

Caregiving at Life's End: The National Train-the-Trainer Program

Title: Caregiving at Life's End – The National Train-the-Trainer Program

Organization: The Hospice Institute of the Florida Suncoast

Principal Investigator: Kathy Egan

Contact Information: 300 East Bay Drive, Largo, FL 33770, (727)586-4432

Project Summary:

Introduction

Over the years, family caregivers have taught us that caring for someone at the end of life is a life-changing experience. Their caregiving experiences have offered challenges, surprises, and even opportunities that go beyond the physical tasks associated with providing care. Our observations have also taught us that many of these Caregiving experiences have been very positive in the midst of one of life's most difficult time. *Caregiving at Life's End: The National Train-the-Trainer Program* is a caregiver-driven training program designed to address end-of-life issues in a manner that helps caregivers to find a sense of meaning, purpose, and value in their experience and helps them support their care receivers in finding a more peaceful life closure. The wisdom of current and bereaved caregivers has been the inspiration for creating and sharing new tools for promoting quality of life for individuals who provide care as well as those in need of caring.

. To better understand this experience, we began by surveying caregivers, trainers and educators at hospices around the country to find out what caregivers need. This first national caregiver needs assessment focused on issues of meaning, value, completion, relationships and closure while caring for another at the end of life. The data from this survey validated our hypothesis that comfort in caregiving can transform a difficult experience into one of personal growth that promotes self-acceptance and fosters a sense of meaning and purpose in life. The survey results became the foundation for a comprehensive curriculum, training and public engagement program that was designed to enhance the abilities of trainers in meeting the needs of caregivers. The materials and training program were developed to address end of life issues in a way that enriches caregivers' lives and gives them the tools to assist their care receiver in finding meaning, peace and closure in the last years of life.

Beginning in March of 2003, we began a series of seven free, 5-day trainings to hospice, aging/elder care, caregiving, long-term care and palliative care professionals nationwide. An additional training three day training was created and added in September of 2004 in Salem Massachusetts to grant access and exposure to the northeastern US, an area where lower participation nationally had been identified. 206 trainers from 44 states have completed the program and made the commitment to train a minimum of 50 caregivers in their own community. To determine the effectiveness of the Caregiving at Life's End training and curriculum we evaluated the participants with pre/post surveys.

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Collection and analysis of pre and post training data from family/friend caregivers to determine if caregivers found comfort with end of life tasks, peace with end of life issues and can achieve a sense of letting go or closure, will they find benefit in the caregiving experience? By attending to end-of-life tasks, can caregiving become a positive transformative experience?

Advisory Committee

A diverse National Advisory Committee comprised of more than 20 leaders in healthcare, caregiver advocacy, law, academia, and hospice care was established by the *Caregiving at Life's End* program to provide advisory input on the creation of the national needs assessment, subsequent curriculum design and development of the train the trainer sessions.

National Needs Assessment

In 2002, we conducted a national survey to see if we could learn more about caregiving in the last years of life from the experts – current and bereaved hospice family caregivers themselves. While much caregiving literature has focused on burden, the needs assessment invited caregivers to share a holistic picture of their personal experience. Questions addressed issues of meaning, value, completion, relationships, and closure at the end of life. This national survey of both caregivers and, separately, trainers and educators at hospices around the country, painted a picture of caregiver needs, end-of-life caregiving experiences, and a comparison between what caregivers say they need and what trainings and resources were available to caregivers across the country. The analysis of this data then served as the foundation for the development of the *Caregiving at Life's End* curriculum and train-the-trainer program. This innovative working model addresses meaning, self-acceptance, comfort with caregiving and closure as transformative aspects of caregiving that can increase caregiver gain and ease end of life transitions including bereavement.

The *Caregiving at Life's End* National Needs Assessment marked the first time hospice caregivers nationwide had been systematically asked about their caregiving experiences. In partnership with the Florida Policy Exchange Center on Aging at the University of South Florida, we developed, validated, and analyzed the first caregiver survey to focus on their caregiving experience. Over three thousand hospice family caregivers, both current and bereaved, were surveyed, nine hundred caregivers completed the survey, and over two hundred trainers/educators at hospices around the country responded to a separate survey on caregiver educational needs and resources.

