

Nurse Navigation and the Transition to Cancer Survivorship: A Review of Determinants Essential to Program Success

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Résumé : (traduction)

Les programmes d'infirmières-pivots occupent une place de plus en plus importante dans le domaine de la cancérologie. Comme nouveau domaine, l'application d'intervenants-pivots engage les infirmières et les professionnels de la santé assistant les patients à surmonter les obstacles qu'ils rencontrent avec le cancer tout au long de la vie. Le concept de navigation des patients par un intervenant-pivot est en train de s'étendre pour se concentrer davantage sur la survie après le cancer, décrite comme étant la période qui suit un traitement actif du cancer et pendant laquelle les patients se heurtent souvent à des obstacles qui influent sur leurs soins et leur qualité de vie. Grâce aux compétences et modalités d'intervention spécifiques, notamment par l'éducation, la communication et la coordination, les intervenants-pivots sont en mesure de contribuer à la réduction des disparités telles que les lacunes en matière de connaissance et communication, et ainsi facilitent l'accès optimal aux soins des survivants du cancer. L'accès aux soins de santé est un déterminant important de la santé au Canada. Ces programmes d'intervention axés sur la survie après le cancer incorporent les services de soins de santé, permettant ainsi aux patients atteints du cancer de surmonter les obstacles et d'améliorer leur état de santé. La présente analyse examinera les origines du domaine de pratique de l'infirmière-pivot, soulignera les compétences d'un intervenant-pivot qui sont essentielles à la réussite de ce programme, et révélera enfin les implications d'un tel programme.

Mots-clés :

les programmes d'infirmières-pivots en oncologie, la survie au cancer, l'accès aux soins.

Abstract:

Nurse navigation programs are becoming prominent in the field of cancer care. As a newly emerging field, nurse navigation employs nurses and other health care professionals who assist patients in overcoming barriers throughout the cancer continuum. The concept of nurse navigation is being extended to focus on survivorship, which is described as the period following active cancer treatment where patients often encounter barriers affecting their care and quality of life. By utilizing specific skills and modalities, including education, communication, and coordination, survivorship navigators are able to assist in reducing disparities such as knowledge and communication inadequacies, thus, facilitating optimal access to survivorship care. Access to health services is an important determinant of health in Canada. Survivorship navigation programs incorporate health services, providing a method in which cancer patients can overcome challenges and improve their health outcomes. This review will discuss the origins of nurse navigation, highlight navigator skills and modalities, which are essential to program success, and finally discuss the implications of a survivorship navigation program.

Keywords:

survivorship nurse navigation, cancer survivorship, access to health care.

Introduction

The concept of nurse navigation is becoming increasingly prominent in the health care field. Often facilitated by nurses or other trained health care professionals, nurse navigation is a method to assist cancer patients and their families in overcoming health care system barriers and in gaining timely access to care throughout all stages of the cancer continuum (Pedersen & Hack, 2010; Oncology Nursing Society, 2010). When nurse navigation first emerged, the program aimed to reduce disparities and improve access to oncological care for marginalized populations (Ferrante, Chen & Kim, 2007; Schwaderer & Itano, 2007; Wells, Battaglia, Dudley, Garcia, Greene & Calhoun, 2008). The concept of nurse navigation is now being applied to survivorship – the period proceeding active cancer treatment where many barriers are often encountered as a result of insufficient educational resources, lack of knowledge exchange between health care professionals and patients, and diminished communication between health care providers. By integrating survivorship nurse navigation programs into cancer care, health services, which are an important determinant of health in Canada, are expanded, facilitating positive health outcomes for patients (Pedersen & Hack, 2010). This review will discuss the origins of the concept of patient navigation as well as highlight skills and modalities essential to the success of a survivorship navigation program. The implications and outcomes of program implementation will also be discussed.

