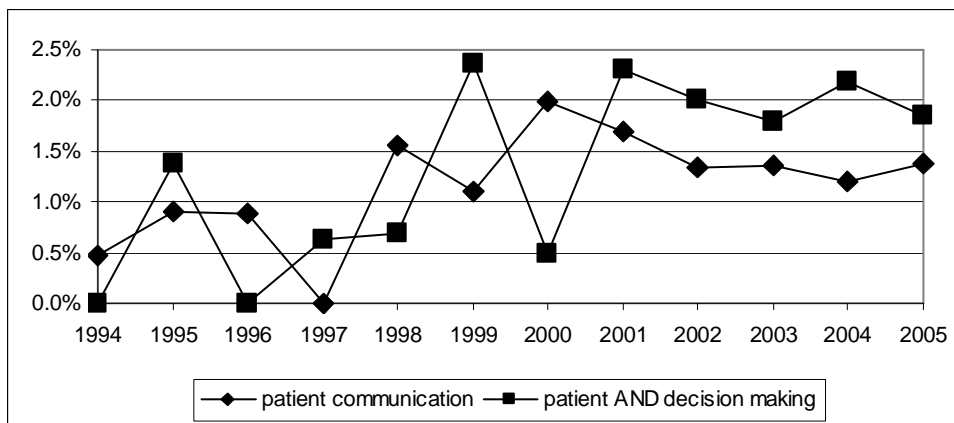
erratic. No articles were written about dementia during the study period. Figure 19 shows these trends.

### ***Quality Research Articles***

Patient participation articles tended to increase ( $p<.001$ ) as a proportion of the articles published by *JCO* during the study period. Patient communication articles did not have a significant trend. Patient participation articles peaked in the pre-deliberative period (1995), and in the deliberative period (1999 and 2001), and seem to have found some stability at about two percent of *CJON* articles per year. Patient communication articles peaked in the pre-deliberative period (1995 and 1996), and again in 1999 and more strongly in 2001. After 2001 the proportion of patient communication articles declined to just less than 1.5% before finding stability at that level. It appears that both patient communication and the issue of consulting patients have become more accepted as issues to be dealt with by oncologists, and are receiving attention in *JCO*.



**Figure 20. Journal of Clinical Oncology Articles that Discuss Patient Communication and Patient Participation in Decision Making**



During the pre-deliberative period, between 1994 and 1996, the vast majority of *JCO* articles that addressed palliative and end-of-life care or symptom management were clinical articles that addressed how a treatment of any modality affected the outcome of a particular diagnosis or class of diagnoses, or impacted a symptom of cancer or a side effect of cancer treatment. Exceptions were rare, but included the psycho-social effects of a particular type or related types of cancer or a particular type or related types of treatment. Other exceptions included prevalence studies, and relations among prognosis, quality of life, and survival. Yet other exceptions addressed pain management, a quality of life scale, and measurement of symptoms. Patient education and patient communication were discussed, as was suicide/euthanasia. The relationship between pain and depression was discussed and depression was discussed as a condition relevant to oncology. There were also studies that addressed nursing interventions in the context of obtaining patient consent. It should be emphasized that except for the clinical studies described at the beginning of this paragraph, none of the categories or articles represent topics that were little more than a small minority of articles within the context of palliative and end-of-life care and symptom management.

During the deliberative period, between 1997 and 2000, the emphasis in *CJO* in palliative and end-of-life care and symptom management continued to be on clinical articles, but interests of *CJO* showed signs of broadening. Increasingly articles focused on the effects of treatment on quality of life. Alternative medicine and euthanasia were discussed. The number of articles dealing with depression and anxiety increased, as did the number of articles addressing patient communication and the role of compassion. Post traumatic stress was discussed. Concern was raised about the quality of life not only of patients but also care givers.

During the deliberative period *CJO* took up the issue of palliative treatment at the end of life. A policy statement was issued in 1998 and is discussed as part of the evaluation of Hypothesis 5. Small numbers of other articles discussed the need for compassion generally and improved communication from oncologists. Other articles somewhat defensively explored regulation of medical practice, while others addressed the possibility that there might be ways that oncologists themselves are barriers to meeting the needs of patients.

During the post-deliberative period, between 2001 and 2005, clinical articles continued to be the majority of articles published in *CJO*, although articles with a primary focus on symptoms and symptom management arising in different situations became increasingly prominent. This last category of articles is analogous to the symptom management articles in *CJON* although with a different emphasis dictated by the target audience. Psychological health was discussed as an outcome and depression was discussed as a negative predictor of survival. Quality of life and functional status were discussed as outcomes and their measurement was discussed. Patient participation

in decision making was raised, generally and in the context of the end of life.

Suicide/euthanasia continued to be discussed. Survivorship became an issue but did not become dominant as an issue in palliative care and symptom management, as appears to have happened with *JPSO*. The mind/body connection was raised and the needs of vulnerable populations discussed.

This chapter presented the findings of Hypothesis 5, which addressed the development of practice guidelines by professional organizations and Hypothesis 6, which addressed the content of the principal journals of each organization. The ONS developed an elaborate program of practice guideline development and many of those guidelines address issues raised in the 2001 IOM report on cancer palliation. The part of the ASCO practice guidelines that address symptom management is quite limited, but this was offset by NCI PDQ web presentation on palliative care, discussed earlier. The AOSW web presentation followed the professional interests of oncology social workers. It was not possible to tie the actions of the ASCO, ONS, and AOSW to the 2001 IOM report on cancer palliation, although it is clear that the guidelines called for by the authors of the 2001 IOM report on cancer palliation now exist. The lack of available data and problems of statistical analysis due to small numbers render the analysis of Hypothesis 6 disappointing, even with the use of grounded theory.

## **CHAPTER 8. DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS**

This policy analysis has been conducted as an evaluation study. The hypotheses were intended to shed light on whether or not the organizational changes called for by the authors of the 2001 IOM report on cancer palliation were made and what effect those changes had in terms of the number and value of projects and the number of published articles addressing palliative and end-of-life care, symptom management and other concerns addressed in that report.

The recommendations evaluated were primarily directed toward NCI as a whole and the Cancer Centers Branch, as well as three professional organizations named in the report (Foley & Gelband 2001b, pp. 50-53). Recommendations 1 and 2 call for the creation of centers of excellence in palliative care and symptom control among the cancer centers and the requirement that the comprehensive cancer centers conduct research in palliative care and symptom control as a condition of recognition of comprehensive status. Recommendation 6 calls upon professional organizations to encourage their members to support the development, testing, and implementation of practice guidelines in physical and psychological symptom management. Recommendation 8 calls for NCI to conduct state of the science conferences in palliative care and symptom management and establish a prominent research agenda based on those conference proceedings. Recommendation 9 calls for NCI to establish an institutional locus or loci for palliative and end-of-life care and symptom control research. The Division of Cancer Treatment and Diagnosis is named as a possibility for such a locus.

The hypotheses were intended to evaluate the success of each of these recommendations. Through Hypothesis 1 we seek to determine whether or not state of the

science research was conducted, what the findings were, what if any institutional locus was established, and what relevant research agenda was established. Through Hypothesis 3 we seek to establish whether the Cancer Centers Branch implemented the recommendations that were directed to it. Through Hypothesis 5 we address the development of the practice guidelines that were called for by professional organizations. Through all of this adoption, rejection, and reinvention of the recommendations is addressed. Hypotheses 2, 4, and 6 address the impact of the 2001 IOM report on cancer palliation in particular, and the impact of the NCPB's work in general on the overall NCI budget, the proportion of the research portfolio carried by the cancer centers, and the publication histories of three professional journals.

### **Study Validity and Limitations**

In a general sense the main limitation of this study is its narrow focus. The 2001 IOM report on cancer palliation, as was amply demonstrated in this study's review of the literature, was one in a series of reports published by the NCPB in its nine-year existence that to be fully understood must be taken as a package. In addition, where cancer research and practice are concerned, the authors of the 2001 IOM report on cancer palliation are very specific in the entities they target. The targeting of professional organizations for oncologists, oncology nurses, and oncology social workers for practice guidelines was indisputable in the sense that the targets were the national organizations of each group. The targeting of NCI in order to bring that organization more prominently into the NIH research program in palliative care and symptom management was clearly a sensible tactical decision. NCI is the premier NIH member institute in the US effort to address cancer, and NIH's largest member. However the focus on the NCI research program of

this research project leaves unexamined significant portions of the NIH research program in palliative and end-of-life care and precludes detection of reinvention of the NCPB's recommendations. That is another research question worth pursuing. The primary purpose of this research was to assess adoption of the NCPB's recommendations in 2001. Reinvention is germane to this study where the actors who reinvent the recommendations are the named actors in the NCPB's recommendations in 2001. However, two points about intervening issues should be addressed here.

The first point is that as called for in Field & Cassel (1997), NINR was made the lead agency in developing the NIH's program in end-of-life care. This was noted in Foley & Gelband (2001b) who recommended that NCI not limit the development of its research program in palliative and end-of-life care to the NINR initiative. NINR led the organization of the 2004 consensus conference on end-of-life care. At the end of the study period NINR was still the lead agency in the NIH end-of-life care research program according to its 2005 budget justification. The lead status of NINR in end-of-life research at NIH has not been challenged in any of the material reviewed here. This means that the impact of NINR, which has a budget that grew in every year from \$63.6 million in 1998 to \$138.1 million in 2005 (NIH Almanac, 2007) is unaccounted for. An expert interview was sought and declined by Alexis Bakos at the NINR Office of Extramural Programs, who however responded with an e-mail (personal communication, 5/4/2007) that she will allow to be cited. In that e-mail Dr. Bakos indicated that NINR had been influenced by Field and Cassel, and not the 2001 IOM report on cancer palliation. It seems plausible that because NINR is not a disease specific agency the influence of other IOM bodies was of great importance and the NCPB's work was of relatively little importance, as Dr.

Bakos suggests. We should then be careful about reading anything into steps taken by organized nurses that coincidentally appear to amount to adoptive behavior, because those connections may be spurious. However, for nurses with a specialty in oncology the lack of interest in the NCPB's work may be less pronounced.

The second point is that much of the initiative listed on the NCI Palliative Care Working Group website (NCI, 2007b) spans members of the NIH. Three program announcements are offered as examples and may be checked on the CRP website. They are: PA-05-090, PAR-06-520, and PA-02-169. The point is that the full impact of many initiatives through NIH, even if they are led by NCI reaches beyond the work done by NCI. The impact of NCI initiatives where some research is done by other NIH members is lost in this analysis.

### ***Budget Data Quality***

This section assesses the quality of the NCI budget data. Problems of temporal distortion in the extramural and intramural data were largely overcome. The impact of missing intramural data is minimal because of the extramural nature of the work of NCI's Working Group on Palliative Care and the Cancer Centers Branch. The impact of missing extramural data is minimal because of the very good luck that it was possible to establish that nearly none of the missing records is relevant to palliative care or related concerns through cross validation of the DEA database with the CRP and ICRP databases. The DEA, CRP and ICRP databases are compared with a budget database that may be queried from the NIH Office of Extramural Research (2007). These databases are superior to the Office of Extramural Research database because they include training programs and cooperative agreements but have the disadvantage that data is only available beginning in

1998 or 2000. Another Office of Extramural Research database (2007a) provides budget data for extramural projects. This study's estimate of pain research for 2003 is validated.

**Data Quality.** Appendix A addresses data quality at length. Queries of the DEA database were made to extract the entire database as a universe of the NCI extramural program. The resulting totals were compared with NCI *Fact Books* (1998-2005). Construction grants were excluded conceptually. Fellowships although interesting conceptually were excluded because of poor coverage when the data were compared with the *Fact Books*. Contracts have substantial gaps as well but are important enough to the study overall that they were not excluded. A second attempt at data finding reduced missing extramural data from between 4.6% and 16.7% per year to between 3.2% and 12.9% per year. However there is still temporal bias in the data. The data is between 92.0% and 97.3% complete from 1998 to 2001. The worst years are 2002 and 2003, which are 88.1% and 87.1% complete, respectively. The data improve after 2003 to 92.6% in 2004 and 94.6% in 2005. However, the impact on this study is minimal because a list of projects identified through CRP and ICRP queries on search terms relevant to palliative and end-of-life care, symptom management, and related terms that were originally missed in the DEA database was reduced to seven projects when the DEA database was searched for the specific contract numbers. In short there is missing data, but nearly all of it does not impact this study. All of the twelve missing records, the only exceptions, were projects from the University of North Carolina at Chapel Hill, which is a comprehensive cancer center.

One issue of temporal bias could not be resolved. Extramural data for 1998 and 1999 were only available on the DEA database. Projects that would have been missed in



the first DEA queries could not be identified from CRP and ICRP global queries if those projects ended in 1998 or 1999. Fortunately the early years of data on the DEA database were relatively complete. Projects that would be identified in the CRP and ICRP databases but would not be identified in the DEA database would also be lost if they ended in 1998 or 1999. To compensate for this an expansive approach was taken in data selection. Directed queries on specific search terms were made opportunistically in each of the three databases using the strengths of each. By using Krippendorf's alpha scores to compare query results among the three search engines it was possible to combine DEA results with the results of the other databases and reduce the temporal bias. Generally speaking the DEA query results were compatible with the CRP query results but not with the ICRP query results. See Appendix A for a detailed presentation of the data extraction. Temporal bias was a primary concern because the data were used in trend analysis.

***Inflation.*** Inflation was adjusted because of 44% inflation between 1998 and 2005 and dollar amounts are expressed in 2001 dollars unless otherwise noted. However, the analysis of the budget data is largely in terms of proportions of the annual extramural budget.

***Cancer Centers.*** Cancer centers were identified from a list published on the Cancer Centers Branch website because the P30 grants were not reliable indicators of cancer center status. Use of this list made it possible to distinguish cancer centers from comprehensive cancer centers, although that distinction is not used in the analysis. See Appendix A.

***Lack of Access to Intramural Budget Data.*** The extramural budget of the NCI is a matter of public record and available for public inspection by anyone who has access to

a PC, a fast Internet connection and no small amount of patience. The NCI intramural budget is much less transparent. Online search engines do well at identifying intramural projects, but attempts to obtain funded amounts for intramural projects online were unsuccessful. Queries of the CRP database identified 1,690 intramural projects in 5,057 project years between 2000 and 2005. No intramural projects were identified in the ICRP database that were not also found in the CRP database. However, it is impossible to corroborate the exact number of intramural projects because the NCI *Fact Books* (2000-2005) do not quantify the number of projects but rather full time equivalents (FTEs). Between 14 and 19 intramural projects met specific search criteria in each year between 2000 and 2005. No intramural projects were identified in 1998 or 1999 because CRP and ICRP coverage begins with 2000. The value of these projects is unknown. The impact of this is mitigated by the fact that elements of NCI's Palliative Care Working Group participants work for extramural divisions.

***Validity of the Estimates.*** It is highly likely that the proportions of the NCI extramural budget dedicated to palliative and end-of-life care, symptom management and related categories are exaggerated in the sense that not every dollar in the estimate is spent in each category. In expert interviews Kathleen Foley (personal communication, 4/25/2007) and Charles Cleeland (personal communication, 5/11/2007) were asked to comment on the estimates of the extramural budget produced by this study. Both indicated that the estimates of the proportion of the extramural NCI budget spent on palliative care and allied concerns sounded high and referred to a study on pain research by Bradshaw, Nakamura and Chapman (2005). Bradshaw et al estimate the proportion of the NCI budget devoted to pain research in 2003 using a method very similar in its

essentials to the one used here with very different results. Bradshaw et al estimate that \$12.2 million of the NCI extramural budget went to projects that had a primary focus on pain while \$29.2 million went to projects that have any focus on pain (p. 289). By comparison the data used in this study put the proportion of the NCI extramural budget devoted to pain research in 2003 at \$278 million in 2001 dollars and \$297 million in unadjusted dollars. There is a nine-fold difference between the two estimates.

The method used by Bradshaw et al (2005) should sound familiar. The authors first identify projects with Boolean searches of an online database, and then classify them. The NIH Office of Extramural Research Computer Retrieval of Information on Scientific Projects (CRISP) database provides information for research and development projects, as well as training, professional, or community service projects or interagency or intra agency agreements, with funding from NIH or a number of other federal health agencies (2007). The records produced by queries include grant numbers, principal investigator's name and the project title, which provides a link to a project abstract. Neither the records nor the abstracts include budgeted amounts, however Bradshaw et al were able to download a list of NIH extramural award amounts from the NIH Office of Extramural Research website (2007a). The database used by Bradshaw et al would have been preferable to the DEA database because it contains data for the entire study period (1994-2005), although specific keyword searches before 1998 would be problematic for reasons that will become clear below.

The classification procedure used in Bradshaw et al (2005) is much more conservative than the method used here. The authors, who are experts in the field, conduct their searches based on a list of search terms that indicate pain or a related topic,

or a condition that is characterized by pain. The authors then use an iterative process to screen out projects that impact painful conditions but where pain is not at least part of the focus of the research. Restricting their analysis to research projects, the authors break down pain projects by whether they are basic science or clinical in nature and by whether or not pain is a primary or secondary focus of the research.

The method used in this study is discussed at length in Appendix A and is summarized here. Pain records were identified through searches of the DEA, CRP and ICRP databases. The DEA and ICRP database queries used *pain* as keyword. The CRP database allows the user to select an NCI-defined special interest category, which is peer reviewed. A Krippendorff's alpha for all three queries was less than 0.500 so the three query results were not combined. However, Krippendorff's alpha for the DEA query and the CRP query (0.513) indicated that the two queries were in overall agreement and were combined. The procedure for extracting the data for this study was deliberately expansive so that it would be sensitive to changes in practice at a number of levels from recognition to core purpose. The difference of an order of magnitude with a comparable estimate was a potentially very disappointing surprise.

However, the difference may not rest entirely with the estimate produced by this study. The projects identified by Bradshaw et al (2005) do not include program grants, training, professional, or community service projects or inter agency or intra agency agreements included in the CRISP database. When this project's budget data are disaggregated the difference between the two estimates is resolved. Training, Career Program grants, and cooperative agreements account for \$114 million and P30 cancer center grants account for \$155 million. The remainder of \$28.2 million, approximates

Bradshaw et al. Notwithstanding, the estimates generated in this research are exaggerated because they include core cancer center funding of institutions that justify their status as cancer centers on the basis of their commitment to pain research, and are undeniably a measure of institutionalization of pain research at NCI. The overall validity of the estimates of this research is not undermined because the data are a valid measure of institutionalization. The data are adequate for evaluation of Hypotheses 2 and 4.

