Professional Navigation Framework: Elaboration and Validation in a Canadian Context

Lise Fillion, RN, PhD, Sandra Cook, RN, BA, HSM, Anne-Marie Veillette, MA, Michèle Aubin, MD, PhD, FCFP, CCFP, Marie de Serres, RN, MSc, François Rainville, MSW, Margaret Fitch, MScN, RN, PhD, and Richard Doll, MSW, MSc

Patients with cancer and their families experience dissatisfaction with service fragmentation, delays, lack of information, and lack of coordination (Turgeon, Dumont, St-Pierre, Sévigny, & Vézina, 2004) and often complain about a sense of isolation, feelings of powerlessness, and a lack of guidance. They express a need for timely information on the disease, treatments, and available resources, as well as better communication between health providers and emotional support throughout the healthcare continuum (Fraser, 1995). Patients often refer to the care system as a maze and express a need for continuity of care and a person-centered approach (Trussler, 2002). To improve continuity and patient-centered care, cancer navigation programs have emerged as a model of care.

Continuity of care can be defined as the degree to which a series of discrete healthcare events are experienced as coherent, connected, and consistent with the patient’s medical needs and personal context (Haggerty et al., 2003). Patient-centered care refers to a model in which patients’ expectations are taken into account, where patients and healthcare providers work as partners, and where they share a common vision about their goals. Therefore, intervention plans are focused on and made in collaboration with the person (Fitch, 2008).

However, the literature has failed to describe cancer navigation consistently. In this article, the authors propose that part of the confusion is related to the lack of acknowledgment of the bi-dimensional nature of the role: organizational and clinical. The goal was to explore the concept of professional navigation within the theoretic concepts of continuity of care and patient empowerment to determine the organizational and clinical nature of the role.

Purpose/Objectives: To elaborate, refine, and validate the professional navigation framework in a Canadian context.

Research Approach: A two-step approach consisting of a qualitative evaluative design and formal consultations.

Setting: Two applications of professional navigators in Quebec and Nova Scotia, Canada.

Participants: Patient navigators, medical oncology specialists, nurses and oncology staff, administrators, family physicians, patients with cancer, and patients’ families and significant others.

Methods: Individual interviews (n = 49) and focus groups (n = 10) were conducted with professional navigators, patients and family members, front-line staff, family physicians, and health administrators. Formal consultations (n = 13) occurred with clinical experts, managers, and researchers from across Canada.

Main Research Variables: The interview guide was based on an evaluative conceptual framework integrating questions related to the implementation process of the role of professional navigators and their organizational and clinical functions.

Findings: Results support a bi-dimensional framework and define key role functions. The first dimension, health system-oriented, refers to continuity of care. The second dimension, patient-centered, corresponds to empowerment. For each dimension, related concepts were illustrated from data. Examples of outcomes also were suggested.

Conclusions: The framework brings clarity to the role and functions of professional navigators and suggests relevant outcomes for program evaluations.

Interpretation: With a clear definition of their role, professional navigators may be more efficient and less challenged in terms of setting priorities and making decisions while having to face demands from the health system and patients. The integrative framework could improve the effectiveness of cancer navigation programs.
Professional Cancer Navigation

In Canada, the Canadian Partnership Against Cancer Corporation (CPACC), an independent organization funded by the federal government, was created to implement Canada’s cancer control strategy. The CPACC supports the implementation of cancer navigation as a crucial component of improving continuity of care, working to create a patient-centered integrated care system (CPACC, 2010). The Cancer Journey Advisory Group of the CPACC proposes three models of cancer navigation: peer or lay led, professionally led, and virtual (online).

The concept of navigation, which originated in the United States, initially was a peer-led model that relied on volunteers to help overcome the barriers to cancer care encountered by socially and economically marginalized people (Dohan & Schrag, 2005; Freeman, Muth, & Kerner, 1995). Researchers in the United States have recognized the complexity of the role, pointing out that defining patient navigation in terms of resolving barriers for individual patients may exclude other patient navigation functions, obscure a variety of related activities, and be too constricting (Parker et al., 2010). Indeed, the principal roles of patient navigators have been portrayed by Pedersen and Hack (2010) as not only removing barriers to care, but also improving patient outcomes and the overall quality of healthcare delivery.

In Canada, although no consensus exists on the actual times of entry and exit in the cancer trajectory, most of the evidence documenting cancer navigation models from diagnosis to palliation have focused on a professional-led model and promoted a comprehensive case management model (BC Cancer Agency, 2005; Cancer Care Nova Scotia [CCNS], 2004; Fillion et al., 2006, 2009; Plante & Joannette, 2009b; Skrutkowski et al., 2008). Professional cancer navigators are intended to ease and expedite patients’ access to services and resources, improve continuity and coordination of care throughout the cancer care continuum, and serve as patient advocates when needed (CCNS, 2004; Doll et al., 2007). Quite similar to Canada, Australia (Liebert et al., 2003) and the United Kingdom (Amir, Scully, & Borrill, 2004) have proposed the role of breast cancer nurses, a professional role that now has spread internationally (Cruickshank, Kennedy, Lockhart, Dossier, & Dallas, 2008) and involves comprehensive needs assessment, evidence-based interventions, and psychosocial support in a responsive and flexible manner at all stages of the cancer care continuum.

