Evidence-Based Practice Project

Survivorship Health Information Counseling for Patients with Prostate Cancer

Joan Colella and Glen Gejerman

In 2006, the Institute of Medicine (IOM) Committee on Cancer Survivorship: Improving Care and Quality of Life concluded with a special report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” which examined medical and psychosocial issues faced by cancer survivors and recognized survivorship as a phase of care within the cancer continuum. Unfortunately, survivorship care is often overlooked, and health-care providers fail to include potential latent chronic problems resulting from the cancer treatment in their patient education interventions. The report suggests that while 80% of cancer patients seek counseling related to survivorship health information, only 20% receive survivorship health counseling for the chronic symptoms related to their cancer therapy. This gap leads to patient dissatisfaction with survivorship standards of care (IOM Committee on Cancer Survivorship: Improving Care and Quality of Life, 2006).

Background of Problem

In 2012, 241,740 new cases of prostate cancer were diagnosed, and 28,170 men died of prostate cancer. Ninety percent of all cases are diagnosed with organ-confined disease. The five-year survival rate for local-regional prostate cancer is nearly 100%. However, the five-year survival for Stage IV disease is only 28%. Over two million men in the United States diagnosed with prostate cancer continue to lead active lives, making survivorship health counseling a high priority (American Cancer Society, 2012).

As the number of prostate cancer survivors treated with radiation therapy increases, so will the number of patients experiencing chronic side effects of urinary incontinence, bowel dysfunction, and sexual dysfunction. According to the Michigan Cancer Consortium (2010), 2% to 4% of patients will develop permanent urinary incontinence, 8% will develop permanent diarrhea, and 45% will develop permanent erectile dysfunction as a result of radiation therapy. The...
adverse side effects of radiation treatment often negatively impact social interactions and family life. Additionally, lost work days may adversely affect income and job security. As patients complete radiation therapy, few would instinctively know what questions to ask related to latent treatment side effects.

**PICOT Question**

To determine if survivorship discharge information impacts patient satisfaction with discharge health information, the following question was formed using the PICOT format: Will the addition of survivorship discharge health information counseling that includes patient health information preferences for men completing radiation therapy for prostate cancer improve satisfaction when compared to usual discharge health information?

The PICOT format for this project is reflected as follows:

- **Population** – Prostate cancer patients completing external beam radiation therapy.
- **Intervention** – Survivorship discharge health counseling.
- **Comparison** – Usual discharge health counseling.
- **Outcome** – Increased patient satisfaction.
- **Time frame** – One-time pilot.

**Definition of Concepts**

**Satisfaction**

Satisfaction has been defined as an individual’s perception of usefulness, effectiveness, or benefit of the health services provided (Medical Conditions Dictionary, 2013). Patient satisfaction for survivorship discharge health information was measured in this project using the Patient Satisfaction Survey (Northouse, 2005).

**Survivorship**

According to the National Cancer Institute (2013), survivorship encompasses physical, psychosocial, and economic issues of cancer. Survivorship extends beyond diagnosis and treatment, and it incorporates follow-up treatment, late effects of treatment, secondary cancers, and quality of life. In 2009, the National Cancer Survivorship Initiative classified the cancer trajectory by stages: acute, intermediate, and after care. Cancer experts have defined survivorship as a lifelong process of self-monitoring and self-evaluation to manage symptoms and the consequences of living with chronic conditions resulting from treatment. Recognition of survivorship as a vital stage in the cancer trajectory can help providers shift patient health information from an illness to a wellness focus and from acute reactive care to proactive care (Cooper, Loeb, & Smith, 2010; McCorkle et al., 2011).

**Survivorship Discharge Health Information Counseling**

Survivorship counseling for patients with cancer refers to providing health information to patients that will empower them to manage chronic symptoms resulting from treatment (Northouse, 2005; Northouse, Mood, Montie et al., 2007; Northouse, Walker, & Schaafnacker, 2002). The intent of this type of discharge survivorship counseling is to increase patient satisfaction with regard to management of chronic treatment side effects (Northouse, 2005; Northhouse, Mood, Schaafnacker et al., 2007).

