

# Pilots of Oncology Health Care: A Concept Analysis of the Patient Navigator Role

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**T**he term patient navigator (PN) has become a healthcare buzz word as organizations strive to reduce systematic burdens generated by program inefficiencies. Patient navigation programs have become a ubiquitous appendage to many oncology centers as administrators attempt to streamline and optimize patient care. The PN concept initially was used to describe a program aimed at reducing the healthcare disparities experienced by people in marginalized communities (Freeman, Muth, & Kerner, 1995). The domains of health care in which PNs are implemented are as diverse as the roles of the PN presented in the literature. Debates continue as to whether a PN should be a nurse (Fillion et al., 2006; Melinyshyn & Wintonic, 2006), a social worker (Darnell, 2007), a peer supporter (Giese-Davis et al., 2006), or a lay individual (Freeman, 2004; Steinberg et al., 2006). Some argue that patient navigation is an approach to mend gaps in the system and that “rather than creating a role that fixes holes in the system, we should be fixing the system” (BC Cancer Agency, 2005, p. 10). Prior to addressing systematic inefficiencies and determining whether a PN position is required within a specific context, one should take a step back and understand what the PN role entails. The purpose of this article is to explore the concept of a PN through Walker and Avant’s (2005) concept analysis model with the aim of providing greater conceptual clarity. Walker and Avant’s model is an eight-step approach: Select a concept; determine the purpose of the analysis; identify the uses of the concept; determine the defining attributes; identify the model case; identify any borderline, related, contrary, or invented cases; identify any antecedents and consequences, and define empirical referents. This article also includes the scope of the functions related to the PN role, arguments for the use of nurses as PNs, and potential enhancements to the role.

## Literature Search

The scientific literature was searched to generate a definition that expounds the concept of a PN. PubMed, CINAHL®, PsycINFO, Google Scholar™, and the Co-

**Purpose/Objectives:** To summarize the current scientific literature pertaining to the role of the patient navigator in oncology using the concept analysis framework developed by Walker and Avant.

**Data Sources:** Published research articles, clinical articles, and Internet sources on patient navigator roles and programs. Literature was obtained from CINAHL®, PubMed, PsycINFO, the Cochrane Library, and Google Scholar™, incorporating reports in English from 1990–2008.

**Data Synthesis:** Patient navigation has received a plethora of attention as healthcare programs strive to streamline care and address current gaps in service delivery. The literature revealed that the role of the patient navigator remains context-specific and has been filled by a variety of individuals, including nurses, social workers, peer supporters, and lay individuals.

**Conclusions:** The role of a patient navigator includes removing barriers to care, improving patient outcomes, and ameliorating the overall quality of healthcare delivery.

**Implications for Nursing:** By examining the role of the patient navigator depicted in the scientific literature, nurses can gain insight into not only the features of navigation but also the current systematic gaps that call for navigation services. This article examines the numerous functions of a patient navigator and exemplifies the significance of the role in various domains.

chrane Library were searched for the following terms: *cancer/oncology patient navigator, breast cancer patient navigator, case management, and patient navigation*. The search was limited to articles published in English from 1990 through November 2008. The articles included in the analysis described the role, including the perceived benefits or disadvantages. Articles were excluded when the term *navigator* referred to navigating through the body during surgical procedures, navigators as pilots, blood glucose system navigators, GPS navigators, or Netscape Navigator software.

## The Origin of the Concept

The concept of a PN was introduced in 1990 by Dr. Harold P. Freeman, a distinguished surgical oncologist

and former president of the American Cancer Society (ACS) (Freeman et al., 1995). Freeman and his colleagues implemented the first patient navigation program in Harlem Hospital in New York to serve marginalized communities. The intent of the program was to expedite diagnostic and treatment services while facilitating access to care for individuals with abnormal breast screening results. The program's success served as the impetus for further use and investigation into the development and understanding of the PN role (Ferrante, Chen, & Kim, 2007; Schwaderer & Itano, 2007; Wells et al., 2008).

