CHAPTER 1

Overview of Nurse Navigation

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Introduction

> *A new nursing role is only developed when there is a real or perceived need by society, the nursing profession, or the larger healthcare system. (Patten & Goudreau, 2012, p. 194)*

The National Cancer Act signed by President Nixon in 1971 is considered the United States' "declaration of war on cancer." This legislation led to increased federal spending in all areas of cancer research. Over the following years, expanded knowledge increased the understanding of cancer and subsequently produced important advances in the detection, diagnosis, and treatment of cancer. Complexities of combined therapy including surgical, radiation, and medical oncology modalities have created the necessity for a comprehensive and multidisciplinary team approach to patient care. As such, a "frontline" movement emerged, transforming the care of patients with cancer.

In 1975, the Oncology Nursing Society was founded and began to define the cancer nursing specialty. Since then, specialized roles have developed to ensure that people affected by cancer will have guidance through all phases of the cancer care trajectory. Nurse navigation is a relatively new role contributing to an exciting and challenging frontier in cancer care. This chapter will review the influences on the evolution of navigation, the political and societal factors significant to the need for and development of patient navigation, and the importance of processes and role delineation of oncology nurse navigation. In addition, the overview will include comprehensive definitions of key terms within nurse navigation, and the specific nursing roles that influence and support this position, as well as the current state of the knowledge about nurse navigation programs within healthcare institutions.

Historical, Cultural, Socioeconomic, and Political Influences in Cancer Care

Cultural, socioeconomic, and legislative influences occurring during the late 1800s and throughout the 20th and 21st centuries have contributed to the introduction, evolution, and dissemination of patient navigation today. The context of the "sick poor" is hardly new but continues to underlie the concept of patient navigation. Nurse Lillian Wald, recognized as the "inventor" of public health nursing, proposed the public health nurse as "a new role for nurses who visited homes of the sick poor" (Buhler-Wilkerson, 1993, p. 1778). Wald's concept emerged from her notion that "all the responsibility of the sick poor has not been assured unless a share is taken in the problem of efficient treatment in their homes" (Wald, 1900, p. 39). She influenced the tradition of holistic nursing—care of the whole person. Wald proposed that the primary goal of public health nurses was to encourage client self-help by promoting the patient's ability to make sound health-related choices. Early public health nurses practiced autonomously to provide direct care as needed and to simultaneously organize and mobilize family and community resources (Buhler-Wilkerson, 1993).

The American Society for the Control of Cancer (ASCC), the forerunner of the American Cancer Society (ACS), was founded in 1913, advocating for patient services, research, care, and understanding of cancer among the general public and healthcare professionals. In response to public pressure and a concerted campaign by ASCC, Congress made the conquest of cancer a national goal in a unanimous vote to pass the National Cancer Act of 1937. This legislation established the National Cancer Institute and authorized annual funding for cancer research and provisions for review of all cancer research.

In 1962, President John F. Kennedy delivered a message to Congress, identifying consumers as the largest group in the U.S. economy. Consumers affect and are affected by every public and private economic decision. He outlined the following consumer rights (Kennedy, 1962).

1. The right to safety
2. The right to be informed
3. The right to choose
4. The right to be heard

The significance of this history is its application to the growing need for patients, as consumers, to realize these rights in an extremely complex and often fragmented healthcare delivery system. Healthcare systems must be able to provide these rights for patients and families.

As the consumer movement continued to grow, the concept of patient rights, with patients as consumers, was introduced. Annas and Healey (1974) defined four general patient rights applicable in a healthcare facility, which

were the rights to (a) receive the whole truth, (b) maintain privacy and personal dignity, (c) retain self-determination by participation in decision making regarding one's health care, and (d) have complete access to medical records both during and after the hospitalization. In this context today, patient navigators are often the voice for patients and families traversing the healthcare system and advocating for these rights.

In 1989, ACS held seven hearings across the nation to solicit testimonies from individuals to facilitate understanding of the challenges that poor people with cancer faced and to make recommendations for change. The published report of these hearings identified the following overall findings (ACS, 1989).

- Poor people face substantial barriers in obtaining cancer care and often do not seek care if they cannot pay for it.
- Poor people and their families often make extreme personal sacrifices to obtain and pay for care.
- Fatalism about cancer is prevalent among the poor and may prevent them from seeking care.
- Cancer education programs are often insensitive and irrelevant.
- Poor people endure greater pain and suffering than other Americans.

