



IMPROVING CARE AT THE END OF LIFE:
A LONG TERM CARE INITIATIVE

*At a
glance*

GEORGIA COLLABORATIVE
TO IMPROVE END OF LIFE CARE

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*At a
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In 1998 the Georgia Health Policy Center contracted with Georgia Medical Care Foundation for the development of a collaborative Quality Improvement Initiative demonstration to improve end of life care in Georgia nursing facilities.

At A Glance was prepared for the dissemination of information about that Initiative. It is a shortened version of Georgia Medical Care Foundation's final report document that details the entire Long Term Care study.¹

An executive summary, project highlights and recommendations for long term care providers, healthcare professionals and regulatory agencies, professional associations and academic institutions are contained in the *At A Glance* report.

¹ Additional findings of the Initiative related to continuity and cost of care have been separately published as "Rough Passages for Long Term Care: The Churning Effect" by Cooney, Landers, Etchason and Williams in Long Term Care Interface, January 2001.

GEORGIA MEDICAL CARE FOUNDATION STAFF

WORKING ON THE STUDY INCLUDED:

Jennifer Harrison, RN, MBA

Director of the Health Services Research Center

Will Battles, MBA-MHA

Project Associate

Joan Stebel, RN, M.Ed.

Health Education Specialist

Rodney Presley, Ph.D.

Director of Data Analysis

Qin Jiang

Data Analyst

Executive Summary

GOAL

The goal of the entire long term care initiative was to demonstrate an improvement in the way end of life care issues are addressed in Georgia long term care facilities. To accomplish this end we first needed to discover what was being done to address end of life care issues in our long term care facilities. Once a picture emerged, an educational initiative was carried out by our study facilities, and then pre and post implementation data was analyzed for improvement in designated areas.

PARTIES

Georgia Medical Care Foundation did principal information collection design, participating facility staff education, field liaison and data collection and analysis. The study was funded through Georgia State University's Health Policy Center by the Georgia Coalition for Health, Joseph P. Whitehead Foundation, Georgia Department of Community Health and Georgia State University. We worked closely with the Health Policy Center at Georgia State University, who initiated and directed the study, and were guided by our technical advisory committee, made up of representatives from various associations, agencies and providers in the state's long term care industry.

COLLABORATORS

From an original group of 20 study and 20 control homes, there were ultimately 17 skilled nursing facilities who received the educational initiative and 19 control facilities who agreed to remain a part of the study. A complete listing of their names can be found at the end of this document.

PHASE I: CURRENT PATTERNS IN GEORGIA NURSING HOMES

Using existing databases, we were able to construct a picture of residents admitted to Georgia long term care facilities between July 1, 1996 and June 30, 1997. Information was taken from the Georgia Department of Medical Assistance's Pre-certification

Form (DMA-6) and Medicare Part A billing records. Demographic characteristics were obtained, as well as hospital discharge and date of death information. This information was obtained for 21,990 subjects from 356 nursing facilities that met study criteria.

CURRENT PATTERNS HIGHLIGHTS

- Newly admitted nursing home residents were found to have high death rates.
- Most deaths occurring within the first 90 days of admission were among very ill individuals and took place in the facility.
- Residents were often hospitalized after their initial admission to a long-term care facility, some with multiple admissions, which could disrupt continuity of care.
- Many of these hospitalizations were for preventable causes, which identified opportunities for facilities to improve resident quality of care.
- Because many deaths occurred within the first 90 days of nursing facility admission, newly admitted residents are in need of advance care planning for end of life decisions.

PHASE II: PLANNING AND DELIVERY OF END OF LIFE CARE

This phase consisted of three parts which gave us information from the DMA-6 Precertification Form, direct patient chart abstractions and a survey that was sent to all of the long term care facilities in the state. Together this data created a picture of what was actually occurring for long term care residents related to end of life care planning and documentation.

Part 1 – Documentation of End of Life Care Planning at Pre-Certification of Clients Prior to Entering Georgia Nursing Facilities

Those persons initiating the pre-certification call for a patient's admission to a skilled nursing facility were asked to indicate if the individual had any advance directives or care limiting orders already in place.

Part 2 – Documentation and Use of End of Life Care Planning in Georgia Nursing Homes

Twenty randomly selected nursing homes that admitted residents under Medicare and Medicaid were asked to

participate in our study. An additional 20 facilities agreed to act as control homes.

Data analysts determined that the abstraction of 30 randomly selected resident charts from each facility would give us the numbers needed for a representative sample for the state.

