



Palliative Care: Education, Tools, and A New Approach

A Report on the Carmelite Sisters for the Aged and Infirm and the Avila Institute Palliative Care Pilot Project

Began Late 2012 Ended May 2015

Background

Upon entrance to the facilities served by the Carmelite Sisters for the Aged and Infirm, all residents are placed in a Palliative Care Program. The mission of the Carmelite Sisters for the Aged and Infirm is to provide holistic care in an atmosphere of Christian understanding and faith. The life of every human being is considered sacred; therefore, there is a moral responsibility to respect and protect the basic right to life. A Palliative Care program provides attentive aid to all, including those with mental and/or physical limitations.

Palliative Care seeks to provide relief from the five domains of pain that all persons experience when faced with a debilitating diagnosis, and is not reserved for those who are imminently dying. The Palliative Care program allows each resident to receive the appropriate treatment that brings him/her comfort and the best possible care. Palliative Care can be combined with curative or with less aggressive care; however it is not the same as Hospice Care or End of Life Care. (All Hospice Care is Palliative Care, but all Palliative Care is not Hospice Care; it's a matter of timing.) End of Life Care is more intense and is reserved for those who are imminently dying.

Every aspect of care given to those who reside in the homes served by the Carmelite Sisters reflects the sanctity of life, the dignity of the human person, and the realization that death is a natural part of life. Great tenderness and concern are shown to the sick, and every effort is made to alleviate pain and to promote comfort. Both the resident and the family are consoled and supported, especially when death is imminent.

The Pilot Project

In late 2012, the Central Ethics Committee and the Avila Institute of Gerontology developed an outline to assess the current understanding of Palliative Care in the homes served by the Carmelite Sisters for the Aged and Infirm.

In addition to gaining insight into the method and level of Palliative Care already being provided to the residents, the committee was interested in designing a formalized Palliative Care program that could be implemented in all the homes served by the Carmelite Sisters.

The Avila Institute set up parameters to first assess the understanding of Palliative Care in the homes served by the Carmelite Sisters. The residents' families and staff took a custom survey, designed to address the understanding of critical elements of Palliative Care. To establish the framework of the Palliative Care program, the Avila Institute designed a training program and implementation process that would be feasible and sustainable in the homes. The Avila Institute designed an assessment included in the training and implementation process, that would identify all the domains of pain a resident might be experiencing.

The homes taking place in the pilot program included: Lourdes Noreen Mckeen Residence, in West Palm Beach, FL, St. Margaret Hall in Cincinnati, OH, St. Patrick's Residence in Naperville, IL, St. Patrick's Manor, in Framingham, MA, Ozanam Hall in Bayside, NY and St. Patrick's Home in Bronx NY.

Project Personnel

The project was conceived by the Central Ethics Committee of the Carmelite Sisters for the Aged and Infirm and was overseen by Avila Institute of Gerontology. Sr. M. Peter Lillian Di Maria O. Carm., Director of the Avila Institute, and Beth Selig, M.A., Coordinator of Educational Programs, collaborated with numerous faculty to create the most comprehensive Palliative Care program and educational curriculum. The educational portion of the Palliative Care program was based on the curriculum designed by the End of Life Nursing Consortium, which was used with expressed permission. Additional materials for the educational curriculum were provided by Mary T. O'Neill BCC,

LMT, D.Min., MC Sullivan, RN, MTS, JD, Fr. Myles Sheehan, SJ, MD, and Sr. Annelle Fitzpatrick, CSJ, PhD. Sr. Lois Wetzel O.Carm, RN, Carole Stathis, MS, RN and Ann Spenard MSN, RN, C assisted with all aspects of the program development. Beth Selig and Heidi Parker completed all tasks associated with the development of the program and incorporated the feedback and input from each of the pilot homes. Mary Tellis Nayak, RN, MSN, MPH, and Vivien Tellis-Nayak, PhD, provided assistance with the survey portions of the pilot program. Stephanie Kolbo and Shannon Summers at My Innerview, a branch of the National Research Corporation, also collaborated with the survey portion of the pilot program. Erin Pietrak designed the layouts of the program curriculum, assessments and implementation guide. A detailed list of all the personnel who collaborated on the project is included at the end of the report.