**Literature Search**

Using the search engines of the Cochrane Library, Evidence-Based Peer-Reviewed Journals, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Joanna Briggs Institute, PubMed, National Cancer Institute, Medline, and Cancer Survivorship National Expert Reports, a review of the literature was completed using the key words cancer survivorship, survivorship education, prostate cancer, cancer chronic care, and patient satisfaction within the time frame of 1966 to 2013. The search identified 62 articles. Despite the use of prostate cancer as a search term, some articles discussed breast, gynecologic, and lung cancers. Others were not written in English. Fifty-five non-English studies and non-prostate cancer studies were excluded yielding seven articles that met the inclusion criteria for further review. An IOM consensus guideline report was also reviewed.

**Literature Review**

The Johns Hopkins Nursing evidence-based practice appraisal tool was used as a guide to assess the strength and quality of research and non-research evidence. Strength of research is indicated by Levels (Levels I to III for experimental, quasi-experimental, and descriptive or qualitative research, and Levels IV to V for non-research guidelines or expert opinions) and quality of research with the terms High, Good, or Low (Newhouse, Dearholt, Poe, Pugh, & White, 2007). The strength of evidence ratings reflected five Level 1 Research (randomized controlled trial [RCT] or meta-analysis of RCTs), one Level II Research (quasi-experimental) study, and one Level III Research (non-experimental or qualitative) study. One Level IV expert committee consensus guideline report was also reviewed. The critical analysis was organized by two themes related to prostate cancer patient satisfaction: survivorship interactive education interventions, and survivorship health content (see Table 1).