In 2000, Long Island College Hospital (2002) established a breast health navigator program to serve individuals living in the Brooklyn, NY, area. Collaboration between the nurse navigator and various other disciplines has been pivotal to the program's success (Long Island College Hospital). In 2000, a navigation project was initiated in Halifax, Nova Scotia, Canada, to improve timeliness in diagnosing breast abnormalities (Psooy, Schreur, Borgaonkar, & Caines, 2004). Cancer Care Nova Scotia (2009) increased navigation services in 2001 by establishing a breast cancer navigation program with intentions of expanding the model in the future. The province has now established nurse navigators who manage five healthcare districts throughout Nova Scotia. Lay educators, who promote awareness and screening in rural areas, report to a patient navigation community liaison nurse, which is another branch of Nova Scotia's extensive navigation system (Cancer Care Nova Scotia). Navigation programs have been initiated in several cities and communities across Canada.

A survey conducted by the National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities in 2003 found that more than 200 programs in the United States incorporate some form of patient navigation. The center launched a pilot program in Oregon to evaluate the efficacy of PNs in assisting Native Americans through potential barriers to accessing oncology care (NCI, 2005). ACS (2006) also has endorsed the PN role, creating partnerships with numerous hospitals across the United States. Many PN programs in the United States focus on assisting individuals in overcoming barriers involving access to care, with emphasis placed on marginalized communities and financial burdens associated with cancer (Schwaderer & Itano, 2007; Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008). Alternatively, Canadian PN programs have placed emphasis on providing timely access to care (Melnyshyn & Wintonic, 2006; Psooy et al., 2004), empowering patients with information and education (Melnyshyn & Wintonic), coordinating care (Fillion et al., 2006), and/or providing links to community resources (Melnyshyn & Wintonic; BC Cancer Agency, 2005; Corporate Research Associates Inc., 2004). The distinction between the foci of care is perhaps a result of the philosophy and organizational

differences between the United States and Canada. The Canadian Partnership Against Cancer (2008) is working to enhance initiatives to promote the development of patient navigation programs on a national level.

## Characteristics and Domains of the Concept

What constitutes a PN? Is it an individual who may periodically assist with the coordination of care, or is it an individual who is educated to provide continuous support to patients along the entire illness trajectory? A review of the literature revealed that both definitions are being used to describe the PN role. Characteristics of the PN role that appeared frequently in the reviewed literature were: facilitating access to care (Freeman et al., 1995; NCI, 2005), providing information and education, and providing links to resources (Battaglia, Roloff, Posner, & Freund, 2007; BC Cancer Agency, 2005; Dohan & Schrag, 2005; Ferrante et al., 2007; Fowler, Steakley, Garcia, Kwok, & Bennett, 2006). The PN strives to reduce barriers that have been identified as financial issues, language differences, cultural factors, healthcare system complexities, transportation issues, and fear (Dohan & Schrag; Ferrante et al.; Fowler et al.; Freund et al., 2008; NCI, 2005).

The duties of a PN include a patient needs assessment, patient education, therapeutic support, and coordination of care along the illness trajectory (Fillion et al., 2006; Gentry & Sein, 2007; Melnyshyn & Wintonic, 2006). Fillion et al. further emphasized the requirement for a PN to assimilate a holistic approach and create a conduit between the patient and the cancer system. The reviewed literature illustrates that the roles and responsibilities of PNs essentially are determined by the facilities or domains in which they serve. Dohan and Schrag (2005) and Fowler et al. (2006) concluded that a PN should concentrate on reducing barriers as opposed to being service-focused to avoid fulfilling the roles of too many healthcare workers. Dohan and Schrag believed that the role should be reactive by "trouble-shooting a patient's problems as they arise" as opposed to being proactive (p. 851).

A caregiver for a patient with head and neck cancer stated, "A PN, to me, is someone who we could have called at anytime throughout my friend's illness that could have provided education to us or at least support. This would have changed our lives. There were so many questions about feeding tubes, speech difficulties, and bandages, not to mention chemotherapy and radiation. It would have been nice to have one point of contact to answer our questions" (anonymous personal communication, January 20, 2008). A director at a Canadian cancer agency described the PN role as follows: "A PN is essentially the eyes and ears of the healthcare system. These are the people who will direct patients to care and

provide tips along the way. Patients and families can contact the PN when they don't know who to call" (S. Bates, personal communication, December 7, 2007).

