New York State Department of Health Dementia Grants Program
2003-2005 Grant Funded Project

Changing the Culture of the Nursing Home: Pilot Project on Special Care Dementia Units

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NEW YORK STATE DEPARTMENT OF HEALTH
2003-2005 DEMENTIA GRANT PROJECT
FINAL REPORT

Project Title:	Changing the Culture of the Nursing Home: Pilot Project on Special Care Dementia Units
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Section 1: Goals, Objectives, Research Questions and/or Hypothesis

The primary, overarching goal of this project is to examine the effects of a pilot culture change initiative on two nursing home special care dementia units based on the BASICS/EDGE model. (The BASICS/EDGE model (Bradley, Ronch & Pohlmann, 2000) is a framework of care aimed at supporting patients' remaining abilities and relationships.

Additionally this project seeks to test whether a comprehensive culture change intervention implementation on a culture change dementia special care unit will improve the following outcomes:

- At least 20% improvement in resident satisfaction as indicated on Apparent Affect Rating Scale
- A 20% decrease in number of residents experiencing behavior problems as indicated by the Cohen/Mansfield Agitation Inventory
- A 20% increase in indicators of positive affect in residents assessed utilizing the Apparent Affect Rating Scale
- A 20% decrease in numbers of residents experiencing unplanned weight loss
- A 10% decrease in use of physical restraints
- A 15% decrease in number of residents taking nine or more medications
- A 10% decrease in number of residents who experience unplanned decline in ADL
- Increase in ratings of the responses to the areas in the Home's annual staff satisfaction survey: Support & supervision, communication & empowerment, role clarity & function, respect & family relations, and collaboration & teamwork & opinions valued
- Decrease CNA, RN, and LPN staff turnover by 10% (non-retirement)
- An increase in self-reported ratings on "Dementia Family Satisfaction Survey," so that 75% of all items will be rated good to excellent
- A decrease in the use of agency RN/LPN staff by 20%

Section II: Background and Rationale

The acute care model has been dominant in nursing homes for decades, focusing efforts on quality of care rather than on quality of life. Loneliness, helplessness and boredom prevail (Thomas, 1994). Daily life tends toward cultural and spiritual sterility. Because the current model of nursing home care has evolved from acute care, the greatest emphasis is on pathology (Barkan, 1981).

Throughout the literature, elements of change are connected by a primary principle, returning the center of control to residents. The needs of the individual must take precedence over the needs of the institution. If nursing home residents are to thrive, they need to have opportunities for continued growth of mind and spirit. Nursing homes must be transformed into open, diverse, caring communities, providing those who live there with individualized care based on their choices and personal control; unlimited opportunities for growth in spirit, mind and body; and continued involvement with family, friends and the outside world (Lustbader, 2001).

A compelling case for the need for changing nursing home culture and the key elements of such change can be linked to quality of life principles for both residents and staff, with particular attention paid to the status and needs of nursing assistants (Lustbader, 2001). It follows that those who spend the most time with residents - nursing assistants - must have greater control and autonomy, as well (Unsino, 1998).

The common themes as expressed by Lustbader (2001) are central to the design of any nursing home culture change project and include:

- Returning the locus of control to residents;
- Enhancing front line staffs' capacity to be responsive;
- Establishing a home-like environment;
- Moving from the Unit to the Community as a means of providing care;
- Communicating a clearly defined alternative to the status quo and;
- Supporting the staff in developing new models of supervision.

The Jewish Home & Hospital LifeCare System, including its SN campus, has been trying to understand culture change and its possibilities and realities intently since 1993. Through that experience Sarah Neuman has come to understand what is really necessary to create, support and sustain profound change. Sarah Neuman, through its administration, Board of Trustees, family members, and its staff on its dementia units understand:

- The need to create a framebreaking change at its facility;
- The priority of the dementia units as a pivotal opportunity for successful change;
- Change is a five-year process, which requires sustained SN and JHH support;
- The potential resistance to such change, and;
- The value that a grant from the New York State Department of Health would make in creating this change.

A culture - one of respect, dignity, individuality, privacy, meaning and relationships - is the goal of this project. We will transform the traditional nursing unit into a resident-centered neighborhood. The neighborhood will be a group of residents who share a common living area, kitchen and dining facility as well as recreational space. This new model will reinforce the idea that each resident is a participant in a living environment that mirrors a real-world neighborhood.