Chart abstractors obtained information related to the presence or absence of end of life care planning documents, discussions, requests and follow up actions related to those requests. Dates and place of completion of end of life documents were also recorded.

Part 3 – Organizational Characteristics of Advance Care Planning in Georgia's Nursing Homes 1997

A professionally developed questionnaire was sent to 356 long term care facilities in the state in order to determine how nursing home staff facilitated and documented end of life care planning. The form was anonymous and self-reporting and 60.4% (215) were returned.

PLANNING AND DELIVERY OF END OF LIFE CARE HIGHLIGHTS

- DMA-6 Precertification information indicated that only a small proportion of individuals (less than 12%) had advance care planning documentation in place on admission to a long term care facility.
- The *Do Not Resuscitate* care limiting order is the most common document in use by long term care residents in Georgia.
- New nursing home residents, who are more likely to die within the first 90 days of admission, were no more likely to have completed an advance care planning document than other residents.
- There was often a discrepancy between the end of life care planning information on advance directive checklists and the information found in the medical charts.
- There was little information in resident care plans regarding advance directives or care-limiting orders.
- The Social Services staff was identified most often as the department responsible for the initiation, documentation and coordination of end of life care planning, as well as for providing facility staff education on end of life issues.

PHASE III: THE EDUCATIONAL IMPROVEMENT INITIATIVE

Part 1 – Choosing the Activities for the Improvement Initiative

After looking at data gathered from the DMA-6 Precertification forms, Medicare Part A billing information, facility questionnaires and patient chart abstractions, we also conducted literature reviews and searched for Best Practices related to end of life issues in skilled nursing facilities throughout the United States.

A meeting was held with our technical advisory committee and all of the compiled information was shared and discussed. Many opportunities for improving end of life care in the nursing home setting were apparent. We did not want our intervention to be too time-consuming for the facility staff, although we wanted them to be able to impact end of life care plan-

ning. The care plan conference emerged as a site of concentration. Many staff members, from several health care disciplines, attend these meetings, which are scheduled regularly per federal regulation.

It was also apparent that if any advance care planning or care limiting documents existed, they needed to be easily accessible and to accurately reflect the patient's, or health care agent's, wishes for treatment. Documents can only be used if they are readily available and current. For this reason we decided to pilot test a POLST (Physician's Orders for Life Sustaining Treatment) form, developed in Oregon and used, with modifications, in other long term care settings throughout the country.

PART 1 HIGHLIGHTS

From all of our information on the picture of end of life care in Georgia skilled nursing facilities, we chose two educational interventions for our study facilities to implement:

- We asked that end of life planning be included as a part of all care plan conferences.
- We asked the study facilities to pilot test the POLST form for documentation of end of life preferences and updated review. The form was modified for use in Georgia, and approved for our limited use by various industry providers and the State Office of Regulatory Services.

PHASE III: THE EDUCATIONAL IMPROVEMENT INITIATIVE

Part 2 – The Improvement Initiative

All study facilities were invited to one of two, day-long, educational workshops, where we presented our research to date and solicited their continued participation in the study. A Quality Improvement (QI) overview was also presented, as we suggested they approach the implementation of our requests from a QI perspective.

Participants were provided with notebooks that included all of the current information we had gathered regarding end of life care in Georgia long term care facilities, a QI review and tool kit, staff in-service materials for introducing the POLST form, resources, references, and additional facility-specific data for direct comparison to state-wide data that had been collected.

Project staff visited facilities that were unable to attend and presented a mini-

workshop to introduce the materials and our request for participation.

The study time frame was designated from January 1, through June 30, 2000. All study and control homes were visited for a new series of chart abstractions, which gave us current pre-implementation data. This data would be compared to post-implementation chart abstractions, which were scheduled for July, August and September of 2000.

During the six-month study period, an informational survey was completed by the study homes. This was used as a basis for discussion in March, when we conducted a series of conference calls to check on their progress, answer questions and address any concerns.

A final survey was also completed by all study homes at the end of the educational initiative.

IMPROVEMENT INITIATIVE HIGHLIGHTS

- Three study homes and one control facility decided to drop out of the project during this time, leaving the final numbers at 17 study and 19 control homes.
- Some of the study facilities had difficulty in implementing the improvement initiatives, began later than anticipated or only participated in one of the requested activities.