Harold P. Freeman, MD, widely acknowledged as the founder of patient navigation, used these findings as a catalyst for the first navigation program implemented in 1990 at Harlem Hospital Center in New York City. His goal was to improve outcomes in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic illnesses. The primary aim of the Harlem navigation program was to decrease the high mortality rate in a population of poverty-stricken African American women, half of whom had presented with stage III and IV breast cancer (Freeman, Muth, & Kerner, 1995). Figure 1-1 outlines the general principles of navigation as established by Freeman (2013).

In his report to the president as chair of the 2001 President's Cancer Panel, Freeman identified several prevalent inequalities in access to health care: lack of health insurance, affecting 44 million people who were unable to pay out-of-pocket costs of cancer care, particularly oral medication costs; public and private health plan restrictions; physical distance from sources of care; and lack of transportation (Freeman & Reuben, 2001). Few people with cancer received full, accurate, and understandable information about their disease, either from healthcare providers or from other sources, primarily because of insufficient provider communication or knowledge and language, literacy, and cultural barriers. Moreover, bias based on cultural and racial differences far too often contributed to some providers offering less than optimal care and caused some patients to avoid accessing care because of fear or mistrust (Freeman & Reuben, 2001).

In 2005, President George W. Bush signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act targeting poor and under-

Figure 1-1. Principles of Patient Navigation

- Patient navigation is a patient-centered healthcare service delivery model.
- The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum.
- Patient navigation may serve to virtually integrate a fragmented healthcare system for the individual patients.
- Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of other providers.
- Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the cancer care continuum.
- The determination of who should navigate should be determined by the level of skills required at a given phase of navigation.
- In a given system of care, there is a need to define the point at which navigation begins and the point at which it ends.
- Patient navigation can serve as a process that connects disconnected healthcare systems, such as primary and tertiary care.
- Patient navigation systems require coordination. In larger systems of patient care, this coordination is best carried out by assigning a navigation coordinator who is responsible for overseeing all phases of navigation with a given healthcare site or system.

Note. From "The History, Principles, and Future of Patient Navigation: Commentary," by H.P. Freeman, 2013, *Seminars in Oncology Nursing, 29,* p. 74. doi:10.1016/j.soncn.2013.02.002. Copyright 2013 by Elsevier. Adapted with permission.

served populations in need of timely access to care. This legislation authorized $25 million in grants to establish patient navigator programs in low-income and rural communities nationwide to help patients evaluate treatment options, enroll in clinical trials, obtain referrals, and apply for financial assistance.

In March 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA) mandating patient navigation processes and functions as a component of health care. A brief description of the goals of patient navigation in this act included (Central Area Health Education Center, n.d.)

- A focus on overcoming individual patient–level barriers to accessing care
- Aims to reducing delays in accessing care
- Provision of navigation to individuals for a defined episode of cancer-related care
- Targeting of a defined set of health services
- A defined endpoint when services are complete.

Some challenges of implementing the ACA are clear, while others are less clear and are likely to emerge over time. The ACA fails to define navigation, leaving definition, role delineation, competencies, and reimbursement questions unaddressed. For example, most nurse navigation services are not yet recognized as billable. Furthermore, the ACA has guidelines for *BRCA*

testing, yet no provision exists for financial support or reimbursement for genetic counseling. Navigators will no doubt have much to learn as the ACA continues to be implemented fully.

Interestingly, the political influences of nurse navigation can be traced back as far as 100 years ago. These notable actions and achievements have laid the foundation for the major emphasis and transformation of cancer care that has occurred over the past 20 years. Table 1-1 outlines significant milestones and initiatives that have influenced and brought navigation to its prominence in healthcare redesign.

Table 1-1. Milestones in the Emergence and Evolution of Patient Navigation

Year	Milestone
1971	President Richard Nixon signs National Cancer Act and declares "War on Cancer"
1983	The Health Care Financing Administration (HCFA, now the Centers for Medicare and Medicaid Services) implements Diagnosis Related Groups (DRGs) for the Inpatient Prospective Payment System (IPPS)
1986	Special Report on Cancer in the Economically Disadvantaged. American Cancer Society
1989	Cancer in the Poor: A Report to the Nation. American Cancer Society
1990	First navigation program launched at Harlem Hospital, New York City
1999	The Unequal Burden of Cancer. Institute of Medicine
2000	The National Cancer Program: Assessing the Past, Charting the Future (articulates the "discovery to delivery" disconnect). President's Cancer Panel Report of the Chairman, Harold P. Freeman
2001	Voices of a Broken System: Real People, Real Problems. President's Cancer Panel Report of the Chairman, Harold P. Freeman
2002	National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities implements pilot project to establish Patient Navigation Research Program
2003	Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. Institute of Medicine
2005	Patient Navigator Outreach and Chronic Disease Act of 2005 signed into law by President George W. Bush authorizes appropriations through FY2010 to establish a competitive grant program designed to help patients access healthcare services
	C-Change defines Patient Navigation Program