It is the belief of the JHH system that it will require five years to achieve lasting, systemic culture change. We will begin with the proposed pilot efforts on the two dementia units which, when replicated, will create the "Tipping Point" (Gladwell, 2000) necessary for that change.

The grant is for the core years (Years 2 and 3) of a five-year culture change project implemented on Sarah Neuman's two dementia Special Care Units.

A project of this magnitude requires a clear framework. The BASICS Hierarchy Model of Resident Needs in Long-Term Care philosophy and the EDGE[1] toolbox (Copyright 1996 LTC. Eddy, Inc) is proposed as that framework. It is resident-centered, resident-directed and recognizes that unless staff needs are met, as well, resident and family needs will not be met.

> "BASICS is built on the biopsychosocial model that provides a system to help staff plan care to support remaining abilities and caring relationships. This assists residents to live well despite their dementia. It creates an optimistic mindset resulting in a better quality of life for residents with dementia and their caregivers. The BASICS system presents the hierarchy of needs, from primary – Biological, through last attained, Symbolic. There are positive and negative outcomes associated with attaining or failing to achieve need satisfaction under each level. All levels of BASICS, that are all levels of human need, should be addressed throughout the entire life of the resident with dementia, even if (s) he is in the 'final' phase and appears barely responsive to the environment." (Copyright 1996 LTC. Eddy, Inc.)

If the BASIC's model meets the needs of the residents with dementia, it is a model that will meet the needs of all residents in the facility. In this way, it can act as the "Tipping Point" for culture change throughout Sarah Neuman.

It is recognized that changing the culture of a 300-bed institution does not happen quickly. We have looked at the project on a five-year continuum. The planning and development of our concept of culture change have occurred in Year 1 (2001). During Years 2 and 3, we will utilize the BASICS philosophy to change the culture on two units and train the staff throughout the Special Care Units. Our Dementia Coordinator/EDGE Coordinator who is committed to culture change will lead this experience. During Years 4 and 5, our new culture will extend to all seven units at Sarah Neuman and the systemic changes necessary to support this new culture will have been accomplished. We recognize culture change is not static; nor should it be. We envision constant examination of our culture and what could/should be better, and see this as an ongoing process.

Section III: Methods

- Study Design

Procedure

The present study had three data collection points (see table below) at which time all measures were administered. Each data collection window was for a three month period in order to allow for completion of all measures. However this interval was fixed in order to standardize the procedure.

Data collection points	Window of data collection
Time 1	September 2003-November 2003
Time 2	April 2004-June 2004
Time 3	February 2005-April 2005

Measures

[1] Electronic Dementia Guide for Excellence

Longitudinal, multi-modal assessment was used to determine overall and specific areas influenced by culture change. A variety of measurement techniques were used including direct and indirect measures as well as observational methods. The table below lists all measures administered in the present study.

Domain	Measure
Resident	Observational ü Apparent Affect Rating Scale ü Cohen-Mansfield Agitation Inventory
	Direct ü Health-related quality of life indicators (e.g., unplanned weight loss, etc)
Staff	Indirect ü Employee Satisfaction Survey
Family	Indirect ü Family Survey
	Indirect ü Family qualitative comments

Resident measures

The families of residents were approached by a research assistant to explain and obtain consent for participation in the present study. This was done due to the fact that research subjects were cognitively impaired and consent could not be gained without their relatives consent. Residents' families were told that staff would be completing measures regarding their relatives' quality of life and that their relatives' medical record would be reviewed. The confidentiality of this data was stressed.

The resident observational measures, the Apparent Affect Rating Scale and the Cohen-Mansfield Agitation Inventory, were completed by two CNAs for each resident. Because affect can change markedly in the day versus evening, it was determined to use CNAs from both shifts. A CNA from the day shift and the evening shift with the most contact with each resident was asked to complete these measures.

The direct measures of resident health (e.g., health-related quality of life indicators) were obtained from medical record review by a research assistant for the project.