Although the term cancer patient navigation is relatively new within the Canadian healthcare system, the concept is not. The following terms have been used to describe the professional navigator role: case manager, clinical coordinator, cancer support nurses, follow-up nurses, breast specialist, breast cancer coordinator, and patient navigator (Farber, Deschamps, & Cameron, 2002). Among them, case manager is sometimes labeled as a professional navigator (Lantz, Keeton, Romano, & Degroff, 2004).

Definitions often relate to a profession, and professional navigators typically have a background in nursing or social work. Regardless, a professional cancer navigator must possess clinical expertise in oncology, have highly developed therapeutic communication and problem-solving skills, and have a broad knowledge of the healthcare system and cancer resources (White & Hall, 2006). The professional navigator role and functions go beyond the initial minimal role of the case manager, who typically helps the patient to follow medical protocol and schedule appropriate appointments. Although basic case management may help to improve delay within the cancer care continuum, it does not necessarily make it connected and coherent from the patient’s perspective. The professional navigator role corresponds to a more comprehensive medical or social model of case management that values humanization of the care trajectory and empowerment of the patient and family; a model based on a patient-centered philosophy of care (Fillion et al., 2006; Plante & Joannette, 2009a).

Professional Navigation Framework

No generally accepted definition exists for patient navigation and very little consensus has been reached as to the actual roles and responsibilities of professional nurse navigators (Wilcox & Bruce, 2010). That, in part, is caused by confusion between navigation and case management to address similar concepts and related to the lack of acknowledgment of the bi-dimensional nature of the role—not only patient-centered but also healthcare-system oriented. Although research has demonstrated that navigation is an effective way of increasing patient satisfaction and decreasing barriers to care, some authors have argued that the key components of a successful navigation program are not well understood. Additional research is needed to explore, confirm, refine, and define the processes and roles of patient navigation (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Fillion, Aubin, et al., 2008; Fillion et al., 2009, 2010; Oncology Nursing Society, Association of Oncology Social Work, & National Association of Social Workers, 2010; Parker et al., 2010; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010).

A well-built and validated model of professional navigation acknowledged by organizations, managers, and clinicians, as well as those living with or affected by cancer, is needed. In the United States, the bi-dimensional nature of navigation has started being acknowledged, having led to the development of a bi-dimensional matrix, one more network-focused and organizational, the other more task-focused and patient-centered (Parker et al., 2010). Canadian implementation studies also
support the relevance of describing professional navigation as a complex concept including two main dimensions: organizational and clinical (Fillion, Aubin, et al., 2008; Fillion, Cook, et al., 2008; Fillion et al., 2006, 2010; Roberge et al., 2004; Tremblay, 2008).

In a previous attempt to clarify the role of professional cancer navigation, Fillion et al. (2009) proposed a theoretic bi-dimensional definition: a professional role aiming to facilitate continuity of care and promote patient empowerment. The first dimension corresponds to the construct of continuity of care proposed by Haggerty, Reid, McGrail, and McKendry (2001) and Haggerty et al. (2003), which includes three concepts (informational, management, and relational continuity) and a set of organizational functions. The second dimension is related to the construct of patient empowerment and identifies a set of clinical functions. Patient empowerment was defined as a process of adaptation to cancer (Pellino & Ward, 1998) that encompasses the acceptance of the illness and the use of active coping strategies to regain control (Bulsara, Styles, Ward, & Bulsara, 2006). To select an operational definition of that broad psychosocial construct, the chronic disease self-management model proposed by Lorig et al. (1999) was adapted for cancer. Lorig et al. (1999) model identified three adaptation tasks: coping with changes in social or role activities, dealing with disease and treatments, and coping with loss and distress. From that model, three additional concepts relevant to the concept of empowerment were added to the definition of professional navigation: active coping, cancer self-management, and social support (Fillion et al., 2009). The initial definition, which included two dimensions and six concepts, was selected as a theoretic framework.

Settings

Two Canadian provinces initiated professional cancer navigation programs in the early 2000s. The CCNS created the role of cancer patient navigators (CPNs) in Nova Scotia in 2001. The CPNs are based in the community, but are coordinated into a network of navigators who are closely linked to the tertiary cancer program’s multidisciplinary teams. Concurrently, the Quebec government’s cancer control strategy established the “infirmerie pivot en oncologie,” or pivot nurses in oncology (PNOs) to facilitate coordination of the cancer services network. Depending on their work setting, PNOs can be attached to supra-regional or regional oncology teams in a tertiary hospital (specialized cancer center) or closer to the community with local oncology teams.

