

Gero-Oncology Nursing Research

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Purpose/Objectives: To analyze the development of gero-oncology research through a critical review of nursing and other relevant research as well as the present state of practice.

Data Sources: Journal articles, book chapters, and personal experience.

Data Synthesis: Cancer in older adults is viewed through two investigative perspectives. The assumptions, questions, theoretical frames, and research design that follow from these investigative perspectives do not adequately meet the need to examine the interplay of responses to aging, cancer, and nursing practice. The mismatch of need, knowledge, and resources marks older adults with cancer as a special population in need of far more sophisticated research. With the synthesis of a new perspective, gero-oncology nursing research becomes age focused, more precisely shaping theoretical, methodologic, and analytic approaches.

Conclusions: Uniform attachment of chronologic age or other simple age-related variables to investigations, which is the primary consideration of age-related research, is irrelevant for older adults who are diagnosed with, treated for, live with, survive, and die from cancer. Shaping the next phase of gero-oncology research with a focus on age precisely integrates theoretical, methodologic, and analytic approaches through language specific to older adults and cancer.

Implications for Nursing: Shifting perspectives in gero-oncology nursing research will better inform future practice.

The volume and sophistication of research in cancer and aging within nursing and across disciplines are incongruent with the demographics of aging and the epidemiology of cancer. Examination of the general perspectives through which this research is conducted illuminates that incongruence. Cancer in older adults commonly is viewed through two investigative perspectives. First and most often, cancer and old age are seen as distinct variables. Cancer and age are linked but are not integrated in theoretical frameworks or research design. Studies stemming from this perspective use an age-related variable. This most often is the simple measure of chronologic age in years. This variable influences study design, sample selection, and findings emphasizing the age analysis of dependent variables. Findings are age related and categorized by chronologic age.

Second, cancer and old age are recognized as inextricably linked and redundant. The relationship is represented in the oxymoron: "If almost everyone who has cancer is old, then we study old age when we study cancer." The assumptions, theoretical frames, questions, and research design that stem from this perspective nominally include age and make little of age-related differences. This stance fails to recognize the unique interplay of responses to aging and cancer and the care needs for the increasing number of older adults at risk for or living with cancer. Ultimately, the research emerging from each of these perspectives largely avoids the critical need for specialty

Key Points . . .

- ▶ Cancer disproportionately affects older adults.
- ▶ Cancer nursing research has inadequately addressed the needs of older adults.
- ▶ Shifting perspectives on research in aging and cancer are necessary to meet the needs of our aging society.

research and care in aging and cancer. Both prominent perspectives are unable to guide age-focused research in cancer that reflects the complexity and chronicity of aging and cancer in nursing. Age-focused research addresses the need for specialty knowledge and the crisis of care for older adults with cancer without trailing the recognized problem with investigations that are limited in scope and utility.

This article argues that nursing and interdisciplinary research in aging and cancer require a shift in perspectives to meet the demands of a rapidly aging society and the burgeoning epidemiology and age demographic of cancer. Current and emerging perspectives for investigation are analyzed by outlining two phases of development. The first phase defines the specialty area of cancer and aging research. The second phase moves beyond the definition and sketches an opportunity to build the language of gero-oncology as a fundamental tool for successful age-focused research. To conclude the article, the new language of gero-oncology is contrasted with standard language and concepts in cancer research to discuss new models for investigation.

Significance

Older adults incur more than 60% of cancers diagnosed and almost 70% of cancer deaths as well as an inestimable proportion of the actual cancer care delivered across the United States (Balducci, 2000b; Campisi, 2000; Yancik & Ries, 2000). Cancer and aging represent a complicated intersection of cancer biology, senescence, cancer treatment, and myriad responses at emotional, psychological, behavioral, and spiritual levels

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(Campisi; DePinho, 2000; Extermann & Aapro, 2000; Ferrell, 1999). Healthcare providers face the societal impact of cancer and aging as a specific threat to the utility of current knowledge as well as an opportunity to extend our grasp of pertinent issues from molecular and cellular levels to personal, familial, and societal levels. The knowledge of cancer becomes increasingly molecular and new therapies emerge from that knowledge, but our understanding of cancer treatment and living with cancer still focuses on the individual (Balducci, 2000b; Hodgson, 2002). However, we have yet to be able to integrate senescence and the aging self into that understanding of cancer. The gap between current knowledge and effective practice affords an opening for nursing to shift perspectives from a simple acknowledgment of age demographics to advance theory, design, and method that are specific to aging and cancer. Advancing the science, as it is framed for the future, can dramatically affect the development of nursing and interdisciplinary research with improved impact on health care.

