



Palliative Training for Caregivers of Cancer Patients

Grant Number: R42CA73284-03

Abbreviated Abstract

The aim of this project was to team with Northern Virginia Community College to produce a multi media training package incorporating recent research and techniques to assist cancer patients to improve their functioning, better communicate symptoms to improve pain and symptom management, and enhance their quality of life. This program is for use by community colleges, long term care facilities and hospice programs to train paraprofessionals, volunteers, and family caregivers. Phase I will research and develop a detailed training program outline, including descriptions of multi media training elements to be developed in Phase II. Expert Panel approval of the training program outline and criteria for evaluating the training program will prove the feasibility of Phase II. In Phase II, multi media materials to implement the training program and a train the trainer module will be produced. The training package will be tested in classes at a community college, long term care facilities and hospices. Trainee knowledge and skills performance will be evaluated. The products to be marketed in Phase III will be a multi media training package consisting of: a palliative care and hospice training curriculum and a train the trainer module for instructors.

Primary Investigator

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Mary Hamil Parker, Ph.D., Managing Director, MKHP Associates, L.L.C., was the small business owner and Principal Investigator of Phase II of the Palliative Care Training Project funded by the NCI. She has over 30 years of research experience in senior housing, long-term care, and health care training.

The Phase I STTR was awarded to Dr. Parker's sole proprietor company: Senior Housing Research Group (SHRG), Alexandria, VA, in 1995. In 1996, MKHP Associates, L.L.C., a woman-owned, small research firm received the Phase II STTR Grant. MKHP Associates specializes in programs for elderly community residents, technology and passive monitoring applications, as well as training programs for health care staff. In 2000, Dr. Parker founded the Institute for Palliative and Hospice Training, Inc., a 501(c) 3 non-profit foundation, to conduct the training programs developed by MKHP Associates under the STTR grant.

Visit the SBIR Product Directory online at <http://cancercontrol.cancer.gov/hcirb/sbir>



MKHP Associates has received positive recognition and support for the STTR research, stemming from presentations at a number of national and international conferences. These include: The Pioneer Network, The National Association for Home Care, The American Association of Hospices, The National Hospice and Palliative Nurses Association (HPNA), the National Hospice and Palliative Care Organization (NHPCO), National Council on the Aging (NCOA), American Association of Homes and Services for the Aged (AAHSA), The Gerontological Society of America (GSA), the Alzheimer's Association International, Hospice of Ireland, International Association of Homes and Services for the Aged and the UICC World Cancer Congress. MKHP Associates received an Outstanding Achievement Award in 1998 from The Office of the Secretary of Technology for the Commonwealth of Virginia.

Research Team & Affiliations

Phase I: Margaret E. Larose, MSN, RN. Principal Investigator, SHRG
Carmen Burrows Goodman, M.Ed. Northern Virginia Community College Program Administrator,
Mary Hamil Parker, Ph.D., Evaluation Director, SHRG

Phase II: Mary Hamil Parker, PhD. MKHP Associates, LLC
Carmen Burrows Goodman, M.Ed. Northern Virginia Community College Program Administrator

Expert Panel: Madelon O'Rawe Amenta, DrPH, Hospice Nurses Association; Rita Munley Gallagher, Ph.D., RN.C., American Nurses Association; Gerald Holman, MD, Chief of Staff, Veterans Administration Medical Center, Amarillo, TX, Academy of Hospice Physicians, Jeanne Martinez, Ph.D., Hospice and Palliative Nurses Association.

Total Budget

\$506,869.00

Research Objectives

- Aim 1: Provide a method of enhancing the quality of palliative care for cancer patients.
- Aim 2: Increase the knowledge and skills of caregivers providing hands-on-care to cancer patients in assisting health professionals in pain management and palliative care.
- Aim 3: Promote better interaction and functioning of paraprofessional and family caregivers as the conduit for information required by professionals in care planning and symptom management.
- Aim 4: Develop, test and demonstrate ad curriculum, implementing multi-media applications and self-learning methods.

Theory/Hypothesis

Direct caregivers—Certified Nurse Aides, Home Health and Hospice Aides—are the eyes and ears of the clinical care team and are in the best position to provide person-centered palliative care.



Experimental Design

Development of a training curriculum implementing adult learning principles and problem-based learning, using case study examples and self-directed learning in application of a targeted communications method and based upon research-based clinical information. Testing the curriculum modules in face-to-face and distance training sessions.

Final Sample Size & Study Demographics

Between 1998 and 2001, the project provided direct face to face or distance training programs to a total of 452 people, located in Virginia, Maryland, Tennessee, Georgia and the District of Columbia. Two distance learning programs were presented at a total of nine sites by the two programs. One program linked sites on the Eastern Shore of Virginia, Alexandria, Richmond and the Tennessee/Virginia Mountain border. Evaluation data was collected from 80 distance trainees and six month post training data, was received from 33 trainees, 41 percent.