Using the results of the national needs assessment, a curriculum, training and public engagement program was designed to enhance the abilities of trainers to meet

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the needs of caregivers in their own communities and to make such education accessible to a wide audience of caregivers. (For full results see attached Executive Summary).

Curriculum Design

The *Caregiving at Life's End* curriculum was designed as flexible curriculum of nine facilitated learning modules representative of aspects of completion and closure that caregivers may experience and share with their care-receiver to gain more meaning and value from the caregiving experience. During the train-the-trainer program, each participant receives a 900 page toolkit which includes data from the needs assessment, nine facilitated learning modules, comprehensive information on designing and implementing outreach and marketing of caregiver programs, and complete lists of resources for trainers and caregivers. Each of the nine modules contains a full trainer's curriculum, participant handouts, resources for trainers, resources for caregivers and activities that are interactive, facilitated and/or self-directed. Included with each trainer's toolkit is a CD with the content of the printed manual for easy adaptation of curriculum and handouts to different populations, cultures, audience type, audience size, trainer skill and training style. Training tools were intentionally designed to be easily tailored to groups large and small and even adapted for use in one-on-one sessions with individual caregivers.

Train-the-Trainer Sessions

Seven free five-day train-the-trainer sessions and one three day session have provided professional and volunteer participants nationwide with the skills and training materials needed to implement an effective community caregiver training program.

Through participatory experiences during the train-the-trainer courses, facilitators identify and foster each trainer's teaching skills and confidence in using the materials as well as their ability to successfully facilitate classes that address the emotional, spiritual and social aspects of caregiving in the last years of life

Innovative approaches to supporting and enhancing the implementation of the *Caregiving at Life's End* materials include the development and use of an internet-based resource center for participants and caregiving professionals and an internet-based list serve which promotes group interaction, information sharing and networking. Participants were encouraged and supported in partnering with Area Associations on Aging, Senior and Community Centers, long term care facilities and hospices to provide their programs.

Caregiving at Life's End has trained over 206 professionals and volunteers from 44 states who in turn have committed to sharing the materials with caregivers in communities across the country.

Diversity

Caregiving at Life's End has actively considered the needs of diverse populations from the time of the needs assessment through to our outreach efforts today. The needs assessment intentionally over-sampled hospices in census tracts with 20% or more African-Americans in order to optimize minority participation. Sessions and activities within the trainer component of the program challenge participants to examine their own definition of diversity and consider a definition that includes not just race or ethnicity but gender, faith tradition, vocation, education, sexual orientation, physical abilities, mental abilities, learning styles, and life experiences among others. A focus is placed on actively identifying and engaging diverse populations of caregivers and working with them to understand their needs and how best to meet them.

The trainers participating in the program are both diverse in relation to their communities of origin as well as in their professional backgrounds, levels of education and experience, organizational affiliations, and job descriptions. The modules contain information comprehensive enough to serve the needs of those with minimal experience in end of life care as well as those with considerably more experience. The curriculum was also designed so that it could be applied in any care setting – with caregivers in a hospital setting, nursing facility, assisted living facility, etc rather than simply caregivers caring for a patient in a private residence.

Nationally, trainers are reporting interest and success in sharing and adapting these materials within a variety of partnerships. Examples of the diversity of these relationships include a Chinese Service Center, a group of former POWs, an Amish community, African-American women in beauty salons on Saturday mornings, and a senior gay & lesbian group among others. Former participants are also working to translate the toolkit materials into other languages including Spanish and Chinese. Locally, we are currently partnering with a multi-cultural service organization to enhance education and support for historically under-served caregivers.

Outcomes

National Train-the-Trainer Program Evaluation

The National Train-the-Trainer Program Evaluation questionnaire included 21 quantitative items to assess how much participant trainers valued the components of the training program and if they understood how to use each component. Because of the overall reports of very high satisfaction with the program, we compared the percentage of trainers who rated each component “very valuable” (5) in order to rank their relative value for all trainers. Three open-ended questions asked trainers to identify the aspects of the program they felt were most and least hopeful and areas that could be added to the program.

