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Telephone Social Support and Education for Adaptation to Prostate Cancer: A Pilot Study

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Purpose/Objectives: To evaluate the feasibility of an intervention of telephone social support and education to increase the physical, emotional, functional, and interpersonal adaptation of men to prostate cancer.

Design: Prospective, random assignment to experimental or control treatments.

Setting: Urban New Jersey.

Sample: 17 men diagnosed with prostate cancer within four weeks of study entry. Mean age was 66 years (range = 51–78); 59% were Caucasian, 35% were African American, and 6% were American Indian.

Methods: Subjects in the experimental group received telephone social support over a 12-month period in addition to education via mailed resource kits. The control group received education through mailed resource kits only. The Functional Assessment of Cancer Therapy Scale—General Physical, Emotional, Functional, and Social/Family Well-Being subscales; Symptom Experience Scale—Prostate; and the Relationship Change Scale were administered initially and at the end of each of the three phases; the International Index of Erectile Function Scale was administered at the end of each of the three phases. Qualitative information was gathered throughout and at the conclusion of the study.

Main Research Variables: Physiologic, emotional, functional, and social adaptation to prostate cancer.

Findings: Results were somewhat more favorable for the experimental group on all outcome measures; however, differences were not statistically significant. Structured interviews with 14 of 17 subjects revealed that telephone social support and education were effective in increasing adaptation to prostate cancer.

Conclusions: Despite the lack of a significant difference between the experimental and treatment groups in this small sample of men, analysis of trends and interview feedback indicated that telephone social support, in addition to education through a mailed resource kit, has the potential to be beneficial by increasing access to supportive services.

Implications for Nursing: Telephone social support when supplementing patient education may assist men in adapting during the year following a prostate cancer diagnosis.

Key Points . . .

- ▶ Prostate cancer is the most common cancer among men in the United States.
- ▶ Diagnosis and treatments for prostate cancer are known to cause deleterious physical, emotional, functional, and interpersonal changes.
- ▶ Telephone social support in combination with education may improve men's adaptation to prostate cancer in the year following diagnosis.

2000; Siegel, Mesagno, Karus, & Christ, 1992). Researchers have yet to determine what types of telephone counseling and education are most effective in treating men and their cancer-related side effects.

Prostate cancer is a life-threatening illness, and men's emotional well-being is affected by the uncertainty and stress that accompany the diagnosis. Men are faced with various treatment choices (e.g., radical prostatectomy, external beam radiation) and sequelae (e.g., erectile dysfunction, urinary incontinence) (Litwin, McGuigan, Shpall, & Dhanani, 1999; Stanford et al., 2000). Even men who forgo immediate aggressive treatment and instead opt for watchful waiting may experience poor health-related quality of life (Galbraith, Ramirez, & Pedro, 2001). Later in the disease or treatment process, men may cope with increasing physical side effects, including

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Digital Object Identifier: 10.1188/04.ONF.335-338

Prostate cancer is the most common cancer diagnosed among men. In 2004, an estimated 230,110 men will be diagnosed with prostate cancer, accounting for 33% of all new cancer cases among men (American Cancer Society, 2004). In response to prostate cancer and its treatment, men experience considerable distress (Fitch, Gray, Franssen, & Johnson, 2000). However, telephone counseling and education can ameliorate distress (Champion, Skinner, & Foster,

localized pain of visceral and neuropathic origin, abdominal cramping, diarrhea, fatigue, and anorexia. Moreover, these physical and emotional changes may affect a man's ability to meet interdependence needs in maintaining loving, nurturing relationships with significant others and perform pretreatment roles within the family and society.

The literature indicates that counseling from the healthcare team can influence adaptation in the physiologic, self-concept, role function, and interdependence domains following cancer diagnosis and treatment (Maliski, Heilemann, & McCorkle, 2001). Walker, Nail, Larsen, Magill, and Schwartz (1996) found a direct relationship between adaptation to prostate cancer and the degree of information available to patients about the disease and treatments. Although cancer support groups traditionally have provided social support for patients with cancer, individual counseling via telephone has proven to be an alternative means of social support. A study on the effectiveness of telephone counseling versus in-person counseling related to mammography screening reported that telephone and in-person counseling were equally effective (Champion et al., 2000). Moreover, patients with advanced cancer who participated in an automated telephone outreach program reported fewer unmet physical and psychosocial needs than control subjects (Siegel et al., 1992). Thus, the purpose of this study was to evaluate the feasibility of an intervention of telephone social support and education to increase the physical, emotional, functional, and interpersonal adaptation of men to prostate cancer. The study design and selection of outcome variables were guided by the Roy Adaptation Model of Nursing (Roy & Andrews, 1999). Roy's model depicts people as biopsychosocial beings who adapt to environmental stimuli.