Methods

A literature search was conducted using the terms “cancer survivorship,” “[survivorship] nurse navigator,” “nurse navigation program,” and “survivorship care plan” to identify essential determinants of a successful survivorship navigation program. PubMed was used and English articles from 1995 to 2012 were collected as the concept of nurse navigation was first founded in 1990 (Freeman, Muth & Kerner, 1995). Grey literature was also searched online, including documents from various cancer care organizations and national and regional cancer agencies such as the Canadian Cancer Society, the Canadian Partnership Against Cancer, and the Ottawa Regional Cancer Foundation.

Concept Origins

In 1990, Dr. Harold P. Freeman, a surgical oncologist and a former president of the American Cancer Society, founded the concept of patient navigation (Freeman et al., 1995). The program initially focused on assisting breast cancer patients from marginalized and underserved populations in gaining access to cancer care (Ferrante et al., 2007; Schwa-

derer & Itano, 2007; Wells et al., 2008). It included cancer screening, diagnosis, treatment, and supportive care (Harold P. Freeman Patient Navigation Institute, 2012). As the program proved to be successful, the concept of nurse navigation was adopted for further use in oncology by many health care institutions and today is becoming a growing area of research and investigation (Ferrante et al., 2007; Schwaderer & Itano, 2007; Wells et al., 2008).

Nurse navigation programs are widely implemented in the United States (Oncology Nursing Society, 2010) and are becoming increasingly popular in Canada (Canadian Partnership Against Cancer, 2010). While United States programs have emphasized the importance of assisting marginalized populations in accessing cancer care (Schwaderer & Itano, 2007; Vargas, Ryan, Jackson, Rodriguez & Freeman, 2008), Canadian programs have placed importance on providing timely access to care, informing and educating patients, coordinating care, and linking patients to proper resources (Melinyshyn & Wintonic, 2006; Psooy, Schreur, Borgaonkar & Caines, 2004).

In Halifax, Nova Scotia a patient navigation project was implemented in 2000 to assist in timely diagnosis of breast abnormalities (Psooy et al., 2004). The following year Cancer Care Nova Scotia established a breast cancer navigation program, later expanding their model to include survivorship care (Pedersen & Hack, 2010). Well-integrated programs also exist in Québec (Canadian Partnership Against Cancer, 2010), British Columbia (BC Cancer Agency, 2005), and at Princess Margaret Hospital in Toronto, Ontario, where a breast cancer survivorship navigation program has been successfully implemented and provides survivors with the appropriate education and support to meet their needs (Princess Margaret Hospital, n.d.).

Survivorship

Cancer is a disease that affects nearly 40% of Canadian women and 45% of Canadian men (Canadian Cancer Society, 2012). While the number of cancer diagnoses each year rises, medical advancements in detection and treatment have decreased the mortality rates of the disease (Canadian Cancer Society, Statistics Canada, Provincial/Territorial Registries, & Public Health Agency of Canada, 2010). This has resulted in an increase in cancer survivors totalling nearly one million in Canada today. This figure is projected to double by the year 2020, compelling health care providers to search for alternate care methods in order to support this growing vulnerable population (Canadian Partnership Against Cancer, 2012).

Often the transition from cancer treatment to survivorship, the period following active treatment, encompasses challenges unanticipated by the patient. As the frequency of visits with the oncology treatment team decreases and care is fragmented between primary care providers and specialists (Pratt-Chapman, Simon, Patterson, Risendal & Patierno, 2011), completion of treatment often leaves the patient feeling isolated with few supports and with a sense of being “lost in transition” (Ganz, Casillas & Hahn, 2008, p. 209). With a sense of ill-preparedness, survivors enter this critical stage unsure of the proper actions to take to maximize their health outcomes (Stanton, Ganz, Rowland, Meyerowitz, Krupnick & Sears, 2005; Alfano & Rowland, 2006).