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The Train-the-Trainer Content Evaluation was used to evaluate the content of the trainings. More than 50% of the participants reported that all 19 content components were very valuable to them and less than five percent of the respondents reported not understanding how to use some of the content. Seven components were very valuable to at least three-fourths of the trainers: self-directed activities (81%), reaching caregivers (79%), developing an outreach plan (79%), participant handouts (77%), trainer resources (76%), caregiver resources (75%), and ways to promote caregiver trainings in the community (75%). Two-thirds of respondents valued eight areas including three transformative tasks: finding meaning in caregiving (74%), finding positive aspects of the caregiving experience (70%), and supporting care receiver life closure (67%).

Most trainers identified the most and least helpful aspects of the curriculum. We categorized these comments into four areas: content, activities, tools, and other comments. The content areas that trainers listed as most helpful included outreach (n=16), diversity (n=9), presentation skills and teaching approach (n=7), and the modules and approaches for using the modules (n=6). They enjoyed group activities (n=24) and networking opportunities (n=13) of all the activities. Moreover, they viewed the curriculum guides and the manual to be helpful (n=23) and found program faculty to be helpful and knowledgeable (n=16).

Family Caregiver Evaluation

To evaluate the family caregiver training, family/informal caregivers who attended *Caregiving at Life's End* programs were asked to participate in pre- and post-test surveys which asked about comfort with carrying out certain caregiving tasks, sense of letting go/closure, and sense of gain. The data collection of the pre- and post-test evaluation began in March, 2003 and continued through August, 2004. 926 out of 1756 caregivers who received training completed one or both evaluation surveys. Descriptive, paired-sample t-test, ANOVA, and multiple linear regression statistics were used to report overall characteristics of participants, group differences between all trainees who completed both pre and post-survey, pre-survey only and all those who completed the post-survey only, the amount of change on the three outcomes between pre and post-surveys for those who completed both, and the role of exposure to the curriculum in improving caregiver outcomes. Caregivers who participated in the training received, on average, four sessions and 7.7 hours of training. The majority of these caregivers was Caucasian (88%) and received the group training (95%) rather than individual training. Among caregivers who completed both pre and post-test surveys, significant improvement was found on three major areas: comfort with carrying out tasks, closure, and gain ($p < .001$). Caregivers who are caring for someone near life's end show benefits from 8 or more hours of training using a curriculum that focuses on the transformative and practical aspects of Caregiving. The ability to support caregivers in this relatively low impact intervention (8 hours of training) can be used in hospice and non-hospice settings. In addition, it is possible to demonstrate training effectiveness even with differential implementation of the curriculum by collecting simple roster information that allows evaluations to control

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for intensity of the training. (Please see attached Benefits of Training End-of-Life Caregivers).

Vignettes

The following comments have been received from trainees who have successfully implemented the *Caregiving at Life's End* training in their community

General Comments

... "we can tell by the responses in our Family Satisfaction Surveys that we are making a difference in educating our caregivers."

"Thank you for offering the training-it was really informative and is material we can keep on using."

"The CGLE program provided a tremendous foundation. As you encouraged us to do, I've added and adapted to make it my own, but I could never have done it from scratch..."

Using the Activities

"Everyone used the materials and that generated a lot of discussion...it opened up a discussion on pre-planning funerals, which some had done and others were struggling with starting."

"I have found the material to be very thorough as a guide to the issues faced by caregivers and resources to help them to develop solutions...it is clear from my experience that this is filling a huge void in our community."

"...the materials promoted amazing group interaction – all they needed was to have the right question asked and they took off helping one another."

About Caregivers – Transforming the experience

*"From a current caregiver in my last class that seems to sum up our efforts!
'My mom ain't fixed and I ain't fixed but now I know I will survive.'"*

"...she really blossomed, reaching out more and more, speaking up more." It was wonderful.

"One of our participants is caring for her dad – he is our hospice patient. The nurse suggested the classes to her, felt she really needed a place to get away to, to be able to speak about her feelings...she has really opened up, she seemed so shy and we had to work to draw her out and be sure she had a turn to speak if she wanted – by last week, she was shutting others up and claiming her turn – it was neat to watch."

"One caregiver left with the realization that 'it's okay for me to take time for myself.'"