PHASE IV – OUTCOMES AND EVALUATION OF THE IMPROVEMENT INITIATIVE

Outcome results came from both quantitative chart abstraction comparison data and qualitative survey responses.

Both sources reflected positive change related to how EOL issues are addressed in the 17 study facilities.

OUTCOME AND EVALUATION HIGHLIGHTS

- One of the indicators abstractors looked for was the ability to quickly find and access any advance directive documents in the chart. Charts that have a special section designated “Advance Directives,” or a method to highlight the documents for easy access, make it easier to use the documents if the need arises. The presence of this highlighting of documents or section increased from 39.4% to 69.2% of the study facility charts.
- Study homes showed an increase from 15.4% to 21.1% in the presence of end of life discussions on the social services intake evaluation.
- Follow up discussions by social services staff for those residents without Advance Directives on admission increased to 40%. Pre-intervention charts recorded this follow up at only 11.9%.
- Final surveys were returned by all 17 facilities and the majority of the responses indicated satisfaction with the experience, a positive change in the way end of life issues were handled in the facility and a resolve to continue addressing end of life issues at care plan conferences, as well as a desire to continue use of the POLST form.
- The majority of survey responses indicated that facility staff had held more end of life discussions with residents, families and physicians since the study began. Eleven of the 17 facilities indicated that the way they now address end of life issues has changed “somewhat” or “significantly.” Thirteen indicated that the End of Life Study had been a positive experience for staff members; eleven felt it had been positive for the residents and eight felt it had been helpful for physicians.

OUTCOME AND EVALUATION HIGHLIGHTS – CONTINUED

- Fourteen of the seventeen stated they would continue to include end of life discussions at care plan conferences. Fifteen felt they have a greater appreciation of the importance of end of life issues, and thirteen would recommend the study opportunity to other facilities. Ten of the seventeen plan to continue using the POLST document in their facilities and nine of the homes indicated that the medical staff and Medical Director liked the form.
- An additional meeting for revision of the POLST form was held in March 2001, with interested staff members from study facilities in attendance. In addition to those present at the meeting, we received faxed recommendations from all but two of the study facilities. Those directly working on the revision took these recommendations into account. Representatives from the Health Policy Center were present for part of the meeting and the Medical Director from the End of Life advisory committee was also in attendance as a participant in the revision. Copies of the revised document have been sent to the Health Policy Center at Georgia State University and will be presented to the Georgia Chapter of the American Medical Director's Association for their consideration.

Project Highlights

HIGHLIGHTS FROM IMPROVING CARE AT THE END OF LIFE: A LONG TERM CARE INITIATIVE

- The changes recorded by the LTC End of Life Initiative showed great variations among the participating facilities. Some have whole-heartedly adopted both recommendations and plan to continue with their use, while some never started or started and stopped.
- There are many reasons for the variations encountered, most of them related to the unstructured nature of the educational initiative and/or the inherent barriers to continuity that exist in the long term care industry and those that are created by the topic of *end of life* itself.
- Positive change related to end of life issues has been documented in many of the study facilities. Considering the short time frame allocated for the designated educational initiative, we are encouraged that the process of change has begun.
- Initial data indicated that only a small number of residents in nursing facilities have completed any advance care planning prior to admission. Other data showed that once admitted to long term care, many new residents are at high risk of death within the first 90 days. Only a small percentage of residents ever have documentation of advance directives, care limiting orders or end of life planning reflected in their charts. Therefore, **any** improvement to end of life care planning in nursing facilities can be interpreted as useful, and probably as significant.

Recommendations

RECOMMENDED OUTCOMES AND STRATEGIES

In order to provide appropriate end of life care for residents in Georgia long term care facilities, certain outcomes should be the goals for best practice. Achieving these outcomes can only be accomplished by affirming and promoting them in the philosophy, policies and practices of the skilled and intermediate care facilities of the state.

- Outcome I* Discussions and decisions about end of life care are a routine part of the care planning process and decisions reached adhere to accepted medical, ethical and legal principles.
- Outcome II* Use of the Georgia-modified POLST form, or equivalent document, will create an easily identifiable and readily accessible document that reflects resident wishes for end of life care. It is a signed physician's order form that allows clinical staff to perform the requested end of life care with documented assurance of resident wishes, and is transferable throughout treatment sites. Attached advance directive documents and recorded update information allow for its use in any care setting, thus avoiding duplication of effort and errors incurred by recopying information.