PNs also have been described as supportive guides who connect patients and families to resources, from the time of abnormal findings to the completion of treatment, facilitating continuity in the domain of cancer care (BC Cancer Agency, 2005; Fillion et al., 2006; Giese-Davis et al., 2006; Steinberg et al., 2006; U.S. Department of Health and Human Services, 2004). Steinberg et al. stated that a PN should develop relationships with the service providers while tracking interventions and outcomes. PN responsibilities also have included community outreach and education services (Schwaderer & Itano, 2007) as well as coordination of insurance (Fowler et al., 2006; Freund et al., 2008).

PNs have become a vital addition to the areas of prevention, screening (Battaglia et al., 2007; Ell, Vourlekis, Lee, & Xie, 2006; Fowler et al., 2006; Jandorf, Gutierrez, Lopez, Christie, & Itzkowitz, 2005), and genetic counseling (Rahm, Sukhanova, Ellis, & Mouchawar, 2007). PNs facilitate ease of access by reducing systemic barriers to screening and preventive care for patients and their families (Battaglia et al.; Fowler et al.; Jandorf et al.; Rahm et al.). Jandorf et al. implemented a PN in the colorectal screening domain to work one-on-one with patients to augment their education and facilitate guidance through the complex medical system. Psooy et al. (2004) reported on the implementation of a PN to enhance timely access to diagnosis and provide emotional support to patients following suspicious mammograms.

## Individuals in the Patient Navigator Role

Giese-Davis et al. (2006) referred to their peer counselors as navigators in their study. The navigators were individuals with a previous diagnosis of cancer. The PNs not only were trained to provide emotional support and links to resources but also were encouraged to share their stories of recovery. Battaglia et al. (2007) required PNs to have previous experience caring for a diverse population and knowledge of the local health system but did not indicate any specific training of an individual hired as a PN.

Social workers also have been used to fill the role of PN by assisting individuals in obtaining services and liaising with other professionals involved in a patient's care (BC Cancer Agency, 2005). Darnell (2007) argued that the functions of social workers are clearly echoed in some of the responsibilities of PNs. She emphasized that social workers assist individuals and communities in obtaining services and stated that "patient navigation borrows from and advances many of the core social work functions" (p. 82).

A vast amount of literature supports the profession of nursing to assume the role of PN (Doll et al., 2003; Fillion et al., 2006; Melinyshyn & Wintonic, 2006; Seek & Hogle, 2007). Seek and Hogle stated that because of the multifaceted responsibilities involved in patient navigation, a nurse practitioner or advanced practice nurse with an oncology background should assume the PN role. Centers that employ nurse PNs emphasize the importance of triaging physical and psychological care needs while lending an empathetic listening ear (Fillion et al.; Melinyshyn & Wintonic). Corporate Research Associates Inc. (2004) identified that some individuals believe that a nursing background is vital to the PN role: "I feel a nursing background is essential because you have had patients that have had cancer . . . (and that experience) provides a deeper insight into the (patient's) experience and the potential problems that may arise." Fillion et al. implemented a program where nurses specializing in oncology enact the role of the PN; qualities such as leadership, comprehensive assessments, and health promotion are vital aspects of the role. The PN follows individuals from diagnosis through the end of the care trajectory, including "recovery, reintegration into environments, (or) palliative care" (Fillion et al., p. 12).

## Critical Attributes and Case Utilization

Critical attributes of a concept are characteristics that are predominant in the literature, serving to further define and enhance the meaning of the concept. Five critical attributes of a PN are present in the literature: an individual who (1) facilitates access to care, (2) is a skilled communicator and listener, (3) is knowledgeable of the cancer system and resources in which they work, (4) acts as an empathic patient advocate, and (5) provides information and education. Walker and Avant (2005) recommended the use of cases to further exemplify the concepts. They suggested identifying model, borderline, and contrary cases.

### Model Case

Walker and Avant (2005) classified a model case as one that demonstrates all of the defining attributes. A fictitious model case is that of Sara, a 32-year-old woman who has been diagnosed with breast cancer. She speaks English and Cree; her husband only speaks and understands Cree. Sara considers delaying her treatment until they can find a place to reside while they are in the city for her care. Upon diagnosis, Sara is connected with a PN who listens to Sara's concerns. The PN educates Sara about her treatment and assists her with locating accommodation in the city. Sara believes that her husband does not understand her diagnosis and approaches the

PN for more help. The PN arranges for an interpreter to assist with educating Sara's husband. Sara now believes that her husband understands her illness. Sara contacts the PN for various resource connections and easily accesses them with the PN's assistance.