The First Phase: Awareness of Cancer and Aging

In the late 1980s, the nursing literature began to recognize that cancer in older adults deserved special attention. Notable investigators including Ferrell (Ferrell, 1995, 1999; Ferrell & Borneman, 1999; Ferrell, Cohen, Rhiner, & Rozek, 1992; Ferrell & Ferrell, 1992; Ferrell, Ferrell, & Rivera, 1995; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Ferrell, Rhiner, Cohen, & Grant, 1992), Given (Given & Given, 1989; Given, Given, Azzouz, Kozachik, & Stommel, 2001; Given, Given, Azzouz, & Stommel, 2000; Given, Given, & Stommel, 1994; Given & Keilman, 1990), McCorkle (Hughes et al., 2002; Hughes, Hodgson, Muller, Robinson, & McCorkle, 2000; McCorkle et al., 1997; McCorkle, Hughes, Robinson, Levine, & Nuamah, 1998; Robinson, Nuamah, Cooley, & McCorkle, 1997), and Weinrich (Nivens, Herman, Weinrich, & Weinrich, 1999; Powe & Weinrich, 1999; Weinrich, Blesch, Dickson, Nussbaum, & Watson, 1989; Weinrich et al., 2000; Weinrich, Haddock, & Robinson, 1999; Weinrich & Nussbaum, 1984; Weinrich & Weinrich, 1986; Weinrich, Weinrich, Boyd, Atwood, & Cervenka, 1994; Weinrich, Weinrich, Boyd, Johnson, & Frank-Stromborg, 1992; Weinrich, Weinrich, Priest, Fodi, & Talley, 2001; Weinrich, Weinrich, Stromborg, Boyd, & Weiss, 1993) and clinical authors including Blesch (Blesch, 1988; Blesch & Prohaska, 1991; Boyle et al., 1992; O'Connor & Blesch, 1992; Weinrich et al., 1989), Boyle (Boyle, 1994; Boyle, Abernathy, Baker, & Wall, 1995; Boyle et al., 1992), Dellefield (1986, 1988), Frank-Stromborg (Frank-Stromborg, 1985, 1986, 1988; Weinrich et al., 1992, 1993), and Ludwick (Ludwick, 1988, 1992; Ludwick, Rushing, & Biordi, 1994) were prominent contributors to the literature on cancer and older adults. A mix of clinical and research papers continued to appear regularly in the most prominent oncology nursing journals. Then, similar work began to appear in gerontologic nursing journals (Burnett, 1997; Ferrell, 1999; Hodgson, 2002; McCaffery & Ferrell, 1991). Concomitant publication of work by nurse researchers was seen in medical geriatric and oncology specialty literature at about the same time (Ferrell & Borneman; Ferrell & Ferrell, 1990; Ferrell, Ferrell, et al., 1995; Given et al., 2000; Given, Given, Azzouz,

Kozachik, et al., 2001; Kurtz, Kurtz, Stommel, Given, & Given, 2000; McCorkle et al., 1997, 1998; Weinrich et al., 1993, 2000; Wyatt, Friedman, Given, Given, & Beckrow, 1999). Sporadic citations with narrow clinical foci on aging and cancer also may be found in other nursing specialty journals (Aubertin, 1997; Biley, Robbe, & Laugharne, 2001).