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Naturally Occurring Communities

I just completed my first series of workshops with my former POW's..a group that is rapidly dying and also taking care of their wives at the end of their lives. I had several former POW's who wept openly in the final session on bereavement about the death of their pet. ...it is "safe" to let down your emotional guard.

We had our first training on Monday night for the gay & lesbian community and it went so well. After explaining the project I found that the group is totally committed to this project and they want it to go statewide. I wish I could put into words how it felt to have a safe space for these elders to communicate. Thanks for this opportunity!

Another class is causing lots of excitement. I have a friend who is Chinese, and on the board of a new Chinese Service Center. We spoke about the Caregiver program, she took my card, and the Community Services Director called me today. I will be teaching a series for them, and will be working with a translator

"...met with members of the Amish community...supplied us with contact to 150 Amish bishops and their congregations."

"...have already had 3 different places in our county asking for the classes -church...nursing home...social club."

"...have had such active participants and so eager for information. The council on aging in our county has been so helpful in providing information and resources for the group. I could not do the program without them."

"Since my community is small I wanted to start out with a community wide program. We partnered with an assisted living facility to hold the program."

"We have hosted them at a senior center, a nursing home, and a hospital thus far. We are trying to build a relationship with the local VFW for one of our fall sessions. We are also looking to provide one in collaboration with the school system that would be offered to their staff during one of their breaks."

"...started with a senior center in my home county.. I now have more requests than I can do."

"...cancer care center, church and individual settings."

"...at a local community college, a Women's Retreat and a church."

"...excited to be approached by the Indian Health Services in a neighboring community."

"... in a school setting for the 'sandwich generation'..."

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Sessions and Sizes

"...have done 5 training sessions, different each time, but focusing on challenges and gains, reframing, love of self and self care – have done trainings of 5 – of 4 and even one all day "workshop."

*"...fewest is 6, the most is 15." "Our smallest group has been 3, the largest 77."
"I love the one-on-one in their homes. This is the only way to get to some of the caregivers who most need help."*

"...led to the creation of a caregiver coalition that meets 1-2 times a month and has representatives from several different area agencies and facilities."

Accomplishments

Presentations:

- NHPCO Management Conference September 2002 Last Acts Partner Call
- Third International Conference on Family Care – October 2002
- 2003 Gerontology Society of America Conference
- American Academy of Hospice and Palliative Medicine February 2003
- 2003 Joint Conference of The National Council on Aging (NCOA) and American Society on Aging March 2003
- National Hospice and Palliative Care Organization (NHPCO) Clinical Conference March 2003
- NHPCO 4th Joint Clinical Conference – April 2003
- NHPCO Audio Conference on Family Caregivers, July 2003
- The Florida Conference on Aging – August 2003
- 16th Annual Florida State Guardianship Association Annual Conference – August 2003
- FHPC 19th Annual Symposium – September 2003
- National Summit on Creating Caring Communities – September 2003
- NHPCO Management Conference – September 2003
- The Josefina Magno Conference Series: The Hospices of the Nation Capital Region – October 2003
- National Adult Day Services Association Annual Conference – January 2004
- NHPCO 2004 5th Clinical Team Conference and Exposition on Hospice and Palliative Care – March 2004
- California Hospice Foundation – May 2004
- Florida Council on Aging (FCOA) Annual Conference - August 2004
- AoA Alzheimer's Disease Demonstration Grantees Annual Meeting – November 2004
- Center for Hospice, Palliative Care and End-of-Life Studies – Quality and Meaning at the End of Life: Practice, Research & Policy Conference – March 2005
- NHPCO's 6th Clinical Team Conference – April 2005

Poster Presentations

The National Caregiver Needs Assessment" with K. Acquaviva and J. Kwak. Gerontological Society of America Annual Meeting, San Diego, CA, November 22, 2003

"Caregiving at Life's End: National Hospice Needs Assessment" with K. Acquaviva. Center for Hospice, Palliative Care & End-of-Life Studies," Tampa, FL, November 6, 2003. **Received Excellence in Research Award**

"Caregiving at Life's End: National Hospice Needs Assessment" with K. Acquaviva. American Society on Aging, Chicago, IL, March 15, 2003