Staff measures

The Employee Satisfaction Survey was administered to employees by trained, in house, staff facilitators using a standardized procedure at a series of group sessions held at each facility. The confidentiality of responses was strenuously emphasized. Employees were given an unmarked survey in an envelope which they sealed upon completion. Respondents were instructed to place the completed survey in the envelope and then to drop it into a designated box. To further convey the efforts being made to ensure confidentiality, it was explained that completed surveys would be sent to an outside organization for data analysis. Demographic, potentially identifying, information was not collected.

2

Family measures

Family members were identified by medical record review and contacted to first obtain their consent. One family member was identified for each resident. Family members were asked to complete a confidential family satisfaction survey at each data collection point. They were also asked to provide qualitative comments about their satisfaction with JHH. This questionnaire was sent via mail and the family members were provided with postage and an envelope to return the survey.

- Sample

Sixty-two residents were enrolled in the present study. Residents were predominantly female (84%) with a mean age of 84.90. By the second data collection, 21 participants were deceased. By the third data collection, four more residents were deceased bringing the total number of residents deceased from the original sample to 25 (40% of the sample).

- Data Collection

IRB approval was obtained from the Jewish Home & Hospital IRB and The Mount Sinai School of Medicine IRB. Our proposal was submitted for review to the Mount Sinai School of Medicine Institutional Review Board. We used written informed consent from all subjects and/or their surrogates using consent forms approved by the Mount Sinai School of Medicine Institutional Review Board. The Mount Sinai IRB provides federal assurances through the Department of Health and Human Services. Our program evaluation was completed by a doctorate level psychologist and statistician Rachel Annunziato Ph. D.

- Quantitative Methods

Data Analysis

Analyses used the SPSS 12.0 © statistical package. Statistical tests were two-tailed whenever applicable, and a "p" value (alpha level) of 0.05 or less was chosen as the level of statistical significance. A series of repeated-measures ANOVAs were conducted on all measures across all three data points. For comparisons between just two data collection points, Independent Samples T-Tests were used.

Section IV: Results including description of analysis and reporting of relevant statistics

Table 1: **Resident Outcomes-Significant Findings**

Measure	Mean Change Time 1 – Time 2	Mean Change Time 2 – Time 3
Positive affect (Day CNA) N=29	3.55-4.59 (29% change)	4.58-4.85 (6% change)
Positive affect (Eve CNA) N=29	3.36-4.13 (23% change)	4.13-4.24 (3% change)
Negative affect (Day CNA) N=30	2.06-3.59 (43% change)	3.59-3.88 (8% change)
Negative affect (Eve CNA) N=29	2.09-3.61 (42% change)	3.61-3.69 (2% change)
Unplanned decline in ADL N=35	14 cases to 0 cases	No new cases at Time 3
Use of physical restraints N=35	13 cases to 0 cases	No new cases at Time 3

Table 1 depicts areas of significant change for residents. Two of the objective medical indicators significantly improved between Time 1 and Time 2. At Time 1, 14 residents experienced unplanned decline in ADL. However at Time 2, no residents did so. Similarly, 13 residents required the use of physical restraints at Time 1 while none did at Time 2. In both instances, 100% of this improvement was retained at Time 3 and there was no decline in either measure.

As rated by both day and evening CNAs, residents experienced significant change in both positive and negative affect between Time 1 and Time 2 and this trend continued at Time 3. One possible interpretation of this is that residents were experiencing improved physical health as evidenced by the above described markers and therefore overall affect improved. Another complimentary interpretation is that aspects of culture change contributed to both increases in positive as well as negative affect.

Table 2: **Staff Outcomes: Significant Findings**

Measure or Item	Mean Change Time 1 – Time 2	Mean Change Time 2 – Time 3
Total Satisfaction Score N=42	40.26-39.31 (2% change)	39.31-35.76 (9% change)
Recommend organization to family or friend N=40	4.45-3.83 (14% change)	3.83-3.35 (13% change)
My opinion seems to count N=39	3.46-3.79 (10% change) *Improved*	3.79-3.38 (11% change)
Comfortable seeking help from supervisor N=42	4.02-3.79 (6% change)	3.79-3.50 (8% change)
Provided with proper tools to do job N=42	4.07-3.81 (6% change)	3.81-3.45 (9% change)
Actions and decisions within organization reflect mission and values N=40	4.15-3.78 (9% change)	3.78-3.50 (7% change)
Feel valued as an employee N=41	3.73-3.85 (3% change) *Improved*	3.85-3.54 (8% change)
Supervisor treats me w/ respect N=41	4.15-4.05 (2% change)	4.05-3.59 (11% change)
Overall satisfaction N=42	4.38-4.07 (7% change)	4.07-4.07 (0% change)
Proud to work here N=42	4.52-4.14 (8% change)	4.14-3.62 (13% change)
Recommend as a good place to work N=41	4.27-4.20 (2% change)	4.20-3.80 (10% change)