In view of the groundbreaking work conducted in Nova Scotia and Quebec to integrate navigation in their respective cancer control plans, the professional navigation role in the two provinces were selected as Canadian models for the current study. The study objective was to elaborate, refine, and validate the content of the initial bi-dimensional professional cancer navigation framework in a Canadian context.

Research Approach

To conduct an empirical content validation of the bi-dimensional framework, this qualitative descriptive study used a two-step approach: empirical and iterative-consultative. A multiple-case design (Yin, 1994) involving three units was selected: one in a community setting in Nova Scotia and two in Quebec, one in a tertiary hospital and the other in a community setting.

Participants and Recruitment

The intentional sample included nine groups of participants, including (a) CPNs, (b) PNOs (supra-regional team), (c) community PNOs (local team), (d) medical oncology specialists, (e) nurses and oncology staff, (f) administrators, (g) family physicians, (h) patients with cancer; and (i) patients’ families and significant others. All were identified by key informants from different health and community organizations from Nova Scotia and Quebec. A nonprobabilistic information-oriented sampling of participants was used to gather rich opinions and experiences.

The CPNs, PNOs, and administrators from Nova Scotia and Quebec contributed to the recruitment, elaborating on lists of eligible participants who were contacted via telephone by the research team. Also, patients with cancer contributed to the recruitment process by identifying family members. All interested participants among the nine groups were contacted via telephone by a member of the research team, and all participants signed an information and consent form. The research project received approval by the ethics board of each participating establishment.

Data Collection

A multimodal data collection was completed with (a) documents from preliminary stages of this study (e.g., literature review, CPNs’ and PNOs’ tools and resources), (b) individual interviews (n = 49), (c) focus groups (n = 10), and (d) data validation consultations (n = 13). For individual interviews and focus group discussion templates, questions related to the implementation process were framed according to a focused evaluation process suggested by Patton (1997) and adapted by Fillion and Morin (2003–2006). Questions related to the selected theoretic framework also were included.

Data Analysis

All individual interviews and focus groups were tape recorded. The recordings were integrally transcribed, reviewed, and matched with the initial bi-dimensional
concept. That served as a foundation for developing a categorization scheme. Working with the NVivo 7® program, descriptive codes were created by attributing a code to each unit of analysis (i.e., words, phrases, or paragraphs) highlighting an issue. Merging similar descriptive codes created thematic categories representing a set of conceptual components. Analysis was carried out by applying the approach of Strauss and Corbin (1990). A constant-comparative process of data analysis occurred within the research team on an ongoing basis to ensure data saturation and to contribute to confidence in the validity of the analysis. Through that inductive and deductive comparison process, relationships between categories emerged to improve the content of the initial theoretic bi-dimensional definition of the professional navigator.

Iterative-Consultative Data Validation Process

To refine and enrich the content validation of each identified organizational and clinical function, an iterative-consultative data validation process was conducted with professional navigators, clinical experts, managers, and researchers from across Canada. A series of formal consultations were completed, applying the three-step interactive analysis model of Huberman and Miles (1991): data condensation, data presentation, and conclusion or inference and validation with stakeholders. The validation process allowed the groups to bring their expertise, which resulted in adapting the vocabulary used in the framework, and added some nuances.

Results

A total of 100 volunteers participated to the empirical validation study (see Tables 1 and 2).

For the second-phase content validation process, a total of 57 experts and professional navigators contributed. Experts (n = 26) included members of the Direction de la lutte contre le cancer (DLCC) from Quebec, a Quebec provincial body responsible for cancer control policies and programs; members of the Inter-Provincial Curriculum Committee from across Canada; and

<table>
<thead>
<tr>
<th>Variable</th>
<th>CPNs—cancer patient navigators; N/A—not applicable; PNO—pivot nurse in oncology</th>
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<tbody>
<tr>
<td>Age (years)</td>
<td>20.25</td>
</tr>
<tr>
<td>Years of experience in oncology</td>
<td>4.63</td>
</tr>
<tr>
<td>Estimated number of new patients with cancer followed per year</td>
<td>228.33</td>
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Note. Because of rounding, not all percentages total 100.