### ***Journal Data Quality***

This section assesses the quality of the professional journal data. As planned, the journal database would have been extracted through PubMed searches of *JCO*, *CJON*, and *JPSO*. Those PubMed searches were to have identified articles from the three journals published from 1994 to 2005 that meet search criteria that were selected *a priori*. The procedure for the searches is discussed in full in Appendix B. There are serious problems with the data that render them all but unusable. Because of the unavailability of data in large enough numbers to permit meaningful statistical significance and difficulties in validating the results through expert interviews, Hypothesis 6 is discarded.

***Data Availability.*** There are serious problems with data availability. Data for *JPSO* are not available on PubMed until 2005. An attempt to extract the data from *JPSO* abstracts for 2005 produced unreliable results when compared with PubMed searches of *JPSO* for 2005. Statistical analysis of *JPSO* content was abandoned at that point. Statistical analysis of *CJON* from its founding in 1997 to 2005 was fruitless for all but two of the largest aggregations of variables because of the low volume of articles published. Only *JCO* was available for all years between 1994 and 2005 and published a

large enough number of articles in each year that trend analysis could produce significant results.

***Coding of Journal Articles.*** In order to assist interpretation of the available data and in the absence of usable data for two of the journals, grounded theory was used to determine the topics of *JPSO* abstracts and PubMed searches including several thousand *JCO* and *CJON* articles. Categories were identified from the source material and classified by pre-defined search terms. Based on those classifications it was possible to identify categories of topics and establish connections with the data selection criteria used in the PubMed searches. However, it is not possible to infer editorial policy from these data.

***Expert Interviews.*** To address editorial policy, expert interviews were attempted with the editorial staff of all three journals and successfully completed with editorial staff of *CJON* and *JCO* who have experience with publication of articles on palliative care and related topics. Rosemary Carroll-Johnson (personal communication, 5/3/2007) who worked in editing *CJON* indicated that the 2001 IOM report on cancer palliation was not familiar to her, although she would not rule out the possibility that it might be a factor in the writing of some of the articles. She stated that the content of *CJON* reflects the content of the articles submitted, although articles are returned for editing. Given the small number of articles published this last assertion is certainly plausible. During the interview the issue of competition with other journals was raised. Patricia Ganz (personal communication, 5/10/2007), who worked in editing palliative care and related articles at *JCO*, indicated that she believes that the 2001 IOM report on cancer palliation had little impact on the content at *JCO*. She suggested further that consensus conferences change

little because by the time they occur the consensus is already in place among professional groups.

*Synthesis.* Based on the poor data availability, and expert opinions that suggest that the 2001 IOM report on cancer palliation may be irrelevant to choices about which articles get written and which get published, and especially in light of the importance of NINR in the development of palliative care, it is doubtful that Hypothesis 6 can be answered meaningfully. Most evidence is the grounded theory based on journal content. These data are used sparingly in the discussion and could reasonably be seen as spurious because the impact of the 2001 IOM report could not be validated by the interviews.

### **Institutionalization at NCI**

Hypothesis 1 predicted that NCI would conduct state of the science conferences and publish proceedings on palliative care and symptom control that would result in a clear and prominent research agenda that is followed by NCI and the comprehensive cancer centers. Determination was sought whether NCI has conducted state of the science conferences and published proceedings on palliative care and symptom control that resulted in a clear and prominent research agenda that is followed by NCI and the comprehensive cancer centers. An institutional commitment to palliative and end-of-life care and symptom management and the establishment within NCI of an institutional locus for these were identified.

On the whole Recommendations 8 and 9 have been fulfilled. The necessary legislative foundation was already in place by 1993. A state of the science meeting called for in Recommendation 8 was held in 2002 with NCI as a lead sponsor and participation from a number of NIH member institutions. The conference focused on pain, fatigue and

depression, with a concern for formalizing the science of treating each. However, the conference did not focus on dyspnea, nausea, anxiety, or cognitive difficulties, some of which are important concerns in managing end-stage cancer. Another state of the science meeting was held on end-of-life care in 2004 although NCI was not a principal sponsor.

An informal working group was created at NCI specifically to implement Recommendations 8 and 9. That working group is composed of individuals from three extramural divisions and the Office of the Director, which makes it a dual network as defined by Alange et al (1998). The strengths and limitations of such an informal body aside, the fact remains that an institutional locus for palliative and end-of-life care and symptom management has been established at NCI per Recommendation 9. The Palliative Care Working Group is coordinated from within the Division of Cancer Treatment and Diagnosis, as suggested in Recommendation 9.

Another more formal institutional locus has been found in the Office of Cancer Survivorship, itself a member of the Palliative Care Working Group. The Office of Cancer Survivorship is within the Division of Cancer Control and Population Studies. This placement is perhaps a step removed from the development of new therapies but closer to cancer control, which is concerned with the development of better interventions. The reader is reminded that many of the authors of the 2001 IOM report on cancer palliation noted the existence of effective therapies but pointed out serious gaps in quality and accountability within interventions. On the whole, at least on paper, it appears that NCI is in substantial compliance with the report's Recommendations 8 and 9. It remains to be seen whether these changes have resulted in a more robust palliative care and



symptom management research program at NCI, which would result in an increased share of NCI research spending.

In addition, a web presentation was found on the NCI website that makes peer reviewed information available to health care providers and the general public. The web presentation addresses all of the symptoms discussed in the 2001 report on cancer palliation, except dyspnea. It also includes a number of related topics not mentioned. The provider portion of this web presentation amounts to practice guidelines, which represent institutionalization within NCI.

### **NCI Budget**

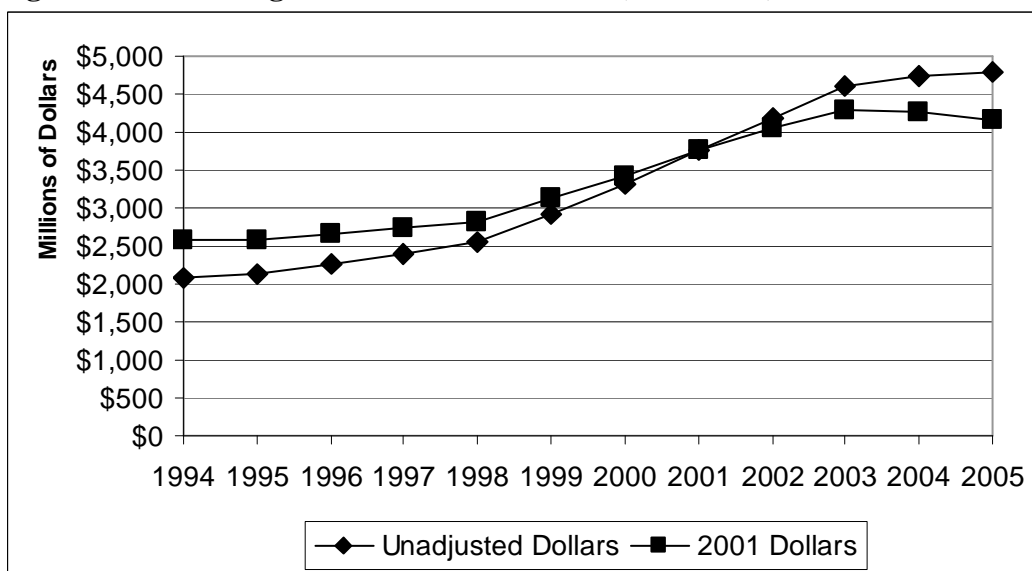
Hypothesis 2 predicted that examination of the NCI intramural and extramural budgets would show that NCI has shifted emphasis in funding to prioritize palliative care and symptom management. Indicators of palliative care and symptom management would show S-curves when graphed by year through the deliberative (1998-2002), and post-deliberative (2002-2005) periods, indicating adoption of the report's recommendations through the theory of diffusion of innovations. Adoption was expected to begin to increase early because of increased public attention to the issues raised in the 2001 IOM report on cancer palliation.

The extent to which NCI shifted emphasis in funding to prioritize palliative care and symptom management was evaluated. To the extent that this happened, indicators of palliative care and symptom management were expected to show S-curves when indicators of adoption of the report's recommendations are graphed by year, which approximate linear trends. Adoption was expected to begin to increase early in the

deliberative period. The direct impact of the 2001 IOM report on cancer palliation was also expected to result in changes in trend at Fiscal Year 2002.

In some cases overall increasing trends had no apparent change points, which suggest that the deliberative process rather than publication of the 2001 report may have driven adoption. In other cases there are readily apparent change points, which suggest that the report's publication impacted interest in the type of cancer research that the authors meant to stimulate. That interest may be increasing or decreasing. Accelerating changes suggest adoption. Decelerating changes may suggest rejection; however they may also suggest that NCI was heavily invested in the NCPB's work, which was completed in Fiscal Year 2002.

**Figure 21. NCI Budget from NCI Fact Books (1994-2005)**



All of the findings reported in the second parts of Chapters 5 and 6 must be seen against a backdrop of rapidly increasing funding of cancer research between 1994 and 2005. Some of the increases reported in Chapter 5 were quite small, on the order of 0.1%. Adjusting for inflation with a specialized inflation index found in an NIH Office of Portfolio Analysis and Strategic Initiatives memo (2006), the purchasing power of dollars

spent to support NCI increased from \$2.6 billion to \$4.2 billion (61%) in 2001 dollars despite inflation of 44%. Adjusted for inflation the NCI budget shows an S-curve as demonstrated in Figure 21.

Extramural grants increased from \$2.1 billion to \$2.9 billion in 2001 dollars between 1998 and 2005, with a single year high of \$3.0 billion in 2003. The extramural research budget represented between 83% and 86% of the total NCI commitment to research. Each tenth of a percent increment of the extramural budget represents between \$2.1 million and \$3.0 million.

Palliative care research increased from 7.6% to 9.0% of NCI extramural research funding between 1998 and 1999 and remained at roughly that level through 2005. End-of-life care research increased steadily and four-fold over the study period, however, at no point did this area of research exceed 0.22% of the extramural research budget. End-of-life care remains a most minor component of the NCI extramural research program. Supportive care increased steadily as a proportion of the extramural budget from 1998 through 2002 from 0.6% to 1.0%, after which it declined to 0.5% in 2003 and remained at that level in subsequent years. It is not clear from this research how much end-of-life care research is conducted through other NIH members. The category supportive care was created using keyword searches because it is not found in either the CSO or the SIC. The term may be subject to variation from its perceived importance by proposal writers, and the decline of its use should not be over interpreted. However it appears on the whole that palliative and end-of-life care taken together grew more in response to the first report on dying (Field & Cassel) in 1997 than in response to anything else. That report resulted in designation of NINR as lead NIH institute in end-of-life care research. However, while

growth of budget share was flat after 2002, the proportion of projects in palliative care grew after 2002 after three years of decline. The growth of end-of-life care research is large in comparison to what it was at the beginning of the study period, but minuscule when compared to the concern expressed in Field and Cassel, Hewitt and Simone (1999), and Foley and Gelband (2001).

Physical symptom management research followed the same pattern as palliative care. Extramural research on all symptoms increased from 7.3% to 8.5% of the NCI extramural research budget between 1998 and 1999 and varied between 8.4% and 8.7% thereafter. The proportion of physical symptom management projects began to increase after 2002 after three years of decline. Most of symptom management research was focused on pain. Dyspnea research increased significantly over the study period as a proportion of extramural funding, although that proportion never exceeded 0.04% of the extramural budget represented by never more than three projects. Nausea research declined while fatigue research, which was addressed in the 2002 NIH consensus conference increased four-fold as a proportion of the NCI extramural research budget from 0.09% to 0.38%. No projects were identified as working with delirium. The term *cognitive difficulties* was not used in searches but might have been productive because it is used in the NCI documents reviewed for Hypotheses 1 and 3.

Psychological symptoms management research breaks with the pattern established with palliative care and physical symptom management in two important respects. Psychological symptoms research began and finished the study period as a much smaller research concern at NCI than either palliative care or pain management research. As a proportion of the extramural budget, but not as a proportion of projects, psychological

symptoms management research increased significantly over the study period from 0.2% of the budget to 0.8%. The NCI extramural investment in depression research grew rapidly from 0.2% in 1998 to 0.4% in 1999. It increased again to 0.5% in 2000, a gain that it gave back over the next two years. There is a positive apparent change point at 2002, after which the proportion of extramural research funding increased steadily through 2005 to 0.6%. NCI extramural funding of anxiety research was flat at about 0.2% from 1998 to 2003. After that it increased to almost 0.4% in 2005. Dementia research was established on a very modest research priority on a scale comparable to dyspnea.

It is plausible that the 2001 IOM report's strong call for psycho-social research, and the 2002 NIH consensus statement's focus on depression, in addition to pain and fatigue, may have positively impacted funding of depression research. It is remarkable that there was an increase of the proportion of projects conducting pain research and a dramatic relative increase although on a small scale in the NCI extramural investment in fatigue research. It is also remarkable that anxiety, while not mentioned as a priority in the 2002 NIH consensus statement, received a relatively larger proportion of NCI extramural funding, but only after 2003. The 2002 NIH consensus conference was called for in the 2001 report on cancer palliation as part of Recommendation 8.

It is also remarkable that concerns of palliative care and symptom management, although given less priority, grew though less dramatically. End-of-life care was not mentioned in Recommendation 8 presumably because of NINR's role. Dyspnea and dementia were not addressed in the 2002 NIH consensus conference. All of these concerns increased as proportions of the NCI extramural budget, but remained quite

small as research priorities, less than 0.02% of the extramural budget in each case.

Nausea research was similar in scale but decreased as a proportion the budget.

The term profession development projects is used here to describe research that addresses palliative care that is specialized to the fields of oncology, oncology nursing, oncology social work, and hospice care. Oncology projects accounted for between 2.0% and 2.1% of the NCI extramural budget between 1998 and 2004, increasing to 2.3% in 2005. Growth in nursing research was also flat varying between 0.5% and 0.6% of the extramural budget. Social work projects did not have significant trends and accounted for no more than three projects in any given year accounting for never more than 0.5% of the NCI extramural budget. However, NCI extramural spending on hospice research had a significant increasing trend with a positive change point at 2002. The proportion of extramural spending invested in hospice research was flat from 1998 to 2002, varying between 2.7% and 2.9%, after which it increased in every year, reaching 3.3% in 2005. The increase in hospice care research represents a significant new investment on the part of NCI in applied end-of-life care research.

Overall quality research in palliative care as a proportion of the NCI budget increased in every year from 3.6% to 6.8% from 1998 to 2002, and decreased in every year thereafter through 2005 to 6.0%. Quality of care research and patient care also peaked in 2002. Quality of care research increased from 2.4% to 4.3% of the NCI extramural budget from 1998 to 2002, and then declined to 4.1% in 2005. Patient satisfaction research increased from 0.8% to 1.6% of the NCI extramural budget between 1998 and 2002 before it declined to 0.9% in 2005. Research on patient participation in decision making is represented by a single project that began in 2001 and ended in 2002.

Effectiveness research increased from 0.3% to 1.2% of the NCI extramural budget between 1998 and 2005, had a significantly positive trend and did not have a negative change point in 2002. Of the measures of quality research, only effectiveness research continued to increase after 2002. The overall pattern suggests rejection of the NCPB's call for quality assessment research.

The discussion of Hypothesis 2 shows that over the study period there was a modest increase in NCI research dedicated to the concerns raised by the NCPB in the 2001 IOM report on cancer palliation. Between 1998 and 2005 that increase was from 13.3% to 16.7% of extramural funding and from 6.1% to 8.7% of NCI funded research projects. Research for managing physical symptoms, driven mostly by pain research, changed little in the amount or the distribution of resources across symptoms, although psychological symptom research increased roughly three-fold. Fatigue and depression research both seemed to benefit somewhat from inclusion of discussion of fatigue and depression in the 2002 consensus statement, but by the end of the study period anxiety research seemed to be increasing as well. Dementia and dyspnea, both important end-of-life concerns, increased much less dramatically, although neither was funded at all at the beginning of the study period. At the end of the study period both remained minor research priorities.

As called for by the authors of the 2001 IOM report on cancer palliation, hospice research increased after publication of the report, but nursing and oncology research were not impacted as much as the authors must have hoped. Nursing research increased slightly in 1999 and remained stable, and oncology research did not increase until 2005. Quality research peaked in 2002 and declined, in strong contradiction to the NCPB's

recommendations. All said, the NCPB's successes, i.e. modest increases in symptom management and hospice research, are outweighed by its failures, i.e. an institutionalization that has not been transformed into increased quality and accountability measurement and profession development research. It is through hospice research that we see NCI fund applied end-of-life research and became a locus of end-of-life care research.

### **Cancer Centers**

Hypothesis 3 predicted that the NCI Cancer Centers Branch would amend its guidelines to require that comprehensive cancer centers engage in palliative care and symptom control as a condition of NCI recognition. In Chapter 5 the legislative basis of the cancer centers was discussed as part of the overall program of cancer control at NCI. In that discussion it was established that the cancer centers act as important change agents within the NCI cancer control program by developing and modeling interventions in treatment, diagnosis and prevention through the translation of basic and applied science. These interventions include but are not limited to rehabilitation and counseling and management of physical and psychological symptoms. This legislative mandate was in place by 1993.

Although it is clear that palliative care and symptom management are addressed by the cancer centers, Cancer Centers Branch Chief, Linda Weiss (personal communication, 5/2/2007) indicated that the Cancer Centers Branch is not an appropriate mechanism to stimulate palliative care or symptom management research or any other type of research because the purpose of the Cancer Centers Program is to provide core support to participating institutions. Neither the creation of centers of excellence, nor the



requirement that all comprehensive cancer centers conduct palliative and symptom management research were realized.

The Cancer Centers Branch website as discussed in Chapter 6 revealed that NCI has not amended its guidelines to require that all comprehensive cancer centers engage in palliative care and symptom control research and dissemination as a condition of NCI recognition. Comprehensive cancer centers are chosen through a two stage process that consists of an application for cancer center status followed by an application for comprehensive status. Proposals are typically written in two parts. Recommendation 2 called for a requirement that the cancer centers be required to engage in palliative care and symptom management research as a condition for receiving comprehensive status. The Cancer Centers Branch has not added a requirement that the cancer centers conduct palliative care and symptom management, however according to its guidelines no specific combination of program elements is required. In other words no area of cancer research is required per se. Instead the comprehensive cancer centers are required to show breadth and depth of scientific interests that span primary prevention, early detection, treatment, dissemination, palliation, and survivorship. A broader scope of scientific interests means a stronger candidacy for comprehensive status.

A report by cancer center directors addresses palliation and survivorship research within the continuum of concerns addressed in cancer control. End-of-life care is not explicitly addressed. That report presents evidence of substantial reinvention by which the work of centers of excellence in palliative care and symptom management could be done. It certainly points to work in these areas by institutions that do that work voluntarily.

