Schering Lectureship 2008

The clinical nurse specialist as nurse navigator: Ordinary role presents extraordinary experience

by Patti Marchand

Patients encounter many health professionals and multiple hospital departments when they seek resolution to a health concern. The information gathering and the decision-making related to a health challenge can be overwhelming. The role of a patient navigator has been introduced by various organizations to target this challenging scenario for patients.

Patient navigation is a concept first introduced in the United States in the early 1990s to improve access to cancer screening, to address delays in clinical follow-up and to identify barriers to cancer care that poor people encounter (Freeman, 2004). This paper will explore the application and growth of the concept, "navigation" within the Canadian health care system. A detailed example of the development of a breast assessment program and the introduction of a nurse navigator role will be shared: outlining challenges and successes alike. Three case studies will illustrate the diversity and richness of the patient and nurse experience.

Prix de conférence Schering 2008

L'infirmière clinicienne spécialisée en tant qu'infirmière pivot : un rôle ordinaire mais une expérience extraordinaire

Lorsqu'ils essaient de résoudre un problème de santé, les patients entrent en contact avec un grand nombre de professionnels de la santé et de services hospitaliers. La recherche d'information et la prise de décision liées à un problème de santé peuvent s'avérer épuisantes. Le rôle d'infirmière pivot ou d'infirmière désignée pour le patient a été institué par divers organismes en vue d'aider les patients à relever ce défi.

Le concept d'intervenant pivot—« patient navigator » en anglais—a vu le jour aux États-Unis au début des années 90 et avait pour but d'améliorer l'accès au dépistage du cancer en abordant les retards au niveau du suivi clinique et en dégageant les obstacles aux soins de cancérologie que rencontrent les pauvres (Freeman, 2004). Cet article explorera l'application et le développement du concept de navigation au sein du système de soins de santé canadien. L'auteure présentera en détail un aspect du développement d'un programme d'examen des seins et la mise en œuvre du rôle d'infirmière pivot et soulignera aussi bien les défis que les réussites. Trois études de cas serviront à illustrer la diversité et la richesse de la relation patient-infirmière.

Cet article montrera, en outre, que les domaines de pratique de l'infirmière clinicienne spécialisée sont mis à profit dans le rôle d'intervenant pivot : un rôle qui est en pleine évolution en cancérologie et qui jouit d'une reconnaissance croissante dans une multitude de sièges du cancer et de domaines d'exercice. L'infirmière clinicienne spécialisée en oncologie, en tant qu'intervenante pivot, assure la continuité et l'uniformité de la fourniture du savoir et du soutien tout au long du cheminement des patients.

Furthermore, this paper will suggest how the domains of practice of the clinical nurse specialist are exemplified in the navigator role: an evolving role in cancer care and one that is gaining recognition among many different disease sites and areas of practice. The oncology clinical nurse specialist, as navigator, provides continuity and consistency in the delivery of knowledge and support throughout a patient's journey.

Three exemplars*

I will begin by sharing the stories of three women. I would like to introduce you to Janice. Janice is a 38-year-old mother of three pre-school girls. Janice was referred by her family physician after receiving an abnormal mammogram report from a community x-ray facility. Janice shares her concerns over the phone: "I hope you are able to help me... my doctor says I need a stereotactic biopsy. What is that? Do you do that there? I have three small children... will this hurt? What do I tell my children? Does this mean they think I have cancer?"

Now meet Joanne. As I try to complete my greeting on the phone... Joanne frantically stops me to say: "I hope you can help me... I have been diagnosed with breast cancer. I am 'Her2' positive... the doctor only did a lumpectomy... doesn't 'Her2 positive' mean I now need a mastectomy?"

Lucy is a 76-year-old married woman. Lucy does not have any children. This is an excerpt from my conversation with Lucy after she was informed about her consultation date with the surgeon.

"I think it's the pits to be diagnosed with breast cancer. My family doctor referred to the lump as invasive cancer. How far outside the starting area would that be? I have had a skin cancer spot removed from my head. This is more involved than that and scarier. How does one decide between a lumpectomy and a mastectomy?"

**Names have been changed.*

Patient navigation

Definitions

Let's step back a moment and explore the term navigation. Wikipedia (n.d.) defines navigation as the art and science of determining one's position so as to safely travel to a desired destination. Merriam-Webster (n.d.) defines navigation as "the science of getting ships, aircraft, or spacecraft from place to place; the method of determining position, course, and distance travelled". And last, Dictionary.com (n.d.) depicts navigation as "the art or science of plotting, ascertaining, or directing the course of a ship, aircraft, or guided missile". It is important to highlight the inclusion of the element of "art" and the potential influence this brings to the navigation experience beyond the facts of a map. In particular, the words safely, desired, and distance travelled, are highly indicative that there is so much more to the navigation experience than simply the starting point and the destination.