Table 1. Participants’ Characteristics According to Their Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>CPNs From Nova Scotia (N = 5)</th>
<th>Managers From Quebec (N = 8)</th>
<th>PNOs (N = 11)</th>
<th>Other Oncology Workers (N = 27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Women</td>
<td>50</td>
<td>2</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Men</td>
<td>50</td>
<td>2</td>
<td>25</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>RN diploma (Nova Scotia)</td>
<td>40</td>
<td>2</td>
<td>40</td>
<td>3</td>
</tr>
<tr>
<td>College (Quebec)</td>
<td>60</td>
<td>3</td>
<td>60</td>
<td>5</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>60</td>
<td>3</td>
<td>60</td>
<td>5</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>60</td>
<td>3</td>
<td>60</td>
<td>5</td>
</tr>
<tr>
<td>Doctorate</td>
<td>60</td>
<td>3</td>
<td>60</td>
<td>5</td>
</tr>
</tbody>
</table>

Note. Because of rounding, not all percentages total 100.
researchers, managers, and clinical experts from Quebec and Nova Scotia. Professional navigators (n = 31) were selected from four different teams in Quebec and Nova Scotia: (a) the Quebec City region, (b) the Montérégie region, (c) the Montreal region, and (d) from Nova Scotia.

**Bi-Dimensional Framework of Professional Navigation**

The presentation of the results, summarized in Table 3, follows the two-theoretic dimensions of (a) facilitating continuity of care and (b) promoting patient and family empowerment. Throughout the text, the term *professional navigators* is used to refer to CFNs or PNOs.

**Dimension 1. Facilitating continuity of care:** The first dimension refers to facilitating continuity of care, following the three related concepts of informational, management, and relational continuity. Results show, in defining functions or key roles, how those three concepts, which mainly are organizational and health system-oriented, contribute together to create a coherent and connected experience of care for patients with cancer.

First, professional navigators report that they play a role in the information continuity by acting as a “transmission belt.” They need access to, and understanding of, high levels of information about the patient with cancer and their care. When this level of patient-centered information is acquired, professional navigators are able to provide timely and tailored information and advice to the patient and to other providers from interdisciplinary teams, enabling them to make appropriate referrals. Professional navigators closely work with the interdisciplinary teams to improve continuity of the information and knowledge of patients’ and families’ needs and changes. They use communication tools and a variety of strategies. Therefore, patients with cancer would not have to repeat information to providers.

Second, professional navigators facilitate management continuity by conducting comprehensive screening and needs and resources assessment, both initially and in an ongoing way throughout the cancer continuum. That ensures more efficient and timely matching of unmet needs with services, resources, and support systems within the cancer care organization and the community. In addition, professional navigators identify lack of resources, find temporary solutions, and report system gaps. With their function of mapping the continuum of cancer care, explaining treatments and care plans while minimizing uncertainty, professional navigators have stated that they increase participation of patients in their own care as well as decrease barriers to cancer care adherence. Management continuity also is facilitated by professional navigators when they are referring to and communicating with hospital and community teams and when they are doing prompt liaison. They also have a role in facilitating coordination and organization of medical and psychosocial care, using care pathways.

Professional navigators have expressed that they have a major interdisciplinary role by contributing to the elaboration and application of the interdisciplinary care and nursing care plans, and by contributing to interprofessional collaboration in the hospital and community settings. In partnership with the team, professional navigators can make changes in coordination of care.

Third, professional navigators are seen as a figure of relational continuity, maintaining a constant relationship with patients and families throughout several stages of the care trajectory. The relationship builds trust and gives patients a sense of predictability, humanization, and coherence in their care. Indeed, navigators initiate and maintain an ongoing relationship with patients with cancer. To do that, navigators must have finely tuned skills in therapeutic conversations, be easily accessible, and be able to map, on the cancer trajectory, how and until when they are involved. Also, by being part of a team and trusted by health providers and team members, professional navigators contribute to relational continuity. For patients with cancer and their families, the sustained presence of a professional navigator decreases their distress and increases feelings of confidence. Often qualified as a safety net, professional navigators act as trusty key informants who provide a more personal contact.

**Dimension 2. Promoting patient and family empowerment:** The professional navigator role contributes to the clinical functions to promote patient and family empowerment. They aim at facilitating adaptation in reinforcing active coping, cancer self-management, and access to supportive care.

First, professional navigators reported that they promote active coping by assisting patients and family members to actively obtain the information, support,
Table 3. Professional Navigation Framework