Methods

Sample

Seventeen subjects were randomized to one of two study treatment groups: an experimental group ($n = 7$) receiving 12 months of telephone social support and education via a mailed resource kit and a control group ($n = 10$) receiving education via a mailed resource kit only, with no telephone social support. Subjects were English-speaking men who were informed of their prostate cancer diagnosis within the previous four weeks and not experiencing major underlying medical problems. All anatomic stages of prostate cancer were included.

Procedures

The experimental protocol (i.e., telephone social support and education) was implemented by the same oncology research assistant in three phases. Phase I provided weekly telephone social support to each subject for two weeks, followed by eight weeks of weekly telephone social support with the addition of a structured formal education component. Phase II began 10 weeks after study entry and continued for five months. During phase II, telephone social support and education were reduced to two times per month. Phase III began approximately seven months after study entry. During this phase, telephone social support and education decreased again to once per month. The interventions during this phase included the termination phase of the research assistant-subject relationship. The research assistant used objectives and guides and maintained logs of all telephone contact with sub-

jects. Subjects assigned to the control group received education via mailed resource kits only. The resource kit included a prostate cancer information manual developed for this study, videotapes, and an audiotape and was similar to a resource kit designed for patients with breast cancer by Samarel et al. (1999). Control subjects did not receive social support via telephone. At the end of phase III, all of the subjects were invited to participate in open-ended interviews conducted by the researcher.

Instruments

Data were collected via mailed questionnaires at four points over a 12-month period for all subjects: at entry into the study (baseline) and at the termination of each of the three phases. The instruments were selected based on their high reliability and validity. A **background data sheet** was used to collect demographic and health information such as age, marital and employment status, education, diagnosis date, type of medical treatment received, and current health status. The **Functional Assessment of Cancer Therapy Scale-General** (Version 3), a self-report instrument with items rated on a five-point Likert scale, was used to assess physiologic, self-concept, role function, and interdependence domains (Cella et al., 1993). This 28-item questionnaire included physical, emotional, functional, and social/family well-being subscales that have Cronbach's alphas of 0.82, 0.78, 0.80, and 0.69, respectively. The **Symptom Experience Scale-Prostate**, adapted from the 24-item Symptom Experience Scale-Breast Cancer, included eight symptoms or sensations that are reported most frequently by men with prostate cancer (Samarel et al., 1996). This instrument has a Cronbach's alpha of 0.94. The **International Index of Erectile Function Scale** was used to measure sexual well-being through a 15-item questionnaire, operationalized as satisfaction with erectile function, orgasmic function, and sexual desire; intercourse satisfaction; and overall sexual satisfaction; Cronbach's alpha ranges from 0.73–0.99 for individual domains and 0.91 and higher for the total score (Rosen et al., 1997). The **Relationship Change Scale** was used to measure changes in the quality of the subjects' relationships with their significant others (Guerney, 1977).

Results

Sample Demographics

All 17 participants in the study ranged in age from 51–78 ($\bar{X} = 66$ years, $SD = 8.3$) (see Table 1). The sample was ethnically varied; 59% were Caucasian, 35% were African American, and 6% were American Indian. The majority of the men (88%) had a household income at or below \$40,000 per year. At the completion of the study, 7 men had selected active treatments and 10 men were continuing watchful waiting. No significant differences were found between the two groups.

Table 2 summarizes the combined data of the two groups at three data collection points during the yearlong study. Scores measuring physical, functional, and sexual well-being were lowest at the end of phase II, coinciding with the period of active treatment. Measures of emotional and social well-being were highest at the end of phase II and then decreased to above phase I levels in phase III. All scales demonstrated good variability at each of the four data collection points.