Use of positivist quantitative design and methods predominate, although the use of naturalistic qualitative methods with the nursing literature on cancer and aging is notable (Duggleby, 2000; Ferrell, Rhiner et al., 1992; Kagan, 1994). The most common disease models are for prostate cancer and breast cancer (Boyd, Weinrich, Weinrich, & Norton, 2001; Dickson, 1990; Gelfand, Parzuchowski, Cort, & Powell, 1991; Koren, 1991; Ludwick, 1988, 1992; Nivens et al., 1999; Weinrich et al., 2000). Research in lung cancer, lymphoma, and gynecologic malignancies also appears in the literature (Blesch & Prohaska, 1991; Boyle & Angert, 1998; Fitch, Gray, & Franssen, 2000; Kurtz et al., 2000). The treatment model of postsurgical care is increasingly visible in the literature, whereas the care of older adults receiving radiation therapy is curiously absent (McCorkle et al., 1997; Wyatt & Friedman, 1998). Coping, self-care, and family caregiving are prominent conceptual and contextual factors (Ferrell, Cohen, et al., 1992; Ferrell, Grant, et al., 1995; Ferrell, Rhiner, et al.; Taylor, Ferrell, Grant, & Cheyney, 1993). The symptoms of pain and fatigue are the primary focus of specific studies (Clotfelter, 1999; Duggleby; Ferrell, Ferrell, et al., 1995; Ferrell, Grant, et al.; Given, Given, Azzouz, Kozachik, et al., 2001; McDonald, 1999; McMillan, Tittle, Hagan, & Laughlin, 2000). However, the areas of success in replication of findings, codification of patterns, and clear delineation of effects by chronologic, biologic, or developmental age remain sparse.

In 1992, Boyle et al. wrote a position paper on cancer and aging for the Oncology Nursing Society (ONS), but it has not been revised in the intervening decade. This position statement was paralleled by the publication of an article by Boyle and Engelking (1993) and followed by Miller's (1999) article. Fortunately, by the 1990s, dissertations and original research publications outnumbered clinical opinion and review articles. However, despite well-cited position statements and nationally prominent programs of research, the body of highly visible work by nurses in aging and cancer currently remains small and is difficult to characterize easily. The need for research and available targeted funding is growing, yet the research lags paradoxically.

My informed review done in January 2003 of some 600 titles culled in a CINAHL® database search using the terms cancer, aged, and nursing for citations with title words that clearly reflect aging and cancer in nursing publications or those authored by nurses elsewhere resulted in a group of only about 50 citations dating from 1986. Most of these samples focused on older adults. Some of the 600 citations imply work in cancer and aging through a focus on recurrence, advanced disease, or end-of-life care (McMillan & Small, 2002; Meares, 1997; Zabalegui, 1999). Although much of this research is valuable, the larger supposition that these disease states are congruent with old age is limiting and inherently ageist in its neglect of chronicity and the prominence it implies for the study of cancer and aging.

The state of the literature is corroborated by the relative invisibility of aging and cancer in professional meetings that disseminate oncology and gerontology nursing research and

practice. Oncology nursing makes cancer and aging increasingly visible at national meetings; the Seventh National Cancer Nursing Research Conference represents a pinnacle in the number and quality of presentations. Conversely, gerontology nursing and interdisciplinary meetings continue to endure extremely poor representations of similar topics in their meetings. As a typical example, the Annual Scientific Meeting of the Gerontology Society of America, held in November 2002 in Boston, MA, included only two sessions out of hundreds dedicated to cancer in older adults. Medicine has attempted to codify cancer and aging as a specialty internationally through establishing a society with international outreach. In 2002, the Society of Geriatric Oncology held its seventh annual conference that included a single session on nursing and posited interdisciplinary collaboration to be between oncologists and geriatricians. The biomedical literature designed to call attention to cancer and aging is more visible and has increased in volume and quality recently. Balducci (Balducci, 2000a, 2000b, 2001; Balducci & Extermann, 2000a, 2000b; Balducci & Stanta, 2000; Balducci & Yates, 2000), Cohen, and Yancik (Yancik & Ries, 2000) are among the most prominent voices, contributing editorial comment, policy projections, and clinical review articles in geriatric oncology.

Within nursing, few investigators and fewer clinicians identify themselves as working in cancer and aging predominantly. This is in stark contrast to the age demographics of cancer in the United States. Further, the ONS Gerontology/Oncology Focus Group has yet to achieve special interest group status and a national role. The group's name reflects the confusion about what to label the field and the investigators and clinicians who work exclusively in cancer and aging. Gerontology/oncology is both awkward and divisive. Oncogerontology seems unfamiliar and contrived. Geriatric oncology may best represent the merging of two medical specialties. What fits nursing and interdisciplinary work best within the frame of what Paterson (2001) called shifting perspectives?

