



Disease Navigation: From Oncology to Chronic and Complex Illness

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“*Maybe we should navigate them*”, said Dr. Harold Freeman of Harlem, New York in 1990 after participating in the *Report to the Nation on Cancer in the Poor*, produced by the American Cancer Society.¹ This statement gave birth to oncology patient navigation programs. As an experienced oncologist, Dr. Freeman witnessed firsthand how our complex health care systems challenge patients and family members with numerous barriers to care, including healthcare disparities and socioeconomic challenges. Combined, barriers to care and difficulty navigating the healthcare system delay both diagnosis and treatments, negatively impacting the lives of patients with cancer and chronic disease.

Dr. Freeman set forth to improve early detection of cancer through access, while working to make healthcare easier to receive despite socioeconomic status. He started the first patient navigator program where community members were taught the gold standard of navigation: Decreasing time to diagnosis through the removal of barriers and providing support to patients across the complex healthcare continuum. Based on Dr. Freeman’s work, the Patient Navigation Act

was passed in 1995, bringing more attention to the importance of navigation as a lifesaving process. Later, the Harold P. Freeman Patient Navigation Institute opened, teaching best practices, standards, and the “Principles of Patient Navigation.”²

Navigation principles define patient navigation as a patient-centric healthcare service delivery model that personalizes and integrates a fragmented healthcare system. Navigation should facilitate timely care by removing barriers, clarifying scope and roles within the healthcare team, and ensuring cost-effectiveness as possible. Navigators should be trained to support their patients’ individualized needs and should utilize entry and exit criteria, becoming the “connection” for disconnected healthcare systems to ensure coordination of care.³

Early models of patient navigation utilized community health workers (CHW), non-licensed individuals trained on and supported by navigation concepts based on Freeman’s principles. To meet the needs of a complex healthcare environment, patient navigation has grown to include many disciplines from trained lay persons to nursing, social work,



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and other disciplines. Patient navigation has also expanded to include sub-categories like financial navigator, resource navigator, community navigator, and care navigator.

An example of navigation's professional journey is the evolution of the Academy of Oncology Nurse Navigators (AONN). Founded in 2008 by Lillie Shockney, AONN set nurse navigation as a nursing specialty supported by a national organization. AONN developed and disseminated best practices, increased networking, provided education, and developed navigation metrics to quantify outcomes for these specialty nurses. AONN has since been renamed as the Academy of Oncology Nurse Navigators & Patient Navigators (AONN+) to include membership of patient navigators. AONN+ has continued to grow and support all oncology navigators through certification, local and national networking, and best practices supported by quality metrics based on the Oncology Navigation Standards.⁴

Whether cancer diagnosis or treatment, lingering post-cancer treatment symptoms, or patients with other complex or chronic diseases, healthcare systems and care requirements frequently necessitate coordination of numerous services to ensure timely care. Patient navigation is not only the standard of care for oncology patients, but it has also quickly become recognized as essential for many different diagnoses, including stroke as presented in this issue of the *Stroke Clinician*. After demonstrating success in improving patient outcomes, navigation services have expanded to include chronic and complex care specialties such as heart failure, addiction medicine, pulmonary hypertension, primary care, trauma, emergency medicine, and of course stroke.

While chronic and complex care navigators have been able to glean methods from the standards, metrics, and best practices framed by Dr. Freeman and oncology navigators, sub-specialized care needs are likely to differ substantially based on disease-type and comorbidities making navigation roles look somewhat different by specialty. Additionally, work relationships may differ considerably, with navigators for chronic and complex illnesses working alongside a variety of different patient care teams instead of working within one specialty team such as oncology. Where oncology navigation has expanded to routinely include sub-navigation consisting of social workers, case managers, financial navigators, pharmacy advocates, and other nursing, medical and clinic staff, navigation for chronic and complex illnesses is slowly evolving to this degree of sophistication.

Today's stroke navigators are most commonly neurovascular educated and clinically trained professionals, often certified in the specialty. Optimally, stroke navigators should on-board patients while still in the hospital, working in concert with interprofessional specialty providers, and assessing for barriers including social determinants of health (SDOH) that may impact recovery and outcome. Stroke navigators provide personalized education and support, address specialty medication assistance needs, facilitate follow up appointments or testing, provide community resources, and become the key point of contact to advocate for the patient and family post-discharge. Classically, navigators maintain contact with patients through phone calls that occur at certain increments post-discharge. These calls assess how patients are



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managing post-hospitalization transitions, identify and remove barriers, and provide opportunities to support individualized needs. In some healthcare systems, stroke navigators also hold stroke survivor support groups and provide community outreach and education. Collectively, stroke navigator interventions have been associated with reductions in unplanned hospital readmissions and improved stroke survivor outcomes.⁶

Chronic and complex navigation continues to grow nationally in the USA. AONN+ founder Lillie Shockney has been consulted by numerous chronic and complex nurse navigator groups that aim to build and standardize their navigator roles to meet specialty patients' needs. Shockney's team conducted a national survey of navigator leaders, finding that chronic and complex nurse navigators needed an organization to bring them together to promote networking, identify and disseminate best practices, and to further growth of the navigator role. These findings fueled the launch of the Association of Chronic and Complex Care Nurse Navigators (ACCCNN) in 2021. ACCCNN's vision is, "*Innovate, elevate, and grow the role of the chronic and complex care nurse navigator*,"⁷ and the organization's mission is

to, "*Provide a platform that educates, supports, and empowers chronic and complex care nurse navigators to drive transformative patient-centered care.*"⁷

ACCCNN is a sister organization to AONN+ and was founded by Lillie Shockney, and co-founded/ co-led by Billie Lynn Allard and myself. ACCCNN's first National Summit was held in conjunction with AONN+ in 2023, where navigators and leaders presented on their programs, shared navigation stories, discussed opportunities for role improvement and growth, and celebrated winning role outcomes. Collectively, the Summit foretold a bright future for chronic and complex patient navigation. ACCCNN's second Summit will be held in November of 2024, and promises to continue building momentum within this growing specialty practice.

Navigation has made a major impact on healthcare, all stemming from Dr. Freeman's original comment, "*Maybe we should navigate them.*" Support for patient navigation has grown substantially since 1990, and 2024 marks the *Year of Navigation*, with the Centers for Medicare and Medicaid launch of coding and payment rules for principle illness navigation. The navigation journey is only just the beginning!

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