**Survivorship Interactive Education**

Gysels and Higginson (2007) conducted a meta-analysis of nine RCTs with 1,678 patients. The meta-analysis revealed a positive correlation between patient and health provider interactive survivorship interventions. The RCTs tested dichotomous interactive educational technology interventions (such as computer use and videotaping)
<table>
<thead>
<tr>
<th>Study</th>
<th>Level of Evidence</th>
<th>Sample</th>
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<tr>
<td>Gysels &amp; Higginson (2007)</td>
<td>High/Level I</td>
<td>$N = 1,685$ Meta-analysis of 9 RCTs. Three studies evaluated use of videotapes and 6 evaluated computer technologies.</td>
<td>Tested innovative interactive educational technology (computer use, videotaping) against conventional interactive educational interventions (written reading material or verbal interactions).</td>
<td>2 reviewers and heterogeneity testing; various instruments used in each study.</td>
<td>Continuous data were summarized as weighted mean differences and dichotomous data as odds ratios with their respective 95% confidence interval.</td>
<td>Study outcome concludes there is significant improvement in prostate cancer survivorship patient satisfaction with interactive PowerPoint™ and health provider education.</td>
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<td>Carstons (2009)</td>
<td>High/Level I</td>
<td>Meta-analysis of 47 studies, 19 RCTs with subject sizes of 1,678 to 3,501.</td>
<td>Multiple interventions and results reviewed.</td>
<td>2 reviewers independently reviewed articles adding rigor to the strength of appraisal; various instruments used in each study.</td>
<td>Studies suggested a positive relationship between providing evidence-based cancer survivorship health information based on readiness to learn, treatment side effects, patients no longer wish to be passive recipients of care.</td>
<td>Cancer related information or education provided based on learner readiness reduces anxiety, improves patient compliance, ensures realistic expectations, promotes self-care, and participation generates feelings of control related to security and safety.</td>
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<td>Demark-Wahnefried et al. (2005)</td>
<td>High/Level I</td>
<td>Meta-analyses of 28 RCTs conducted from 1966 and beyond, subject sizes ranging from 24 to 5,965.</td>
<td>Cancer survivor health information education. Cancer survivorship patient. Health information preferences and satisfaction.</td>
<td>3 reviewers involved with meta-analysis, multiple instruments used in various studies.</td>
<td>Important content areas: for osteoporosis, obesity, functional design, impotence, incontinence, fatigue. Desire for diet, exercise, and other lifestyle changes information.</td>
<td>As survivor numbers increase so do risks for developing co-morbid chronic medical conditions resulting from treatment, incidence of secondary cancers, and recurrence of primary cancer progression. Clinical evidence is significant that survivors will seek guidance and counseling from oncology health providers for lifestyle change information and behavioral interventions.</td>
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<td>Hawes et al. (2006)</td>
<td>Good/Level I</td>
<td>Multi-center site</td>
<td>Secondary analysis of randomized-controlled trial (RCT). Identified spouse issues. Tested problem-solving education interventions for prostate cancer patients and partners to see if quality of life (QOL) improved. Identified if additional survivorship health problems exist as a result of treatment.</td>
<td>Social Problem-Solving Inventory (construct validity determined via factor analysis, good reliability measured by internal consistency and test, re-test reliability, adequate validity). Profile of Mood States.</td>
<td>Summary interpretive effect size for patient side effect significance was impotence 50%, incontinence 25%, general side effects 25%. Findings suggest a negative relationship between chronic health problems experienced by patients and satisfaction with health information addressing chronic symptoms.</td>
<td>Need to provide information about side effects/challenges. Need to address and identify partner/patient problems separately. Most common side effects of treatment issues for patients evolve around impotence, urinary issues, and communication dysfunction.</td>
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<td>Northouse, Mood, Schafenacker et al. (2007)</td>
<td>High/Level I RCT</td>
<td>N = 263 spouse-patient dyads; 123 in control group, 112 in the experimental group.</td>
<td>Assess patients’ and spouses’ quality of life, appraisal of illness, resources, symptoms, and risk for distress across three phases of prostate cancer: newly diagnosed, biochemical recurrence, and advanced.</td>
<td>39-item Functional Assessment of Cancer Therapy (FACT) to assess domains of quality of life: physical, social/family, emotional, and overall functions. Functional Assessment Cancer Therapy-G (FACT-G) and (FACT-P) scales measured well-being appraisal of variables for illness/care-giving scales. Mishel Uncertainty in Illness Scale. Beck Hopelessness. Concepts: Uncertainty, Hopelessness.</td>
<td>Comprehensive psychosocial assessment of patients with prostate cancer and their spouses across three phases of illness. Psychosocial experiences of couples facing prostate cancer are affected more by the phase of illness than by whether they are patient or spouse. Patients and spouses were more similar than different; both were affected by the illness, indicating that psychosocial interventions should be targeted to patients and their spouses, but tailored to dyads’ specific phase-related needs. Findings support the need for survivorship education for patients and partners living with prostate cancer.</td>
<td>Phase-specific programs of care are needed to assist both men with prostate cancer and their spouses to manage the effects of illness. Patients reported less uncertainty and better communication with spouses than control patients. Intervention spouses reported higher quality of life, better communication and less negative appraisal of caregiving and uncertain at later points of follow up (4, 8, 12 months).</td>
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<td>Harden et al. (2009)</td>
<td>Good/Level II</td>
<td>112 couples</td>
<td>Secondary analysis of earlier study. Subset focus groups used to provide patients &amp; spouses with a supportive-educative, family-based intervention. Results of intervention measured 2 weeks after completion of intervention.</td>
<td>Patient Satisfaction Survey.</td>
<td>Prostate cancer patients reported high satisfaction with survivorship health information (all means scores &gt; 4.01). 71% patients reported survivorship health information content most valuable coping with diagnosis, treatment, and treatment side effects.</td>
<td>Expanded the phenomena of living with prostate cancer. Prostate cancer patient survivorship health information preferences improved satisfaction. Need for cancer survivorship to become part of the cancer trajectory. Couples preferred provider face-to-face for counseling and prostate cancer survivorship information.</td>
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<td>Harden, Northouse, &amp; Mood (2006)</td>
<td>Good/Level III Qualitative</td>
<td>N = 15 subjects, 50 to 84 years old.</td>
<td>Open-ended questions, interviews. Focused on prostate cancer survivorship, health information preferences, needs and satisfaction.</td>
<td>Identification of themes.</td>
<td>Adaptation comparison across ages groups of couples. Expanded body of knowledge related to phenomena of living with prostate cancer. Noted age-related adaptation differences related to fatigue, role reversal, fear, decreased social interactions, intimacy.</td>
<td>Need to provide information in ways to maximize open partner communication and intimacy.</td>
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<td>Institute of Medicine (2006)</td>
<td>High/Level IV (consensus report by experts)</td>
<td>Not Applicable</td>
<td>Clinical experts.</td>
<td>Evidenced-based national and public guideline development for survivorship cancer care to be a seamless. Transition along the cancer care continuum and address the survivorship stage of cancer.</td>
<td></td>
<td>Recommends implementation of clinical guidelines for cancer survivorship education for prostate cancer patients for health information which includes patient preferences related to information about chronic side effects from cancer treatment, long term care. Patient and family need support and teaching.</td>
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against conventional interactive educational interventions (such as written reading material or verbal interactions). Interactive technologies improved patient knowledge and satisfaction.