The Second Phase: Language of Gero-Oncology

Exploration of language in cancer and aging begins with a title or label. I would argue that gero-oncology fits nursing's metaparadigm and social contract within the frame of shifting perspectives but avoids being too cumbersome (American Nurses Association, 2003). The prefix "gero" connotes the focus on health and function that gerontology emphasizes as a cross-disciplinary term. Although medicine and basic science commonly have adopted geriatric or the prefix "geri," its reinforcement of a disease focus limits nursing and collaborative interdisciplinary work. Oncology, as the term describing the study of and care for people with cancer, has shown broad utility and cross-disciplinary value in psychosocial oncology and other specialty titles. Parallel to or perhaps preceding a working title or label is the evolution of language that frames the daily exchange within a specialty area. Scientific perspectives are created through language that imparts value, vision, and approach. Most simply, language gives us the structure of what follows in research.

For example, quality of life (QOL) is language that emerged from philosophical assumptions about the value of comfort, activity, will, and desire (Corner, 1999). QOL is a concept that frequently is employed in nursing and interdisciplinary work. From the conceptualization of QOL follows the scientific discourse that begets measurement in relation to a specific popu-

lation defined by a set of characteristics such as a specific cancer. As a concept, QOL has been so successful that we rarely stop to consider its larger relevance to individuals or populations. Specifically, the same QOL score on an instrument may have different meanings for individuals with similar diseases but different experiences (Corner). QOL fundamentally assumes a time frame for evaluation; instruments measuring QOL most commonly ask for reflection on a period of time in answering the items in the tool itself. Yet how relevant is this relatively longitudinal frame for older adults? My theoretical work strongly reflects that QOL is irrelevant for older adults with cancer and that the analogous term is quality of daily living (Kagan, 1994, 1997). Quality of daily living connotes the frame within which older adults—and often their families—evaluate the quality of their lives. The frame of the older adult's evaluation is the present, with a short time frame that may change daily or hourly. Time is tied to shifting interpretation when what is unacceptable yesterday is tolerable today (J. Foust, personal communication, January 28, 2003). Although the future for one older adult may be marked by a particular milestone to be achieved, it is not without a proximate end.

Older adults live in the context of recognizing a life mostly lived (Kagan, 1994, 1997). The concept shaped by "a life mostly lived" is qualitatively derived. Although "a life mostly lived" must be operationalized for use in quantitative studies, it can be used to gauge popular outcomes variables such as "quality-adjusted years of life" or other similar survival measures for their relative pertinence to cancer in older adults. The conceptualization of variables, such as QOL and survival, is paradoxical in relation to the proximate mortality implied by recurrent, uncontrolled, or terminal cancer or other advanced diseases. Measures of such variables fundamentally must assume that survival is the consequential concern. Clinically, nurses and physicians attuned to the needs of older patients often help them choose alternative evaluation of treatment outcomes in equilibrium with desires for daily living. Yet research persists in employing irrelevant models and measures. New models for investigation that include relevant concepts and congruent variables must emerge for more sophisticated research to proceed.

Models for Investigation

Models used to guide oncology research often are predicated on a specific cancer and may include a theoretical or conceptual model as an overarching frame. Although this approach can be successful, cancer care is focused largely on youthful success and triumph with metaphors such as winning the war, surviving the battle, and overcoming the threat that imply the rest of life has yet to be lived (Kagan, 1994, 1997). In clinical discourse, cancer is considered to be a matter of a person's success or failure, so deeply imbedded in our thoughts that we say a patient has "failed" a particular therapy. Shifting this perspective and attending to the second phase of developing gero-oncology language provoke a reassessment of models for investigation. Diseases previously neglected may offer new dimensions in modeling approaches to investigation. More radically, we can discard standard approaches, borrow from gerontology, and redefine outcomes sought.