In addition, survivors may experience personal alterations in physical and psychosocial domains (Alfano & Rowland, 2006). Physical symptoms such as residual pain, fatigue, and alterations in body form and function caused by previous surgical interventions and other forms of treatment may persist after treatments have ceased. Psychological symptoms such as anxiety, fear of reoccurrence, and distress may continue beyond the course of the disease and treatment. Survivors may also be challenged with overcoming cognitive alterations such as memory and concentration difficulties as a result of the primary disease or treatment side effects (Pratt-Chapman et al., 2011; Alfano & Rowland, 2006; Ganz et al., 2008; Canadian Partnership Against Cancer, 2009). With knowledge inadequacies, patients enter survivorship unsure of how to overcome challenges and maximize their health outcomes, even when physical and psychosocial effects are not apparent (Pratt-Chapman et al., 2011).

Role Characteristics

When entering survivorship, patients often have insufficient knowledge and tools to successfully overcome obstacles related to their health, survivorship care, and societal re-integration (Pratt-Chapman et al., 2011). Navigators strive to use a holistic approach to health care (Fillion, de Serres, Lapointe Goupil, Bairati, Gagnon & Deschamps, 2006; Canadian Partnership Against Cancer, 2010), addressing issues that include and surpass those directly associated with the remnants of cancer treatment. This empowers patients and reduces disparities associated with survivorship care (Canadian Partnership Against Cancer, 2010). Navigators must facilitate timely access to survivorship care and alternate services, as well as function to assist survivors with physical, informational, psychosocial, and practical needs (Pratt-Chapman et al., 2011).

The efficacy of patient navigators also hinges on the skills that they possess. Many programs, such as those in Nova Scotia, Québec, and Alberta, are managed by Specialized

Oncology Nurses (Canadian Partnership Against Cancer, 2010). These individuals are qualified registered nurses who have extensive training, knowledge, and experience in oncological care (Canadian Partnership Against Cancer, 2010; Canadian Nurses Association, 2008). Navigators must be strong communicators equipped with the ability to identify informational inadequacies and emotional issues (Canadian Partnership Against Cancer, 2010). As an empathetic advocate for the patient (Pedersen & Hack, 2010), navigators should be able to provide supportive encouragement while facilitating problem-solving and self-management strategies. They should have extensive knowledge regarding each patient’s condition, treatment plan, and prognosis, as well as an awareness of the patient’s environment and available services and supports (Canadian Partnership Against Cancer, 2010).

Intervention Modalities

There are many components noted within the literature as imperative to a successful navigation program. These elements have been organized into domains consisting of education, communication, and coordination; modalities that are deemed essential for program success.

Education

Following cancer treatment, patients report unawareness of long-term and late effects (Pratt-Chapman et al., 2011; Ganz et al., 2008). To illustrate this lack of knowledge, research shows that many breast cancer survivors admit to having been uninformed of lymphedema, a potentially debilitating side effect of breast cancer treatment, until they experienced the complication first-hand (Paskett & Stark, 2000). This clearly exemplifies an absence of knowledge exchange. In order to maximize health outcomes and decrease distress throughout survivorship, it is important that navigators adequately educate patients regarding the effects of their disease and treatment (Pratt-Chapman et al., 2011).

Providing cancer survivors with detailed diagnostic information, including their medical history and a summary of all completed treatments, has been shown to assist patients in the comprehension of their health condition and the associated risks (Ganz et al., 2008; Pratt-Chapman et al., 2011; Institute of Medicine, 2007). This information exchange allows survivors, their family, and their friends the opportunity to gain an understanding of the patient’s condition and expectations to have following treatment. Navigators should also provide survivors with information on surveillance for cancer reoccurrence, including the signs and symptoms that require monitoring and/or medical attention (Ganz et al., 2008). Through knowledge exchange, survivors

become better prepared to face and resolve late and chronic effects, as well as to mitigate risks associated with recurrence. Even in the absence of long-term or chronic side effects, survivors benefit from educational resources on general health and wellness, including information on balanced diets, exercise regimes, and components of a healthy lifestyle (Ganz et al., 2008).