Harden and colleagues (2009) and Northouse, Mood, Schafenacker, and colleagues (2007) reported similar findings that suggest a strong positive correlation between interactive, face-to-face family and health provider counseling sessions to allow survivorship health information to manage chronic treatment side effects and satisfaction. Following a cross validation RCT, Northouse, Mood, Schafenacker, and colleagues (2007) reported that men with prostate cancer and their spouses had positive outcomes from interactive and face-to-face counseling interventions that offered information and support. The information included survivorship and symptom management content that focused on urinary incontinence and bowel and sexual difficulties. Similarly, Harden and colleagues (2009) reported that patients with prostate cancer had high satisfaction with survivorship health information programs. Most patients (71%) reported the survivorship health information content most valuable was information to cope with diagnosis, treatment, and post-treatment side effects.

Similar findings among researchers support that providing prostate cancer survivorship education and counseling for management of chronic and/or adverse side effects of prostate cancer treatment is important. Face-to-face interaction of the health care provider with the patient and family may be the most valuable intervention to improve patient satisfaction (Gysels & Higginson, 2007; Harden et al., 2009; Northouse, Mood, Schafenacker et al., 2007). Moreover, the IOM (2006) recommends an interactive exchange of health information between the patient and the health provider addressing chronic symptoms resulting from treatment.

Survivorship Health Content

Hawes and colleagues (2006), in a secondary analysis of an RCT, focused on identifying if additional survivorship health problems exist among patients as a result of prostate cancer treatment and need to be included in patient health information. They noted that education regarding how to live with the effects of prostate cancer treatment, such as impotence, incontinence, and osteoporosis, were important concepts for survivorship content. A meta-analysis by Carstons (2009) focused on these same key concepts for cancer patient health information, health care decision-making, and the effectiveness of patient education about cancer. The evidence of the studies reviewed suggested a positive relationship between providing evidence-based cancer survivorship health information on effects of treatment following assessment of patient readiness to learn and the desire to no longer be a passive recipient of care.

Demark-Wahnefried, Aziz, Rowland, and Pinto (2005) also supported the need for the provision of prostate cancer survivorship health content based on patient needs and preferences to manage chronic side or adverse effects of prostate cancer treatment. They further noted the education material should be tailored to patient needs and may include topics such as fatigue, impotence, incontinence, obesity, and functional decline, as well as methods to improve overall health with diet, exercise, and other lifestyle changes. The study also examined the preferences of patients with prostate cancer for learning to apply problem-solving steps as active participants in managing their care. A qualitative analysis by Harden, Northouse, and Mood (2006) also noted that educational material include the topics noted by Demark-Wahnefried and colleagues (2005).

Similar findings among researchers support that prostate cancer survivorship education must be specific to the needs of each patient but may include

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<th>Table 2. Usual Discharge Versus Survivorship Intervention Patient Satisfaction Frequency Distribution (N = 52)</th>
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<td><strong>Content</strong></td>
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<tr>
<td>Information about how to cope with your illness and side effects?</td>
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<tr>
<td>Health information met needs?</td>
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<tr>
<td>Bowel health information</td>
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<td>Urinary health information</td>
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<tr>
<td>Fatigue</td>
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<td>Stress</td>
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<td>Coping</td>
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<td>Sexual Concerns/Feeling Like a Man</td>
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information related to impo-
tence, incontinence, obesity, osteoporosis, fatigue, functional
decline, and health promotion
strategies related to diet and exer-
cise (Carstons, 2009; Demark-
Wahnefried et al., 2005; Harden 
et al., 2006; Hawes et al., 2006).
These studies support the IOM
(2006) recommendations that
cancer survivorship health edu-
cation be focused on patient-spe-
cific management of side effects
to improve patient satisfaction.