This case demonstrates the defining attributes of the PN role. The PN connected with the individual and removed potential barriers to care (i.e., accommodation). Education also was provided, and the need for culturally sensitive care was addressed. The PN understood the system in which he or she was operating, facilitating necessary links to resources.

### Borderline Case

In a fictitious borderline case, Anne is a single mother of three who is on social support. Her mother and aunt recently died of colorectal cancer. The PN at the screening clinic tells Anne she is too busy to hear her story of loss but encourages Anne to come in for screening. Anne is unable to attend because of transportation and child-care issues. The PN arranges for transportation and child care so that Anne can attend a screening. No education or information is provided to Anne concerning colorectal cancer. Anne attends the screening test, which comes back normal.

In this borderline case, the PN facilitated access for Anne to get a screening test by providing links to transportation and child care. The PN did not provide an empathic response to Anne's concerns nor did she provide information about the disease. This case illustrates only some of the defined critical attributes.

### Contrary Case

A fictitious contrary case is that of Jennifer, a 67-year-old woman diagnosed with breast cancer. She is from a small community and receives social support. She fails to return to the city for her follow-up appointment. She is incapable of attending because of transportation issues and fear of the healthcare system. She believes that the breast cancer will go away as long as she stops drinking alcohol and smoking. Jennifer dies at home. This contrary case exemplifies all of the missing attributes of the PN role.

## Antecedents and Consequences

Antecedents are events or incidents that must occur prior to the occurrence of the concept (Walker & Avant, 2005). The PN essentially facilitates access to various components of oncology care for patients and their families. The antecedent that must be present is the potential for a patient to be "lost" or experience significant obstacles in gaining access to treatment or resources within the context of oncology care. Many articles have purported that patients have the potential to be lost in

the follow-up process (Battaglia et al., 2007; BC Cancer Agency, 2005; Psooy et al., 2004; Steinberg et al., 2006) or experience difficulty navigating through their treatment (BC Cancer Agency; Fillion et al., 2006; Melinyshyn & Wintonic, 2006).

Consequences are conditions or events that occur as a result of the concept (Walker & Avant, 2005). The intended consequence of a PN is to improve the physical and psychological outcomes for patients (ACS, 2006; Ferrante et al., 2007; Hede, 2006; Psooy et al., 2004). PNs reportedly have facilitated access to timely diagnostics (Psooy et al.) and treatment (Fillion et al., 2006; Freeman, 2004). The literature also has illustrated that PNs help to ease patients' anxieties associated with their illness and assist in preparing them for upcoming treatments (BC Cancer Agency, 2005; Fillion et al.; Melinyshyn & Wintonic, 2006).

## Empirical Referents

Walker and Avant (2005) defined empirical referents as classes or categories of actual phenomena that by their existence demonstrate that the concept is present. They may be observable properties or measurements derived from the defining attributes. For the purpose of this analysis, a review of the variety of tools proposed for measuring the value of a PN will be discussed. The breadth of measurement tools examining the efficacy of the PN role has evolved over time. The original method used for measurement was a noticeable increase in the number of patients obtaining earlier-staged cancer diagnoses with a consequential improvement in survival rates (Freeman, 2004).

Qualitative interviews with patients, family members, and healthcare professionals have become an essential method of measuring PN efficacy (BC Cancer Agency, 2005; Corporate Research Associates Inc., 2004; Vargas et al., 2008). Other strategies for measuring PN program efficacy are diagnostic time intervals (ACS, 2006), anxiety scales, and patient and caregiver satisfaction surveys (Ferrante et al., 2007; Schwaderer & Itano, 2007). Despite the potential for a variety of measurement tools, many individuals have reported a scarcity of published, peer-reviewed literature evaluating the efficacy of PN programs (Dohan & Schrag, 2005; Hede, 2006; Schwaderer & Itano; Wells et al., 2008). While preparing this article, the authors attempted to contact an Internet-advertised PN program directed out of the United States. The original individual answering the "Patient Navigation Hotline" had not heard of patient navigation and proceeded to transfer the call to another individual. After the telephone call was transferred to three individuals and finally to the call center, no one could figure out what patient navigation was, and the individual politely asked if she could return the call at a later date. This was simply an attempt to gain further insight into patient navigation.