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The meeting of “navigation” and health care was first introduced by Dr. Freeman, a surgeon by training, who sat on numerous councils and boards that influenced the delivery of health care within the United States. Dr. Freeman established that nation’s first patient navigation program in 1990 at Harlem Hospital Center. This pilot program compared five-year survival rates of breast cancer patients who were navigated and those who were not and found improved survival rates for the navigated patients (Freeman, 2004).

“Patient navigation is a process by which an individual—a patient navigator—guides patients with a suspicious finding (i.e., test shows they may have cancer) through and around barriers in the complex cancer care system to help ensure timely diagnosis and treatment. Patient navigation helps ensure that patients receive culturally competent care” (Freeman, 2004, p. 44). Dr. Freeman succinctly captures the essence of navigation highlighting the concept of circumventing a barrier; whether that barrier may be socioeconomic, geographic, cognitive, or emotional.

Development

As the concept of “navigation” became a more familiar term in health care, it began to appear in the medical literature around 1995, consistent with Dr. Freeman’s work with the under-served. As navigation begins to be introduced in the Canadian health care system, the concept and model of care focuses less on the barrier of affordability of health care to challenges of accessibility related to geography and specialists’ availability per capita of a region.

The province of Nova Scotia provides a specific example of how a screening program used navigation to positively influence the delivery of care. Dr. Brian Psooy, breast imaging radiologist, was part of a team that first evaluated the concept of navigation, as part of a formal screening program. Their study concluded that: “Patient navigation significantly improves timeliness in the diagnosis of breast abnormalities and can potentially improve quality of life with more timely reassurance for women with benign conditions and earlier treatment for those with malignancy” (Psooy, 2004, p. 145).

This program demonstrated the substantial benefit navigation brings to the patient experience and, after the year 2000, navigation became available to all women regardless of their enrolment in the formal program. Dr. Psooy (2004) defines patient navigation as *“a process whereby designated individuals proactively guide patients through the bureaucracy of the health care system to facilitate the successful completion of a specific diagnostic or therapeutic task”* (p.146).

Furthermore, in Nova Scotia during 2001, Cancer Care Nova Scotia evaluated overall cancer services throughout the province. Geographic challenges were acknowledged since there are just two cancer centres serving the entire province. A system of navigation was introduced with the establishment of navigators in districts throughout the province. The objectives of these navigators were to:

- help guide cancer patients and their families through the maze of the health care system
- improve the quality and consistency of cancer care within health care by informing senior leaders of gaps in cancer services
- provide an added source of cancer expertise for health professionals in the community
- ensure that patients have access to supportive and rehabilitative care, palliative care, volunteers and other supports in their home communities (Cancer Care Nova Scotia 2004).

The evaluation of this “navigation system” demonstrated high levels of satisfaction among patients and health professionals. Patients had increased knowledge, not only of disease entities and treatments, but also of available resources. Additional outcomes not

directly attributed to the bedside, but most definitely affecting the bedside were improved collaboration and communication among health professionals and the leadership team (Cancer Care Nova Scotia, 2004).

As navigation continued to gain recognition, the importance of studying and researching the concept and model of care became evident. In 2005, the National Cancer Institute’s Center to Reduce Cancer Health Disparities, with support from the American Cancer Society, awarded grants to nine academic research institutions to evaluate patient navigators. The overall aim of the program was to decrease the time between an abnormal finding, diagnosis and delivery of quality standard cancer care while targeting communities and populations experiencing a disproportionate share of the cancer burden. Evidence to date has demonstrated improved survival rates among African American breast cancer patients in Harlem (National Cancer Institute, 2005).

This work has led to additional programs utilizing a “patient navigator” approach. The first is a pilot program looking at the effectiveness of patient navigators to help American Indians overcome their unique barriers to cancer care. A second example is to enhance clinical trial recruitment among medically under-served, low-income and minority communities (National Cancer Institute, 2005). Subsequently, navigation has become a growing model of care with many examples of its application throughout North America (see Figure 1).

Figure 1

- Elizabeth Anderson Cancer Institute, Savannah
 - APN as breast cancer and gynecologic cancer nurse navigator
- Palo Alto Medical Foundation: Integrated Prostate Cancer Centre
 - CNS as Prostate Cancer Nurse Navigator
- Pennsylvania Life Insurance Company, USA
 - Nurse Navigator
- Red Deer Regional Hospital, Alberta
 - Cardiac Nurse Navigator Program
- Tom Baker Cancer Centre, Calgary, Alberta
 - Nurse navigation in breast cancer
- Maryland, Ohio
 - Multidisciplinary lung cancer clinic: Nurse navigator

(Author: Google search, May 2008)

Many attributes have been put forth by the specific models highlighted thus far in this paper. Dr. Freeman stresses problem solver and highly resourceful. Cancer Care Nova Scotia identifies a health care professional with cancer expertise. Finally, the National Cancer Institute emphasizes cultural competence. How does this compare with attributes specifically explored in the nurse as navigator?

