Utilizing Research to Guide Clinical Practice in Prostate Cancer Education

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Conducting research in problem solving and utilizing findings involves decision making. These are the activities of leaders in oncology nursing. Specifically, providing patients newly diagnosed with cancer with information to assist them in their treatment decision-making efforts is an integral part of clinical practice. Nurses and other allied healthcare professionals must participate in and conduct empirical research to ensure that the provision of such services is supported by a reliable understanding of what information consumers actually require to make informed choices. This article outlines the steps taken by oncology nurses to use research to improve patient services and transform cancer care. It describes how a patient-focused program has been developed and currently is being evaluated with one specific patient population—men with prostate cancer. The article also describes how past and current research has been used to guide clinical practice. The author will discuss challenges that were encountered during the initial three years, along with plans for the future development of the center.

Background

Prostate cancer has become one of the most common forms of cancer in men in North America, second only to skin cancer. Increased public awareness has resulted in more men being screened and diagnosed at earlier ages with cancers that are localized to the prostate gland. At the time of diagnosis, men usually have a multitude of questions concerning the eradication of the cancer. In most centers, urologists diagnose and provide answers to many of these questions within the context of treatment consultations. However, the type and amount of information discussed often are dependent on the individual urologist’s practice. Some urologists focus on surgery as a treatment option and provide very little information about other available treatment options, and others fully inform patients about each available treatment option. In addition to information given orally, some urologists also provide written materials in the form of brochures or reprints.

In 1999, the Prostate Centre at Vancouver General Hospital in British Columbia, Canada, received a $20 million private donation from Mr. Jim Pattison, a local businessman. Funds from the donation were used to hire a nurse scientist at the Prostate Centre in September 1999. The role of this individual was to establish a patient education and resource center for men with prostate cancer. The Prostate Education and Research Center (PERC) at Vancouver General Hospital opened in January 2000. PERC’s mission is to provide men and their families with timely and accurate evidence-based information to assist them in making informed treatment decisions in collaboration with their physicians. The initial provision of services was provided by the nurse scientist based on her previous research conducted with this patient population. In addition to the nurse scientist, PERC now has three grant-funded nurses. Patient services are based on an ongoing program of research that is examining the provision of information to support treatment decision making from the prediagnostic to palliative phase.

Reviewing the Literature

First, the literature was reviewed. Davison, Degner, and Morgan (1995) identified nine categories of information that patients newly diagnosed with cancer considered important. These nine categories of information were confirmed as being appropriate by a group of men who were within six months of prostate cancer diagnosis. After the content was validated, a paper-and-pencil questionnaire was developed to assess information preferences using a Thurstone methodologic approach (Thurstone, 1974). Thurstone’s method asks individuals to rank order a set of items two at a time. The idea of paired comparisons helps to overcome difficulties encountered when a researcher wants an individual to rank a set of items in order of perceived importance or preference.

The nine categories of information were presented to men in fixed-order pairs, and the men were asked to select the one category from each pair that was most important on that day. Results showed that men rated information about prognosis or likelihood of cure, treatment options available for their stage of disease, side effects of recommended treatments, and stage of disease (how far the disease has spread) as the top four information priorities. A Likert scale also was used to measure the amount of information they wanted about each category. When given the choice, most men wanted a lot of information about each category of information. This approach revealed that the Likert scale created a ceiling effect and was not able to assist clinicians in identifying patients’ top information priorities.

Developing the Pilot Study

Next, a study was conducted to determine whether assisting men in obtaining the information they wanted would help them be more active participants in treatment decision making (Davison & Degner, 1997). A decision-support intervention was developed based on what previous researchers had identified as being most beneficial. For example, men in the intervention group received a written information package with discussion, a list of questions they could ask their physicians, and an opportunity to have the medical consultation audiotaped. Men in the control group received the same written package with no discussion. This written package also included a few of the brochures that patients already had access to in the clinic’s

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waiting area. At six weeks, men who received the intervention reported taking a more active role in decision making and having lower levels of state anxiety than men in the control group.