(Continued on next page)

Table 1-1. Milestones in the Emergence and Evolution of Patient Navigation *(Continued)*

Year	Milestone
2007	NCI Community Cancer Centers Program (NCCCP) established
2008	National Coalition of Oncology Nurse Navigators (NCONN) incorporated
	Harold P. Freeman Patient Navigation Institute launched; first Navigation Training Course
2009	Academy of Oncology Nurse Navigators (AONN) incorporated
	Association of Community Cancer Centers (ACCC) Cancer Program Guidelines, Chapter 4, Section 10, Guideline I: Patient Navigation Services
	Association of Community Cancer Centers Patient Navigation: A Call to Action
	NCONN issues Core Competencies of Oncology Nurse Navigators
2010	Oncology Nursing Society (ONS)/Association of Oncology Social Work/National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation
	ONS Role Delineation Study begins
	Affordable Care Act (ACA) includes Patient Navigation
2011	Future of Nursing: Leading Change, Advancing Health. Institute of Medicine
2012	American College of Surgeons Commission on Cancer issues Accreditation Standard 3.1, stipulating phase-in of patient navigation process by 2015
	ONS publishes: Oncology Nurse Navigator Role Delineation Study

Note. From "Patient Navigation in the Oncology Care Setting," by C. Cantril and P.J. Haylock, 2013, *Seminars in Oncology Nursing, 29,* p. 79. doi:10.1016/j.soncn.2013.02.003. Copyright 2013 by Elsevier. Reprinted with permission.

Nursing Roles Influencing Navigation

Nurse navigation, although a relatively new concept and nursing role, has deep roots in nursing history. In 1965, Peplau described the role of the clinical nurse specialist (CNS), which originated in the 1940s and was further developed by nurse educators in efforts to decrease the fragmentation of patient care apparent after World War II (Peplau, 2003). Little (1967) defined the role of a nurse specialist as one who assumes full responsibility for the quality of nursing care provided to a patient. The specialist prescribes, organizes, and guides others in the care of a particular type of patient. Fur-

thermore, the specialist adds unique competencies to others on the healthcare team.

Theresa Christy, a preeminent nursing leader and historian, acknowledged the importance of the advocacy component of nursing in the early 1970s (Christy, 1973). She proposed that nurses should be a voice for individuals and families traversing the complicated and confusing aspects of the American healthcare system.

Montemuro (1987) wrote that it was not until 1982 that consensus regarding the functions of the CNS role was reached. At that point, agreement existed within the nursing community whereby the CNS was viewed as an expert practitioner, educator, consultant, researcher, and change agent.

Similar to public health nursing, the case management nursing role has influenced nurse navigation. Kersbergen (1996) looked at the history of case managers coordinating care to control costs, noting that case management has been used to coordinate care for more than a century. Regardless of the setting or sophistication of the model, the overall goal of case management is to coordinate complex and fragmented care to meet the needs of the patient.

The *crafting* of nurse navigation may be seen as building upon the fundamental values, roles, and skills of nurses over the past century to address and meet the new challenges in cancer care nursing.

Nurses Supporting Patient-Centered Care

The concept of patient-centered care has been discussed in nursing since the beginning of the profession. Mitchell (2008) described the approach as characterized with meaningful interpersonal relationships between patients and providers. The patient is the center of care delivery and consequently is engaged in decision making and care planning.

In the late 1970s, a paradigm shift in health care emerged with the concept of patients as consumers and active participants in healthcare decisions. In 1978, the Planetree model of care was created and dedicated to restoring a holistic, patient-centered focus to healthcare delivery. The model includes personalized care for patients and supports individual patient autonomy by allowing full participation in illness management and treatment decisions. Planetree was the first healthcare model in the country to foster the support of full access to medical information, patient decision making, and a comprehensive healing and holistic care environment organized first and foremost around the needs of patients (Planetree, n.d.).

Traditional and contemporary nursing requires nurses to apply critical-thinking skills and appropriate assessment and interventions while responding to and advocating for patients in the dynamic healthcare environment.

Reverby (1993) observed, "Nurses, whether operating as lone public health professionals . . . or presenting position statements from large professional organizations, have offered this country vision after vision, demonstration after demonstration, of what decent, affordable, and appropriate health care could be" (p. 1663).