The nurse as navigator

In addition to being highly organized and skilled at coordination, Seek and Hogle (2007) acknowledge “theoretically, anyone knowledgeable about the nuances of a physician’s practice could act as a navigator of a multidisciplinary clinic; however, oncology RNs who are knowledgeable of all aspects of oncology care actually are best suited for such a role” (p. 84). In stating such, Seek and Hogle highlight critical attributes of the oncology nurse namely:

- Knowledge and understanding of
 - the continuum of oncology care
 - the importance of a complete work-up and accurate staging
 - the risks and side effects of procedures/treatment modalities

- Expert in nursing interventions for side effect management and complication recognition
- Advocate for patients/families
- Promoter of patient empowerment/decision making
- Skill in collaboration/communication among physicians and support services.

Seek and Hogle (2007) remind us to reflect on the dictionary definitions of “navigation” shared earlier in this paper, remembering the significance of the distance travelled and not simply getting from point A to point B. We find relevance in the steps taken by the patient and the implications of missed appointments or untimely turns in the path. We appreciate the nurse’s ability to anticipate these turns and intervene appropriately.

Judy Kneece (2006) has taken “navigation” to another level with the establishment of a certification program specifically for nurses practising in breast health. Kneece has published widely on breast health management and psychosocial support of patients and their families. Her work describes specific roles of the breast health navigator, and they mirror the nursing process (see Figure 2).

Figure 2

- Address both the art and science of breast health care
- Assessment to identify high-risk patients
- Plan health care pathways with team
- Coordinate care with other team members
- Provide education and support for patient and family
- Monitor patients’ total response to cancer diagnosis

(Kneece, 2006)

Clinical nurse specialist as navigator

Reflecting on the evolving navigator role, one is able to identify an apparent fit into the competencies of a clinical nurse specialist (CNS): clinical, research, leadership and consultant/collaboration (Canadian Nurses Association, 2008).

The clinical components of the CNS are demonstrated through the daily interactions with patients and the direct interventions that influence their path of care. Examples of these interventions include, but are not limited to: referral to community supports, symptom assessment and management, provision and explanation of test results, and communication with primary care physicians.

Education goes hand in hand with the clinical practice domain. In conjunction with the multidisciplinary team, the CNS plays a critical role in ensuring that information provided to health professionals and patients is representative of research-based recommendations. Our program initiated patient care education bags in each surgeon’s office. Each bag contains the contact information of team members. This intervention enhances interactions completed by phone and in person. Education also spans a large multidisciplinary team including clerks, mammography technologists, sonographers, family physicians, and nurses from the many realms of patient care: pre-op, surgery, medical and radiation oncology and palliative care.

Generating, synthesizing, and using research evidence is central to advanced nursing practice (CNA, 2008, p. 23). In my own work, I am a primary investigator in a current research project exploring abnormal breast screening results and the psychological consequences experienced by these women. This research will serve to inform the practice of the multidisciplinary team, influence patient care and contribute to the design and operation of an onsite breast centre.

Consultation and collaboration is truly reflected in the essence of everyday practice for the CNS. This domain of practice spans a dynamic and sizeable portfolio of colleagues including the breast health care team, patients, health care colleagues in general, community organizations, and professional associations.

The leadership domain of the CNS role incorporates the competencies of program development and evaluation, quality assurance, professional standards, and system influence and change. Examples of practice include assisting in developing policies, protocols and clinical guidelines in collaboration with the multidisciplinary team that is necessary to support the developing service. It is through leadership competencies that the CNS shapes and influences the direction of the program. It is clinical practice encounters that enable the CNS to bring the lived experience of the patients to the decision-making table. This impacts not only the individual patient, but also the system, as a whole. Such actions actualize the role of nurse as advocate, “a central tenant of nursing practice” (Seek & Hogle, 2007, p. 84).

Multiple competencies of the CNS are strongly evident in the CNS as navigator. It is important at this point in time to note the fluid nature that must exist in this role. One must acknowledge that although all domains are present, the CNS is also skilled at recognizing when a specific competency or domain will take priority based on the needs of the patient and the needs of the health care system caring for the patient. The CNS will shift percentages of time and focus to prioritize based on these needs.

Provincial breast screening program

Our road began with the introduction of the formal provincial breast screening program in September of 2006. The next logical step was to establish an organized and predictable means of providing follow up for any woman with an abnormal screen. This next step is referred to as Breast Assessment (see Figure 3).