Although the intervention was effective, the impact that partners had on the actual decisions was unknown. The information questionnaire was converted into a computerized program capable of providing immediate feedback to patients, their partners, and clinicians. The computer program, titled Patient Information Program (PIP), was validated at the Prostate Centre to measure the information and decision preferences of men newly diagnosed with prostate cancer and their partners (Davidson et al., 2002). Graphic printouts became available for nurses to use in counseling sessions with couples. Differences in patients’ and their partners’ information and decision preferences now could be identified and discussed within the context of this counseling session. This also provided the nurse scientist with additional clinical experience with patients in Vancouver and an opportunity to learn about differences in urologists’ practices. This funded research project was a means to meet the clinical service requirement of providing informational support to men and their partners at the time of diagnosis.

Patients and their partners also were provided with a choice of other information resources to learn more about other topics of interest. For example, they had access to written information (books, brochures, reprints), videos, related Web sites, and information on how to access prostate support groups. The types of resources that they accessed and actually used were recorded and used as a guide when PERC acquired resources. Written information and videos were the two main resources that men and their partners wanted to access. About 55% of couples used the Internet to access information. However, computer use was limited to individuals with access to computers at home or work. Most patients who used a computer had difficulty sorting through the numerous sites and distinguishing what information was pertinent to them. Few patients used the support group even though they were given information about how to access them. Perhaps this was because the couples were younger and most were employed full-time. Older, retired couples had a tendency to join support groups.

Based on the results of this survey, staff at PERC decided that having one computer available for patients to use was adequate and that a take-home list of suggested Internet sites along with a brief description of each was sufficient to meet the needs of these couples. Resources at PERC then focused on written materials and videos. A few CDs also were purchased for computer users.

Based on this one-group, quasiexperimental study, PERC was able to obtain funding to conduct a study to compare a generic approach (written information package and video) with an individualized approach to providing information to men to facilitate treatment decision making. A nurse was hired and trained to conduct this study at the Prostate Centre. The intervention includes providing both written and oral information to men and their partners based on their specific information preferences, disease characteristics (stage of disease, Gleason score, prostate specific antigen, biopsy results), medical history, age, and personal preferences and biases. Men in the intervention group also receive the standard information package. PIP now prints information sheets on each category that patients rank as being most important to discuss on that particular day. Information sheets are individualized according to the patients’ and partners’ specific questions and concerns about how suggested treatment options will impact future lifestyle and quality of life. One major benefit of this computer program is that changes in any of the information categories can be quickly incorporated as new research results emerge or changes in clinical practice occur. This ensures that the information will be current and accurate at all times. In addition, partners are able to access the information needed to meet their individual needs.

**Pilot Study Uncovers New Needs**

During the initial pilot work, information related to sexual functioning and treatment for erectile dysfunction following treatment was identified as a major area requiring development. Funding was received from the Canadian Cancer Society to develop a video and booklet that would provide couples with information about the impact of treatments on sexual function and treatment currently available for erectile dysfunction. Having younger couples on the video also was identified as important because many of the patients and their partners were younger than 60. The videos and booklets were distributed to urologists, patient support groups, and cancer agencies in Canada. So far, the response to this project has been favorable. A research project is under way to identify the sexual rehabilita- tion needs of 200 men following either brachytherapy (n = 100) or radical prostatectomy (n = 100). Another nurse was hired and trained to conduct this study. Results from this study will be used to guide the provision of sexual health counseling services at PERC. The center will hire a grant-funded sexual health clinician in the spring of 2003.