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Process and Function</th>
<th>Outcomes</th>
</tr>
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<tbody>
<tr>
<td><strong>Dimension: Facilitating continuity of care</strong> (experience of care as coherent and connected) Organizational functions of the role (Dimension health system-oriented)</td>
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<tr>
<td><strong>Informational continuity</strong> Use of information, disease- or person-focused, to make current care appropriate for each individual. Information is relevant to link care from one provider to another and from one healthcare event to another (Haggerty et al., 2003).</td>
<td>- Having access to, and understanding, a high level of information on the patients with cancer and their care - Providing timely and tailored information and advice to the interdisciplinary team(s) and patients with cancer (patient-centered information) - Working closely with the interdisciplinary team(s) to improve continuity of the information and knowledge of family and patients’ needs and changes - Using communication tools and strategies to increase continuity of information</td>
<td>- Effectiveness in which coherent information is transferred and understood (information on medical condition, patient’s preferences, values, and context)</td>
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<td></td>
<td></td>
<td>- Among providers (e.g., SECON) - Between institution (discharge plans, transfer of discharge information, and referral data inventory) - Between primary and specialty care (referral documents) (e.g., PCAT) - From patient perception (e.g., PCCQ, ECC, continuity of care questionnaire)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>✓ Accumulated knowledge: Patients can be asked if they know their providers at earlier steps of the care trajectory, how well they know their providers, or providers can be asked how well they know their patients. ✓ Satisfaction about information exchange in the team (e.g., EORTC-QLQ-SAT32)</td>
</tr>
<tr>
<td><strong>Management continuity</strong> A consistent and coherent approach to the management of cancer that is responsive to a patient’s changing needs. Providing a sense of predictability and security in future care for both patients and providers (Haggerty et al., 2003)</td>
<td>- Conducting comprehensive screening and needs and resources assessment (initial and ongoing) - Matching unmet needs with services, resources available, and support systems within the cancer care organization and the community - Identifying lack of resources, finding temporary solutions, and reporting the system gaps - Mapping continuum of care, explaining treatment and care plans, minimizing uncertainty (patient orientation), and decreasing barriers to cancer care adherence - Referring to and communicating with hospital and community teams - Doing prompt liaison - Facilitating coordination and organization of medical and psychosocial care (using care pathways) - Contributing to the elaboration and application of the interdisciplinary care plan and nursing care plan - Contributing to interprofessional collaboration (hospital and community settings)</td>
<td>✓ Coherent and timely coordination of services (shared care plan and facilitate access to a broad range of services) ✓ Longitudinal follow-up completion rates of recommended treatment for cancer-specific diseases or for “gaps” in care for chronic diseases (particularly in transition) ✓ Perception of continuity of care (e.g., PCCQ, ECC, continuity of care questionnaire)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>✓ Participation of patient in care (flexibility in adapting care to individual’s needs and circumstances) ✓ Consistency in care: adherence to cancer care. Applied from primary care, a measure of compliance in preventive care for cancer survivors ✓ Satisfaction with coordination of care (EORTC-QLQ-SAT32) ✓ Delays or waiting time ✓ Symptoms relapse; worsening conditions ✓ Hospitalizations; emergency visits</td>
</tr>
<tr>
<td><strong>Relational continuity</strong> A therapeutic relationship between a patient and at least one provider, who develops accumulated knowledge of the patient as a person and bridges the past to current and future care (Haggerty et al., 2003)</td>
<td>- Initiating and maintaining an ongoing relationship with the patient with cancer - Being easily accessible through the cancer continuum - Mapping on the cancer trajectory how the professional navigator is involved and until when - Being part of an oncology team - Being trusted by health providers and team members</td>
<td>✓ Effective professional navigator and patient communication (bridges not only past to current care, but is a link to future care) ✓ Extent to which the same provider sees the patient in different settings ✓ Strength of patient-provider affiliation (e.g., PCAT, satisfaction with providers)</td>
</tr>
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Table 3. Professional Navigation Framework (Continued)

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Process and Function</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| **Dimension: Promoting patient and family empowerment** (care providers as supportive partners in care)  
Clinical functions of the role (Dimension patient-centered) |
| Active coping  
Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects (Carver et al., 1989). | - Assisting the patient and family to actively obtain information, support, and referral they needed  
- Enhancing or reinforcing the patient’s and family’s senses of autonomy (self-care) and self-determination through education and support to maintain their sense of control and quality of life  
- Enhancing recognition of the patient’s and family’s inner resources  
- Reinforcing active coping  
- Facilitating problem solving  
- Facilitating decision making  
- Setting and prioritizing goals | - Perceived sense of mastery for self-care and self-action to manage family, social, and practical problems (e.g., CASE-cancer)  
- Capacity to cope with family, social, and practical changes. Active coping strategies: planning, problem solving, etc. (e.g., COPE, CHIP, CSE)  
- Numbers of cancer-related problems (e.g., IRLE-C) |
| Cancer self-management  
Supporting the person and family and reinforcing his or her ability to accept the illness and regain control, regardless of prognosis (Bulsara et al., 2006). | - Assessing and monitoring symptoms  
- Providing or facilitating symptom management  
- Assisting and reinforcing the patient in adjusting to and managing his or her altered health state and symptoms proactively, not reactively, through timely and tailored information and self-care instructions  
- Reinforcing self-care behaviors  
- Assisting in following individualized treatment and care plans  
- Supporting the patient and family in decision making and cancer transition (palliative care)  
- Supporting the patient and family on how to negotiate care (advocacy role)  
- Optimizing self-care capabilities and skills  
- Educating, modeling, and coaching to facilitate the patient’s, family’s, and team members’ behavioral changes toward patient-centered care (hospital and community resources) | - Unmet physical needs (e.g., SCNS)  
- Symptom distress (e.g., SDS)  
- Decisions to be made involve choices about treatment options and lifestyle changes (e.g., PES).  
- Perceived sense of mastery for self-care and self-action to manage cancer, treatment, and physical side effects (e.g., CASE-cancer, heiQ, self-efficacy) |
| Supportive care  
Providing the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs (Fitch, 2008). | - Providing access to supportive care through screening, assessment, direct care and intervention, and referral  
- Screening for distress and conducting comprehensive supportive care needs and resources assessment  
- Identifying unmet supportive care needs  
- Educating on distress and distress management  
- Assessing available support and reinforcing it  
- Supporting patient and family to mobilize their own resources and to explore new ones  
- Providing transitional support  
- Identifying policies or structural barriers limiting access to supportive care and suggesting ways to address it  
- Assisting and facilitating the development of community and healthcare resources (leadership)  
- Referring (mobilizing resources and services within the cancer care organization and the community to address unmet supportive care needs) | - Unmet psychological, social, spiritual, and practical needs (e.g., SCNS, CIPS, IRLE-C, CaSUN, SUNS)  
- Emotional distress (e.g., POMS, HADS, PSSCAN)  
- Emotional and spiritual quality of life (e.g., FACIT)  
- Perceived support (e.g., MOS, PSSCAN) |