Definitions of Nurse Navigation

Definition of terms is essential to advancing the concept of nurse navigation. Yet, no universally accepted definition of navigator nor consensus on necessary preparation and competencies for fulfillment of the role exists. Based on the available literature, Cantril and Haylock (2013) described nurse navigation as "a function and process that shares characteristics with other clinical patient services and assistance including health education, case management, clinical nurse specialists, social workers, community health workers, patient advocates, and lay health advisors" (p. 78).

The Academy of Oncology Nurse and Patient Navigators, a nurse navigator specialty organization, defines a navigator as "a medical professional whose clinical expertise and training guides patients and their caregivers to make informed decisions, collaborating with a multidisciplinary team to allow for timely cancer screening, diagnosis, treatment, and increased supportive care across the cancer continuum" (Academy of Oncology Nurse and Patient Navigators, n.d., "Navigation" section, para. 2).

In 2010, the Oncology Nursing Society, the Association of Oncology Social Workers, and the National Association of Social Workers developed a joint position on navigation. The position adapted a definition of navigation from C-Change: "individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care . . . from prediagnosis through all phases of the cancer experience" (C-Change, n.d., "What Is Cancer Patient Navigation?" section, para. 1). The position does not differentiate nursing from social worker navigation roles but suggests that navigators' knowledge and skills extend beyond basic professional education and oncology experience to include community assessment and interventions that promote timely access to needed care and services. Navigators must possess skills to effectively collaborate with multiple providers and disciplines, excel at meeting and exceeding patient expectations, and have comprehensive knowledge of all cancer treatment modalities, side effects, and evidence-based interventions. The collaborative position stipulates that navigation processes should reflect strengths and desired outcomes related to the communities, systems, and facilities in which navigation programs reside. Figure 1-2 details the specific elements of the joint position statement.

Figure 1-2. Oncology Nursing Society, Association of Oncology Social Work, and National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation

It is the position of the Oncology Nursing Society, Association of Oncology Social Work, and National Association of Social Workers that

- Patient navigation processes, whether provided on-site or in coordination with local agencies or facilities, are essential components of cancer care services.
- Patient outcomes are optimal when a social worker, nurse, and lay navigator (defined as a trained nonprofessional or volunteer) function as a multidisciplinary team.
- Patient navigation programs in cancer care must address underserved populations in the community.
- Patient navigation programs must lay the groundwork for their sustainability.
- Nurses and social workers in oncology who function in patient navigator roles do so based on the scope of practice for each discipline. Educational preparation and professional certification play roles in regulating the practice of both disciplines. Nationally recognized standards of practice specific to the discipline and specialty also define safe and effective practice.
- Nurses and social workers in oncology who perform navigator services should have education and knowledge in community assessment, cancer program assessment, resolution of system barriers, the cancer continuum, cancer health disparities, cultural competence, and the individualized provision of assistance to patients with cancer, their families, caregivers, and survivors at risk.
- Additional research to explore, confirm, and advance patient navigation processes, roles, and identification of appropriate evidence-based outcomes measures must be supported.
- Ongoing collaboration to identify and/or derive metrics that can be used to clarify the role, function, and desired outcomes of navigators must be supported and promoted.
- Navigation services can be delegated to trained nonprofessionals and/or volunteers and should be supervised by nurses or social workers.

Note. From "Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation," by Oncology Nursing Society, Association of Oncology Social Work, and National Association of Social Workers, 2010, *Oncology Nursing Forum, 37,* pp. 251–252. Copyright 2010 by the Oncology Nursing Society. Reprinted with permission.

The common theme inherent to every description and definition of navigation is succinctly: advocating for and providing guidance and support for patients and families with cancer while they traverse the very complex cancer care environment.

State of the Knowledge Today

Despite the emerging literature regarding nurse navigation in oncology, no consensus exists concerning the scope of practice, qualifications, and competencies for navigators (McMullen, 2013). Although many training and

certificate of completion programs are available for navigation, wide variation exists in the entry-level educational preparation for these programs. Navigator education and preparation are further discussed in Chapter 2.

The National Coalition of Oncology Nurse Navigators in 2009 was the first organization to articulate core competencies for navigation, which are included in Chapter 2. In 2010, the Oncology Nursing Society initiated a role delineation study to identify and prioritize critical tasks, as well as essential competencies of oncology nurse navigators, with findings published in 2012 (Brown et al., 2012). Data analysis clearly defined tasks and skills specific to oncology nurse navigator roles (see Figure 1-3) but did not delineate the portion that are also basic oncology nursing tasks and skills or those that fall within advanced practice nursing competencies.