## **Cancer Centers Budget**

Hypothesis 4 predicts that examination of the NCI extramural budgets will show that the cancer centers and comprehensive cancer centers have reorganized to incorporate palliative care and symptom control into their research agenda. Indicators of palliative care and symptom management would show S-curves when graphed by year through the deliberative (1998-2002), and post-deliberative (2002-2005) periods, indicating adoption of the report's recommendations through the theory of diffusion of innovations. Adoption was expected to begin to increase early in the deliberative period because of increased public attention to the issues raised in the 2001 IOM report on cancer palliation and that research-based adoption curves would lead adoption curves in professional journals by one or two years as new research findings get published.

The extent to which the cancer centers have reorganized to incorporate palliative care and symptom management into their research agenda was evaluated. It was expected that as a whole the comprehensive cancer centers would show an overall trend toward increasing the number of research projects and the funded total of those projects between 1998 and 2005. It was also expected that there would be a trend toward integrating symptom management. This overall trend would occur within the context of the ebb and flow of NCI research interests. Therefore we may expect that these increases would occur proportionately within the number of intramural and extramural projects funded by NCI as well as in terms of the proportion of NCI extramural funds dedicated to these research goals and objectives. It was expected that the cancer centers would increase their share of extramural funding in these areas overall. It was also expected that the cancer centers would develop disproportionately in key areas that make sense to a careful reader of

Foley and Gelband (2001) who is knowledgeable about cancer epidemiology and etiology, in some research areas to the point of exclusivity.

In the discussion of Hypothesis 2 in Chapter 5, a general NCPB recommendation was evaluated that calls for NCI to incorporate palliative care, symptom control, and end-of-life care into their research agenda. This section evaluates a somewhat more precise mandate for the cancer centers to develop practice guidelines for palliative and end-of-life care; incorporate palliative care practice into clinical trials; develop quality indicators, especially for end-of-life care; develop hospice and best practices in oncology, nursing, and social work, and conduct training in these areas; and improve health care delivery, in addition to improved symptom management. The volume of research relevant to each mandate is addressed in the following discussion in turn. The recommendation also calls for information dissemination, improvement of access to vulnerable groups and development of fellowship programs. None of the last three mandates is addressed here.

The cancer centers have been at the center of a modest increase in activity that should result from the development of centers of excellence within the cancer centers as recommended by the NCPB. Flat growth in palliative care research and modest growth in supportive care and end-of-life research could point to development of palliative and end-of-life care guidelines, although the NCPB was very concerned, as were the authors of the 2002 NIH consensus statement, with the underdevelopment of this field. That might suggest a more aggressive research program at the cancer centers.

In the development of quality indicators for end-of-life care, it appears that the cancer centers are leaders in the field, however limited that field may be. However, as with NCI-funded research generally, growth of cancer center research in quality research

within palliative care fell off dramatically after 2002, to a level approximating stability or zero growth. The development and testing of quality indicators, even on a pilot basis, suggests other research necessary to develop these indicators, especially in what the NCPB considered to be the underdeveloped state of the field.

The cancer centers spearheaded NCI-funded hospice research. The NCPB called for hospice research including the areas of health care delivery, and staff training. Overall the proportion of NCI extramural spending increased ( $p=.024$ ) during the study period. Growth was flat through 2002 (range = 2.7%-2.9%), but grew to 3.3% by 2005. However, this growth is largely attributable to the cancer centers, which did most of the research. The trend in the cancer centers' share of extramural funds spent on hospice research within palliative care was negative ( $p<.001$ ), falling from 99.6% in 1998 to 88.7% in 2005. Although there was no significant trend in the proportion of NCI extramural funding the cancer centers received for this type of research (range = 2.4%-2.9%), there was an apparent change point at 2002. Before 2002 the range was 2.4%-2.7% and after it was 2.7%-2.9%.

The NCPB called upon the cancer centers to incorporate state of the art palliative care into clinical trials. This research found that no clinical trials in palliative care were funded by NCI, although the Palliative Care Working Group did substantial work in symptom management clinical trials.

The NCPB called for creation of faculty development in oncology, nursing and social work. The proportion of palliative care oncology ( $p<.001$ ) and nursing ( $p<.001$ ) research in terms of extramural NCI funding dollars decreased over the study period from 82.17% and 70.87% in 1998 to 73.20% and 59.95% in 2005, respectively. It bears

repeating that extramural palliative care oncology and nursing research did not increase significantly over the study period. If profession development research had been stimulated by the cancer centers then it makes sense that the cancer centers would have done significantly more research in palliative oncology and nursing research. This was clearly not the case. The cancer centers did no work on palliative care research within social work research between 1998 and 2005.

### **Professional Organizations**

Hypothesis 5 predicted that examination of the websites of the professional organizations of oncologists, oncology nurses, and oncology social workers would show that these organizations developed best practices in accordance with the state of the science and their professional interests.

All three of the professional groups responded positively to the conceptual framework laid down in the 2001 IOM report on cancer palliation. All three discussed issues relevant to that conceptual framework in their formal policies. It is another question, however what the impact of those discussions has been on the practice of oncology, oncology nursing, and oncology social work. Although a more complete answer to the practice question is beyond the scope of this research, the findings presented in this chapter suggest some hints.

One hint is the scope of these responses. For example, before 1997 the Oncology Nursing Society did not have a professional journal. As direct care givers nurses have a professional concern with the health and phenomenological well-being of their patients which they realize through direct interventions with their patients as individuals. Nursing interventions provide comfort, safety, and reassurance to cancer patients and their

families, as a primary function. The 2001 IOM report on cancer palliation and the four-year process that led up to it provided organized oncology nursing with an opportunity to formalize its practice. It has done this with attention to professionalism and science, while retaining a phenomenologically grounded human approach that characterizes it. As a result the practice of nursing has been formalized and the profession developed.

Oncology nurses as a professional community have made far-reaching changes in the practice of nursing by thoroughly and thoughtfully reorganizing, in a way which supports the effectiveness and affirms the importance of their profession. However, the development of oncology nursing may have been driven more by NINR and Field and Cassel (1997) than by NCI and Foley and Gelband (2001). Oncologists' palliative practice guidelines mostly include management of issues related to chemotherapy and radiation therapy.

Among social workers, there was clearly a community of interest with the agenda set forth in the 2001 report on cancer palliation. This coincidence flows logically and by necessity from the orientation of social workers as a profession, which seems nearly identical to the orientation of that report's authors. But social workers are advocates and do not work through direct interventions with cancer patients in the same way that oncological physicians and nurses do. It is ironic that this professional group should show signs of reinvention, as it did after publication of the IOM on cancer survivorship reports. This stems from the same irony by which, in the context of a document that crowns a four-year effort to improve palliative care for the dying as its primary thrust and calls also for effective palliative care for people at all stages of cancer, the end-of-life focus is eclipsed by the revolutionary concern that came about with it. It seems that social

workers have followed the trends in evidence-based health policy. It also makes sense that advocates who are relative outsiders to the context of healthcare relationships might be opportunistic in the development of their fields. It would be irresponsible to speculate how this shift has impacted oncology social work practice.

While some interesting patterns were found in the development of practice guidelines for oncologists, oncology nurses, and oncology social workers, care must be taken in over interpreting what may be spurious findings. Expert interviews conducted with editorial staff of *JCO* and *CJON* suggested that the content of neither journal had been impacted much by the 2001 IOM report on cancer palliation.

The case for adoption by professional organizations, if it can be made at all, is much more difficult to make than for adoption by NCI. The case for uneven and modest adoption of Recommendations 1, 2, 8, and 9 at NCI, with or without reinvention, has been made more or less convincingly with documentation from the Internet, expert interviews and other document review. Consensus conferences were held. A clear link was found between the 2001 IOM report on cancer palliation and the creation of a dual network in the form of the Palliative Care Working Group at NCI. The Office of Cancer Survivorship, whose director is a member of the Palliative Care Working Group, has a highly visible program. These findings are supported by clear although quite modest NCI budget trends.

By contrast it is difficult to interpret the actions of the professional groups. Oncology nurses clearly developed practice guidelines and an elaborate process for validating these. However, that process probably owes more to the 1997 IOM report on dying than to the 2001 IOM report on cancer palliation. On the other hand oncologists

through the ASCO website have developed little by way of practice guidelines in palliative care and symptom management; however practice guidelines that meet those needs exist on the NCI PDQ website. Development of palliative care and symptom management guidelines would have been redundant. AOSW representatives were unavailable for interviews and web-based document review was inconclusive regarding the impact of the 2001 IOM report on cancer palliation.

The impact of the 2001 report on professional groups has not been determined through Recommendation 6. There are two exceptions. The first is the ASCO policy statement on cancer at the end-of-life (1998) which followed the 1997 IOM report on dying by one year and anticipated the 1999 IOM report on quality of care in cancer by one year. The second exception is found in Figures 17 and 19 in Chapter 7, which show PubMed hits for palliative, end-of-life, and supportive care and depression and anxiety, respectively. The proportions of palliative and supportive care articles in *JCO* peaked in 1996 and again in 2002 for palliative care and supportive care. The first peaks anticipated the 1997 IOM report on dying by one year, suggesting that consensus in the professional network of oncologists preceded the formal consensus of an IOM report. The pair of peaks followed the 2001 IOM report on cancer palliation by one year, suggesting that the report may have at least induced interest in the topic. *JCO* articles addressing psychological symptoms show a sustained increase after 2001. It should also be noted that whether or not it was instrumental, the call in the 2001 IOM report on cancer palliation for practice guidelines in Recommendation 6 was answered in the affirmative. The extent to which these guidelines are followed is beyond the scope of this research. This paragraph summarizes findings for Research Question 2.



### **Linkage of Findings to Theory**

This research begs several questions. The first is why did NCI respond so favorably in an organizational sense through the Palliative Care Working Group but not the Cancer Centers Branch? Recommendations 1 and 2 target weak ties while Recommendations 8 and 9 target strong ties. The targets of Recommendations 1 and 2 are institutional actors, i.e. the Cancer Centers Branch and the cancer centers. Although Recommendations 8 and 9 target NCI as a whole, the main adopting entity is a network of strategically placed individuals who support the recommendations that apply directly to them because those recommendations support their work. Recommendations 8 and 9 have been largely adopted in a way that is voluntary, implemented through horizontal ties through individuals, a dynamic with a large element of strong ties. By contrast Recommendations 1 and 2 call for implementation through coercive regulation through vertical ties at the institutional level, which creates a dynamic with a large element of weak ties. The friction caused by the element of coercion in Recommendations 1 and 2 is exacerbated by the institutional culture of the Cancer Centers Branch and the cancer centers, which give and receive core support grants without mandatory elements in research agendas.

The second question is what form did reinvention take at the Cancer Centers Branch and the cancer centers? The cancer center guidelines clearly cover cancer survivorship, palliative care, and symptom management. The cancer centers may use these types of research as elements of a justification for comprehensive status. Although no centers of excellence in palliative care and symptom management were created (Linda Weiss, personal communication, 5/2/2007), it is clear from the cancer centers directors'

report, cited above, that palliative care and symptom management are a part of the cancer centers. It must be acknowledged that the legal and regulatory basis for including these concerns existed by 1993, and the 2001 IOM report on cancer palliation may not have directly stimulated any palliative care and symptom management research at the cancer centers, but there is also evidence that the cancer centers are doing work in those areas. Whatever impact Recommendations 1 and 2 have had on the cancer centers program has been voluntary and has been the result of coordinated efforts by the cancer centers' directors.

The third question that this research raises is why did the NCI responses translate so poorly into a palliative and end-of-life care and symptom management portfolio that addresses training, profession development, and quality measurement? Research in palliative care and pain management, two of the largest NCI funding categories in that portfolio, were stimulated by the 1999 IOM report on quality of cancer care but not by the 2001 IOM report on cancer palliation. Quality of life and survivorship research increased. Some success in targeted initiatives was found, specifically fatigue, psychological distress, and hospice care. Depression research and anxiety research both increased. Depression research was targeted along with pain and fatigue research in the 2002 consensus conference and began to increase sooner than anxiety research, which was not reported on in the consensus statement (2002). Dyspnea research, end-of-life research, and dementia research grew significantly but are represented by a tiny number of projects, mostly conducted by the cancer centers. The cancer centers also provided leadership in the development of quality research and hospice research. Quality research, strongly emphasized by the NCPB, increased steadily until 2002 then it declined slightly.

The authors of the 2001 IOM report on cancer palliation can point to some successes with NCI, but those successes have not changed either the basic composition of the NCI extramural budget or the overall composition of the budget for palliative and end-of-life care, symptom management and allied concerns. Those successes are indeed modest. Dyspnea research, according to Charles Cleeland (personal communication, 5/11/2007), is a high priority in symptom management in a cluster of issues behind pain and fatigue, but is conspicuously missing in all of the material reviewed here. The reason for the limited nature of this success can be found in the institutional culture of NCI. In the interview with Cleeland he also pointed out that NCI and similar federal agencies are more concerned with prevention and curative treatment than with palliative care and the need to manage symptoms. Kathleen Foley (personal communication, 4/25/2007) concurred.

The fourth question raised is what sort of impact can usefully be expected of professional groups in health care from consensus statements? Practice guidelines for symptom management have largely been created, although their use is not addressed by the methodology of this study. Recommendation 6 calls on professional groups to encourage their members to participate in the development, testing, and implementation of practice guidelines. The NCPB asked the professional groups to communicate to individual members through weak ties, without coercion, as successfully as was necessary to meet the objective of the recommendation.

The answers to these questions will allow constructive criticism of the recommendations evaluated and will suggest the extent and manner in which palliative care and symptom management and other concerns raised by the NCPB in the 2001 IOM

report on cancer palliation can be expected to be embraced by the medical establishment, given its institutional culture. The balance of this dissertation will briefly examine network characteristics of NCI and the professional groups, and through that discussion competition over professional turf, friction caused by gaps in deliberative process, inertia, and power will be discussed.

### ***Network Characteristics, Institutional Culture, and Power***

In the literature review it was established that group identity has its basis in shared history, interests and approaches, and strategies for the control of resources. Resources may be economic, political or social and usually more than one of these in something as complicated as culture, depending on the network to which they apply. A key part of the culture of any network is the manner in which members communicate with each other and make decisions. These structures are characterized by relations of authority and communications channels--vertical and horizontal ties, respectively. Centralized networks such as NCI, through vertical ties, are controlled through high status members and tend to be homogeneous, cohesive and able to impose innovations. Decentralized networks such as professional groups function more through communication and innovations are more difficult to impose. Innovation decisions are made by the perceptions of decision makers about the likely consequences of the innovation. Decisions to continue or reinvent an innovation are based on the experience of actual consequences associated with the innovation. All decisions are made, in the last analysis by individuals, in whatever roles they play in networks.

On more or less this basis, Alange et al (1998) point out that both knowledge and culture are tacit or path-driven. When culture and the knowledge base become counter

productive they become sources of inertia by which opportunities to improve the mix of positive and negative consequences are lost. Dual networks allow well-placed individuals within networks to communicate across networks to share information increasing the knowledge base, and potentially, to coordinate action. NCI has created two dual networks that produced work of interest to this research including the Palliative Care Working Group, which was created explicitly to address the concerns of the 2001 IOM report on cancer palliation, and the cancer center directors. Dual networks are the means by which the cancer centers and the extramural program addressed palliative care, symptom management, and allied concerns at NCI.

Deliberative process is the means by which policy entrepreneurs and epistemic communities advance their agenda. The purpose of both policy entrepreneurs and epistemic communities is to convince decision makers of the wisdom of a certain course of action. Policy entrepreneurs typically address the means of power directly. State tax innovation (Berry & Berry, 1992), federal incentives to influence state policy (Mintrom & Vergari, 1998), and attempts to induce democracy in underdeveloped nations (Wejnert, 2005) all target legislatures directly. Epistemic communities do roughly the same thing through the ability to define knowledge for better (Adler & Haas, 1992) or worse. Strang and Meyer (1993) fear the development of theoretical models as a means of unnecessary regulation at national and global scales. The key to the success of epistemic communities as policy entrepreneurs and change agents is to frame debates on terms that are favorable to the policy agenda and consistent with the culture of the policy making community (Mintrom 1997) so that the credibility of the change agent can be used to establish the

need for the innovation, based on a shared understanding of the likely consequences which will create an intention to change that is followed through (Rogers, 2003).

### ***Who Are the Intended Adopters?***

It is worth a page or two in the waning part of this dissertation to examine the culture and history of NCI and the professional groups for clues about how to approach them. This discussion will end with an explanation of the findings summarized above.

***National Cancer Institute.*** Rettig's (1977) history of the NCI among others, from its organization in 1937 until just after the passing of the National Cancer Act of 1971, provides a basis for understanding the relative importance of treatment, prevention and palliation. According to it the creation of NCI was in many ways an act of political desperation because of discontent with the horror of agonizing and nearly certain death from cancer at a time when many of the other scourges of human illness were being brought under control (p. 1). NCI was created and expected to make progress against cancer before the basis of carcinogenesis was understood (Proctor, 1995; Rettig). One unintended result of this was that scientists who made their careers in cancer research, and particularly cancer control were not taken seriously by other medical scientists because of the underdevelopment of the field of oncology (Rettig). However, the political desperation was such that cancer research was always heavily funded, and remains the largest NIH component. By the 1990s the NCI cancer program had been successful enough at extending life without actually being able to provide a cure that cancer prevalence and the need for palliation increased (Proctor). Increasing the number of people living with cancer without lowering mortality advances in cancer treatment amounted to halfway measures that ended up consuming a lot of medical resources

(Weisbrod, 1991). The need for palliative care, as is abundantly clear from the writing of the authors of the 2001 IOM report on cancer palliation is the result of physical and psychological morbidity among the many who now live with the disease instead of dying from it.

When the literature review for this study was done, it was not yet clear that a decreasing trend in cancer mortality in the mid 1990s in the United States reported by the American Cancer Society was stable. However, a recent ACS report (Howe et al, 2006) shows a trend of decreasing mortality between 1994 and 2003, the last year for which data were available. A decreasing trend in mortality could work against the urgency with which development of the field of palliative oncology is pursued.

In any case, because of the political power and importance of NCI based on its successes in preventing, treating and controlling cancer, and because of the importance given to eradication of cancer by a nation that has made a huge investment in cancer research, it is clear that NCI is a prestigious and powerful member institute of NIH. NIH has shown itself willing to address palliative care and symptom management on a voluntary basis through dual networks. This approach reflects a culture that allows scientists and research institutions the freedom to do the work they are good at and see as needed. Linda Weiss (personal communication, 5/2/2007) indicated that requiring comprehensive cancer centers to incorporate any part of a research agenda would pull some institutions away from their strength, and would set a new precedent for other such requirements. In other words, it would change the culture in a way that would make that culture more hierarchical. In a book introduction Stanton (2002) observes that in medicine and in other contexts resistance can either shape adoption or halt it altogether.