Table 1. Sample Demographics

Characteristic	n	%
Age (years)		
\bar{X} = 66	–	–
Range = 51–78	–	–
Marital status		
Married or in a permanent relationship	7	41
Not married or in a permanent relationship	10	59
Employment status		
Full-time	1	6
Unemployed	3	17
Retired	13	77
Highest education level		
Primary school	2	12
High school	11	65
College or graduate school	4	24
Ethnicity		
Caucasian	10	59
African American	6	35
American Indian	1	6
Gross annual household income		
< \$20,000	9	53
\$20,000–\$40,000	6	35
> \$40,000	2	12
Treatment at entry into the study		
Watchful waiting	9	53
Radiation treatment	2	12
No treatment started	6	36

N = 17

Note. Because of rounding, not all percentages total 100.

The research assistant took detailed notes during every phone encounter. Content analysis of the research assistant logs revealed the most frequent phase I theme was information seeking about prostate cancer and treatment choices. Subjects reported the importance of leaving a legacy to family and friends by passing along information about prostate cancer. During phase II, men most frequently spoke of coping with disease and treatment side effects such as fatigue, pain, diarrhea, urination problems, and erectile dysfunction. Men who had undergone surgery or radiation treatment generally reported improved well-being in phase III. Men continuing to experience erectile dysfunction sought treatment during this phase.

Table 2. Outcome Variables and Instruments

Scale	Scale Range	Cronbach's Alpha	Phase I		Phase II		Phase III	
			\bar{X}	SD	\bar{X}	SD	\bar{X}	SD
FACT-G Physical Well-Being	0–28	0.82	25.1	4.0	21.6	7.8	23.9	6.1
Symptom Experience	0–96	0.94	19.7	17.4	23.0	19.7	19.1	12.9
FACT-G Emotional Well-Being	0–24	0.78	18.6	4.5	19.8	4.1	18.9	5.0
FACT-G Functional Well-Being	0–28	0.80	18.0	7.9	16.8	9.6	19.2	8.6
FACT-G Social Well-Being	0–28	0.69	15.9	5.7	18.0	6.6	16.5	6.7
International Index of Erectile Function	5–75	0.92	26.2	23.9	15.8	18.9	22.7	21.6
Relationship Change	–50 to 50	0.98	3.5	23.8	5.4	20.4	7.6	16.9

N = 17

FACT-G—Functional Assessment of Cancer Therapy Scale—General

Fourteen of the 17 subjects agreed to participate in telephone interviews with the researcher at the end of the study. These interviews were audiotaped and transcribed in full. In the interviews, the men in the experimental group offered opinions about the intervention.

The video helped me learn about my body. The phone calls were wonderful. It helped me get through the process. I shared the information and video with the other men in my senior building. They enjoyed the information, and it was helpful to them.

Participation in this program was handled with sensitivity [which helped because] I'd rather do my learning quietly and privately.

Having someone to call me helped 100%. I am too weak to go out for help. The phone calls were something to look forward to.

Discussion and Nursing Implications

During the 12-month pilot study, the experimental group reported the importance of talking to someone with whom they could discuss their fears, indecisions, and treatment side effects. They also felt confident in knowing that a specially trained individual was available to them by telephone. All of the men in the experimental group indicated that they found receiving a variety of information helpful in understanding the disease and treatment options.

The trend toward declining physical, functional, and sexual well-being measures from phase I to phase II and an increase at the end of phase III is consistent with research conducted by Litwin et al. (1999) and can be attributed to the side effects of prostate cancer treatments and the subsequent healing and adaptation to physiologic and functional changes. The slight improvements in emotional, social, and family well-being data from phase I to phase II mirrored the findings of Fitch et al. (2000), in which 44% of patients with prostate cancer reported that cancer had a positive impact on their relationship with a significant other. These trends were consistent across time for the experimental and control groups. The small sample size precluded comparing outcome measures for statistically significant differences between the groups. The subjects had no difficulty understanding and completing the questionnaires measuring outcome variables.

The data from this pilot study and anecdotal information from men with prostate cancer provide evidence that men are willing to participate in a telephone intervention and that the support may be beneficial for one year. Moreover, as evidenced by previous telephone intervention studies, telephone counseling increases access to supportive services for men,

specifically for those of lower socioeconomic strata and men of color, who usually are under-represented in support groups.

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