Training was provided for 22 hospices (61%); 8 Home Health Agencies (22%); 5 Nursing Homes (14%) and one Assisted Living facility. The positions of those trained were: CNA, 36%; RN, 17%; LPN, 11%; Patient Care Volunteer, 12%; Home Health Aide, 9 %; Home Health Aide/CNA, 6%; Other, 8% and No Answer, 1%. Demographics: Gender: Female, 88%; Male, 6%; No Response, 6%. Ethnicity: White, 52%; African-American Black, 38%; Hispanic, 1%; Asian-Pacific Islander, 1%; American Indian-Alaskan, 1%; Other, 4%; No Answer, 3%.

Data Collection Methods

Evaluations were received from site trainings. Forms were completed by 452 people who received one or more of the curriculum training presentations.

Evaluations of the two separate two-hour distance training programs on Observing and Reporting Pain and Other Symptoms were received from 80 participants. Because the names of trainees were available from agency registration lists, it was possible to send a post-evaluation to each agency, with individual letters addressed to the trainees requesting that they complete the evaluation and return in the enclosed addressed envelope to MKHP. Employers were asked to distribute the evaluations and collect them for return. If the trainee had left the agency, it was not possible to obtain a post-evaluation. Post evaluations were received from 33 trainees, 41% of the original trainee group.

Outcome Measures

In the post-training evaluations, participants were asked to answer seven questions scored on a 1 to 5 scale, with 1 being the lowest score and 5 the highest.

The questions were:

- 1) Did you learn something in this session you will use in your job?
(1 Nothing..... 5 A Lot)
- 2) Were the handout materials easy to read and understand?
(1 Not easy.....5 Very Easy)



- 3) Did the case examples help you to understand more about the topic?
(1 Not Helpful.....5 Very Helpful).
- 4) Did the case examples help you learn to use the 5-POINT Guide?
(1 Not Helpful.....5 Very Helpful).
- 5) Will you use the 5-POINT Guide when reporting patient/family needs?
(1 Not use.....5.Always use)
- 6) Will using these materials make it easier to communicate with other staff?
(1 Not easier.....5 .Much Easier)
- 7) Would using these materials help provide better care for patients at the end of life?
(1 Not helpful.....5 Very Helpful)

Evaluation Methods

In the face-to-face trainings, participants evaluated the training experience and utility of training principles in daily care. The same data was received for all training programs presented. Since several different programs were offered at the same sites, evaluations of different programs were received from the same trainees. However, due to human subjects requirements, none of the participants in any of the training programs were identified by name. Therefore, it is not possible to do an extensive analysis of these data due to overrepresentation of some participants and groups.

Research Results

Since the training was particularly targeted to paraprofessional health care staff and also to health care staff without experience in hospice, separate analyses were done by employment position and work experience. The response of paraprofessionals to the program materials and the use of the 5-POINT Guide was very favorable. The training was well received and perceived as useful by the majority of Home Health Aides and Certified Nurse Aides, particularly those with no work experience in hospice. Hospice nurses, RN and LPN, were least likely to find the training useful. An analysis of variance showed significant differences between responses of nurses with no hospice experience and those with hospice experience. Nurses with no hospice experience considered the training useful in their jobs, the case studies helpful in understanding the topics and in learning to use the 5-POINT Guide and the materials contributing to easier communications with other staff. In general, nurses were less interested in using the 5-POINT Guide, comments indicated that some felt they were already using this method. High assessments were received from the new hospice volunteers trained by the project. New volunteers and those with 4-16 years of hospice experience more highly ranked the training, usefulness of materials and 5-POINT Guide than did volunteers with 1-3 years of experience.

Evaluations of the two separate two-hour distance training programs on Observing and Reporting Pain and Other Symptoms were overwhelmingly positive. In the evaluation at the time of the training, 78 percent of trainees said they would use the 5-POINT Guide when reporting patient/family needs. In the post-evaluation responses to the evaluation questions, 57 percent reported using the 5-POINT Guide to Communications 50 percent or more of the time when reporting patient and family needs. Of these, 54 percent said using the 5-POINT Guide helped them to provide better care for patients at the end of life. This is a very encouraging result from a single two-hour training with no additional follow-up or reinforcement.



Barriers & Solutions

One of the major barriers encountered was the inability to do more distance learning presentations, as a result of a change in transmission software by the Virginia Department of Education, which eliminated interactive multi-point presentations. A solution was not available during the remainder of the project.

Product(s) Developed from This Research

The Palliative Care Training Program for Caregivers; Culture Change Training for Care Teams