The process that resulted in the 2001 report on cancer palliation had its origin in the pre-September 11, 2001 period and the Clinton Administration. There has since been a society-changing event and a change in Administration, the effect of which was not made clear in the expert interviews. However, it is clear that the Cancer Centers Branch of 2007 was not willing to follow the mandate of an IOM recommendation from 2001 that would require it to change its culture. The lesson is that culture changing should be undertaken with care and only as necessary, to avoid friction. The wording of Recommendation 2 that alludes to mandatory components was counter productive. The vague wording of Recommendations 8 and 9 was perhaps more vague but less intrusive.

*Professional Groups.* The lesson from the previous section is that a powerful collective adopter with high status will be less likely to adopt an innovation if that innovation is a threat to its status and power, and especially if it is inconsistent with institutional culture. While this section looks at nurses and physicians as professional groups it does not address social workers because these were not interviewed. Stanton's introduction (2002) attributes much of the resistance described in her volume to perceived threats usually to professional turf, as well as perceived risk. Stanton also characterizes many technological innovations as requiring enough logistical support that they are in effect organizational innovations. The implication is that much of the change in medicine and among allied professions is often more complicated than it might appear.

In an essay where he develops a conceptual model of professions and the process of professionalization, Abbott (1988) observes that professional groups control knowledge through abstraction. This process of knowledge creation is the basis of epistemic communities. "The crucial envioning question is how societies structure



expertise (p.323).” According to Abbott, professional groups compete with each other to control themselves, essentially as a network, and their knowledge base. This behavior was clearly observed on the ONS website, with an elaborate procedure to produce evidence-based nursing practice guidelines for a plethora of concerns in cancer palliation and symptom management. It may also be evident in the NINR dismissal of the 2001 IOM report on cancer palliation as irrelevant to their work (Alexis Bakos, personal communication, 5/4/2007). It was clear from the ONS website that nurses were building a professional knowledge base. The Dr. Bakos’s response was remarkable because it separates the recognized role of NINR from an initiative that calls for a lead role by NCI. Kathleen Foley (personal communication, 4/27/2007) voiced concern about marginalization of palliative care within nursing. In fact both make valid points. NINR has provided leadership in end-of-life care, while physicians are clearly underutilized in symptom management in ways already documented in the 2001 IOM report on cancer palliation and reviewed here. The continuation of underutilization of physicians in symptom management was confirmed in the interview with Dr. Foley and the interview with Charles Cleeland (personal communication, 5/11/2007).

Nursing as a profession is historically a low status profession with little power (Starr, 1982). Abbott (1988) while discussing the early history of nursing in Britain describes nursing as a subordinate profession at its origin. Starr discusses parallel development of nursing in the United States. According to both Starr and Abbott professionalization of nursing took place because it increased the prestige of physicians. Brannon (1995) argues that community of interests with management in the 1970s contributed to professional nurses and the ascendancy of registered nurses. According to

Brannon as nurses gained prestige through higher status work they became vulnerable to displacement by workers of lower status, which resulted in overwork. Professionalization has not come easily to the nurses and negotiation around their professional interests in turf wars with physicians should be undertaken with care and only when necessary by policy entrepreneurs.

Within the medical profession there is well documented high status and independence from outside influence. The core of this independence according to the parsonians (Parsons, 1978; Twaddle, 1979) who are important ideologically to the development of the culture of Medicine, call for the medical profession as a professional network to be listened to as an authority by actors who are not members of that network, but to be largely unregulated from outside of the network and regulated from within the network in as voluntary a way as possible. The development of such a professional network is illustrated in depth from origins in the Enlightenment by Starr's historical account (1982). In that account the medical profession is transformed from a low status, poorly organized, poorly defined, and often feuding network with low cohesion, and little control of resources into a high status, powerful, well organized network that was conservative and able to unify effectively to defend a favorable status quo in which it was not questioned much, certainly not effectively. That transformation was fueled by technological advances, many of which had more to do at first with better public health than medical science, and true faith in progress through science, which was eventually expressed in public investment in science. It should be emphasized that in its rhetoric ASCO does not tell oncologists how to practice medicine, a position that appears to have clear origins in professional autonomy and physicians' historical resistance to practice

guidelines. The ASCO website (2007) states that “Clinical practice guidelines serve as a guide for doctors and outline appropriate methods of treatment and care.” With both oncologists and oncology nurses it seems that the authors of the 2001 IOM report on cancer palliation did well not to overstate what was requested in Recommendation 6.

## **Conclusions**

With apologies to Charles M. Schultz (Wilcox, 2005), phenomenologically the problem with pain is that it hurts. By extension, the problem with nausea is that it makes us sick. The problem with dyspnea is that it takes our breath away. Cognitive difficulties, including delirium and dementia make us crazy. Depression can break our hearts and anxiety may terrify us. These symptoms identified by the authors of the 2001 IOM report on cancer palliation cause discomfort and even misery for millions of cancer patients and survivors in the United States. Most of those who are unfortunate enough to be diagnosed with cancer will suffer with one or more of these symptoms before they die of the disease, its complications or something else. The successes of the traditional US cancer program have lengthened survival times, but for the most part have not succeeded at curing many forms of cancer. Definitive cure usually remains elusive. As a result survivors live longer with the disease, but are not free of it. The prevalence of cancer and the burden of physical morbidity ironically have increased rather than decreased. The burden of psychological morbidity is increased as well, as cancer survivors live with the fear and the memory of cancer treatment and recurrence. Hospice arose as a place where mostly cancer patients could die in peace and dignity when medicine abandoned their hopes and needs in favor of simple survival time.

The irony of this situation is that the traditional US cancer program of prevention and cure was born of a concern to control the physical and psychological burden of cancer by preventing and reversing the disease. NCI is the oldest member institute of NIH, and has always been its largest member. President Nixon's initiative that began the War on Cancer used the rhetoric of manned space flight to the moon as a metaphor for a national commitment to a Herculean task, the success of which could not be arrived at cheaply. Huge expenditures were made to develop the science of curative oncology even before the mechanisms of carcinogenesis were understood, and at a time when oncologists were taken less seriously by other medical researchers because of the state of underdevelopment of the field. The driving force behind the US cancer program has been politics rather than an objective estimation of the effectiveness of curative and preventive cancer research in comparison with other forms of health care research. The reason is simply that cancer, despite our successes, is still in our estimation, one of the nastier ways to die. It is an important unintended consequence of the success of our war against cancer that we have increased rather than decreased the physical and psychological morbidity from cancer by extending survival times. Effective palliative and end-of-life care and symptom management are a logical, sensible, and necessary corrective to the added misery that accompanies our new abilities to extend life. The NCPB was absolutely correct in calling for the incorporation of palliative care and symptom management into the US cancer research program and other components of the health care system that deal with cancer. We need incorporation of palliative care and symptom management into health care practice as a component of oncology from the point of diagnosis until the point of death, and resolution for those left behind to grieve.

Although NCI has made organizational changes in the form of two dual networks, the most pertinent of which is the Palliative Care Working Group, the reader is reminded that the successes of the NCPB's recommendations from the 2001 IOM report on cancer palliation were on such a small scale that the composition of neither the overall NCI budget nor the combined budget for palliative care, symptom management or any of the other concerns raised by the NCPB were much impacted. The apparatus for a paradigm shift that would add a component of palliative care and symptom management to the overall US cancer research program was created but that apparatus was funded at such a low level that the NCI extramural budget was largely unaffected.

The data examined by this work were taken from a time of rapid growth in the NCI budget. At a time of greatly slowed growth one wonders, as Kathleen Foley asked (personal communication, 4/27/2007), how these initiatives will fare. The reasons for this state of affairs include a combination of an exaggerated historical commitment to prevention and cure at NCI, NCI's great prestige and power, and the lack of a readily apparent alternative locus within NIH for the breadth of palliative medicine and symptom management. The other reason things are as they are is that IOM reports do not have the stature of Federal policy but must stand on their own merits in a sea of epistemic communities vying for pride of place. In the absence of a sufficient power base the work of the Palliative Care Working Group and other committed individuals, however well placed, have not yet been able to transform palliative care research to the reality envisioned by the authors of 2001 IOM report on cancer palliation. Priorities in cancer research, and arguably other types of health care research, are set politically rather than

rationally. For this reason we cannot effectively confront the need to induce necessary health care innovations without a strategy for overcoming political inertia.

The 2001 IOM report on cancer palliation made a serious call to several sectors of the health care system to improve the ways that the fragmented medical system of the United States deals with the very real human need that millions of sufferers have for relief from the discomfort and misery of cancer symptoms. These recommendations include attempts to develop medical science and medical standards so that the talents of oncologists are brought to bare against this problem. Unfortunately, these recommendations did not affect the NCI cancer research portfolio much, although significant organizational changes were made. While practice guidelines now exist and voluntary associations of individuals in the form of dual networks committed to palliative care and symptom management have been created at NCI, the overall commitment to palliative care and symptom management has not been translated into a change in the entrenched culture of oncologists, despite the need. As of December 2005 and the replacement of the NCPB by an IOM forum, the 2001 IOM report on cancer palliation had been rendered largely ineffective by the failure of NCI to commit adequate funding to a program that looks promising on paper because of the human resources committed.

Unless NCI has dramatically increased funding to palliative care and symptom management research, and future research should check this, political pressure is needed to overcome political inertia in the form of the entrenched culture of NCI. That pressure should focus on adequately, therefore dramatically, increasing the funding levels of research conducted through the members of NCI's Palliative Care Working Group. History suggests three means of applying political pressure on NCI to meaningfully

increase the funding of palliative care and related funding concerns. The first route to political power is through the US Congress. After about ten years of calls for its creation in Congress NCI was created in 1937 (Rettig, 1977). This came about in the wake of advances in public health and infectious disease control, and the resulting belief among the public, which was incorrect, that if we can control infectious disease we must certainly be able to control cancer. Horror at the human cost of cancer was the other component of that political will. The second route to political power is through the Executive Branch. For example, in 1972 President Nixon led the reorganization of NCI, which greatly increased its activities and funding, again with strong public support. The third route to political power is the credibility of the deliberations of the IOM.

This third route should not be discounted because some IOM reports have been quite successful. Specifically, the 1997 report on death was quite successful at establishing an institutional locus at NINR, funding it, and garnering the support of the nursing profession. However, it seems a relatively simple matter to convince nurses of the need to provide comfort to the dying, and others facing physical and psychological morbidity. It is apparently a much tougher sell to incorporate palliative care and symptom management into medicine. The placement of palliative care and symptom management guidelines on the NCI website rather than the ASCO website indicates the central importance of NCI in the incorporation of these concerns into oncology. This will likely require public support from organized cancer survivors, their advocates, and concerned professionals, even if a fortuitous accident brings the election of a US president who is concerned with the issue.

Clearly a champion is needed. It is not clear when that champion will come. It is also not clear what combination of champions history will reveal in Congress, the Presidency, in NCI Director John Niederhuber who has presided over implementation of an ambitiously named plan to eliminate suffering and death from cancer published just after the close of the study period for this research in 2006, or in a future NCI Director. However, what is clear is that public support for cancer research has driven and shaped the US cancer program. The history of cancer research has been written in significant part by players such as Mary Lasker, a philanthropist who was effective at influencing the work of ACS and NCI (Rettig, 1977), ACS itself, and others. The NCPB owed its existence in large part to the efforts of cancer survivors, their advocates, and concerned health care providers. Grass roots efforts with varying degrees of success have supported or opposed, but certainly shaped control of HIV/AIDS, Medicare and Medicaid reform in the United States. Cancer survivors and their advocates and supporters must now apply political pressure and provide cover for elected officials and key players at NIH to not only mandate, but also fund palliative care and symptom management research at NCI. The following short list of recommendations outlines an agenda for grass roots and other actors to support the work of NCI's Palliative Care Working Group, the creation of which was the most solid accomplishment of the research and practice components of the 2001 IOM report on cancer palliation.

### **Recommendations**

1. ACS and other cancer survivor grass roots organizations and advocates should lobby for increased and dedicated funding of the NCI Palliative Care Working Group's initiatives through Congress, the President's National Cancer Advisory



Board, and within NIH and NCI. Further research should determine the maximum funding levels that the Working Group can use effectively.

2. ACS and other private research foundations and the cancer centers should seek out opportunities to collaborate with NCI Palliative Care Working Group members in projects that address palliative and end-of-life care and symptom management to the extent they are not already doing so. Future research should monitor these collaborations.

3. NCI should further institutionalize the Palliative Care Working Group, according to the recommendations of the Working Group's members. Cancer survivor grass roots organizations and advocates should lobby, where appropriate for these changes.

4. Further research should compare NCI's palliative care and symptom management research portfolio for years 2006 – 2008 with these findings.

5. Further research should address confusion or disagreement in the definitions of palliative care, end-of-life care, and supportive care.

These recommendations, if followed, could put teeth and muscle behind the efforts of those at NCI who work to complement the traditional US cancer program with a program of palliative care and symptom management research that should systematically bring relief to people who face symptomatic cancer. The cancer survivorship community is a natural power base to support the findings of the 2001 IOM report on cancer palliation. IOM reports can be effective when they call on a willing power base, as policy entrepreneurs must do. An epistemic community fails as a policy entrepreneur when it fails to convince a power base.

## **APPENDIX A. PROCEDURES FOR EXTRACTION AND ANALYSIS OF NCI BUDGET DATABASES**

Evaluation of Hypotheses 2 and 4 requires calculation of adoption curves of program dollars spent for the extramural program. Because Hypothesis 2 also has an intramural component adoption curves are calculated with individual projects as the unit of analysis for the combined extramural and intramural programs at NCI. Frequencies and relative frequencies are calculated by year using budget dollars and individual projects as units of measurement for each measure of compliance with Board recommendations discussed in Chapter 4. The following curves are calculated for each variable by year: 1) number of dollars spent in the extramural budget, 2) number of extramural dollars as a proportion of the total NCI extramural program, 3) combined number of extramural and intramural projects, and 4) combined number of extramural and intramural projects as a proportion of the total number of projects supported or carried out by NCI. In order to evaluate Hypothesis 4, Cancer Centers and Comprehensive Cancer Centers are identified from a list of P30 Cancer Center grant recipients published online by the Cancer Centers Branch (2006).

Two types of query were conducted on the three databases named in Chapter 4: the DEA, CRP, and ICRP databases. Global queries were conducted to establish the universe of NCI research projects. These queries seek to identify all projects on the databases of the types and time period covered by this research project. The projects identified in this way were compared with the NCI *Fact Books* (1998-2005) for validation. Fellowships were excluded because of poor coverage. Construction grants were also excluded. Data quality improves enough because of this further restriction to

justify it. The main work of evaluating Hypotheses 2 and 4 is done through directed queries, which seek to establish the number of projects and the amount spent on extramural projects by NCI and the amount of funding used by the Cancer Centers to implement the Board's recommendations in Foley and Gelband (2001). Because there is no intramural component to the Cancer Centers Program the curves to evaluate the growth of the number of projects are done only for Hypothesis 2, with DEA data.

The combined extramural and intramural program of the NCI is captured through global queries of the three databases. The extramural program and its budget are identified through global queries of the DEA database for fiscal years 1998-2005. Because of inflation a specialized price index is used (National Institutes of Health, Office of Portfolio Analysis and Strategic Initiatives, 2006). NCI *Fact Books* (1994-2005) provide denominators for the extramural budget data (1998-2005) and allow for assessment of overall growth of the NCI budget (1994-2005). However, beginning in 1998, the data used here do not include the pre-deliberative period (1994-1997).

Due to problems with missing data an attempt was made to reconcile the projects from the three databases with the NCI *Fact Books* (1998-2005). Some projects are not listed in the databases especially NCI contracts and fellowships. As a result, fellowships are excluded from the analysis, although contracts, which are extremely relevant to this research because they include cancer control, were not excluded. It was also observed that there are records in the DEA database that have blank funded amount fields.

### **Extraction of NCI Budget Database (1998-2005)**

Between 1994 and 2005 the total overall NCI budget increased steadily from \$2.1 billion to \$4.8 billion, in unadjusted dollars. However, an NIH Office of Portfolio

Analysis and Strategic Initiatives memo (2006) shows that the purchasing power of dollars spent to support research spent by NIH saw 44% inflation during the study period and therefore lost considerable purchasing power. When adjusted for inflation to 2001 dollars the NCI budget increased from \$2.6 billion to \$4.2 billion. In unadjusted dollars the NCI budget increased by 131% but when adjusted to 2001 dollars the increase was reduced to 61%. This reduction shows that simply controlling for inflation is not sufficient to avoid confounding real increases in the NCI budget between 1994 and 2005. The reader is reminded that theoretically S-curves are based on cumulative relative frequencies. Relative frequencies are used as the basis of measurement for Hypotheses 4 and 6.

### ***Assessing the NCI Budget***

Between 1994 and 2005 the NCI yearly *Fact Books* break down the yearly NCI budget. Taken as a whole, extramural grants increased from \$1.5 billion to \$2.6 billion in 2001 dollars, between 1994 and 2005. These figures exclude National Research Service Award fellowships. The extramural research program at NCI is rounded out by research contracts, cancer control and prevention. Research contracts are further broken down into Research and Development contracts and Small Business Innovation Research contracts. The research component as just described was roughly \$1.8 billion in 1994 and changed little in real dollars until 1997. It peaked in 2003 at almost \$3 billion, and declined slightly to just over \$2.9 billion in 2005. Cancer control and prevention is a special case and will be distributed into the extramural and intramural budgets shortly.

The intramural research component is much less transparent than the extramural research component. It is presented with program and management subcomponents. The

intramural management component is separate from extramural research management and support. Research management and support is treated in the NCI budget as separate from the extramural budget as well. To make the intramural and extramural budgets comparable the intramural management component is excluded from the intramural budget. The program component of the NCI intramural budget increased from \$315 million to \$510 million between 1994 and 2005 in 2001 adjusted dollars. The relative size of each component changed little between 1994 and 2005. The extramural component includes the lion's share of the program budget, between 83% and 86%. Excluded are management costs for both extramural and intramural program components, construction grants, and improvements to NCI facilities.