CASE-cancer—Communication and Attitudinal Self-Efficacy Scale for Cancer; CaSUN—Cancer Survivors Unmet Needs Measure; CHIP—Coping With Health Injuries and Problems Scale; CIPS—Cancer Inventory of Problem Situations; COPE—Multidimensional Coping Inventory; CSE—Coping Self-Efficacy Scale; ECC—Experienced Continuity of Care; EORTC-QLQ-SAT32—European Organisation for Research and Treatment of Cancer Quality-of-Life Group Cancer Inpatient Satisfaction Questionnaire; FACIT—Functional Assessment of Chronic Illness Therapy; HADS—Hospital Anxiety and Depression Scale; heiQ—Health Education Impact Questionnaire; IRLE-C—Inventory of Recent Life Experiences for Cancer Patients; MOS—Social Support Survey; PCAT—Primary Care Assessment Tool; PCCQ—Patient Continuity of Care Questionnaire; PES—Patient Empowerment Scale; POMS—Profile of Mood States; PSSCAN—Psychosocial Screen for Cancer; SCNS—Supportive Care Needs Survey; SDS—Symptom Distress Scale; SECON—Sequential Continuity Index; SUNS—Survivors Unmet Needs Survey
and referral needed. Through education and support to maintain their sense of control and quality of life, professional navigators enhance or reinforce patients’ and family members’ senses of autonomy and self-determination, thus facilitating adjustment to role changes. It also was stated that professional navigators contribute to enhance recognition of patients’ and family members’ inner resources in reinforcing active coping among them. In addition, they provide education and information on coping options to deal with several role changes, facilitate problem solving and decision making around those changes, and help patients and family members set and prioritize goals.

Second, professional navigators are actively involved in cancer self-management. They use a variety of specific efficacy-enhancing techniques. In contact with a professional navigator, a patient with cancer can feel increased self-efficacy expectations on how to better deal with health problems and symptom management related to his or her cancer, and can be reinforced in his or her ability to accept the illness and regain control, regardless of prognosis. Professional navigators enable better self-management and self-care, notably by assessing and monitoring symptoms, by providing or facilitating symptom management, and by assisting and reinforcing the patient in adjusting to and managing their altered health state and symptoms proactively, not reactivly, through timely and tailored information and self-care instructions. In addition, professional navigators reinforce self-care behavior and assist patients and families in following individualized treatment and care plans while supporting them in decision making and demanding cancer transitions, notably to survivorship, palliative care, and end-of-life care. Professional navigators play an advocacy role, as they support patients and families on how to negotiate care. In addition, professional navigators optimize self-care capabilities and skills. That has been described as being done by educating, modeling, and coaching to facilitate patients’, family members’, and team members’ behavior changes toward patient-centered care. Generally, patients with cancer and family members attribute being better informed and able to manage their cancer journey to their professional navigator’s involvement in care.

Finally, as a third way of reinforcing empowerment, the authors’ results suggest some limitations with the initial use of the concept of social support. That concept was replaced with the concept of supportive care to better integrate the clinical functions related toward addressing global distress and patients’ unmet needs. Supportive care, according to Fitch (2008), refers to a patient-centered model of care provision that offers to assist patients and families with the full range of needs (physical, informational, practical, emotional, psychological, social, and spiritual). All participants agreed that professional navigators help patients with cancer and their families access supportive care by screening, assessment, direct care or intervention, and referral. The goal is to provide access to the necessary services, as defined by those living with or affected by cancer, to meet their needs.