Process

To begin the program, Sr. M. Peter Lillian Di Maria, O. Carm. of the Avila Institute interviewed several facilities that had education curricula and Palliative Care programs in place, identifying both the challenges and successes they had encountered. Sr. Peter Lillian attended the End of Life Nursing Education Consortium (ELNEC) training program in order to identify the necessary components and steps in designing a Palliative Care education curriculum. With the ELNEC principles and a series of program and training goals in mind, she and the Carmelite Sisters/Avila Institute faculty developed an outline of the program as a whole. The next step was determining the level of understanding around Palliative Care present in the six homes served by the Carmelite Sisters for the Aged and Infirm, hereafter, "pilot homes," that agreed to partake in the process of surveying Residents, Staff and Family. The homes were asked to choose 25 members of each specific group, particularly those who were involved within the pilot unit. These surveys were designed to identify the general understanding and level of working knowledge of Palliative Care by each group. The survey used non-persuasive questions that would present the most accurate, useful, and informative results.

The surveys were mailed to each participant and returned anonymously to My Innerview, a branch of the National Research Corporation in Chicago, IL. Two sets of surveys were completed: One prior to a training (identified as "pre"), and the second subsequent to the training (identified as "post.") My Innerview generated detailed reports for each specific group. The report detailed the findings both prior to and after the training program, and provided a comparative analysis.

Between the two surveys, the six pilot homes implemented a training program and assessment protocol for

a specific area of their home. For the purposes of the pilot program, the participating homes were asked to identify a specific unit/wing/floor in the home where the program could be implemented on a small scale. Then, the pilot homes were asked to train their staff initially on the first two sessions of the curriculum, as well as the last session, and complete the Pain Assessments (Emotional, Mental [Psychiatric], Familial and Spiritual) on the residents in the chosen unit.

Training

The training curriculum, developed with the assistance of the aforementioned faculty, includes power point presentations and teaching notes, supplemental teaching tools, case studies, student handouts, pain assessments, and reference materials. The Palliative Care curriculum also includes an outline for the overall implementation process.

The homes participating in the pilot program formed a Steering Committee to oversee training for the staff assigned to the pilot unit. The first two sessions, along with the last session of the curriculum, focuses on training caregivers to understand:

- The principles and importance of Palliative Care
- The importance of identifying and managing different types of pain
- The importance of being an advocate for the resident
- The importance of each resident's culture and faith traditions
- The importance of an interdisciplinary approach to each resident's care
- The implementation process that will be used to form a Palliative Care Program

Program

Once training was completed, the Palliative Care Unit teams began assessing all residents on the pilot unit with the Palliative Care Assessment that was developed as part of the program. The Palliative Care Pain Assessment identifies all elements of pain and suffering experienced by a person living with a life-limiting illness in a long term care facility. This assessment focuses on identifying the Emotional, Psychiatric, Spiritual, and Familial pains a resident may be experiencing. The goal of the assessment is to identify the root cause of the person's pain and suffering, so that interventions that are implemented to comfort and console the resident. The Assessment did not cover Physical pain, as all facilities have a procedure and assessment

that they currently use.

Once the assessments were completed, the results were discussed with the Palliative Care Committee. The goal of this discussion was to identify a resolution utilizing the input and skills of all care disciplines. The Committee decided on several interventions that would address the concerns raised in the assessment. These interventions were implemented over a period of time and evaluated for their appropriateness.

Site Visit and Program Evaluation

Once these phases of the program had been completed, Sr. M. Peter Lillian Di Maria visited each of the pilot homes to provide support to the staff. During the visit, she also met with the Palliative Care Steering Committee, staff, family and residents of the pilot units. These meetings helped to gain insight into the challenges and barriers, as well as successful resolutions involved in piloting the program. The interviews with each home's Palliative Care Committee identified unique challenges and resolutions. These challenges included:

- Identifying assessment questions for non-verbal residents and family members
- Defining examples of Emotional, Psychiatric, Spiritual, and Familial Pain and a similar glossary of terms for the assessment
- Integrating the results of pain assessment information into Electronic Medical Records
- Understanding initial startup and team protocol
- Identifying the importance of advance directives
- Developing communication strategies for staff and families

The Avila Institute, in collaboration with the Pilot homes, developed the following resolutions in response to these challenges:

- Created a user-friendly template for a resolution plan and/or action plan
- Refined the learning objectives for the training sessions to help staff express their understanding of Palliative Care and the importance of Advance Directives
- Developed a templates for a consistent way to report pain and progress, as well as to establish team protocols
- Established ways to follow up on Emotional pain authenticity, Physical pain, relationships, and empathy education

Findings

The pilot program identified several factors relevant to establishing a formal palliative care program. The study did not include quantitative outcomes of Palliative Care in long term care facilities, but rather identified the importance of educating residents, families and staff on the principles of Palliative Care and the five domains of pain. Overall, the results of the survey showed that there was an increase in each group's understanding of Palliative Care. The staff participating in the pilot shared their observations, experiences and challenges in using the Palliative Care curriculum and the pain assessments. Ultimately, both aspects provided overlapping information and repetitious results.