The Patient Navigation Research Program (PNRP) sponsored by the National Cancer Institute's Center to Reduce Cancer Health Disparities in 2005 was the first multicenter program to examine the role and benefits of patient navigation. The PNRP developed a definition of navigation and metrics by which to assess the process and outcomes of navigation. The working definition of patient navigation was support and guidance offered to vulnerable populations. Freund et al. (2008) reviewed the metrics, results, and outcomes of the project. The primary outcomes studied included time to diagnostic resolution, time to initiation of treatment, patient satisfaction with care, and cost-effectiveness for specific cancer types including breast, cervical, colorectal, and prostate cancers. Other navigation program outcome studies have been conducted with findings published in the literature. Further details on specific program metrics and outcomes are discussed in Chapter 9.

Importance of the Oncology Nurse Navigator

In 2011, the American College of Surgeons (ACoS) Commission on Cancer (CoC) revised its accreditation standards for cancer programs and facilities, adding a navigation process requirement to be phased in by 2015 to address healthcare disparities and access to care (ACoS CoC, 2012). Additionally, other associations and program accreditations have also designated patient navigation as a priority, such as the Association of Community Cancer Centers and the National Accreditation Program for Breast Centers.

With regard to the new CoC program standards, community cancer centers are required to assess health disparities, identify needs of patient populations, describe a patient navigation process to address those needs, and document outcomes. This standard has broad implications for cancer care in the United States, as approximately 70% of the 1.5 million newly diagnosed patients each year are treated at CoC-accredited facilities (ACoS CoC, 2012). This standard compels CoC-accredited institutions to articulate and

Figure 1-3. The Top Tasks, Knowledge Areas, and Skills as Rated by Respondents to the Oncology Nursing Society's Oncology Nurse Navigator Role Delineation Study

Tasks
- Provide emotional and educational support for patients.
- Practice according to professional and legal standards.
- Advocate on behalf of the patient.
- Demonstrate ethical principles in practice.
- Orient patients to the cancer care system.
- Receive and respond to new patient referrals.
- Pursue continuing education opportunities related to oncology and navigation.
- Collaborate with physicians and other healthcare providers.
- Empower patients to self-advocate.
- Assist patients to make informed decisions.
- Provide education or referrals for coping with the diagnosis.
- Identify patients with a new diagnosis of cancer.

Knowledge Areas
- Confidentiality and informed consent
- Advocacy
- Symptom management
- Ethical principles
- Quality of life
- Goal of treatment
- Therapeutic options
- Evidence-based practice guidelines
- Professional scope of practice
- Legal and professional guidelines

Skills
- Communication
- Problem solving
- Critical thinking
- Multitasking
- Collaboration
- Time management
- Advocacy

Note. From "Oncology Nurse Navigator Role Delineation Study: An Oncology Nursing Society Report," by C.G. Brown, C. Cantril, L. McMullen, D.L. Barkley, M. Dietz, C.M. Murphy, and L.J. Fabrey, 2012, *Clinical Journal of Oncology Nursing, 16,* p. 584. doi:10.1188/12.CJON.581-585. Copyright 2012 by the Oncology Nursing Society. Reprinted with permission.

substantiate navigation, thereby emphasizing patient navigation programs as a key component of patient-centered care.

The evolution and emergence of navigation processes and the nurse navigator role reflect departures from the status quo of the American healthcare system and traditional nursing role boundaries. The oncology nurse navigator is one of the few roles in nursing in which an individual professional nurse is ac-

countable for and invested in providing patient-centered care throughout an entire disease trajectory (McMullen, 2013). Patient navigation and nurse navigators are viewed by some as a "Band-Aid" for enormous failures in health systems, communications, and lapses in professional nursing leadership. Others envision navigation and navigators as potential solutions to the ever-expanding quagmire of disparate outcomes, fragmentation, and complexities associated with the delivery of cancer care in modern societies. It is apparent that navigation and navigators will be an ongoing presence in cancer care and even more broadly in the provision of care for people with other chronic conditions.

Conclusion

Throughout the United States and globally, nurse navigators facilitate care in all phases of the cancer prevention, detection, diagnosis, treatment, and transitional care continuum. Cancer care in the 21st century presents all professionals caring for patients with cancer and their families with new challenges and new rewards. Nurse navigators empower patients in decision making, advocate for and uphold the physical and psychosocial dimensions of care, and ensure that navigation services are accessible to all those affected by cancer.

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