Synthesis of Literature

Research findings are con-
gruent among researchers and
national experts that the focus of
cancer survivorship health infor-
mation content needs to shift from
acute reactive care to chronic
survivorship care (Harden et 
al., 2009; IOM, 2006; Northhouse, 
Mood, Schafenacker et al., 2007).
Research and national experts
support the need for health
providers to overcome barriers
that preclude interactive coun-
seling on survivorship health
information to prepare prostate
cancer survivors in the manage-
ment of chronic health problems
resulting from treatment (Harden 
et al., 2009; Hawes et al., 2006; 
IOM, 2006).

Survivorship health informa-
tion provided through health
provider interactive counseling
is a critical component of sur-
vivorship cancer care for prostate
cancer patients and necessary to
improve satisfaction (Harden et 
al., 2009; Hawes et al., 2006; 
IOM, 2006; Northhouse, Mood, 
Schafenacker et al., 2007). Likewise, the IOM (2006) recom-
mends that the cancer survivor-
ship standard of care includes
evidence-based health informa-
tion for patients on managing
chronic symptoms of post-treat-
ment provided by the health pro-
fessional.

The primary studies that
were analyzed and synthesized
in this review used similar
research questions to address
prostate cancer patient chronic
treatment problems of fatigue, in-
continence, general side effects,
and sexual dysfunction. Findings
suggest a negative relationship
between chronic health problems
experienced by patients and sat-
fisfaction with health information
addressing chronic symptoms.
The IOM (2006) recommends all
cancer survivor patients com-
pleting treatment be provided
with a standard of care inclusive
of evidence-based survivorship
guidelines, which are based on
patient informational preferences
to manage chronic symptoms by
using sequenced interactive com-
munication skills.

Pilot Project

In response to the results of
the literature reviewed and IOM
(2006) recommendations, a pilot
project was envisioned to ad-
dress the gap in the cancer trajec-
tory by developing and imple-
menting a prostate cancer sur-
vivorship counseling program for
patients with prostate cancer
completing external beam radia-
tion therapy. For the pilot proj-
ect, an evidence-based survivor-
ship health information dis-
charge counseling program for
English-speaking patients with
prostate cancer was developed to
address self-management of ad-
verse side effects of treatment.
The goal was to promote health
maintenance using evidence-
based fact sheets and to encour-
age a sense of well-being and
self-confidence to manage possi-
ble chronic latent symptoms. The
information included physical
symptom management, and psy-
chosocial and spiritual interven-
tions.

Survivorship Discharge
Health Information
Counseling Program

The evidence-based prostate
cancer survivorship program
implemented was “Managing
Symptoms after Prostate Cancer
Fact Sheets” (Michigan Cancer
Consortium, 2009). The survivor-
ship fact sheet program resulted
from prior prostate cancer stud-
ies along with IOM (2006) recom-
mendations. The consortium
findings suggested prostate can-
cer survivorship discharge health
information improved patient
satisfaction (Harden et al., 2009;
Michigan Cancer Consortium,
2009, 2010; Northouse et al.,
2002; Northouse, Mood, Schafen-
acker et al., 2007).

Protection of Human
Subjects

The project was submitted to
an academic institutional review
board (IRB) and the health care
facility’s IRB for review. Both
boards determined that the proj-
ect did not meet the criteria for
human subjects research. Confi-
dentiality was assured by elimi-
nating any patient identifiers on
the satisfaction surveys and by
reporting aggregate data.

Data Collection Methods

Fifty-two patients were re-
cruited for the pilot study. Par-
ticipants consisted of two sepa-
rate groups of men. Thirty-two
patients did not receive the sur-
vivorship intervention. These
men received the usual care
health counseling at the conclu-
sion of radiation therapy treat-
ment followed by patient com-
pletion of the Patient Satisfaction
Questionnaire during an eight-
week period (May 16, 2011, to
July 9, 2011). This baseline data
measured satisfaction with usual
care health information counsel-
ing and provided evaluative data
to compare the effectiveness of
the survivorship counseling pro-
gram to be implemented with the
intervention group.