The implementation of the Palliative Care assessment led to a more holistic approach to care and an increase in the satisfaction of the residents and family. The Palliative Care Committees also noted that the definitions of the five pains were not detailed enough, and that the staff struggled with the differences. The pilot homes shared their observations about the assessment, and they found it to be too long and repetitive.

Phase 2

The next phase of the program involved streamlining the assessment questions for clearer identification of the type of pain the resident may be suffering. Revisions included simplifying the assessment questions, shortening the form, updating policy changes in the curriculum, streamlining the information in the first two sessions and updating the implementation and barrier information in the final session. An action plan guide was developed, which delves into the resident's biography and network looking for the causes of his or her pain. With this information, staff and families can marshal available resources of support. In addition, several new pieces were added to the implementation guide, which include a definition of the each of the five domains of pain to help understand suffering, a list of guiding questions to accompany the pain assessment, and an outline for the meeting process with the Palliative Care Committee and unit teams.

The Palliative Care Steering Committee at each pilot home guided the above revisions. Each member of the team submitted information based on the results of their experience implementing the program in their respective homes. The assessment forms, guiding questions, template for meetings, and communication strategies for staff were developed collaboratively for clarity.

The revisions were a combination of what worked best in each home and direct feedback from and observation by the Committee and staff. Continued training will take place to include ongoing communication strategies among the

team, residents, and families.

Palliative Care Certificate Program at Calvary Hospital

Calvary Hospital provided an additional three-day educational program on Palliative Care from June 12-14, 2015, which was coordinated by the Avila Institute of Gerontology, Inc. and Dr. Robert Brescia, Director of the Palliative Care Institute. The goal of the program was to share principles of effective, compassionate Palliative Care used at Calvary that recognize the dignity and enhance the quality of life for those facing end-of-life issues and life-threatening illnesses. Calvary Hospital's philosophy was developed and put into practice under the supervision of Dr. Michael Brescia, MD, Executive Medical Director of Calvary Hospital.

Homes served by the Carmelite Sisters that sent staff were: Ozanam Hall, Bayside Queens; St Patrick's Home, Bronx, NY; and St. Patrick's Manor Framingham, MA. Topics covered for the eleven participants included Pastoral care of families, pain management, bereavement, wound care, and psychiatric issues in Palliative Care.

The program included lectures and discussions as well as practical rounds with several of Calvary's seasoned doctors to see the Palliative Care program in action. Presentation topics included:

- *"The Challenges of Palliative Care (Is it Just Good Medicine)"* and *"Psychiatric Issues in Palliative Care"* presented by Robert Brescia, MD
- *"Recreation"* presented by Edward Gorman
- *"Spirituality"* presented by Fr. Okochi Chux
- *"Bereavement"* presented by Sherry Schacter, PhD
- *"Special Nursing Problems in the Palliative Care"* presented by Marcia Mulligan, RN
- *"Enterostomal Wound Care"* presented by Jeanne Nusbaum, RN
- *"Management of Pain and Physical Causes of Distress"* and *"Pain and Symptom Management Interdisciplinary Collaboration Case Study"* presented by Christopher Comfort, MD
- *"Nutritional Services"* presented by Donna De'Esso, MSRD
- *"Caring for the Family"* presented by Debbie Feldman, J.D., LCSW
- *"Wound Care"* presented by Oscar Alvarez, Ph.D.

Participants and doctors engaged in lively discussion to reach compassionate solutions for questions surrounding palliative care. Both Calvary's physicians and the participating nursing home staff are enthusiastic for similar future collaborative programs that will strengthen their united goal of providing exceptional Palliative Care to residents and patients.

PROGRAM PERSONNEL

Sr. Peter Lillian Di Maria, O. Carm., BA, LNHA
Director, Avila Institute of Gerontology
Germantown, New York

Sr. Lois Wetzel, O.Carm, RN
Postulant Director, RN, Carmelite Sisters
for the Aged and Infirm
Germantown, New York

Sr. Annelle Fitzpatrick, CSJ, PhD
Associate Professor of Sociology, Co-Director
Geriatric Nursing Leadership Program,
St. John's University,
New York, New York

Ann Spenard, MSN, RN, C
Vice President, Consulting Services
Wethersfield, Connecticut

Beth Selig, MA
Coordinator of Educational Programs,
Avila Institute of Gerontology
Germantown, New York

Carole M. Stathis, MS, RN
Nurse Educator
Ridgefield, Connecticut

Carole Michelsen, MD, CMD
Medical Director, St. Patrick's Home for the
Aged and Infirm, Evercare/OptumHealth
New York, New York