Developing and adhering to effective policies and practices that advance these outcomes requires the commitment and actions of several important groups:

- The corporate, administrative and clinical leadership of the nursing home industry
- Licensed and non-licensed healthcare professionals and primary care providers.
- Regulatory agencies, professional associations and academic institutions.

Recommendations – Leadership

RECOMMENDED STRATEGIES FOR THE CORPORATE, ADMINISTRATIVE AND CLINICAL LEADERSHIP OF THE NURSING HOME INDUSTRY

Recognizing that the individual nursing home facility is directly responsible for establishing a culture and climate that encourages and supports attention to comprehensive end of life care, the following strategies can help to establish that desired culture and climate:

- (1) Develop a written statement of the institution's philosophy for the provision of end of life care that
 - is distributed to all residents/agents and/or family on admission to the facility.
 - highlights the need for an integrated team approach when assessing, communicating and delivering appropriate end of life care.
 - is in keeping with the facility's organizational mission and is provided to all staff with the expectation that they will adhere to the policies and procedures developed around this guiding philosophy.
- (2) Develop and use policies and procedures that stress the importance of the role of the resident/agent in the care-planning and decision-making process and that encourage their direct and continued input to whatever degree is practicable and attainable.
- (3) Uphold policies and procedures for the appropriate identification of a health care agent/decision-maker when a resident lacks capacity.
- (4) Integrate current legal and ethical principles related to end of life care with facility policies and procedures for medical and nursing care decision-making.
- (5) Develop and use a policy and procedure for the care plan conference that includes a review of the resident's advance directive status, discusses end of life planning and assigns responsibility for documentation and follow-up.

Recommendations – Leadership

RECOMMENDED STRATEGIES FOR THE CORPORATE, ADMINISTRATIVE AND CLINICAL LEADERSHIP OF THE NURSING HOME INDUSTRY – CONTINUED

- (6) Use the POLST form, or equivalent document, as a standard form for the documentation of physician orders related to resident preferences for end of life care.
- (7) Develop and follow procedures for resident transfer situations that will allow for transfer of POLST form, advance directive documents, and information verifying the resident's personal beliefs and goals of care.
- (8) Define expectations of staff responsibility for implementing all advance care planning policies and procedures. Include this information at orientation/training programs and on performance evaluations.
- (9) Provide education for staff to help them facilitate their role in end of life care planning and treatment options. This education should include, but is not limited to:
 - communication skills in talking with residents and agents about end of life care
 - communicating resident/agent end of life wishes to other team members
 - diversity and cultural differences related to end of life issues
 - skills in conflict resolution for disputes about care among the resident, family or agent and staff
 - understanding legal and ethical concepts related to end of life care
- (10) Monitor established policies and procedures related to end of life care planning through research utilization, best practices care protocols, quality improvement or quality assurance measures.
- (11) Develop criteria and procedures for transferring dying residents to hospitals that are based on evaluation of benefits, burden, and risks of therapeutic options.
- (12) Establish and disseminate a *do not hospitalize (DNH)* protocol for dying residents.

Recommendations – Healthcare Professionals

RECOMMENDED STRATEGIES FOR LICENSED AND NON-LICENSED HEALTHCARE PROFESSIONALS AND PRIMARY CARE PROVIDERS

Individuals who provide direct care to residents are ultimately responsible to act as patient advocates and to see that the wishes of the resident/agent are carried out when the time comes to implement their choices. With this responsibility in mind, the following strategies may help to obtain desired outcomes:

- (1) Healthcare professionals use effective communication techniques with residents/agents when discussing advance care planning, end of life care and palliative care.
- (2) Healthcare professionals involve all non-licensed care providers in the end of life care communication process and acknowledge their vital role as a link among residents, families and the rest of the health care team.
- (3) Healthcare professionals develop skill in:
 - assessing decision-making capacity of residents
 - educating families about the dying process and end of life care
 - explaining end of life care treatment options and the benefit/burden concept to residents/agents and/or families
 - understanding legal and ethical implications of withholding and withdrawing life-sustaining measures
- (4) Primary care providers and other healthcare professionals understand and apply key concepts critical to the care planning process, such as:
 - incorporating resident goals and perceptions of quality of life when considering end of life decisions
 - recognizing cultural, religious and personal values of residents
 - addressing questions about life-sustaining measures and alternatives
 - assisting in resolving conflicts that may occur concerning the appropriate plan of care

Recommendations – Healthcare Professionals

RECOMMENDED STRATEGIES FOR LICENSED AND NON-LICENSED HEALTHCARE PROFESSIONALS AND PRIMARY CARE PROVIDERS – CONTINUED

- (5) Primary care providers, when addressing end of life issues with residents/agents
 - provide sufficient information about current prognosis and treatment options
 - provide supporting documentation for clinical status of terminally ill residents
 - document preferences on POLST form, make sure advance directives, if they exist, are attached to the form and have signed orders for treatments or withholding care
- (6) Healthcare professionals provide care services consistent with resident/agent wishes as determined during the care planning process.
- (7) Healthcare professionals and non-licensed care providers assure their skill in providing the clinical and emotional care needs of residents and their families.