- Further efforts are required in designing and implementing tools that measure the efficacy of navigation. Program leaders should review the entire illness trajectory in their cancer centers, locate the major system gaps, and target those areas for system changes or navigation services. For example, if a gap is identified in patient education and information retention, the role of the navigator could be tailored specifically to that need. The concept of informed consent comes into question because information exchange and treatment decision-making often occur during times of high stress when patients are sometimes unable to process or retain information they have received. Navigation efforts could be directed toward education and treatment-decision counseling to ensure that patients truly understand all of the available treatment options.
- Although research has provided insight into barriers patients have faced when accessing the system, further study is required to examine obstacles along the entire illness trajectory, including reintegration into the community or palliative care. Navigation protocols could be designed for specific domains of care, such as transitioning from surgeon to oncologist or changing treatment regimens (e.g., chemotherapy to radiation), which are known to induce feelings of elevated distress and anxiety in patients.
- After the implementation of a navigation program, research efforts should be directed toward maintaining a database of frequent obstacles patients continue to face despite navigation services. The database can provide further insight into areas that necessitate changes in the navigation role or perhaps systematic changes that might be required.

### Figure 1. Future Directions for Research of Patient Navigation in Oncology

## Discussion

The qualifications of a PN depend on the objective of the domain being considered. For example, as illustrated previously, lay individuals have been used for follow-up of suspicious mammograms and screening promotion (Psooy et al., 2004). In some cancer centers, lay individuals also may provide practical information, schedule appointments, and offer a variety of resources such as support groups. Social workers also can assume the PN role for emotional and psychological supportive services, outreach activities, and resource connections (Darnell, 2007). Many individuals insist that nurses assume the role of the PN (Fillion et al., 2006; Melinyshyn & Wintonic, 2006; Seek & Hogle, 2007). This may be dictated by the required scope of the position, such as the need for regular and proficient assessments of patients' physical and emotional status as well as specialized training in oncology education and research. Nurses also may be best suited for assuming the PN role because they are more likely to be available throughout the disease trajectory to educate and answer questions concerning pathology reports, treatment decision-making, surgical options, and chemotherapy side effects. Patients may be reluctant to ask their doctors to repeat missed information; however, nurse navigators can repeat or confirm vital information that may have been missed because of anxiety.

Some wonder why navigation programs are even necessary. If nurses and doctors are doing their jobs in providing appropriate guidance and care, why does a demand exist for navigation services? The multifaceted treatments and consultations indicated for a disease such as breast cancer are provided in different care settings throughout the trajectory. This can result in fragmented care, missed information, and patients feeling burdened as they navigate through the system on their own. A single point of contact along the disease continuum can provide patients with a familiar individual and assist in reducing their anxiety. The nurse navigator can provide necessary information to the patient over time, allowing the individual to truly understand and process the considerable amount of information that often is received. Nurses may be the most appropriate healthcare professionals to orchestrate an often complex labyrinth of care, while providing the necessary education, guidance, research, and emotional support required for the improvement of patient outcomes.

The literature has illustrated that a variety of individuals can assume the role of PN; however, the organizational context, cost-effectiveness, and goals of the program must be considered before the implementation phase occurs. Notwithstanding the variety of individuals who may serve as PNs within particular contexts, the foundation of patient navigation begins with system changes to facilitate holistic care. Efforts are needed to ensure that patient navigation programs are subjected to empirical scrutiny to maximize the effectiveness of their development, implementation, and evaluation (see Figure 1).

## Conclusion

The emergent definition of a PN encompasses all of the following: (a) a trained individual who facilitates timely access to appropriate health care and resources for patients and their families; (b) a skilled communicator who provides holistic care, empowering patients with education and knowledge about their illnesses; and (c) an individual who is knowledgeable of the cancer system. The concept of the PN will continue to evolve over time, and future research must be directed toward evaluating the effectiveness of the PN role within the oncology delivery system.

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