The nominal models for cancer and aging are gendered such as prostate cancer and breast cancer models (Boyd et al., 2001; Dickson, 1990; Fehring, Miller, & Shaw, 1997; Gelfand et al., 1991; Given, Given, Azzouz, & Stommel, 2001; Given,

Given, Azzouz, Kozachik, et al., 2001; Hughes et al., 2000, 2002; Koren, 1991; Kurtz et al., 1999; Ludwick, 1988, 1992; Ludwick et al., 1994; Morrison, 1996; Nivens et al., 1999; Robinson et al., 1997; Wallace, 2001; Weinrich et al., 2000, 2001; Wood, Duffy, Morris, & Carnes, 2002; Wyatt et al., 1999; Wyatt & Friedman, 1998). Gendering models of cancer in later life require significant caution, given unequal life expectancy for men and women by gender and race and the differential influence of variables such as marital status on health and function across cultures (Balducci, 2000b; Balducci & Extermann, 2000b). Prostate cancer is a useful model because it maintains a generally linear relationship with advancing age but offers the quandary of poorly explicated racial and ethnic variation (National Cancer Institute, 2002b). Breast cancer, which has a weaker association between advancing chronological age and disease, may be ill suited as a disease-based model in later life with survivorship becoming increasingly likely for those diagnosed in later life (National Cancer Institute, 2002a). Consequently, breast cancer may offer far more opportunity in considering survivorship and comorbidity in late life.

Purely biomedical research in comorbidity should focus on disease mechanisms, treatment, and toxicity management to advance the science of treatment. Although these matters are of concern to older adults and their families, daily management of cancer and comorbid disease while maintaining function is generally more imperative. Nursing, with expertise in symptom management, is poised to extend research in cancer and comorbidity by developing models that can identify new dimensions in disease states (e.g., breast cancer) in which human response and function become prominent. Other novel models might make use of underexplored diseases such as recurrent non-melanoma skin cancer to expose intersections of tumor biology (e.g., the neurotrophism prominent in these cancers), health behavior, and aging in the environment; head and neck cancer to illustrate functional disability, aesthetics, social stigma, and identity in aging and cancer; and gynecologic cancers, especially cervical cancer, to reveal the intersections of infectious disease and cancer risk in an aging female population, cohort effects, and health behaviors over time.

The majority of nursing and interdisciplinary research in aging and cancer is completed at the individual level and may extend to family-related work. Shifting the perspective to achieve levels of research in the family and community is critical to addressing an aging society's needs in cancer care. Family-level research—not family-related research—must redefine the older family and incorporate gerontologic concepts such as informal social support systems. Community-level research can address the multifaceted issues in communities with a high risk and prevalence of cancer and break down myths and ageism in healthcare disparities. For example, exploring the layered ramifications of limited access to adequate skilled and custodial home care for poor elders and their families during cancer treatment may uncover unacknowledged human and financial costs. Moreover, cross-cultural and cross-national research must incorporate comparisons among countries facing similar concerns in disease, patterns of care, and care delivery systems, including acute, long-term, and palliative care. For example, Japan, Korea, Hong Kong, and China are highly distinct aging societies in Asia; Iceland is one of the oldest societies in the world and maintains exceptional demographic records; Sweden and other Scandinavian

countries are aging societies with well-established socialized healthcare systems; and African countries such as Nigeria, which faces acute need in development of long-term healthcare models, offer future global value in research (de Rijke et al., 2000; Kennedy, 2000; Miyaishi, Ando, Matsuzawa, Kanawa, & Isobe, 2000; Sharp et al., 2002; Tishelman, 1993; Yancik & Ries, 2000). This sort of work can address elements from genomic parallels to understanding responses by individuals, communities, and societies to evaluating models of care and translating them across settings, cultures, and countries.

Shifting Perspectives

Most health and social care for older adults who have cancer occurs outside formal systems of oncology care and, as such, limits access to both adequate cancer care and resources designed to meet the needs of older adults. The mismatch of needs, knowledge, and resources marks older adults with cancer as a special population in need of more sophisticated research. The perspective of gero-oncology provides a means to more effectively investigate burgeoning societal need, contribute to an interdisciplinary research agenda, delineate the unique contributions and outcomes of nursing to the care of older adults with cancer, and improve the care of these individuals and their families across healthcare settings.

Implications

The demography of the aging population and the baby boomer generation argues stridently for this more sophisticated investigation of cancer in older adults. Study of cancer in older adults (i.e., those generally older than 70 years of age (Balducci, 2000b) and the old-old (i.e., those 85 years and older) (Balducci & Extermann, 2000b; Balducci & Stanta, 2000; Ferrell, Ferrell, et al., 1995; Hodgson, 2002; Neumark, Stommel, Given, & Given, 2001) may better elucidate the intricate biology and human responses of aging and cancer, the interconnections between aging and cancer in phenomena such as multiple primary malignancies, and the influence of those interconnections at functional, behavioral, emotional, and spiritual realms for older adults and their families. Too often, the distinctions among cell and organ senescence, biologic age, chronological age, and developmental level for the precise effect or outcome under investigation are ignored in favor of the easy measurement of age in years and a flexible age cutoff (Neumark et al.). Shifting the perspective of inquiry to more meticulous qualification of age offers the opportunity to address looming concerns about disease management, research-based treatment decisions, and symptom management in frail individuals.