The success of a survivorship navigation program relies heavily on the educational resources and informational exchange that is provided and facilitated by navigators. Improving patient education and access to knowledgeable health care professionals, such as that provided in a survivorship navigation program, allows survivors to gain an understanding of their condition and better control their health outcomes (Ganz et al., 2008; Pratt-Chapman et al., 2011).

Communication

In order for a survivorship navigation program to succeed, knowledgeable navigators should be readily able to communicate with their patients. To accomplish this, navigators can utilize a variety of mediums such as face-to-face meetings, online communication, and telephone consultations. Adopting these means of communication allows the survivor to conveniently contact the nurse navigator with concerns or questions, alleviating any confusion, anxiety, and distress (Canadian Partnership Against Cancer, 2010).

The Canadian Partnership Against Cancer (2010) and Pedersen and Hack (2010) report that having a navigator as a single point of contact is crucial in the success of a survivorship navigation program. Patients know whom to contact when they are in need of assistance or support, and are able to approach one individual with all of their questions and concerns. This single point of contact improves consistency for survivors. Familiarity with the appropriate contact can result in patients being more comfortable inquiring about their health care, thus greatly reducing anxiety and distress (Pedersen & Hack, 2010).

Coordination

After cancer treatment is complete, patients often find that communication is fragmented between primary care providers and specialists, leaving them “lost in transition” (Ganz et al., 2008 p. 209). Throughout treatment, primary care providers are often excluded from patient management and may not be reintroduced until the patient returns for regular appointments, potentially years later (Ganz et al., 2008). Navigators can prevent fragmentation by facilitating communication between specialists and primary care physicians, as well as between patients and their family doctors

(Pratt-Chapman et al., 2011). Patients are often reluctant to transition back to their general practitioner following cancer treatment. Survivors may believe that they are not in need of a physician’s assistance or that a family physician cannot adequately care for their health care needs and that a specialist would be more appropriate (Ganz et al., 2008). Consequently, navigators should initiate conversations with survivors with the goal of a successful transition back to a primary care provider (Pratt-Chapman et al., 2011).

To ease the transition from cancer treatment to survivorship, navigators can track clinical follow-up to ensure that patients adhere to their appointment schedule. It may be helpful to provide patients with a timeline of when appropriate follow-up appointments should take place and a list of physicians to contact (Pratt-Chapman et al., 2011). This decreases fragmentation and ensures that patients receive timely follow-up care from their family physician. It is also important that nurse navigators address psychological difficulties that the patient may be experiencing and refer them to the appropriate designated professionals (Ganz et al., 2008; Canadian Partnership Against Cancer, 2009).

Implications

Through the implementation of survivorship navigation programs, cancer care becomes increasingly accessible and understandable for patients (Braun et al., 2012). Positive outcomes in patient satisfaction result from the individualized care that navigators provide (The Ottawa Regional Cancer Foundation, 2009; Wilcox & Bruce, 2010). Navigators are also able to reduce fragmentation in follow-up care and assist survivors in identifying their needs (Braun et al., 2012). Collectively, these actions decrease survivor anxiety and facilitate self-management skills, which allow the survivor to approach and overcome societal, medical, and psychological barriers, as well as develop a personal action plan for their future (The Ottawa Regional Cancer Foundation, 2009).

Conclusion

Survivorship navigation is an emerging concept in cancer care (Pedersen & Hack, 2010). Nurse navigation programs expand upon available health services, positively impacting the health of individuals living with chronic illnesses such as cancer. Navigation programs with a strong focus on education, communication, and coordination assist cancer survivors in overcoming social, medical and psychological barriers following treatment (Pratt-Chapman et al., 2011; Alfano & Rowland, 2006; Ganz et al., 2008; Canadian Partnership Against Cancer, 2008). With the number of cancer survivors rising, the role of survivorship navigators will

become increasingly influential as they improve patients' quality of life and facilitate access to survivorship care (Canadian Partnership Against Cancer, 2012).

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