#### ***Extramural Budget Data (1998-2005)***

Budget data is taken from the DEA database described in Chapter 4. This database was queried by year to establish the universe of NCI extramural program spending. There were gaps in the data. In the first place, data are available beginning in 1998, which entirely excludes the pre-deliberative period. Also there were gaps in the data for the years covered, which are 1998-2005. There is missing data on the DEA database, which is evident where funding amounts are blank. There are also records that indicate a funding level of zero, which may indicate missing data. An attempt is made here to account for these gaps and to discuss their importance to the evaluation of Hypotheses 2 and 4.

Table 4 shows gaps in the coverage of the NCI extramural program budget compared with the NCI *Fact Books* (1998-2005) by activity code. Grants and cooperative agreements include Research Program Grants (P01), a variety of Research Project Grants

**Table 4. Gaps in DEA Database Coverage by Activity Code**

FY	Grants & Cooperative Agreements			Contracts			Fellowships		
	Gap	Error	Percent of Gap	Gap	Error	Percent of Gap	Gap	Error	Percent of Gap
1998	\$56,953	4%	34.8%	\$33,017	11%	20.2%	\$47,300	100%	28.9%
1999	\$70,153	4%	43.3%	\$51,492	16%	31.8%	\$50,805	89%	31.3%
2000	-\$9,487	-1%	-7.8%	\$98,244	27%	80.5%	\$50,459	90%	41.3%
2001	\$64,885	3%	23.0%	\$172,759	42%	61.2%	\$51,424	89%	18.2%
2002	\$75,017	3%	16.8%	\$311,268	72%	69.7%	\$58,595	92%	13.1%
2003	\$108,305	4%	20.9%	\$378,188	72%	73.0%	\$60,177	91%	11.6%
2004	\$102,879	4%	29.1%	\$230,335	45%	65.1%	\$59,901	90%	16.9%
2005	\$111,268	4%	17.5%	\$496,350	100%	78.1%	\$59,035	88%	9.3%

FY	Career Program			Centers			Combined		
	Gap	Error	Percent of Gap	Gap	Error	Percent of Gap	Gap	Error	Percent of Gap
1998	\$22,782	100%	13.9%	\$2,257	1%	1.4%	\$160,052	8%	99.1%
1999	\$502	2%	0.3%	-\$12,927	-7%	-8.0%	\$172,952	7%	98.7%
2000	\$435	1%	0.4%	-\$19,579	-9%	-16.0%	\$139,651	5%	98.4%
2001	\$2,795	5%	1.0%	-\$12,781	-5%	-4.5%	\$291,863	10%	98.9%
2002	\$2,760	5%	0.6%	-\$5,980	-2%	-1.3%	\$447,640	14%	98.9%
2003	\$2,415	3%	0.5%	-\$35,786	-9%	-6.9%	\$549,085	14%	99.0%
2004	\$1,895	3%	0.5%	-\$41,463	-10%	-11.7%	\$395,010	10%	100.0%
2005	\$1,858	2%	0.3%	-\$41,219	-9%	-6.5%	\$668,511	17%	98.8%

**Note. Gap amounts are expressed in Thousands of Unadjusted Dollars**

(R01, R03, R13, R15, R18, R21, R24, R25, R29, R33, R35, R37, R41, R42, R43, R44, R55, R56), Biomedical Research Support Grants (S06, S07, S10), Training Programs (T15, T32, TU2), and Cooperative Agreements (U01, U09, U10, U13, U19, U24, U43, U44, U56). Contracts include Research and Development and related contracts (N01, N02, N43, N44) and NIH Interagency Agreements (Y01), which include contracts listed in CRP and ICRP queries, to be described later, as cancer prevention and control contracts. Fellowships included pre-doctoral (F31), post-doctoral fellowships (F32) and

National Research Service Awards for senior fellows (F33) but not other types of fellowships. Career Program grants (K01, K04, K05, K07, K08, K11, K12, K14, K22, K23, K24, K25, K30) include a number of directed career development programs. Centers grants include basic support through the Cancer Centers Program (P30), SPORE grants (P20, P50), and Specialized Center grants (U54).

Negative values indicate that the total funding according to the *Fact Books* was less than the combined values of projects identified from the DEA database. The DEA queries exceeded the *Fact Book* for grants and cooperative agreements for fiscal year 2000 by approximately one percent, which may be due to rounding errors compounded by addition of the rounded data from the 2000 *Fact Book*. It is clear from the negative gaps in the Centers category that not all activity codes indicating a center were recorded as such in the *Fact Books*. This means that a reported award of a P30 grant from the DEA database is not a reliable indicator that an institution was a Cancer Center or a Comprehensive Cancer Center through the NCI Cancer Centers Program.

The principal data gaps may be summarized from Table 4. Between 2000 and 2005 missing Contracts accounted for most of the missing projects (roughly 61% - 81%). The DEA queries exclude all of the Fellowships and Career Program grants for 1998. Although coverage improves dramatically in subsequent years for the Career Program, with five percent of the data missing or less, the fellowships are missing for the most part (88% - 92%). Grant and cooperative agreement coverage is satisfactory. Missing data are three or four percent for all years but 2000.

Fellowships were excluded from the analysis because they are poorly represented. Taken together, fellowships account for just over one billion dollars of grants identified

by the three databases as relevant to palliative care and symptom management between 1998 and 2005. However, fellowships account for between \$47 million and \$60 million of missing extramural program budget per year and the vast majority were not found on the DEA database. We must conclude that with the data, it is not possible to know how NCI fellowships were impacted by the recommendations in Foley and Gelband (2001). The missing fellowship data was consistent at roughly 90% of all fellowships.

**Table 5. Ability of the Downloaded DEA Database to Account for NCI Cancer Research and Related Spending Excluding Fellowships and After Data Finding on NCI Contracts**

	<b>Extramural Program</b>	<b>DEA Database</b>	<b>Missing Data</b>	<b>Percent</b>
1998	\$1,893	\$1,831	\$61	3.2%
1999	\$2,185	\$2,109	\$75	3.5%
2000	\$2,507	\$2,438	\$69	2.7%
2001	\$2,839	\$2,611	\$228	8.0%
2002	\$3,159	\$2,785	\$375	11.9%
2003	\$3,509	\$3,058	\$451	12.9%
2004	\$3,620	\$3,354	\$266	7.4%
2005	\$3,681	\$3,483	\$197	5.4%

Note. Amounts are expressed in Millions of Unadjusted Dollars

The problem of missing contracts in the DEA database is not consistent with a range of 11% of contract dollars in 1998 and virtually 100% in 2005. An attempt to requery the DEA database specifically for missing contracts reduced the value of missing contracts somewhat. Table 5 shows the gaps in extramural budget data after excluding fellowships and adding missing contracts.

Coverage is improved substantially. Missing data account for between 3.2% and 12.9% per year rather than between 4.6% and 16.7% before the corrections. However there is still substantial temporal bias in the missing data with highest proportion of



missing data falling in 2002 and 2003. It is tempting to exclude the contracts as well, but this is not practical as it would eliminate cancer control contracts, which may be a rich source of quality of life research at NCI. This would be a matter of substantial importance if palliative care specific queries were only to be made using the DEA database.

However, there were a number of ICRP and CRP database queries that identified projects not found in the first global queries of the DEA database. The impact of missing DEA data on this study is assessed after the number of records either missing funding amount fields or missing entirely from the DEA data that are ultimately defined as meeting the search criteria.

One additional problem with the data is that receipt of a P30 grant is not a reliable indicator of participation in the Cancer Centers Program, which must be determined to evaluate Hypothesis 4. An online list (National Cancer Institute Cancer Centers Branch, 2006) was used to identify Cancer Centers and Comprehensive Cancer Centers instead.

#### ***Combined NCI Extramural and Intramural Program Database (2000-2005)***

The DEA database includes projects that are grants and contracts. The CRP and ICRP databases include grants, contracts, and intramural projects. Project type is most discernible on the CRP database, which provides records including three-character funding mechanism codes that identify the project type, and project identifiers, which have eight characters, including a two-character prefix that identifies the administering agency, followed by a six-digit identification number. In addition, the search engine allows users to specifically request, grants, contracts, or intramural projects. The DEA database records also include funding mechanism codes and administering agency codes,

but is not explicitly searchable by project type. The ICRP database records include project identifiers, but not funding mechanism codes, unless projects are queried individually. The ICRP database cannot be searched explicitly by project type. There is a reasonably straightforward way to distinguish among grants, contracts, and intramural projects. Intramural projects have a funding mechanism code of 'Z01.' Contract funding mechanism codes are the letter 'N' followed by two digits (N##). NCI grants usually, but not always, have administering organization identifiers 'CA.'

The extramural program as extracted from the DEA database includes 14,359 extramural projects and 40,420 project years between 2000 and 2005, once fellowships are excluded. This query identified 1,690 intramural projects and 5,057 project years between 2000 and 2005. The result is a known universe of 16,037 projects in 45,465 project years. In addition 305 grants and two contracts that are on the CRP and ICRP databases but not on the ICRP database were identified. The *Fact Books* (2000-2005) are not particularly helpful in corroborating the total number of funded projects because contracts, intramural research and cancer prevention and control are expressed as full time equivalents (FTEs), while only grants and fellowships are expressed as separate projects. It has been demonstrated that there are missing grants. There are twelve known instances of missing data. However, all of these are from the University of North Carolina at Chapel Hill, a Comprehensive Cancer Center.

The intramural program is identified primarily through global queries of NCI's CRP database for fiscal years 2000-2005. By checking the two digit prefix of the administering organization code it is possible to confirm that no intramural projects are found in the ICRP database that are missing in the CRP database, because all but two

projects (126) found in the ICRP but not in the CRP have administering organization codes of 'CA' and are grants. The other two projects are contracts (N01) for cancer control or prevention (CN) clinical trials. Queries done on the CRP and ICRP datasets do not identify projects that ended in 1998 or 1999 but many of the extramural projects identified through those queries were in effect in 1998 and 1999. However, the intramural projects identified cannot be traced prior to 2000. The quality of intramural project coverage cannot be determined because the *Fact Books* do not address the number of individual intramural projects at NCI.

*Queries.* The three budget search engines queried function either by searching for words or combinations of words in the project title and/or abstract, or by *a priori* assignments based on the Common Scientific Outline (CSO) or NCI Special Interest Category (SIC). Use of CSO or SIC designations is preferable to keywords because these represent deliberate and expert classifications. This presumably removes any element of randomness from the query hits. It also removes the element of faddishness that can accompany buzzwords. Designation as a palliative care project based on SIC may be considered more valid than designation as a palliative care project based on the wording of the title and abstract, because it represents a qualified decision to so classify. The presence of the term *palliative care*, or the other terms operationalized here, may be a buzzword for a different kind of project dressed up to look like a palliative care project because of a proposal writer's perception that those projects are more fundable than other projects. Conversely, if the opposite is true, the terms could be avoided. In any case the SIC and CSO codes are protection against randomness and the possibility that proposal-writing scientists do not wear their interests entirely on their sleeves.

The advanced search engines of the CRP and ICRP allow keyword searches that are pretty much self-explanatory. In these it is possible to search *all of these words*, which implies a Boolean AND between each of the search terms, *this exact phrase*, which implies that the phrase is treated like a word in its own right, as is done with quotation marks on other search engines, *any of these words*, which implies a Boolean OR between each of the search terms, and *none of these words*, which implies a Boolean NOT before each term and a Boolean AND linking each negative term. Keyword searches may target the title and abstract or the title only. In addition both search engines allow more than one of these type of keyword search, and searching within the Common Scientific Outline by type of research and special interest categories.

The three search engines used here make different use of the CSO and SIC. The DEA database does not make mention of the CSO and even though it uses SICs, these proved difficult to use in practice. Both the CRP and ICRP databases refer to and make use of the CSO in their advanced search pages. However, the CRP database also uses SICs. Of particular importance, the CRP database advanced search page has an SIC category for palliative care. Also worth noting when contemplating research with the cancer research databases is that while the CRP and ICRP databases will allow searches by multiple years, the DEA database will not.

***Selection Criteria for Budget Queries.*** These queries were written in the hope of maximizing legitimate hits. Because the CSO represents an authoritative classification better than a simple keyword search, queries that use the CSO are preferred to queries that do not. Agreement with CSO-based searches is also a criterion for inclusion. Where a CSO-based search is possible the results of that query and any other query that can be

added without creating a Krippendorf's alpha score less than 0.500. When two queries search by the CSO, the CRP query is preferred because the search engine is the only one that allows the user to restrict by the CSO special interest category *palliative care*. Many ICRP CSO queries were discarded because this user did not understand the behavior of quotation marks in the ICRP queries. As a result attempts to restrict to palliative care projects on the ICRP were largely ineffective. When no query for a given variable referenced the CSO an attempt was made to find consensus among the keyword searches. This was done by calculating Krippendorf's alpha scores for the three queries together. If the combined Krippendorf's alpha score was not less than 0.500 then the projects identified by each query were combined. There is one exception to this rule because the difference between the benchmark and Krippendorf's alpha score was very small (0.005). Otherwise an attempt was made to combine pairs of the queries and select the Highest of the Krippendorf's alpha scores for the highest of the three pair comparisons as long as that score was at least 0.500. This benchmark was selected because a Krippendorf's alpha score of 0.500 indicates that agreement is at least as likely to be based on real agreement as it is on random chance. When all query searches are unable to reference the CSO and no combination of two or more queries on that variable produced a Krippendorf's alpha score of 0.500 or more, that variable was discarded.

### **Budget Queries**

The first task in development of the queries is to assess research activity on palliative care and related issues, including end-of-life care, and supportive care. Because we are limited to keyword searches within titles and abstracts on the DEA database, separate queries were made for years 1998-2005 on the following expressions: palliative

OR palliation OR palliate, 'end of life' OR end-of-life, and 'supportive care.' The ICRP database was queried on research type 6.6 of the CSO Cancer Control, Survivorship and Outcomes Research - End-of-Life Care, with any of the words searched for 'palliative care' and 'supportive care' for years 2000-2005. The CRP database was queried on palliative care as a special interest category, and research type item 6.6 of the CSO Cancer Control, Survivorship and Outcomes Research - End-of-Life Care within the CSO and supportive care as an exact phrase for years 2000-2005. Because of the more extensive use of the CSO we might expect the CRP queries, taken as a whole, to be more accurate than the queries on the other two databases.

**Table 6. Palliative, End-of-Life, and Supportive Care Results**

	DEA	CRP	ICRP	Krippendorf's Alpha
<b>Palliative Care</b>	252	315	2,291	0.155
<b>End-Of Life Care</b>	70	35	38	0.720
<b>Supportive Care</b>	66	33	374	0.187

Table 6 shows that there was large variation in the number of hits for palliative care and supportive care but much better agreement for end-of-life care. The dramatic difference between the palliative care and supportive care queries between the DEA and the ICRP suggests that the ICRP any word search option ignored the quotation marks in the query, whereas the DEA search engine treated the expression in quotation marks as a single query. The high level of agreement on *end-of-life* projects makes sense because two of the search engines were able to search based on the CSO. When the CRP and ICRP databases are compared alone, Krippendorf's alpha increases from 0.720 to 0.959, presumably because of strong agreement within the CSO.

On this basis a new query was run using the CRP using the CSO special interest category *palliative care*. This query identified 315 projects, and has a Krippendorff's alpha score of 0.599 with the DEA query. Those 396 projects identified, either by the DEA query or the new CRP query, are treated here as the palliative care records in this study. Because of the very good reliability between the CSO defined *end-of-life care* queries within CRP and ICRP the 38 projects identified by either will be treated as *end-of-life care* projects. The ICRP keyword search "*supportive care*" is discarded because the search engine does not accept quotation marks. This leaves the DEA query and the CRP query, which have a Krippendorff's alpha score of 0.513. On this basis the 73 records identified by either the DEA database or the CRP database will be treated as supportive care records.

The next task is to assess symptom management by particular symptom and in general. For the DEA database there were general queries for symptom management as follows: '*symptom management*' OR '*symptom control*,' physical symptoms, '*physical symptoms*,' and psychological symptoms, '*psycho-social*' OR '*psycho social*.' Individual symptoms were queried as follows: pain as *pain*, dyspnea as *dyspnea*, nausea as *nausea* OR *vomiting* OR *emesis*, fatigue as *fatigue*, delirium as *delirium*, depression as *depression*, anxiety as *anxiety*, and dementia as *dementia*. With the ICRP database, it was possible to query by the exact phrases *symptom management* and *physical symptoms*, as well as *psycho-social* and *psycho social*. The last two searches together are equivalent to a single search joined by a Boolean operator OR. Specific symptoms were queried as follows: *pain*, *dyspnea*, *fatigue*, *delirium*, *depression*, *anxiety*, and *dementia* were queried as *all of these words* searches on the term, while nausea as queried as Any of the words,

*nausea, vomiting, or emesis*. The CRP database was queried identically to the ICRP database, except that *pain* was queried as a NCI designated Special Interest Category. The quality of the queries in light of the availability of CSO and special interest categories depends on the impact of the pain variable.

**Table 7. Symptom Control**

	DEA	CRP	ICRP	Krippendorf's Alpha
<b>Symptom Management</b>	71	21	7	0.302
<b>Physical Symptoms</b>	6	6	24	0.333
<b>Pain</b>	200	282	56	0.375
<b>Dyspnea</b>	4	-	3	0.429
<b>Nausea</b>	21	13	7	0.536
<b>Fatigue</b>	71	44	20	0.495
<b>Psycho-social</b>	7	-	4	0.364
<b>Depression</b>	102	75	33	0.579
<b>Anxiety</b>	72	48	27	0.000
<b>Dementia</b>	16	8	6	0.343

In general there was little agreement on the variables. *Nausea* and *depression* are acceptable. *Fatigue* is borderline. There was little opportunity to use predefined categories. Only the CRP database allowed a search on *pain* as a special interest category. The CRP database does not support CSO searches on other symptoms. For *pain* Krippendorf's alpha scores were calculated between the CRP and the DEA databases and the CRP and the ICRP databases. Krippendorf's alpha between the CRP and ICRP databases was negative, but between the CRP and DEA databases Krippendorf's alpha was an acceptable 0.513. Those 357 projects selected by the *pain* queries of either the DEA or CRP databases are considered to be relevant to pain. The DEA *dyspnea* query identified four records, three of which were the only records identified by the corresponding ICRP query. The three records on which the DEA and ICRP agree are



kept. This raises the Krippendorff's Alpha score to 0.500, because the CRP query did not identify any records. The *nausea* variable has an acceptable Krippendorff's alpha score, so all 23 records identified by any of the databases are kept. The *nausea* variable has a borderline acceptable Krippendorff's alpha score (0.495). All 76 records identified by any of the databases are kept because the loss of power to fill eliminate a 1 in 200 risk that selection was random seems disproportionate. The depression variable has an acceptable Krippendorff's alpha score, so all 107 records identified by any of the databases are kept. The Krippendorff's alpha shows that the *anxiety* variable is unreliable and that the three queries performed did not use the same criteria. However, when comparing all three possible combinations of the query results it becomes clear that the DEA and ICRP databases are in the most agreement with a Krippendorff's alpha score of .524, which is acceptable. Therefore the 73 records chosen either by the ICRP or the DEA queries are kept. Because the three *dementia* queries produced an unacceptably low Krippendorff's alpha score, scores were calculated on all three combinations of two. Of these only ICRP and CRP produced a high enough Krippendorff's alpha score (0.714) to warrant acceptance. As a result the nine projects identified by either query are considered *dementia* projects.