Recommendations – Agencies, Associations, Institutions

RECOMMENDED STRATEGIES FOR REGULATORY AGENCIES, PROFESSIONAL ASSOCIATIONS AND ACADEMIC INSTITUTIONS.

If a change in the way we discuss, plan for, and ultimately experience death in the nursing home facilities of Georgia is desired (and the study personnel feel that such a change is not only desired, but also necessary) education has to be one of the keys to reaching that goal. Education is necessary for the regulatory agencies that monitor care practices within the industry. Education is necessary for those practitioners who may have completed their formal training in an era when the mere mention of the death of a patient was considered a failure rather than the natural end to a long life. Education is necessary for the health care professionals who will someday practice in this environment. It will allow them to work in conjunction with their patients to provide the level and intensity of care desired, so that the last experience of life can be labeled “a good death.” To this end, the following strategies need to be considered:

Recommendations – Agencies, Associations, Institutions

RECOMMENDED STRATEGIES FOR REGULATORY AGENCIES, PROFESSIONAL ASSOCIATIONS AND ACADEMIC INSTITUTIONS

- (1) Regulatory agencies, professional associations and academic institutions will encourage and/or develop educational programs for their constituents – state surveyors, ombudsman programs, nursing home leadership, healthcare providers, etc., on:
 - ethical decision-making processes
 - improving communication related to end of life issues
- (2) Regulatory agencies and professional associations encourage educational opportunities, materials, and policy positions consistent with the need for appropriate end of life care and advance care planning in nursing home facilities.
- (3) The Georgia Medical Association supports and sponsors medical education for practicing physicians to improve their skills in end of life care and communications.
- (4) The Georgia Medical Directors Association develops training curricula specifically for physicians on the end of life care of long term care facility residents and recommends this curricula to nurse practitioner, clinical nurse specialist and physician assistant programs.
- (5) The Georgia Board of Nurses provides recommendations to Georgia schools of nursing, including Advance Practice programs, for education in end of life issues, discussions, decisions and care.
- (6) Georgia schools of medicine include end of life education, including palliative care practice, in the core curricula of physician education.
- (7) Regulatory, professional and academic institutions, healthcare providers and payers develop and use a vocabulary of consistent terms related to end of life and advance care planning.
- (8) The Georgia Department of Human Services (DHS) and State and local Long Term Care Ombudsman Programs support advance care planning, and designate end of life care as an appropriate goal of care and train regulators to appropriately distinguish between palliative care and criminal neglect.
- (9) Ensure that nursing home practitioners participate in the development of care plans specific to residents at the end of life.

Closing

Due to the complex nature of the issues surrounding end of life decisions, and the unique position of the long term care industry related to these issues, this study has merely initiated a change process that we hope will continue to evolve.

Clearly the participating facilities have had some change in thought and practice related to end of life issues for their residents. A small change has been effected in a small number of facilities in Georgia. As outlined in the recommendations, there is room for continued and greater change within the long term care industry, but also within other healthcare delivery systems, all of which are intricately connected, all of which are related to end of life issues in some way.

The information and recommendations contained within this report can be a valuable resource for others interested in continuing this process, particularly in the skilled nursing facility environment.

For a copy of the detailed report or to schedule a program, call or write:

Georgia Medical Care Foundation
Health Services Research
57 Executive Park South, Suite 200
Atlanta, GA 30329
404-982-0411

Care at the End of Life Technical Advisory Board

CARE AT THE END OF LIFE TECHNICAL ADVISORY COMMITTEE

Mary Arthur

Executive Director
Presbyterian Village

James P. Cooney, Ph. D.

Professor of Health
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Beverly Tyler

Executive Director
Georgia Health Decisions

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PARTICIPATING FACILITIES

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Fifth Avenue Health Care Rome	Sunbridge for Mount Berry Rome	Sadie G. Mays Nursing Home Atlanta
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