



Self Advocacy & Empowerment for People with Cancer

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Abbreviated Abstract

EMPOWER is a CD-ROM-based education and support program for adults who are newly diagnosed with cancer. Changes in the healthcare system and greater access to information are compelling a growing segment of patients to participate more actively in their healthcare, and to be increasingly proactive within medical systems. The program is intended to help patients cope more effectively with the stresses and demands of treatment, and in becoming more effective partners in care and self-advocates within medical systems. A more collaborative partnership between patient and provider has numerous benefits for each. In order to participate actively as a partner in care, and pro-actively deal with the stresses treatment, patients need skills to: acquire reliable information and make sense of it; navigate and understand treatment systems; communicate with providers; act as self-advocates; and acquire skills to manage the emotional and physical side-effects of treatment. Intervention at the earliest stages of treatment helps inoculate patients from the potential negative consequences of illness and treatment that cancer patients normally experience. The empowerment of people with cancer has the potential to facilitate better medical outcomes and provision of higher quality care. The use of CD-ROM technology allows material to be presented in a highly engaging, interactive format with visual and audio enhanced explanations. Using full-motion video, the program highlights the stories of four cancer survivors, the challenges they faced, and the successful coping strategies they used. Grant funding from NIH-NCI and involvement of key stakeholders in the development process, ensures the inclusion of accurate and essential information. The program is intended to supplement the direct services provided by health psychologists, medical social workers, and other oncology support professionals.

Primary Investigator

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Simon H. Budman, Ph.D. is the founder and president of Innovative Training Systems, Inc. in Newton, Massachusetts. He is also on the faculty of the Harvard Medical School. Trained as a clinical psychologist, Dr. Budman worked for 20 years at the Harvard Community Health Plan, first as the Director of Mental Health Research and then as the Director of Mental Health Training. He also served as the Associate Director of the Harvard School of Public Health Institute for Health Research. His work at ITS has focused on several major areas: the use of multimedia (CD-ROM, Internet and

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video) in behavioral oncology, smoking cessation and smoking prevention, substance abuse and college student health. Dr. Budman is the 2000 winner of the American Psychological Association Award for Distinguished Contributions to Professional Knowledge and the 2000 recipient of the Cummings Foundation Psyche Award.

Research Team & Affiliations

Simon Budman, Ph.D., Principal Investigator; Jonas Bromberg, Ph.D. Co- Principal Investigator; Evelyn Corsini, M.S.W. Project Manager; Stacey Decembrele, B.A. Research Coordinator; Jessie Cohen, B.A. Research Coordinator; Debbie Trotter Data Manager; Julie Cunningham, M.S. Biostatistician; Traci Craig Green, M.S. Biostatistician

Total Budget

\$845,619.00

Research Objectives

Aim 1: To develop an interactive CD-ROM patient education program for people newly diagnosed with cancer.

Aim 2: To implement a clinical field trial to test hypotheses.

Theory/Hypothesis

1. That exposure to the program would result in increased self efficacy in coping with cancer.
2. That exposure to the program would result in improved quality of life.
3. Assess the safety of the CD-ROM program.
4. To assess consumer satisfaction with the CD-ROM program.

Experimental Design

269 participants who had received a new cancer diagnosis within that last 12 months were given a baseline assessment and then randomly assigned to an experimental group or a control group. The experimental group received the “Facing Cancer with Confidence” CD-ROM and the control group received a 60 page National Cancer Institute booklet. Subjects were retested at 6 and 12 weeks after their baseline assessment. The main outcomes tested for were: satisfaction with the educational information they had received; their scores on the Cancer Behavioral Inventory; and their scores on the FACT-G, a quality of life scale for cancer patients.

Final Sample Size & Study Demographics

269 participants were involved in the study. Participants were recruited from the following sites: St. Elizabeth’s Medical Center, Buddy Kemp Caring House, Maine Medical Center, and the Internet. There were 74 males and 195 females. 92.3 percent of the participants were white and 7.7 were minorities. 58 percent of participants were married and 13.8 were divorced. The others fell into the following categories; single, widowed, separated, remarried, or living with partner. 60.2 percent of the



participants fell into the income range of less than twenty four thousand to seventy four thousand a year. The remaining fell into the income range of seventy five thousand to more than two hundred thousand a year. 1.5 percent of participants did not respond to the income question. Participants were categorized into stages of their cancer. 30.1 percent were categorized into stage 1, 23.8 percent into stage 2, 17.1 percent into stage 3, and 7.8 percent into stage 4. 5.2 percent responded with N/A and 16 percent did not know. 24 participants did not finish the study.

Data Collection Methods

All study participants completed an initial demographic questionnaire and self-assessment measures, including recording their pattern of health care utilization. They completed this at three points in time: at baseline, at six and twelve weeks after the provision of the educational material. At their final assessment they also completed a satisfaction survey.

Outcome Measures

1. The Cancer Behavior Inventory- Long Form v.2.0 (CBI-2.0) including 7 factors:
2. The Functional Analysis of Cancer Therapy-General Form (FACT-G)

Evaluation Methods

Two-tailed t tests were performed on subject satisfaction ratings to see if there was a difference between experimental and control group satisfaction. To test the Cancer Behavior Inventory and the FACT-G scores, t-tests were performed to see if the following groups differed in outcomes over time: gender, stage of cancer, income, education, marital status, and use of antidepressant or anti-anxiety. Based on these analyses, income, stage of cancer, and gender were selected as covariates for the analyses. A repeated measures ANOVA was performed on the score from the seven CBI subscales and the four FACT-G subscales, with gender, income, and stage of cancer entered as covariates.

Research Results

Control and experimental subject scores on the CBI and the FACT-G were not significantly different. However, on most measures both groups improved over time. On the Maintenance of Activity and Independence scale, participants generally improved with time. There was also a time by stage interaction effect; therefore participants with stage 1 or 2 cancer improved over time. However, participants with stage 3 or 4 cancer worsened over time. There were no significant effects found for the Seeking and Understanding Medical Information scale, the Stress Management for Medical Appointments scale, the Coping with Treatment Related Side Effects scale, or the Accepting Cancer and Maintaining a Positive Attitude scale. On the Affective Regulation Scale there was an effect for time. Therefore participants scores increased over time. On the Seeking Support Scale there is a time by gender interaction. Males improved over time, female scores stayed the same. On the Emotional and Functional Well Being scales on the FACT-G there was no significant effects for time, condition, or interaction effects.



Barriers & Solutions

No major problems encountered

Product(s) Developed from This Research

Facing Cancer With Confidence™: is an educational support program for adults who are newly diagnosed with cancer. Changes in the healthcare system and greater access to information are compelling a growing segment of patients to participate more actively in their healthcare, and to be increasingly pro-active within medical systems.