Skills and competencies in screening for distress and conducting comprehensive supportive care needs and resources assessment are imperative for navigators to identify unmet needs. Professional navigators help educate patients and family members on distress and its management. Notably, when a specific concern and related distress are identified, professional navigators assess and reinforce available support and resources to cope with it. They support and help patients and family members mobilize their own resources, as well as explore new ones, while providing transitional support. In addition, identifying policies or structural barriers limiting access to supportive care and suggesting ways to address those issues has been identified as part of what they do. Professional navigators are described as leaders that assist and facilitate the development of health care and community resources. They have developed an expertise in mobilizing resources and services within the cancer care organization and the community to address unmet supportive care needs and referring patients to them.

Discussion

The objective of the current study was to elaborate, refine, and validate a bi-dimensional conceptual framework for professional cancer navigation. Although the empirical validation supported the complexity of the professional navigators’ roles and functions in facilitating continuity of care and promoting patient and family empowerment, the iterative-consultative data validation process enabled the adaptation and clarification of the professional navigation framework’s content in meaning creation with the intercomprehension and intersubjectivity of both the research team and the consultation groups. The two dimensions, the related concepts, and the list of functions are coherent with several recent works aiming to define key roles of professional navigators.

Continuity of Care

The first dimension, health system-oriented, refers to the continuity of care. Several functions of the model correspond to key health system-oriented roles identified by Wilcox and Bruce (2010). Similarly, Parker et al. (2010) stressed the importance of the organizational role of patient navigators using the term network framework (i.e., engaging others in their networks in a proactive way or in response to a specific barrier so as to arrange services).

The authors’ integration of the three concepts, including informational, management, and relational continuity, as proposed by Haggerty et al. (2001, 2003)
to define continuity of care, appears particularly relevant to regrouping major functions. For informational continuity, Wilcox and Bruce (2010) also described how documentation and communication with the primary oncologist correspond to key roles of the nurse navigator, specifying that navigators enhance quality of care when they identify and communicate valuable information on behalf of patients to other nurses, physicians, and healthcare providers.

Some authors emphasized management continuity as a key role for cancer navigators. Wilcox and Bruce (2010), for instance, have illustrated that navigators initiate follow-up, return phone calls in a prompt fashion, relay messages to physicians on a patient’s behalf, and obtain answers to patient and family concerns. By being in close contact with their patients, navigators can quickly and effectively triage patients for management of physical symptoms and treatment-induced side effects (Wilcox & Bruce, 2010). Other authors have emphasized that a significant component of the navigator role involves coordination and liaison with team members, as well as management of the bureaucracy, to respond to patients’ and families’ immediate needs (Amir et al., 2004). Bowman and Grim (2008) reported that, in their role of facilitating management continuity, nurse navigators are required to respond to individual patient needs by tailoring interventions to personal requirements and facilitating care coordination. Finally, the authors’ framework particularly pays attention to relational continuity and the importance of the therapeutic relationship. Wilcox and Bruce (2010) also have stressed how a navigator becomes a consistent, constant, and easily accessible resource for patients and families.

Empowerment

For the second dimension, which is patient-centered, the authors sorted functions below three concepts regrouped in the broader construct of empowerment: active coping, cancer self-management, and supportive care. First, the authors’ framework proposes active coping as a way to increase empowerment. Similarly, Wilcox and Bruce (2010) identified that a navigator provides patients and family members with knowledge and understanding, thereby lessening their anxieties. Patients develop tools to cope with their difficulties, they feel more at ease, they are more empowered, and they focus their energy on getting well and taking back some of the control that they were robbed of by their diagnosis.

The second concept, promoting cancer self-management, which includes active participation in treatment, is also coherent with recent literature. Wilcox and Bruce (2010) stressed that navigators are professionals who are assigned to guide patients and family members through decision making and problem solving. In some models, the navigator is seen as an advocate of health education, and patient teaching is described as a large component of the job description. Navigators are in a position to review information about treatment recommendations (Seek & Hogle, 2007).

The authors’ framework defines supportive care as a third concept. To facilitate supportive care provision, navigators have been described as leaders (Amir et al., 2004), important community and healthcare resources collaborators (Seek & Hogle, 2007), and professionals who help to identify and overcome barriers to supportive care (Fillion, Aubin, et al., 2008; Fillion, Cook, et al., 2008; Fillion et al., 2010; Lantz et al., 2004). With the help of ongoing assessment by the navigator, patients receiving concurrent therapies can be monitored more closely (Wilcox & Bruce, 2010).

Strength of the Framework

The framework’s strength resides in its rigor and comprehensiveness. It carries theoretic rigor by putting forward recognized concepts for which operational definitions are available; empiric rigor from the grounded description of navigators’ functions, derived from empirical data and a variety of actors; and ecologic rigor because of the thorough validation process that has taken place in the field. That validation process was carried through until the framework had reached complete consensus among all participating groups (Mukamurera, Lacourse, & Couturier, 2006). Comprehensiveness also comes from the fact that the framework recognizes, concurrently, the bi-dimensional nature of the role.