The general variables *symptom management*, *physical symptoms*, and *psycho-social* were disappointing. No combination of two queries on *symptom management* produced a Krippendorff's alpha score over 0.500. An attempt to remove the three out of seven *psycho-social* projects where the DEA and ICRP search engines gave different results lowers the Krippendorff's alpha score to zero because the CRP query database did

not return any records. Both of these variables are eliminated. The DEA and CRP were in complete agreement about six projects that are now classified as *physical symptoms*.

In addition to *symptom management*, *quality of life* and *cancer survivorship* were queried. In the DEA database the expression '*quality of life*' was searched as a keyword query (428 projects) and *cancer survivorship* was searched as a cancer activity query. *Cancer survivorship* was searched as a CSO special interest category in the ICRP and CRP databases.

**Table 8. Quality of Life and Survivorship**

	DEA	CRP	ICRP	Krippendorff's Alpha
<b>Quality of Life</b>	428	-	-	N/A
<b>Cancer Survivorship</b>	158	95	402	0.369

Table 8 shows a low level of reliability on the *cancer survivorship* variable. This is largely due to fact that the CRP database is the only one that allows restriction by the CSO special interest category *palliative care*. The CRP as it turns out is the only database that reliable restricts based on relevance to palliative care. So the 96 projects that were identified by the CRP database as relevant to *cancer survivorship* and *palliative care* are accepted as *survivorship* projects.

Keyword searches were made to identify projects relevant to oncologists, nurses and social workers and hospice, as follows. In the DEA database oncologists were searched using the term *oncology OR oncologist*; nurses were searched using *nursing OR nurse*; social workers were searched using '*social work*' *OR* '*social worker*;' and hospice was searched using the word *hospice*. In the ICRP database *oncology* and *oncologist* were searched with and without the phrase '*palliative care*' '*end-of-life care*' '*supportive*

*care.*' When taken together without the expression the result is equivalent to the Boolean expression *oncology OR oncologist*. When used with the expression the result is equivalent to the expression (*oncology OR oncologist*) AND ('*palliative care*' OR '*end-of-life care*' OR '*supportive care*'). Analogous pairings were made with *nurse* and *nursing*, and *social work* and *social worker*, with but not without the phrase that restricts to topic. *Hospice* was run with the restricting expression, as well. In the CRP queries were made as in the ICRP queries with the difference that the expression *palliative care* '*end-of-life care*' '*supportive care*' was substituted with *palliative care* as a CSO special interest category. One may reasonably expect the CRP queries to be more valid because they restrict to the field of palliative care using the CSO. Again, because the CRP database allows for reliable restriction within *palliative care* using the CSO, the CRP database is considered authoritative. The queries identified 28 *oncology* projects, 65 *nursing* projects, 3 *social work* projects, and 78 *hospice* projects within *palliative care*.

The methodology in Chapter 4 calls for assessment of projects that address *functional status* and *suicide/euthanasia*. The DEA was queried for *functionality OR 'functional status'* and *suicide OR euthanasia* as keyword searches. The result was disappointing as most of the hits were projects not related to functionality in patients or intentional ending of human life. The ICRP was queried for *functionality* and *suicide euthanasia* as *any of these words* searches, with predictably the same result. However, with the CRP database it was possible to search *functionality* and *suicide* and restrict them to *palliative care* attributed within the CSO. Regrettably *functionality* was not restricted in this way. These two variables were discarded.

*Training and clinical trial* projects were identified with the field of *palliative care*. In the DEA database after restricting for *training* and then *clinical trials* as cancer activities, keyword searches were done on the expression (*palliative OR palliate OR palliation OR 'symptom management'*) OR (*'end of life' OR end-of-life OR 'supportive care'*). In the ICRP database *clinical trial* and *training* were entered as exact phrases and *any of these words* searches was done on the expression *palliative care 'end of life' 'end-of-life' 'supportive care.'* In the CRP database it was possible to query palliative care training projects entirely with the CSO, where *palliative care* was a special interest and *training and clinical trial* was a project type. Again, the CRP search engine is considered authoritative. The CRP identified 34 training projects, excluding fellowships and no clinical trials when queried for *training and clinical trial* as project type and *palliative care* as CSO special interest category.

Until this point there has been an attempt to conduct analogous queries across all three databases. However because of the variation in the power of the three search engines, queries of issues regarding the quality and measurement of the quality of palliative care were done opportunistically. Queries of the ICRP database were restricted by any of the words *palliative care 'end of life' end-of-life 'supportive care'*. Individual queries were on the following terms using exact phrase searches: *quality, shared decision making and shared decision making, patient satisfaction, coordination of care, effectiveness research, accountability, and indicators*. Cost of health care delivery was searched with an *all of these words* search on *cost* with an *exact phrase* search of *health care delivery*. Because of the ineffectiveness of quotation marks at combining groups of words into unique expressions, these queries were discarded. The following areas within

the CSO were queried as well: types of research: *6.1 Cancer Control, Survivorship and Outcomes Research - Patient Care and Survivorship Issues, 6.4 Cancer Control, Survivorship and Outcomes Research - Cost Analyses and Health Care Delivery, and 6.5 Cancer Control, Survivorship and Outcomes Research - Education and Communication.* Despite the fact that these queries are within the CSO, they were not restricted by *palliative care* under the CSO classification. These queries were also discarded.

Queries of the CRP database were restricted by the CSO special interest category *palliative care*. An *all of these words* search was done on the word *quality*. Also *exact phrase* searches were conducted on the expressions *shared decision making, patient satisfaction, and coordination of care*. Because it was also possible to query within the CSO-designated special interest category, there was accurate assessment of the types of research: *6.1 Cancer Control, Survivorship and Outcomes Research - Patient Care and Survivorship Issues, 6.4 Cancer Control, Survivorship and Outcomes Research - Cost Analyses and Health Care Delivery, and 6.5 Cancer Control, Survivorship and Outcomes Research - Education and Communication* fully within the CSO. CSO special interest searches were also done for *health care delivery, and effectiveness research*. CRP queries, which were grounded in the CSO are considered authoritative.

Combined, the queries described above identified 4,548 projects. After removing the records that held only discarded variables, 1,113 records were left. This should not have been unexpected because of the relative difficulty creating expressions on the ICRP queries. Of these remaining projects 2% are intramural, a majority of 54% are conducted by participating institutions in the NCI Cancer Centers Program, and 44% are conducted by other institutions.

## **Significance Testing**

For Hypothesis 4 there is budget data, at least in theory, for all records because these projects are by definition, extramural. Much of this analysis addresses the portion of the extramural NCI research agenda, which accounts for 98% of projects identified by relevant queries. Cancer Center research overall accounts for a majority (54%) of research projects identified for this study. The significance of trends in the proportion of research activities carried out by the Cancer Centers is measured with a Mantel trend statistic where projects conducted by Cancer Centers are treated as cases and projects conducted either by NCI intramurally or by other institutions, are treated as controls, among projects meeting the search criteria. The exposure as in other Mantel trend statistic analysis here is time measured by fiscal year. Significance of growth of the proportion of the NCI extramural budget is measured, as in the discussion of Hypothesis 2 above based on  $t$  values resulting from univariate regression of budget share as the dependent variable and fiscal year as the independent variable.

## APPENDIX B. PROCEDURES FOR EXTRACTION AND ANALYSIS OF JOURNALS DATABASE (1994-2005)

Hypothesis 5 is evaluated through a dataset obtained through queries of the online PubMed database published by the National Library of Medicine and NIH (2006). Through PubMed, volumes published between 1994 and 2005, where possible, were searched for the following journals: The *Clinical Journal of Oncology* and the *Clinical Journal of Oncology Nursing*. The *Clinical Journal of Oncology Nursing* was first published in 1997 and is searched from that year until 2005. The *Journal of Psycho Social Oncology* was in publication throughout the time period of this study, but is not covered on PubMed before 2005. On closer review it became clear that of the ONS publications only the *Clinical Journal of Oncology* is a professional journal, while the *ONS News* and the *Oncology Nursing Forum* are more properly described as newsletters and are dropped from the analysis. The *Journal of Oncology Practice* is also a newsletter published online by ASCO. The quantitative portion of Hypothesis 5 is addressed through statistical analysis of the *Journal of Clinical Oncology* (1994-2005) and the *Clinical Journal of Oncology Nursing* (1997-2005), and a descriptive treatment of those two journals as well as the *Journal of Psycho Social Oncology* (1994-2005).

As with the NCI program, global queries were conducted to get a count of articles published in each journal. Directed queries were then conducted on the *Journal of Clinical Oncology* and the three ONS publications, to determine how many were relevant to the recommendations in Foley and Gelband (2001). The findings are reported briefly.

Table 9 shows that like NCI budget expenditures, the overall output of the *Journal of Clinical Oncology* increased steadily over the study period. Output increased

**Table 9. Total Articles, by Journal**

	<i>JCO</i>	<i>CJON</i>	<i>ONS News</i>	<i>ONF</i>
1994	419	--	14	133
1995	438	--	20	143
1996	448	--	19	110
1997	483	14	19	142
1998	581	29	49	140
1999	549	44	33	136
2000	602	68	27	105
2001	653	71	12	110
2002	744	92	28	100
2003	889	131	35	111
2004	827	91	64	107
2005	1,461	86	38	99
Total	8,094	626	358	1,436

Source: PubMed

from 419 in 1994 to 827 in 2004, an increase of 97%, and then spiked to 1,461 the next year. The *Clinical Journal of Oncology Nursing* began publication in 1997, conceivably in response to the Board's activities. The output of this journal is modest by any standard, but is dwarfed by comparison with the *Journal of Clinical Oncology*, where output increased steadily for the first four years of production, peaked in 2003 and changed little after that. *ONS News* output was small, and showed little discernible pattern in volume. The *Oncology Nursing Forum* produced the largest volume of articles of the ONS publications. However, its output declined somewhat over the study period by 26%.

### **Selection Criteria for Journal Queries**

These queries were written for use on a single search engine. The set of queries used for each topic are identical except for journal title and year of publication. Reliability is not an issue since the queries were conducted through a single search engine using standard language.



## Journal Queries

All Queries were done from PubMed in the Fall of 2006. Twenty queries were made of each journal as shown in Table 10. The first term *journal title* is the exact name of each journal searched in lower case, i.e. journal of clinical oncology, oncology nursing forum, ons news, and clinical journal of oncology nursing. The term *data-year* was each year between 1994 and 2005, except in the case of the *Clinical Journal of Oncology Nursing*, which began publication in 1997. The third element was the search term.

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**Table 10. Journal Queries**

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1	journal title[ta] AND date-year[dp] AND palliative care
2	journal title[ta] AND date-year[dp] AND end-of-life care
3	journal title[ta] AND date-year[dp] AND supportive care
4	journal title[ta] AND date-year[dp] AND (palliative care OR end-of-life care OR supportive care)
5	journal title[ta] AND date-year[dp] AND pain
6	journal title[ta] AND date-year[dp] AND dyspnea
7	journal title[ta] AND date-year[dp] AND (nausea OR emesis)
8	journal title[ta] AND date-year[dp] AND fatigue
9	journal title[ta] AND date-year[dp] AND delirium
10	journal title[ta] AND date-year[dp] AND (pain OR dyspnea OR nausea OR emesis OR fatigue OR delirium)
11	journal title[ta] AND date-year[dp] AND anxiety
12	journal title[ta] AND date-year[dp] AND depression
13	journal title[ta] AND date-year[dp] AND dementia
14	journal title[ta] AND date-year[dp] AND (anxiety OR depression OR dementia)
15	journal title[ta] AND date-year[dp] AND (pain OR dyspnea OR nausea OR emesis OR fatigue OR delirium OR anxiety OR depression OR dementia)
16	journal title[ta] AND date-year[dp] AND comprehensive care
17	journal title[ta] AND date-year[dp] AND (suicide OR euthanasia)
18	journal title[ta] AND date-year[dp] AND functionality
19	journal title[ta] AND date-year[dp] AND patient communication
20	journal title[ta] AND date-year[dp] AND patient AND decision making

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The first three queries develop the variables *palliative care*, *end-of-life care*, and *supportive care*. The fourth query develops a combined variable including hits of the three previous variables. The next four queries identify individual physical symptoms:

*pain, dyspnea, nausea, fatigue, and dementia*. The tenth variable combines those symptoms into an all *physical symptoms* variable. Variables eleven through thirteen identify psycho-social conditions *anxiety, depression* and *delirium*. Variable 14 combines these last three into a general *psycho-social conditions* variable. Variable 15 combines all physical and psycho-social conditions. The rest of the variables identify areas of concern not restricted to articles relevant to palliative care and summarize those. The last variable summarizes all articles of interest to this study.

### **Significance Testing**

Significance testing is done on the proportion of journal articles by journal title that meet test criteria. Testing on proportions avoids confounding with overall growth of journal output. The analysis of journal articles in Hypothesis 6 uses binomial polytomous data. In this case we are interested in the proportion of professional journal articles that meet *a priori* definitions of relevance to the Board's recommendations, at several one-year time intervals. The procedure for significance testing of binomial polytomous data calculates the Mantel trend statistic (1963), as described in Greenland (1998). This statistic measures a linear trend that may be positive or negative. The value squared has a one-tailed chi-squared distribution with one degree of freedom. The statistic uses a single degree of freedom because it estimates a regression coefficient (Mantel). Critical values of .05 are used. As discussed above, change points are determined by visual inspection of graphed data because this method is more conservative and specific than the statistical methods considered in Chapter 4 when applied to these data.

## APPENDIX C. QUANTITATIVE FINDINGS TABLES

**Table 11. Hypothesis 2 - NCI Extramural Spending by Selected Concepts in 2001  
\$1,000,000s**

	1998	1999	2000	2001	2002	2003	2004	2005	Total	sig.
Palliative Care	162	217	238	259	278	294	298	291	2,036	
End-of-Life Care	1	2	3	3	3	5	5	7	29	*
Supportive Care	14	21	22	28	30	18	17	18	167	
All Palliative Care	176	237	259	285	304	306	309	306	2,182	
Generic Physical Symptoms	0	0	0	1	1	1	1	0	4	
Pain	153	199	221	246	262	278	279	278	1,916	
Dyspnea	0	0	0	0	1	1	1	1	4	*
Nausea	3	3	3	3	1	2	2	2	20	*
Fatigue	2	4	5	6	6	8	9	12	54	*
All Physical Symptoms	157	203	226	252	267	283	283	284	1,956	
Depression	3	10	13	13	13	16	18	20	106	*
Anxiety	3	4	5	5	5	6	10	12	49	*
Dementia	0	0	0	0	1	1	1	0	3	*
All Psychological Symptoms	5	13	16	16	16	19	23	26	134	*
All Symptoms	161	214	240	265	279	298	302	303	2,061	
Quality of Life	77	113	127	145	161	201	202	193	1,219	*
Survivorship	3	11	15	16	17	21	21	22	126	*
Pal. Nursing Projects	11	15	15	16	18	19	20	18	132	
Pal. Oncology Projects	43	50	57	61	66	69	68	75	489	
Pal. Social Work Projects	1	1	1	1	1	1	1	1	6	*
Pal. Hospice Projects	57	70	74	81	83	101	105	108	678	*
All Professional Projects	82	100	110	119	125	143	146	153	977	*
Training Projects	0	1	1	2	3	4	5	5	21	*
Quality of Pal. Care	51	90	104	114	134	138	138	133	903	
Patient Participation In Decision making	0	0	0	0	0	0	0	0	0	
Pal. Patient Care	17	28	39	46	50	47	36	28	291	
Pal. Health Care Delivery	7	10	11	10	10	8	9	11	77	
Pal. Effectiveness Research	7	8	12	26	32	37	40	38	199	*
All Pal. Care Delivery Research	78	131	159	185	213	218	211	195	1,389	
Total of these Concepts	285	391	433	485	522	571	565	545	3,797	

\* p &lt; .05.

**Table 12. Hypothesis 2 - Percentage of NCI Extramural Spending by Selected Concepts**

	1998	1999	2000	2001	2002	2003	2004	2005	T	p	sig.
Palliative Care	7.56	9.03	8.95	8.94	8.91	8.77	8.92	8.88	1.382	0.216	
End-of-Life Care	0.06	0.08	0.10	0.11	0.10	0.14	0.15	0.21	5.642	0.001	*
Supportive Care	0.64	0.86	0.83	0.97	0.96	0.54	0.51	0.55	-1.355	0.224	
All Palliative Care	8.18	9.88	9.73	9.83	9.76	9.15	9.26	9.34	0.419	0.690	
Generic Physical Symptoms	0.01	0.00	0.00	0.02	0.03	0.02	0.02	0.01	1.111	0.309	
Pain	7.14	8.28	8.33	8.48	8.39	8.31	8.36	8.48	2.009	0.091	
Dyspnea	0.00	0.00	0.01	0.01	0.03	0.02	0.02	0.02	4.844	0.003	*
Nausea	0.14	0.12	0.12	0.11	0.05	0.06	0.06	0.07	-4.306	0.005	*
Fatigue	0.09	0.18	0.19	0.22	0.20	0.25	0.27	0.38	5.757	0.001	*
All Physical Symptoms	7.29	8.47	8.51	8.70	8.56	8.45	8.49	8.69	1.883	0.109	
Depression	0.12	0.42	0.50	0.46	0.41	0.48	0.54	0.62	3.241	0.018	*
Anxiety	0.14	0.17	0.18	0.16	0.15	0.17	0.30	0.36	2.904	0.027	*
Dementia	0.00	0.00	0.00	0.00	0.02	0.02	0.02	0.01	2.505	0.046	*
All Psychological Symptoms	0.25	0.54	0.62	0.55	0.51	0.57	0.68	0.79	3.241	0.018	*
All Symptoms	7.50	8.94	9.03	9.14	8.93	8.89	9.04	9.25	2.030	0.089	
Quality of Life	3.61	4.73	4.78	4.99	5.16	5.99	6.06	5.89	6.266	0.001	*
Survivorship	0.16	0.46	0.55	0.54	0.55	0.61	0.62	0.68	3.803	0.009	*
Pal. Nursing Projects	0.51	0.63	0.55	0.56	0.57	0.56	0.61	0.56	0.571	0.588	
Pal. Oncology Projects	2.00	2.10	2.14	2.10	2.11	2.06	2.04	2.28	1.416	0.206	
Pal. Social Work Projects.	0.04	0.03	0.04	0.03	0.02	0.03	0.02	0.02	-3.078	0.022	*
Pal. Hospice Projects	2.66	2.91	2.80	2.78	2.65	3.02	3.14	3.29	3.000	0.024	*
All Professional Projects	3.80	4.17	4.14	4.10	3.99	4.26	4.38	4.67	3.578	0.012	*
Training Projects	0.00	0.04	0.04	0.06	0.09	0.12	0.15	0.15	13.101	0.000	*
Quality of Pal. Care	2.39	3.75	3.93	3.95	4.29	4.10	4.14	4.07	2.441	0.050	
Patient Participation in Decision making	0.00	0.00	0.00	0.01	0.00	0.00	0.00	0.00	-0.018	0.986	
Pal. Patient Care	0.79	1.18	1.48	1.59	1.59	1.40	1.08	0.85	-0.065	0.950	
Pal. Health Care Delivery	0.34	0.42	0.42	0.35	0.32	0.24	0.28	0.34	-1.915	0.104	
Pal. Effectiveness Research	0.32	0.34	0.46	0.88	1.02	1.09	1.20	1.15	7.290	0.000	*
All Research in Pal. Care Delivery	3.65	5.44	5.97	6.38	6.83	6.51	6.31	5.96	2.169	0.073	
Total of these Concepts	13.3	16.3	16.3	16.7	16.7	17.0	16.9	16.7	2.325	0.059	

\* p &lt; .05.