"Caregiving at Life's End: National Hospice Needs Assessment" with K. Acquaviva. American Academy of Hospice and Palliative Medicine 15th Annual Assembly, Orlando, Florida, February 6, 2003

"Comparison of the Needs of African-American and Caucasian Family Caregivers in Palliative Care Settings" with J. Kwak, M. Deming, K. Egan, K. Acquaviva, and K. Brandt. Gerontological Society of America Annual Meeting, Boston, MA, November 26, 2002

Articles Published

Salmon, J.R., Kwak, J., Acquaviva, K.D., Brandt, K., Egan, K. (2005). Transformative aspects of caregiving at life's end. *Journal of Pain and Symptom Management* 29 (2), 121-129.

Salmon, J.R., Kwak, J., Acquaviva, K.D., Brandt, K., Egan, K. (2005). Validation of a caregiving life's end questionnaire. *American Journal of Hospice & Palliative Medicine* 22(3).

Works in Progress

Kwak, J., Salmon, J.R., Kwak, J., Acquaviva, K., Brandt, K., and Egan, K.A. Benefits of Training End-of-Life Caregivers

Kwak, J., Salmon, J.R., Kwak, J., Acquaviva, K., Brandt, K., and Egan, K.A. Caregiver and Hospice Staff Perceptions of End-of-Life Caregiver Needs

Kwak, J., Salmon, J.R., Acquaviva, K., Brandt, K., and Egan, K.A. Comparison of the Experience of African-American and Caucasian Family Caregivers in Hospice Settings

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Awards

- NHPCO Award of Excellence – NHPCO Management and Leadership Conference – September 2003
- Finalist 2003 Award of Excellence in Patient and Family Services, Florida Hospices and Palliative Care
- National Council Hospice and Palliative Professionals (NCHPP) 2003 recipient Award of Excellence for Education in Public Education Program for Patients and Families
- Highlighted on AoA website as a hospice site recognized as a “Caregiver Champion” - 2004
- 2005 Healthcare and Aging Awards – Recognizing Innovation and Quality ASA –NCOA 2005
- 2005 Caregiver Friendly award in the Service category. Today's Caregiver Magazine

Lessons Learned

The *Caregiving at Life's End* program has done much teaching in the past 3 years and not without learning a wide range of lessons. Successfully implementing this program with caregivers involves skills in “facilitation” as much if not more than in “training”. Our advice is to utilize these materials to facilitate a process that encourages the caregivers to become the teachers. Caregivers have taught us to create the environment, provide the stimuli to ask questions, and encourage caregivers to teach each other. It is not a formal “education” process but one that empowers caregivers to find meaning, closure, peace, and sustenance in their experience by creating an opportunity to repeatedly ask themselves and the care-receivers, “What is most important to you today?” Finding that many of our participating trainers lacked skill and experience as facilitators, we adapted the training to include more content and evaluated practice in that essential skill.

We have learned that the Hospice Experience Model of Care that focuses on the experience of completion and closure for patients translates to caregivers. Helping caregivers deal with issues of advance care planning, completion and closure is a process that happens over time and cannot be addressed as effectively in one time trainings. Caregivers have taught us that they want to be prepared, want to talk about issues surrounding illness, caregiving, completion and closure of life and relationship, dying, and bereavement before a time of crisis, even when only anticipating taking on a caregiving role.

Reaching caregivers is a challenge that is inherent in being of service to them. We have learned that caregivers can be reached and do participate when the principles of social change and social marketing are combined with a community partnership approach to naturally occurring communities. We as facilitators had to make adjustments in order to provide trainers with more opportunities to practically apply the social marketing skills included in the curriculum. Those participating

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trainers who have embraced the social change approach have had tremendous results in integrating into naturally occurring communities and creating dynamic partnerships. Those that fell back on traditional marketing approaches have found it difficult to reach caregivers.

Mostly we have learned about the power of the human spirit from family caregivers - that positive experiences can happen in the midst of suffering. When we honor that experience amazing things can happen. The true outcomes are heard when those who have been providing care to their loved one for many months or years state, "the last months my (husband) was with me was nothing like I expected," or, "This program allowed us to plan ahead, know what was important to us and spend those precious months focusing on those things while comforting each other... My memories of those times have sustained me."