Twenty English-speaking par-
ticipants received the survivor-
ship intervention from an ad-
vanced practice nurse by attend-
ing a one-on-one 45-minute indi-
vidual counseling session during
the last week of radiation ther-
apy. Survivorship health counsel-
ing was scheduled in advance
with patients and was coordinat-
ed with scheduled treatment
times to avoid patient inconveni-
ence. Patients who received sur-
vivorship discharge health coun-
seling were provided with health
information for prostate cancer
using the Managing Symptoms
after Prostate Cancer Fact Sheets
developed by the Michigan Cancer Consortium (2009). The survivorship discharge health counseling was reviewed verbally with each intervention patient. Patients received a copy of the written survivorship health information packet, which included community resources to review and maintain for future reference at home. After the health counseling intervention, patients completed the Patient Satisfaction Survey. Data were collected during a six-week period (January 15, 2012, to February 25, 2012).

**Patient Satisfaction Questionnaire.** A five-point, Likert-type patient satisfaction survey was used to measure patient satisfaction at both data collection points. The Patient Satisfaction Questionnaire, developed by cancer experts and previously utilized in prostate cancer studies, was used to collect information following discharge intervention (usual and post-intervention) with the two groups of men (Northouse, 2005). Previous evaluation of the Patient Satisfaction Questionnaire demonstrated reliability and validity (Harden et al., 2009; Northouse, 2005; Northouse, Mood, Schafenacker et al., 2007). In an RCT of 86 prostate cancer subjects, there was high internal consistency and reliability alpha values measured 0.89 (Harden et al., 2009; Northouse, Mood, Schafenacker et al., 2007). Northouse, Mood, Schafenacker, and colleagues (2007) and Harden and colleagues (2009) tested content and construct validity of the satisfaction questionnaire for the effectiveness of supportive-education on prostate cancer patients assessing satisfaction with health information content. Content and construct validity supported interpretation of scores on the instrument based on the theoretical implications associated with the survivorship program, creating the overall satisfaction score (Harden et al., 2009; Northouse, Mood, Schafenacker et al., 2007).

**Data Analysis and Findings**

Demographic participant characteristics were collected for the usual discharge and survivorship intervention groups indicating participants’ age and education. The mean pre-intervention (usual discharge and counseling) participant age was 63.2 years, and the survivorship intervention participant mean age was 68.1 years. Fifty percent of usual discharge/counseling participants held baccalaureate or graduate degrees, and 55% of the survivorship intervention counseling participants held baccalaureate or graduate degrees.

Descriptive statistics using frequency distribution were used to analyze and compare usual discharge instruction satisfaction with the survivorship intervention satisfaction. The survivorship intervention participant results reflect increased patient satisfaction (see Table 2).

The frequency distribution represented the respondent agreement or disagreement for satisfaction with health information content, inclusive of patient preferences to manage chronic side effects resulting from treatment. Data showed lower satisfaction scores with usual discharge health information and counseling. In comparison, the survivorship intervention discharge health information counseling data showed higher satisfaction scores. Based on the comparative satisfaction data collected, a survivorship discharge health information counseling program, which includes patient health information preferences, does increase patient satisfaction.

**Conclusion, Implications, And Recommendations**

The pilot project results provide initial support for the implementation of cancer survivorship information for patients with prostate cancer undergoing external beam radiation treatment. Further research in multiple sites with a larger sample size is warranted to gather additional data to support this approach to patient discharge and counseling instructions.

Survivorship cancer care using health information discharge counseling provides one strategy to meet the IOM (2006) recommendations for care within the cancer trajectory. The current evidence-based practice project focused on one model of cancer survivorship care by providing disease-specific survivorship discharge health information counseling to increase patient satisfaction. Based on the project outcome findings, prostate cancer survivorship health information counseling inclusive of patient content preferences increases cancer patient satisfaction.

The opportunity exists for advanced practice nurses in oncology to take the lead in establishing and managing survivorship models. In the future, these models could be used to coordinate cancer survivorship care for patients and families, primary care providers, and specialty care providers to improve the cancer trajectory gap (Badger et al., 2013).

**References**