**Table 13. Hypothesis 2 - NCI Projects by Selected Concepts**

	1998	1999	2000	2001	2002	2003	2004	2005	$\chi$	P	Sig.
Palliative Care	158	246	250	256	243	267	291	297	-0.885	0.376	
End-of-Life Care	5	5	11	14	16	16	18	22	2.733	0.006	*
Supportive Care	14	23	27	33	31	39	42	37	1.682	0.093	
All Palliative Care	170	267	275	283	269	293	318	325	-0.802	0.422	
Generic Physical Symptoms	1	1	1	4	5	3	1	1	-0.268	0.788	
Pain	155	239	239	230	221	248	276	289	-0.999	0.318	
Dyspnea	0	0	1	1	3	2	3	3	1.983	0.047	*
Nausea	5	6	8	8	8	8	11	11	0.595	0.552	
Fatigue	8	14	20	27	26	30	41	51	4.771	0.000	*
All Physical Symptoms	161	250	253	251	245	268	301	320	-0.158	0.874	
Depression	10	21	37	34	48	48	48	58	3.930	0.000	*
Anxiety	11	16	20	19	24	25	33	46	3.450	0.001	*
Dementia	0	0	4	4	6	6	6	4	1.841	0.066	
All Psychological Symptoms	19	33	55	48	64	64	67	83	3.865	0.000	*
All Symptoms	174	276	299	288	297	320	353	377	0.961	0.337	
Quality of Life	94	148	178	200	213	214	231	259	3.553	0.000	*
Survivorship	11	18	27	39	44	47	50	53	4.183	0.000	*
Pal. Nursing Projects	11	18	21	19	21	21	18	19	-0.847	0.397	
Pal. Oncology Projects	39	67	56	72	65	60	63	65	-1.785	0.074	
Pal. Social Work Projects	2	2	2	3	1	1	1	1	-1.626	0.104	
Pal. Hospice Projects	22	48	52	53	50	73	77	84	3.331	0.001	*
All Professional Projects	56	104	104	115	108	124	131	138	1.100	0.271	
Training Projects	0	7	8	11	16	20	24	23	4.527	0.000	*
Clinical Trials	0	0	0	0	0	0	0	0	-	-	-
Quality of Pal. Care	69	106	108	130	121	118	128	127	-0.749	0.454	
Patient Participation in Decision making	0	0	0	1	1	0	0	0	-0.223	0.824	
Pal. Patient Satisfaction	0	0	0	0	0	0	0	0	-	-	-
Pal. Coordination of Care	0	0	0	0	0	0	0	0	-	-	-
Pal. Patient Care	35	68	114	133	146	143	141	102	2.398	0.016	*
Pal. Health Care Delivery	4	10	10	6	8	7	6	18	0.610	0.542	
Pal. Effectiveness Research	6	11	15	29	43	46	70	76	8.946	0.000	*
All Research in Pal. Care Delivery	104	181	228	271	288	288	316	287	3.996	0.000	*
Total of these Concepts	303	490	562	566	607	634	694	704	3.064	0.002	*

\* p &lt; .05.

**Table 14. Hypothesis 2 - Percentage of NCI Projects by Selected Concepts**

	1998	1999	2000	2001	2002	2003	2004	2005	Sig.
Palliative Care	3.19	4.45	3.90	3.70	3.29	3.51	3.61	3.68	
End-of-Life Care	0.10	0.09	0.17	0.20	0.22	0.21	0.22	0.27	*
Supportive Care	0.28	0.42	0.42	0.48	0.42	0.51	0.52	0.46	
All Palliative Care	3.43	4.83	4.29	4.10	3.64	3.85	3.95	4.02	
Generic Physical Symptoms	0.02	0.02	0.02	0.06	0.07	0.04	0.01	0.01	
Pain	3.13	4.33	3.73	3.33	2.99	3.26	3.43	3.58	
Dyspnea	0.00	0.00	0.02	0.01	0.04	0.03	0.04	0.04	*
Nausea	0.10	0.11	0.12	0.12	0.11	0.11	0.14	0.14	
Fatigue	0.16	0.25	0.31	0.39	0.35	0.39	0.51	0.63	*
All Physical Symptoms	3.25	4.52	3.95	3.63	3.31	3.52	3.74	3.96	
Depression	0.20	0.38	0.58	0.49	0.65	0.63	0.60	0.72	*
Anxiety	0.22	0.29	0.31	0.27	0.32	0.33	0.41	0.57	*
Dementia	0.00	0.00	0.06	0.06	0.08	0.08	0.07	0.05	
All Psychological Symptoms	0.38	0.60	0.86	0.69	0.87	0.84	0.83	1.03	*
All Symptoms	3.51	4.99	4.67	4.17	4.02	4.21	4.39	4.67	
Quality of Life	1.90	2.68	2.78	2.89	2.88	2.81	2.87	3.21	*
Survivorship	0.22	0.33	0.42	0.56	0.59	0.62	0.62	0.66	*
Pal. Nursing Projects	0.22	0.33	0.33	0.27	0.28	0.28	0.22	0.24	
Pal. Oncology Projects	0.79	1.21	0.87	1.04	0.88	0.79	0.78	0.80	
Pal. Social Work Projects	0.04	0.04	0.03	0.04	0.01	0.01	0.01	0.01	
Pal. Hospice Projects	0.44	0.87	0.81	0.77	0.68	0.96	0.96	1.04	*
All Professional Projects	1.13	1.88	1.62	1.66	1.46	1.63	1.63	1.71	
Training Projects	0.00	0.13	0.12	0.16	0.22	0.26	0.30	0.28	*
Clinical Trials	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	-
Quality of Pal. Care	1.39	1.92	1.69	1.88	1.64	1.55	1.59	1.57	
Patient Participation in Decision making	0.00	0.00	0.00	0.01	0.01	0.00	0.00	0.00	
Pal. Patient Satisfaction	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	-
Pal. Coordination of Care	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	-
Pal. Patient Care	0.71	1.23	1.78	1.92	1.97	1.88	1.75	1.26	*
Pal. Health Care Delivery	0.08	0.18	0.16	0.09	0.11	0.09	0.07	0.22	
Pal. Effectiveness Research	0.12	0.20	0.23	0.42	0.58	0.61	0.87	0.94	*
All Research in Pal. Care Delivery	2.10	3.28	3.56	3.92	3.89	3.79	3.93	3.55	*
Total of these Concepts	6.12	8.87	8.77	8.19	8.21	8.34	8.62	8.72	*

\*p &lt; .05.

**Table 15. Hypothesis 4 - NCI Extramural Spending by Cancer Centers by Selected Concept in 2001 \$1,000,000s**

	1998	1999	2000	2001	2002	2003	2004	2005	Total	sig.
Palliative Care	130	154	163	179	187	207	208	204	1,430	
End-of-Life Care	1	1	2	3	3	4	4	6	23	*
Supportive Care	4	6	5	11	12	13	12	13	76	*
All Palliative Care	134	160	167	189	196	217	217	216	1,496	
Generic Physical Symptoms	0	0	0	0	1	1	1	0	2	
Nausea	112	131	138	162	168	188	187	190	1,276	*
Dyspnea	0	0	0	0	1	1	1	1	4	*
Pain	2	2	2	2	0	1	1	1	11	*
Fatigue	1	2	2	3	4	5	6	9	33	*
All Physical Symptoms	114	135	142	166	172	191	190	194	1,305	*
Depression	2	8	11	11	10	12	12	14	80	
Anxiety	1	1	3	2	2	3	4	5	22	*
Dementia	0	0	0	0	1	1	1	0	2	*
All Psychological Symptoms	3	9	13	12	11	14	14	17	94	
All Symptoms	117	143	153	176	179	201	200	205	1,373	*
Quality of Life	45	58	67	71	74	82	84	85	568	
Survivorship	1	3	4	6	8	11	10	11	54	*
Pal. Nursing Projects	8	11	10	11	13	12	13	11	88	
Pal. Oncology Projects	35	38	43	47	51	52	48	55	369	
Pal. Social Work Projects	0	0	0	0	0	0	0	0	0	
Pal. Hospice Projects	57	65	67	73	76	91	92	95	617	
All Professional Projects	73	82	88	97	102	116	115	122	796	
Training Projects	0	1	1	1	2	3	3	3	13	*
Quality of Pal. Care	32	40	42	48	59	69	74	70	433	*
Patient Participation in Decision making	0	0	0	0	0	0	0	0	0	
Pal. Patient Care	5	12	18	26	26	26	22	17	150	
Pal. Health Care Delivery	7	10	11	10	10	8	9	10	76	
Pal. Effectiveness Research	7	8	11	20	25	28	31	29	157	*
All Research in Pal. Care Delivery	47	65	75	94	109	121	124	113	746	*
Total of these Concepts	190	237	253	288	295	331	325	322	2,241	

\*p < .05.

**Table 16. Hypothesis 4 - Percentage of Cancer Center Spending by Selected Concepts**

	1998	1999	2000	2001	2002	2003	2004	2005	t	P	sig.
Palliative Care	6.06	6.41	6.12	6.18	5.98	6.17	6.23	6.23	0.130	0.901	
End-of-Life Care	0.05	0.04	0.07	0.09	0.08	0.12	0.11	0.18	5.354	0.002	*
Supportive Care	0.18	0.26	0.20	0.38	0.40	0.39	0.36	0.38	3.357	0.015	*
All Palliative Care	6.25	6.67	6.30	6.52	6.29	6.47	6.49	6.59	0.836	0.435	
Generic Physical Symptoms	0.00	0.00	0.00	0.01	0.02	0.02	0.02	0.01	2.432	0.051	
Pain	5.21	5.46	5.21	5.58	5.38	5.61	5.61	5.80	3.503	0.013	*
Dyspnea	0.00	0.00	0.01	0.01	0.03	0.02	0.02	0.02	4.844	0.003	*
Nausea	0.10	0.10	0.08	0.08	0.01	0.02	0.02	0.03	-4.741	0.003	*
Fatigue	0.03	0.09	0.09	0.12	0.14	0.15	0.18	0.27	7.262	0.000	*
All Physical Symptoms	5.32	5.61	5.34	5.74	5.51	5.71	5.68	5.94	3.020	0.023	*
Depression	0.07	0.34	0.41	0.39	0.32	0.36	0.34	0.42	1.776	0.126	
Anxiety	0.06	0.06	0.10	0.08	0.07	0.09	0.13	0.16	3.441	0.014	*
Dementia	0.00	0.00	0.00	0.00	0.02	0.02	0.02	0.01	2.648	0.038	*
All Psychological Symptoms	0.13	0.38	0.47	0.43	0.36	0.42	0.43	0.52	2.283	0.063	
All Symptoms	5.43	5.94	5.74	6.07	5.74	6.00	6.00	6.26	2.787	0.032	*
Quality of Life	2.11	2.44	2.53	2.44	2.39	2.46	2.52	2.59	2.409	0.053	
Survivorship	0.05	0.11	0.16	0.21	0.26	0.31	0.30	0.33	10.426	0.000	*
Pal. Nursing Projects	0.36	0.44	0.38	0.37	0.41	0.35	0.39	0.34	-1.075	0.324	
Pal. Oncology Projects	1.64	1.57	1.62	1.62	1.63	1.56	1.45	1.67	-0.646	0.542	
Pal. Social Work Projects	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	-	-	-
Pal. Hospice Projects	2.65	2.69	2.53	2.51	2.44	2.73	2.76	2.92	1.462	0.194	
All Professional Projects	3.42	3.41	3.32	3.34	3.27	3.45	3.46	3.73	1.729	0.134	
Training Projects	0.00	0.03	0.03	0.03	0.06	0.08	0.08	0.10	8.328	0.000	*
Quality of Pal. Care	1.49	1.65	1.58	1.66	1.89	2.05	2.22	2.14	7.408	0.000	*
Patient Participation in Decision making	0.00	0.00	0.00	0.01	0.00	0.00	0.00	0.00	-0.018	0.986	
Pal. Patient Care	0.21	0.51	0.66	0.89	0.83	0.76	0.64	0.51	1.073	0.324	
Pal. Health Care Delivery	0.34	0.42	0.42	0.35	0.32	0.24	0.28	0.32	-2.294	0.062	
Pal. Effectiveness Research	0.32	0.32	0.41	0.69	0.79	0.83	0.92	0.88	7.187	0.000	*
All Research in Pal. Care Delivery	2.19	2.70	2.81	3.25	3.49	3.60	3.71	3.44	5.174	0.002	*
Total of these Concepts	8.86	9.89	9.52	9.92	9.46	9.86	9.74	9.85	1.599	0.161	

\*p &lt; .05.



**Table 17. Hypothesis 4 – Percentage of Cancer Center Share by Selected Concepts**

	1998	1999	2000	2001	2002	2003	2004	2005	t	P	sig.
Palliative Care	80.2	70.9	68.4	69.1	67.1	70.3	69.9	70.1	-42.6	0.000	*
End-of-Life Care	81.5	48.0	69.4	86.7	86.9	84.2	72.0	84.0	17.7	0.000	*
Supportive Care	27.8	29.8	24.2	39.2	41.2	72.4	70.0	70.1	142.0	0.000	*
All Palliative Care	76.5	67.6	64.8	66.3	64.5	70.7	70.1	70.5	7.4	0.000	*
Generic Physical Symptoms	0.0	0.0	0.0	26.5	64.1	70.8	100	100	44.4	0.000	*
Pain	73.0	66.0	62.5	65.7	64.1	67.5	67.0	68.4	2.9	0.003	*
Dyspnea	-	-	100	100	100	100	100	100	-	-	-
Nausea	74.7	81.8	70.4	71.9	25.7	33.9	32.6	39.4	-52.5	0.000	*
Fatigue	39.0	48.5	47.1	52.7	68.2	59.7	66.2	70.9	41.9	0.000	*
All Physical Symptoms	72.9	66.2	62.8	66.0	64.3	67.6	67.0	68.4	1.5	0.122	
Depression	59.6	82.0	83.0	85.2	79.5	75.2	63.7	67.4	-43.1	0.000	*
Anxiety	42.9	35.7	55.1	47.2	47.4	50.7	42.5	45.8	1.3	0.198	
Dementia	-	-	-	-	87.4	87.5	79.1	100	1.5	0.129	
All Psychological Symptoms	52.4	70.1	76.9	77.7	71.0	72.8	63.9	66.6	-12.7	0.000	*
All Symptoms	72.4	66.5	63.6	66.4	64.2	67.5	66.4	67.7	-7.0	0.000	*
Quality of Life	58.4	51.5	52.9	48.9	46.3	41.0	41.6	44.0	-100.9	0.000	*
Survivorship	32.3	23.8	29.1	39.8	47.0	51.1	47.9	49.1	57.7	0.000	*
Pal. Nursing Projects	70.9	70.5	69.4	67.4	72.6	63.5	64.4	60.0	-25.5	0.000	*
Pal. Oncology Projects	82.2	75.1	75.3	77.2	77.2	75.7	71.1	73.2	-33.8	0.000	*
Pal. Social Work Projects	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	-	-	-
Pal. Hospice Projects	99.5	92.5	90.4	90.3	91.9	90.4	88.0	88.7	-67.2	0.000	*
All Professional Projects	89.8	81.8	80.2	81.5	82.1	81.1	79.0	79.9	-47.2	0.000	*
Training Projects	-	78.6	68.5	50.6	68.7	66.0	55.9	64.3	-6.2	0.000	*
Quality of Pal. Care	62.2	44.0	40.2	42.1	43.9	50.0	53.6	52.5	40.3	0.000	*
Patient Participation in Decision making	-	-	-	100	100	-	-	-	-	-	-
Pal. Patient Care	27.3	43.2	44.9	56.1	52.1	54.3	59.9	60.0	77.3	0.000	*
Pal. Health Care Delivery	100	100	100	100	100	100	100	93.6	-40.8	0.000	*
Pal. Effectiveness Research	100	93.9	88.5	78.3	77.6	75.9	76.8	76.0	-52.4	0.000	*
All Research in Pal. Care Delivery	60.1	49.7	47.0	50.9	51.0	55.3	58.8	57.7	57.8	0.000	*
Total of these Concepts	66.9	60.7	58.4	59.3	56.5	57.9	57.5	59.1	-60.7	0.000	*

\*p &lt; .05.