Figure 3

Breast Assessment:

- is the diagnostic process to reach final diagnosis
- facilitates transition to treatment modalities, as indicated
- is completed through the collaboration of a multidisciplinary team guided by coordinated pathways of assessment
- focuses on timeliness and quality work-up procedures

(Cancer Care Ontario, 2005)

Ideally, the components of breast assessment would be best achieved through a dedicated centre. However, challenges of space and budget prohibited the timely initiation of an onsite centre with all resources under one roof. This resulted in the development of a *virtual* diagnostic breast assessment program whereby women with a screened detected or clinically detected breast abnormality will have access to a coordinated, rapid diagnostic program.

Our program included the introduction of a CNS as nurse navigator. The CNS as navigator would become the critical link within this virtual set-up. This role was carved out of existing expertise in the oncology program through a critical review of roles and responsibilities among nursing leadership. The nurse navigator will: a) enhance and bridge interdisciplinary interaction and communication, b) guide patients proactively through diagnostics with mindful adherence to targeted timelines, c) provide education regarding the health care system, procedures, and disease process, d) facilitate referral to allied health members such as social work, and e) review data and facilitate knowledge transfer to involved parties.

Three exemplars revisited

The following figures will provide examples of the contribution and application of the many attributes the nurse navigator brings to patients in a breast assessment program. One is able to note that though the needs of the individual patient may be addressed in any single encounter, it is also critical to reflect on each episode of care to evaluate its potential for larger change within the system.

Janice: "I hope you are able to help me... my doctor says I need a stereotactic biopsy. What is that? Do you do that there? I have three small children... will this hurt? What do I tell my children? Does this mean they think I have cancer?"

Nurse Navigator:

- As educator
 - Information/knowledge needs:
 - procedure and the side effects
 - mammography report
- As clinician
 - Physical and psychosocial assessment
- As source of support/counsellor
 - Acknowledge her concern for children
 - Skilled listener
- As case coordinator
 - Facilitate biopsy appointment
 - Maintain communication with Janice
 - Inform results to family MD/next steps
- As collaborator:
 - Consider social work referral results

Joanne: I hope you can help me... I have been diagnosed with breast cancer. I am "Her2" positive... the doctor only did a lumpectomy... doesn't "Her2" mean I need a mastectomy?

Nurse Navigator:

- As educator
 - Information needs: definitions and standards of care
- As source of support
 - Skilled listener
- Role of leader
 - Information being shared at the time of consult
 - Update patient care education bags to include adjuvant Her2

Lucy: I think it's the pits to be diagnosed with breast cancer. My family doctor referred to the lump as invasive cancer. How far outside the starting area would that be? I have had a skin cancer spot removed from my head. This is more involved than that and scarier. How does one decide between a lumpectomy and a mastectomy?

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Nurse Navigator:

- As educator
 - Information needs
- As source of support
 - Skilled listener
 - Decision-making
- Resource utilization and communication and collaboration

I would like to summarize the exemplars with the words of a patient evaluation that truly exemplifies the outcomes I have set to be achieved by the nurse navigator: "I felt so comfortable discussing my health issues with her. She has answered my many questions, listened to my concerns about what I was experiencing and directed me to valuable information on the cancer websites. My husband and I were kept informed, as my treatment progressed. This is a devastating diagnosis, which can be very stressful. It's always someone else. Now it's me. I found my situation overwhelming. The navigator's calm and pleasant manner has been uplifting to me over the last few months. She is a valuable supportive care person. I am glad we were paired together." Lucy, and others like her, reminds me that components of our daily work that we may deem as routine or another ordinary day have the potential to result in extraordinary outcomes!

The ultimate goal is to provide care that is coordinated and navigated along a pathway of care that is shared with and understood by the patient. The navigator ensures information is available to patients when they need it and plays an integral role in partnership with the team to minimize time intervals necessary in seeking a resolution to their health concern. The nurse navigator functions as a consistent care coordinator during the diagnostic phase of care while working collaboratively within the interprofessional team. In essence, the nurse navigator applies knowledge of the health care system and the cancer system to successfully advocate for the patient/family with mindful accountability to facilitating the necessary next steps along the care trajectory.

In closing, I would like to share the words of Karlene Kerfoot, reported in *Nursing Economics* in 2000. Kerfoot leaves us with a thought-provoking insight and challenge to meet in our daily practice: "...patients today learn to evaluate the success of a procedure/intervention based on their experience *surrounding* the procedure, not the intervention itself" (Kerfoot, 2000, p. 96). It is without hesitation that I offer that the nurse navigator brings the knowledge, skills and ability to positively impact this "surrounding".