A second need was identified from the pilot study. Discharge teaching for men after radical prostatectomy often was inconsistent. Based on an additional review of the literature, a comprehensive discharge program is being implemented and evaluated on the urology unit. Men are provided with the information booklet “Pre- and Post-Radical Prostatectomy” in the preadmission clinic. Staff members on the urology unit use the booklet to guide discharge teaching. When released after surgery, patients are provided with a discharge bag that includes incontinence supplies, a brochure of community resources, and medical supplies. Staff members on the urology unit contact patients by telephone within 48 hours after discharge to answer any questions they have about home self-care. This project is evaluating the various components of the discharge program and identifying community resources that couples may need within the first month after surgery. Changes to the discharge program will be made based on the results of the survey. Again, funding allowed PERC to hire another nurse to work with staff members on the urology unit and conduct the study. Results from this study will be used to standardize care and discharge teaching that is provided to men after radical prostatectomy.

Originally, all resources at the center were coded according to the information categories associated with the computer program. The categories included prognosis, stage of disease, treatment options, side effects, family risk, home self-care, and sexuality. The resources were entered into a database program that provided individuals with an opportunity to select the category or categories that they wanted to have information about and the method or type of resource (i.e., brochure, book, reprint, video, or CD) they wanted to access. This system was inefficient and cumbersome. For example, one resource could include several categories. Doing a comprehensive coding on each type of resource became exhausting for staff members. At about the same time, PERC received a two-year donation of $16,000 to purchase books for the library. This was appreciated but led to another dilemma. PERC now needed assistance to organize, track, and establish a new coding system for the library. A patient’s daughter volunteered to enter and code all the books into a new database that could grow with the center. Books and videos were slotted into six major categories: prostate cancer; prostate disease; diet, nutrition, and lifestyle; sexuality; complementary and alternative treatments; and spiritual, emotional, and personal experiences.

A miscellaneous category also was created to cover other related topics such as ethics and participation in clinical trials. These new categories were entered into the computer database. Patients and their families can select the topic they wish to access, and a computer printout indicates the title and call number of the selected resources. All videos and books can be signed out for varying lengths of time. In addition, all brochures and reprints have been cataloged and coded according to these main categories. Although this database was necessary to assist patients and their families who visit the center, it also will facilitate the future use of trained volunteers as a means of cost containment.

**Challenges**

Several challenges were experienced in the first three years, and many are ongoing. The major challenge has been to simultaneously...
provide a clinical service to patients and conduct research necessary to develop the center. Currently, new patients are referred to PERC by urologists practicing at the Prostate Centre and in the surrounding community. As more urologists choose to use PERC, more staff and resources will be needed. Self-referrals also are becoming commonplace as more patients use and learn about PERC. This raises the concern of who will pay for the continued salaries of staff after the research projects are completed. The Canadian healthcare system does not allow for nurses to bill the system for such services. The second greatest challenge was to ensure that the PERC had the most current educational resources. The center has been fortunate to receive contributions and funding from patients and industry sources to meet these needs. However, the ordering and coding of such resources is time consuming and requires constant attention.

Future Plans

Although this program currently focuses on informational support at the time of diagnosis, several time points must be studied to address the needs of patients and their families. For example, additional resources are needed for health promotion. Lifestyle issues have been identified as important for men over the trajectory of the cancer experience. Prostate cancer has become a chronic disease, and the medical community has little knowledge about the optimal time to discuss and implement palliative care. In addition, the staff at the center do not know whether a separate information program should be developed for the partners of these men. The center will continue to evolve to meet the changing and ever-increasing needs of this patient population. Local prostate support groups have become extremely important in providing input into study protocols and disseminating results. Changes in practice will be based on the results of research studies being conducted at the center and on findings of other researchers in this area. The way PERC is using research to guide clinical practice in prostate cancer education may serve as a model that oncology nurses can use to develop similar programs in their particular areas of clinical expertise.

John Gardner wrote, “Leaders must foster the process of renewal” (1990, p. 21), even if the process of change sometimes seems slow. By working within the existing structures of healthcare institutions, oncology nurses can preserve the processes that work and build on the values held by their teams. Empirical evidence from responsible and reliable scientific research can facilitate acceptance of changes, reenergize forgotten goals, and generate new goals that respond to the changing needs of patients and families affected by cancer.

References