Advances in treatment, including new agents and multimodality therapies, demand investment from nursing to reshape outcomes design and measurement to effectively investigate comprehensive effects of cancer therapies for older adults. An example is found in conceptualizing the outcomes to be measured in evaluating the response of the old-old and those individuals with comorbid disease to treatments that may affect function but not survival (Balducci, 2000a; McGill & Paul, 1993; Muss, Cohen, & Lichtman, 2000). The language of QOL—as it now is conceptualized and measured—and increasingly popular outcome variables such as “quality-adjusted years of life” are irrelevant end points for many older adults. This language captures the priorities of a youth-oriented cultural

metaphor for cancer treatment without a perspective relevant to older adults who recognize the proximate mortality of late life and the impetus for a focus on living.

Our investment now, as a discipline and as profession experts who coordinate the collaboration of other disciplines, buys the knowledge necessary for building science and developing care. Hesitating puts our science and care, which historically lags because of latent interest in gero-oncology, at a disadvantage in relation to demographic trends, patient needs, and societal burden.

Areas for Emphasis

Knowledge imparted by genomics and other areas in molecular biology suggests that we must separate more delicately defined issues of aging and cancer. More sophisticated investigation will build understanding of the phenomena that make cancer in older adults unique, intriguing, and multifaceted. At the individual level, many questions about what differentiates the natural history of cancer in late life, including tumor behavior and response to treatment, still are unanswered. This gap becomes more concerned as we consider it in light of the need to make evidence-based treatment decisions with and for older adults with cancer. Treatment decisions for older adults often are complicated by comorbid conditions, symptom confusion, and performance and functional status. This composite “biologic age” then, in turn, influences treatment decisions and supportive care needs but lacks specific evidence to guide those decisions. Supportive care needs impart the added concerns of the quality and economics of delivering such care as symptom and side-effect management, palliative care and end-of-life decision making, and long-term institutional and home care. Investigation of the influence of psychosocial factors must be part of building research and policy in this area. Individual and family coping style, culture, and socioeconomic status likely influence screening behaviors, risk reduction, access to care, treatment, and goals of care.

At the societal level, we face compelling concerns about allocations of resources for care, treatment decisions, and the influence of perceptions about age, performance status, and symptom experience on outcomes of care for older adults at risk for or suffering from cancer. Among the most pressing

issues are the requisite translations of knowledge into realistic evidence-based care with delineated outcomes while overcoming ageism and planning for care delivery in an extremely fragmented and constrained healthcare environment. New models of care delivery are being tested in general and disease-specific older adult populations (Bixby, Konick-McMahon, & McKenna, 2000; Naylor, 2000; Naylor, Bowles, & Brooten, 2000; Rich, 1999; Temkin-Greener, Meiners, & Gruenberg, 2001). Nonetheless, we have yet to face the logistics and economics of delivery in frail older adults with cancer in a manner analogous to successful nationalized efforts to control other diseases (Khayat & Auclerc, 2000). Adaptation of templates from other illness groups may be helpful. However, development and testing of clinically and economically sound models to effectively screen, detect, and treat while balancing cure and palliation in the context of lives mostly lived lag behind molecular and cellular advances in cancer care. Links between aging and cancer from the cellular to social levels must match advances in treatment to create research and care that are relevant to older adults with cancer.

Uniform attachment of chronologic age to investigations, the perspective of age-related research that frames research through chronologic age alone, does not completely fulfill the challenge of investigating cancer in older adults. With the synthesis of a new perspective, gero-oncology, nursing research becomes age focused, more precisely shaping theoretical, methodologic, and analytic approaches. We then can move on to exceed that current challenge and shape a third phase of sophisticated research that anticipates future needs and revisions care.

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- American Association of Colleges of Nurses: Geriatric Nursing Education Project
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