Karin "Teddi" Tomsic, BCC
Board-Certified Chaplain
Shelton, Connecticut

MC Sullivan, RN, MTS, JD
Director of Ethics, Covenant Health Systems
Tewksbury, Massachusetts

Michelle Pandolfi, MSW, LNHA
Director, Consulting Services, Qualidigm
Wethersfield, Connecticut

Erin Pietrak
Coordinator of Design and Marketing,
Avila Institute of Gerontology
Germantown, New York

Linda Rutledge
Administrative Assistant,
Avila Institute of Gerontology
Germantown, New York

Fr. Myles N. Sheehan, SJ, MD
Provincial of the New England Province of Jesuits
Jesuit Community

End of Life Nursing Consortium (ELNEC)
One Dupont Circle, NW Suite 530 Washington DC 20036
www.aacn.nche.edu/ELNEC

Mary T. O'Neill, BCC, LMT, D.Min.
Vice President for Spiritual Care and Pastoral
Education, Catholic Health Services of Long Island
Stoneybrook, New York

Researchers

Mary Tellis-Nayak, RN, MSN, MPH
VP for Quality Initiatives at My Innerview
Chicago, Illinois

Vivien Tellis Nayak, Ph.D.
Senior Research Advisor, National Research Corporation
Lincoln, Nebraska

Calvary Hospital Coordinators

Dr. Michael J. Brescia
Executive Medical Director, Calvary Hospital

Dr. Robert Brescia
Director of the Palliative Care Institute at Calvary Hospital

Co-Editors

Zoe Gathers
Freelance Editor

Stacey Jackson
Coordinator of Programmed Services,
Avila Institute of Gerontology, Inc.

PILOT HOMES PERSONNEL COMPLETED PROJECT

OZANAM HALL, BAYSIDE, NY

Chairperson Ms. Carol O'Dette, LCSW-R, *Director of Social Work Services*

Sr. Joseph Catherine Raymond, RN, BA, MA, LNHA, *CEO*

Sr. Philip Ann Bowden, RN, BS, LNHA, *Administrator*

Ms. Magdalene Smolen, MPA, LNHA, *Assistant Administrator*

Sr. Madeline Fasano, BS, LNHA, *Administrative Assistant*

Dr. Luigi Capobianco, MD, AAFP, C-FP, C-GM, *Medical Director*

Ms. Theresa Kempf, RN, MSN, NP, DON, *Director of Nursing Services*

Ms. Marilyn Gindi, COTA, *Director of Activities*

Sr. Joanne Donovan, LMSW, *Director of Pastoral Care*

Ms. Ana Tagle, BS, MS, RD, *Director Clinical Nutrition*

Ms. Maria Luttrell, GM, *Food Service Director*

Mr. Andrew Maxwell, RN, *Education Supervisor*

Ms. Alma Holler, RN, *Supervisor*

ST. PATRICK'S HOME BRONX, NY

Sr. Kevin Patricia, O.Carm., *Administrator*

Betty Dunleavy, RN, BSN, *Assistant Administrator*

Sr. Leda Domino, LMSW, *Social Worker and Coordinator of Program and Trainer*

Joan Deignan, RN, MSN, CHLN, *Director of Staff Development and Trainer*

Kathy Mayer, *Director of Pastoral Care and Trainer*

Rosemarie Waters, RN, *Nursing Supervisor*

Christine DeLuca, LMSW, *Social Work Director*

Christina Di Napoli, MSW, *Social Worker*

Colleen Mc Coe, *Social Worker*

Lurline Ferdinand, RN, *Director of Nursing*

Sandra Valladares, LPN, *Charge Nurse on Pilot Unit*

Ginny O'Keefe, LPN, *Charge Nurse on Pilot Unit*

Marie Ordonez, *Pastoral Care Assistant*

Janet Kibassa, *Director of Recreation*

ST PATRICK'S MANOR, FRAMINGHAM, MA

Sr. Maureen McDonough, *Administrator*

Danna Lynch, LPN, *Nurse Manager*

Joan Murphy, LICSW, *Director of Social Service*

Geraldine Gracey, RN, BA, CCRN, *Clinical Instructor*

Sheila Flynn, RN, *Pain Management/Palliative Care Nurse*

Sr. Shawn Flynn, RN, *Ethics Chairman, Compliance Officer*

ST PATRICK'S RESIDENCE, NAPERVILLE, IL

Prisca Wynter, RN, *Unit Manager*

Marilyn Steffel, *Staff Organizational Development Coordinator*

We are grateful to St. Margaret Hall in Cincinnati, Ohio and Lourdes McKeen Residence in West Palm Beach, Florida for their participation in the Palliative Care Pilot Project.