**Table 18. Hypothesis 4 - Projects of Selected Types Conducted by Cancer Centers**

	1998	1999	2000	2001	2002	2003	2004	2005	$\chi$	P	Sig.
Palliative Care	76	142	141	140	133	153	157	173	0.971	0.331	
End-of-Life Care	3	2	8	11	13	13	12	18	1.175	0.240	
Supportive Care	8	12	13	17	21	25	25	20	0.690	0.490	
All Palliative Care	84	154	154	155	150	169	172	188	0.857	0.392	
Generic Physical Symptoms	0	0	0	1	2	2	1	1	2.304	0.021	*
Pain	75	128	132	129	123	145	155	179	2.607	0.009	*
Dyspnea	0	0	1	1	3	2	3	3	-	-	
Nausea	1	3	2	2	2	3	5	3	0.315	0.753	
Fatigue	2	6	8	10	14	16	24	33	3.019	0.003	*
All Physical Symptoms	77	134	137	139	137	156	167	193	2.460	0.014	*
Depression	5	13	22	25	32	33	29	36	0.139	0.889	
Anxiety	4	6	10	10	11	12	16	23	0.775	0.438	
Dementia	0	0	0	0	1	1	1	1	1.201	0.230	
All Psychological Symptoms	9	17	28	30	35	38	38	49	1.093	0.275	
All Symptoms	84	147	159	160	161	182	193	221	2.117	0.034	*
Quality of Life	52	86	103	111	124	134	142	153	1.164	0.244	
Survivorship	5	8	13	18	25	25	24	27	0.486	0.627	
Pal. Nursing Projects	5	10	12	10	12	11	6	9	-0.849	0.396	
Pal. Oncology Projects	20	40	29	38	36	33	31	38	0.003	0.998	
Pal. Social Work Projects	0	0	0	0	0	0	0	0	-	-	
Pal. Hospice Projects	20	43	44	43	39	55	52	63	-3.245	0.001	*
All Professional Projects	34	71	67	71	66	77	75	90	-0.636	0.525	
Training Projects	0	5	5	6	11	14	14	14	-0.365	0.715	
Clinical Trials	0	0	0	0	0	0	0	0	-	-	
Quality of Pal. Care	20	38	43	55	54	52	61	63	3.269	0.001	*
Patient Participation in Decision making	0	0	0	1	1	0	0	0	-	-	
Pal. Patient Satisfaction	0	0	0	0	0	0	0	0	-	-	
Pal. Coordination of Care	0	0	0	0	0	0	0	0	-	-	
Pal. Patient Care	13	33	52	72	82	84	75	53	1.800	0.072	
Pal. Health Care Delivery	4	10	10	6	8	7	6	10	-3.736	0.000	*
Pal. Effectiveness Research	6	10	13	19	26	30	46	49	-2.047	0.041	*
All Research in Pal. Care Delivery	36	82	105	132	147	153	165	150	3.321	0.001	*
Total of these Concepts	160	278	306	308	332	367	383	403	1.096	0.273	

\*p < .05.

**Table 19. Hypothesis 4 - Percentage of Projects of Selected Types Conducted by Cancer Centers**

	1998	1999	2000	2001	2002	2003	2004	2005	Sig.
Palliative Care	48.1	57.7	56.4	54.7	54.7	57.3	54.0	58.2	
End-of-Life Care	60.0	40.0	72.7	78.6	81.3	81.3	66.7	81.8	
Supportive Care	57.1	52.2	48.1	51.5	67.7	64.1	59.5	54.1	
All Palliative Care	49.4	57.7	56.0	54.8	55.8	57.7	54.1	57.8	
Generic Physical Symptoms	0.0	0.0	0.0	25.0	40.0	66.7	100	100	*
Pain	48.4	53.6	55.2	56.1	55.7	58.5	56.2	61.9	*
Dyspnea	-	-	100	100	100	100	100	100	
Nausea	20.0	50.0	25.0	25.0	25.0	37.5	45.5	27.3	
Fatigue	25.0	42.9	40.0	37.0	53.8	53.3	58.5	64.7	*
All Physical Symptoms	47.8	53.6	54.2	55.4	55.9	58.2	55.5	60.3	*
Depression	50.0	61.9	59.5	73.5	66.7	68.8	60.4	62.1	
Anxiety	36.4	37.5	50.0	52.6	45.8	48.0	48.5	50.0	
Dementia	-	-	0.0	0.0	16.7	16.7	16.7	25.0	
All Psychological Symptoms	47.4	51.5	50.9	62.5	54.7	59.4	56.7	59.0	
All Symptoms	48.3	53.3	53.2	55.6	54.2	56.9	54.7	58.6	*
Quality of Life	55.3	58.1	57.9	55.5	58.2	62.6	61.5	59.1	
Survivorship	45.5	44.4	48.1	46.2	56.8	53.2	48.0	50.9	
Pal. Nursing Projects	45.5	55.6	57.1	52.6	57.1	52.4	33.3	47.4	
Pal. Oncology Projects	51.3	59.7	51.8	52.8	55.4	55.0	49.2	58.5	
Pal. Social Work Projects	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	-
Pal. Hospice Projects	90.9	89.6	84.6	81.1	78.0	75.3	67.5	75.0	*
All Professional Projects	60.7	68.3	64.4	61.7	61.1	62.1	57.3	65.2	
Training Projects	-	71.4	62.5	54.5	68.8	70.0	58.3	60.9	
Clinical Trials	-	-	-	-	-	-	-	-	-
Quality of Pal. Care	29.0	35.8	39.8	42.3	44.6	44.1	47.7	49.6	*
Patient Participation in Decision making	-	-	-	-	-	-	-	-	-
Pal. Patient Satisfaction	-	-	-	-	-	-	-	-	-
Pal. Coordination of Care	-	-	-	-	-	-	-	-	-
Pal. Patient Care	37.1	48.5	45.6	54.1	56.2	58.7	53.2	52.0	
Pal. Health Care Delivery	100	100	100	100	100	100	100	55.6	*
Pal. Effectiveness Research	100	90.9	86.7	65.5	60.5	65.2	65.7	64.5	*
All Research in Pal. Care Delivery	34.6	45.3	46.1	48.7	51.0	53.1	52.2	52.3	*
Total of these Concepts	52.8	56.7	54.4	54.4	54.7	57.9	55.2	57.2	

\*p < .05.

**Table 20. Hypothesis 6 - Clinical Journal of Oncology Nursing - Query Hits**

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	$\chi$	p	Sig.
Palliative Care	N/A	N/A	N/A	0	0	2	0	2	4	5	3	4	1.448	0.148	
End-Of-Life Care	N/A	N/A	N/A	0	0	0	0	0	0	2	0	1	1.303	0.193	
Symptom Management	N/A	N/A	N/A	0	3	4	2	2	4	9	5	4	-0.120	0.904	
Combined General	N/A	N/A	N/A	0	3	4	3	2	5	9	5	4	-0.293	0.770	
Pain	N/A	N/A	N/A	2	2	2	7	8	7	9	6	10	0.075	0.940	
Dyspnea	N/A	N/A	N/A	0	1	2	0	1	0	3	0	0	-1.524	0.128	
Nausea	N/A	N/A	N/A	0	2	2	1	0	4	2	5	4	0.699	0.485	
Fatigue	N/A	N/A	N/A	0	3	2	0	1	4	3	2	3	-0.487	0.626	
Delirium	N/A	N/A	N/A	0	0	0	0	0	0	0	0	1	1.379	0.168	
All Physical Symptoms	N/A	N/A	N/A	2	5	8	8	9	12	15	12	16	0.087	0.930	
Depression	N/A	N/A	N/A	0	0	1	0	0	0	3	1	1	0.881	0.378	
Anxiety	N/A	N/A	N/A	0	0	1	0	0	2	1	2	2	1.242	0.214	
Dementia	N/A	N/A	N/A	0	0	0	0	0	0	0	0	0	-	-	
All Psychological Symptoms	N/A	N/A	N/A	0	0	2	0	0	2	3	2	2	0.087	0.930	
All Symptoms	N/A	N/A	N/A	2	5	9	8	9	13	16	14	18	0.479	0.632	
Comprehensive Care	N/A	N/A	N/A	3	14	17	15	7	12	26	27	15	-2.008	0.045	*
Suicide/Euthanasia	N/A	N/A	N/A	0	0	0	0	1	0	1	0	0	0.000	0.961	
Functionality	N/A	N/A	N/A	0	0	0	0	0	0	0	0	0	-	-	
Patient Communication	N/A	N/A	N/A	0	3	2	1	1	3	3	5	4	0.244	0.808	
Patient AND Decision making	N/A	N/A	N/A	0	0	0	2	0	0	3	1	5	2.176	0.030	*
Total	N/A	N/A	N/A	14	29	44	68	71	92	131	91	86			

\*p &lt; .05.

**Table 21. Hypothesis 6 – Clinical Journal of Oncology Nursing – Query Hits Percentage**

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Sig.
Palliative Care	N/A	N/A	N/A	0.0	0.0	4.5	0.0	2.8	4.3	3.8	3.3	4.7	
End-Of-Life Care	N/A	N/A	N/A	0.0	0.0	0.0	0.0	0.0	0.0	1.5	0.0	1.2	
Symptom Management	N/A	N/A	N/A	0.0	10.3	9.1	2.9	2.8	4.3	6.9	5.5	4.7	
Combined General	N/A	N/A	N/A	0.0	10.3	9.1	4.4	2.8	5.4	6.9	5.5	4.7	
Pain	N/A	N/A	N/A	14.3	6.9	4.5	10.3	11.3	7.6	6.9	6.6	11.6	
Dyspnea	N/A	N/A	N/A	0.0	3.4	4.5	0.0	1.4	0.0	2.3	0.0	0.0	
Nausea	N/A	N/A	N/A	0.0	6.9	4.5	1.5	0.0	4.3	1.5	5.5	4.7	
Fatigue	N/A	N/A	N/A	0.0	10.3	4.5	0.0	1.4	4.3	2.3	2.2	3.5	
Delirium	N/A	N/A	N/A	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.2	
All Physical Symptoms	N/A	N/A	N/A	14.3	17.2	18.2	11.8	12.7	13.0	11.5	13.2	18.6	
Depression	N/A	N/A	N/A	0.0	0.0	2.3	0.0	0.0	0.0	2.3	1.1	1.2	
Anxiety	N/A	N/A	N/A	0.0	0.0	2.3	0.0	0.0	2.2	0.8	2.2	2.3	
Dementia	N/A	N/A	N/A	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	
All Psychological Symptoms	N/A	N/A	N/A	0.0	0.0	4.5	0.0	0.0	2.2	2.3	2.2	2.3	
All Symptoms	N/A	N/A	N/A	14.3	17.2	20.5	11.8	12.7	14.1	12.2	15.4	20.9	
Comprehensive Care	N/A	N/A	N/A	21.4	48.3	38.6	22.1	9.9	13.0	19.8	29.7	17.4	*
Suicide/Euthanasia	N/A	N/A	N/A	0.0	0.0	0.0	0.0	1.4	0.0	0.8	0.0	0.0	
Functionality	N/A	N/A	N/A	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	
Patient Communication	N/A	N/A	N/A	0.0	10.3	4.5	1.5	1.4	3.3	2.3	5.5	4.7	
Patient AND Decision making	N/A	N/A	N/A	0.0	0.0	0.0	2.9	0.0	0.0	2.3	1.1	5.8	*
Total	N/A	N/A	N/A	100	100	100	100	100	100	100	100	100	

\*p < .05.

**Table 22. Hypothesis 6 - Journal of Clinical Oncology - Query Hits**

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	$\chi$	p	Sig.
Palliative Care	3	6	8	3	3	6	11	15	27	13	18	23	2.418	0.016	*
End-Of-Life Care	0	1	0	0	1	1	0	3	5	5	3	7	2.741	0.006	*
Symptom Management	3	5	8	3	2	7	11	14	26	13	17	22	2.401	0.016	*
Combined General	5	14	10	8	10	11	18	19	34	22	28	33	1.683	0.092	
Pain	14	24	13	12	22	24	18	24	25	34	38	43	-0.417	0.677	
Dyspnea	2	1	3	0	2	3	3	7	4	5	4	9	1.073	0.283	
Nausea	31	35	30	41	33	49	46	36	38	37	30	40	-6.921	0.000	*
Fatigue	7	8	12	17	12	21	18	24	19	30	32	48	2.178	0.029	*
Delirium	0	0	0	0	0	0	0	0	2	0	0	2	1.605	0.108	
All Physical Symptoms	47	52	45	57	60	82	69	71	73	82	78	118	-3.410	0.001	*
Depression	3	3	1	3	6	3	8	2	9	12	13	20	2.791	0.005	*
Anxiety	2	0	3	2	4	4	6	6	7	13	13	15	3.024	0.002	*
Dementia	0	0	0	0	0	0	0	0	0	0	0	0	-	-	
Psychological Symptoms	3	3	3	3	7	6	10	8	12	18	18	26	3.502	0.000	*
All Symptoms	50	54	48	57	65	84	77	78	78	96	93	135	-2.321	0.020	*
Comprehensive Care	0	1	3	1	2	4	2	9	8	13	11	18	4.045	0.000	*
Suicide / Euthanasia	2	1	0	4	3	4	1	2	3	3	5	4	-0.244	0.807	
Functionality	0	0	0	0	0	0	0	1	2	1	1	0	1.086	0.277	
Patient Communication	2	4	4	0	9	6	12	11	10	12	10	20	1.847	0.065	
Patient AND Decision making	0	6	0	3	4	13	3	15	15	16	18	27	4.090	0.000	*
Total	419	438	448	483	581	549	602	653	744	889	827	1461			

\*p &gt; .05.

**Table 23. Hypothesis 6 - Journal of Clinical Oncology - Query Hits Percentage**

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Sig.
Palliative Care	0.7	1.4	1.8	0.6	0.5	1.1	1.8	2.3	3.6	1.5	2.2	1.6	*
End-Of-Life Care	0.0	0.2	0.0	0.0	0.2	0.2	0.0	0.5	0.7	0.6	0.4	0.5	*
Symptom Management	0.7	1.1	1.8	0.6	0.3	1.3	1.8	2.1	3.5	1.5	2.1	1.5	*
Combined General	1.2	3.2	2.2	1.7	1.7	2.0	3.0	2.9	4.6	2.5	3.4	2.3	
Pain	3.3	5.5	2.9	2.5	3.8	4.4	3.0	3.7	3.4	3.8	4.6	2.9	
Dyspnea	0.5	0.2	0.7	0.0	0.3	0.5	0.5	1.1	0.5	0.6	0.5	0.6	
Nausea	7.4	8.0	6.7	8.5	5.7	8.9	7.6	5.5	5.1	4.2	3.6	2.7	*
Fatigue	1.7	1.8	2.7	3.5	2.1	3.8	3.0	3.7	2.6	3.4	3.9	3.3	*
Delirium	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.0	0.0	0.1	
All Physical Symptoms	11.2	11.9	10.0	11.8	10.3	14.9	11.5	10.9	9.8	9.2	9.4	8.1	*
Depression	0.7	0.7	0.2	0.6	1.0	0.5	1.3	0.3	1.2	1.3	1.6	1.4	*
Anxiety	0.5	0.0	0.7	0.4	0.7	0.7	1.0	0.9	0.9	1.5	1.6	1.0	*
Dementia	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	
All Psychological Symptoms	0.7	0.7	0.7	0.6	1.2	1.1	1.7	1.2	1.6	2.0	2.2	1.8	*
All Symptoms	11.9	12.3	10.7	11.8	11.2	15.3	12.8	11.9	10.5	10.8	11.2	9.2	*
Comprehensive Care	0.0	0.2	0.7	0.2	0.3	0.7	0.3	1.4	1.1	1.5	1.3	1.2	*
Suicide/Euthanasia	0.5	0.2	0.0	0.8	0.5	0.7	0.2	0.3	0.4	0.3	0.6	0.3	
Functionality	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.2	0.3	0.1	0.1	0.0	
Patient Communication	0.5	0.9	0.9	0.0	1.5	1.1	2.0	1.7	1.3	1.3	1.2	1.4	
Patient AND Decision making	0.0	1.4	0.0	0.6	0.7	2.4	0.5	2.3	2.0	1.8	2.2	1.8	*
Total	100	100	100	100	100	100	100	100	100	100	100	100	

\*p &lt; .05.

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## CURRICULUM VITA

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### EDUCATION

**2002 – 2007** Edward J. Bloustein School of Planning and Public Policy  
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Ph.D.

*The Institute of Medicine (IOM) as an Agent of Innovations in  
Palliative Oncology*

**1998 – 2001** Hunter College, City University of New York (C.U.N.Y.), New  
York, NY  
M.A. (Geography)

*Geographic Variation in the Utilization Rate of Breast Conservation  
Therapy for Early Stage Breast Cancer in New York City and Long  
Island 1984-96*

**1979 – 1981** Graduate School of Planning, University of Puerto Rico, San Juan,  
PR (55 graduate credits completed)

**1975 – 1978** University of Delaware, Newark, DE  
B.A. (Sociology)

### EXPERIENCE

**2001**            **Research Scientist, New York State Cancer Registry, Albany, NY**

**1993 – 1997**   **Research Director/Senior Policy Analyst, Institute for Puerto Rican  
Policy, Inc., New York, NY**

**1991 – 1993**   **Redistricting Staff Associate, Institute for Puerto Rican Policy, Inc.,  
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**1990 – 1991**   **Manager, Neighborhood Energy Center, Friends Neighborhood  
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**1988 – 1990**   **Community Organizer, Friends Neighborhood Guild, Philadelphia,  
PA**

**1990 – 1991** Coordinator, Eastern North Philadelphia Initiative Coalition, Philadelphia. PA

**1987 – 1988** Field Organizer, United Electrical, Radio and Machine Workers of America (UE) Philadelphia. PA

**1983 – 1987** Various jobs that supported volunteer community and civil rights activism, chiefly through the National Congress for Puerto Rican Rights (NCPRR).

## **PUBLICATIONS AND MAJOR REPORTS**

1. **Report on the NJCCR Clinical Trial Survey for 2005.** New Jersey Commission on Cancer Research, Trenton, NJ (2007). Unpublished manuscript, 8 pp.
2. **Report on the NJCCR Post Doctoral Fellowship Program.** New Jersey Commission on Cancer Research, Trenton, NJ (2006). Unpublished manuscript, 4 pp.
3. **Report on the NJCCR Research Grants Program.** New Jersey Commission on Cancer Research, Trenton, NJ (2006). Unpublished manuscript, 12 pp.
4. With Angelo Falcón, *Latino Immigrants and Electoral Participation: Puerto Ricans, Dominicans, and South Americans in the New York City Political System*, Institute for Puerto Rican Policy, New York (1996), 23 pp.
5. With Angelo Falcón, *New York City Latino Voter Handbook*, Institute for Puerto Rican Policy, New York (1996), 132 pp.
6. *New York City Latino Neighborhoods Databook*, Institute for Puerto Rican Policy, New York (1996), 780 pp.
7. *Toward Fair Latino Representation in Bridgeport Municipal Government: Proposals for New Aldermanic Districts*, Institute for Puerto Rican Policy, New York (1993), 40 pp.
8. *Discriminatory Voter Purges of Latinos in Bridgeport*, Institute for Puerto Rican Policy, New York (1992), 22 pp.
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