In addition, the framework provides useful theoretic foundations to better understand its origin and implementation process, as well as to assure durability and sustainability. Navigation models often are partially described, and often only from a clinical angle (Parker et al., 2010) or from the perspective of managers and decision makers (DLCC, 2008).

By being comprehensive, the professional navigation framework can be adapted according to the needs of any organization, thus guiding managers and decision makers on organizational, clinical, and evaluative levels. Indeed, the need to work out definitions, titles, role delineation, and scope of practice for patient navigators was reported by Moore (2010). On the organizational level, the framework can allow the scope of navigators’ practice to be specified, the functions to be listed, and the necessary resources and education to be identified. On the clinical level, it becomes possible to describe associated competencies. As an example, Cook et al. (2010) are working at identifying standards of practice and core competencies in five key areas of practice, namely supportive care, collaborative care, coordinated care, information and teaching, and clinical expertise. Finally, on the evaluative level, the framework can be used to select relevant outcomes that theoretically are linked to the selected concepts and
to the related functions. Examples of validated instruments are suggested as potential indicators or outcomes to be included in program evaluations.

The framework could contribute to filling in the gaps reported in previous work, such as the need for identifying nursing-sensitive outcomes to establish evidence-based practice outcome measures and metrics that can be used to clarify the role, function, and desired outcomes (Moore, 2010; Oncology Nursing Society, Association of Oncology Social Work, & National Association of Social Workers, 2010).

Limitations

A limitation to the current study is that the majority of participants were women. However, that often is the case in nursing and in most of the healthcare professions. In addition, the specific groups of specialized and family physicians were quite small. The limited understanding of the role by physicians, as reported in previous studies (Fillion et al., 2006), may have contributed to the difficulty to recruit those groups of key actors. Finally, the vast majority of participants were supporters of the professional cancer navigation role and believed in the role.

Despite the limitations, the sample was comprised of many targeted groups of stakeholders from the studied settings and was theoretically relevant to the research objectives. In addition, because the studied sample comprises professional navigators and key informants from various Canadian settings, and because of the thorough validation process, transferability is conceivable for at least other Canadian settings (Huberman & Miles, 1991; Mukamurera et al., 2006).

Implications and Recommendations

The professional navigation framework described here can be used to validate the content of the curriculum training modules to provide a coherent and patient-centered definition of the role and a well-balanced training reflecting the functions of continuity of care and empowerment.

Data validation with experts across Canada revealed that the framework captures many definitions of professional navigation and represents how broad the definitions are. Several functions have to be mobilized to correspond to a comprehensive model of professional navigation. The identification of outcomes in the framework also responds to a practical need. Prior to implementation, adopters have to ask themselves which kind of model they want to implement and which outcomes they want to measure.

Conclusion

An integrative framework of professional navigation could improve the effectiveness and uptake of cancer navigation programs. A clear definition and expectation of professional navigators’ functions could facilitate the identification of relevant indicators and outcomes for program evaluation. With a clear definition of their role, professional navigators may be more efficient and less challenged in terms of setting priorities and making decisions while having to face both the health system’s and patients’ demands. That could contribute to improving quality and continuity of cancer care.

Lise Fillion, RN, PhD, is a professor in the Faculty of Nursing at Laval University and a researcher at the Laval University Cancer Research Center in Quebec City; Sandra Cook, RN, BA, HSM, is the manager of the Patient Navigation and Surgical Oncology Network at Cancer Care Nova Scotia in Halifax; Anne-Marie Veillette, MA, is an anthropologist at the Research Center of Centre Hospitalier Universitaire de Québec in Quebec City; Michèle Aubin, MD, PhD, FCFFP, CFPP, is the Laval University Chair of Palliative Care, Faculty of Medicine; Marie de Serres, RN, MSc, is a clinical nurse specialist, CON(C), at Centre Hospitalier Universitaire de Québec; François Rainville, MSW, is a social worker at Centre Hospitalier Universitaire de Québec; Margaret Fitch, MScN, RN, PhD, is the head of oncology nursing and co-director of the Patient and Family Support Program at Odette Cancer Center, Sunnybrook Health Science Centre, in Toronto; and Richard Doll, MSW, MSc, is the director of the Sociobehavioural Research Centre, and Provincial Leader of Cancer Rehabilitation, BC Cancer Agency, in Vancouver, British Columbia. This research was funded by the Canadian Institute of Health Research, the Canadian Partnership Against Cancer Corporation Cancer Journey Action Group, and the Agence de Santé et de Services Sociaux de la Capitale-Nationale. Fillion can be reached at lise.fillion@fsi.ulaval.ca, with copy to editor at ONFEditor@ons.org. (Submitted October 2010. Accepted for publication January 20, 2011.)

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References