The decline in satisfaction on most of the items listed above likely reflects an overall decline in satisfaction across the organization, particularly in the context of organizational change. There is a consistent body of literature reflecting that organizational change is often negatively experienced initially by staff. However, one important area targeted by the culture change initiative was improving employees' sense of empowerment. Significant improvement on "At work my opinion seems to count" and "I feel valued as an employee" seems to indicate that this objective did occur.

Despite the consistent decline on satisfaction items, one objective indicator did not suggest that decline in satisfaction was having a more serious impact. All staff that participated at Time 2 completed the measures at Time 3 indicating no turnover among this sample during an over one year period between Time 2 and Time 3.

Nurse Agency usage was also monitored during this time. During Time 1 there were 37

shifts of agency nurses used to covering all 3 shifts. During Time 2, there were 5 shifts of agency nurses used. During Time 3 there were no agency usage.

Staff Turnover Rate

	2003	**2004**	**2005 thru 6/30**
RN	10%	11%	5%
LPN	8 %	2.5%	9%
CNA	13%	9.7%	4%

We have seen a significant decline in the turnover rates for RN's and nursing assistants. The increase in turnover of the LPN is attributed to 2 LPN's completing their RN degree and moving into RN positions.

Table 4: **Resident Outcomes with No Statistically Significant Change Over Time**

Measure or Item
Agitation (Day CNA) N=31
Agitation (Eve CNA) N=30
Untreated depression N=35
Nine or more medications N=35
Unplanned weight loss N=35

The above indicators were all likely insignificant due to low base rates. Agitation scores were extremely low at all three data points. Very few residents exhibited any of the above medical outcome measures at any time point. Therefore the above table displays items where there was no room for improvement. The intervention however did not cause decline in any of the above indicators.

Table 5: **Family Satisfaction Survey Results**

Measure or Item	Mean Change Time 1 – Time 2	Mean Change Time 2 – Time 3
Family Satisfaction Scale N=19	73.16-71.79	71.79-75.05

(trend towards improvement over time but did not reach statistically significant change)

Family satisfaction likely did not improve over time because of two factors. One is the small sample size which reduced the statistical power to detect significant findings. Only 19 families completed this measure at all three time points. The difficulty in collecting collateral data from individuals outside of the nursing home is highlighted by this sample. However, perhaps more importantly, family satisfaction at baseline was high (73.16 out of a highest possible score of 90). At baseline, the average rating per item was already "somewhat satisfied" which is a 4 on a 5-point Likert scale. This finding indicates that the families who agreed to complete the survey were already satisfied with the organization. We did reach our target goal of 75% of all items on the survey rated by family members as "good to excellent" by the end of the project.

Family members were also invited to provide qualitative comments on the satisfaction survey. As part of the qualitative piece, they were asked to respond with a comment rather than categorically answering with "yes" or "no" if they would refer someone to Sarah Neuman. At Time 2, 92% of those who responded indicated that they would, in many instances, quite emphatically (e.g., "Yes, absolutely", "already have", "Yes, without a doubt", etc). At Time 3, this figure rose to 95%. Finally, family members were given an opportunity to provide any other comments. Overall,

responses were positive and some reflected aspects of the culture change initiative. Illustrative comments are listed below:

Data collection point	Sample of Spontaneous Family Comments
Time 2	"The outdoor sessions started by Mercy Issac has been wonderful! My mother's become sharper, is much more verbal and is happy to be outdoors. This program has made the most significant improvement in my mother's mental health. G-d bless Mercy!"
Time 3	"My family and I can rest assured that my Mother is safe, content, and well taken care of. Her transition was smooth and easy- It was the hardest decision of my life, but the only right answer to bring her to Sarah Neuman- We love it! It has made improvements on an ongoing basis. I hope once my life slows down a little I will be able to participate more in activities and planning of functions i.e. wine and cheese parties- which are coming soon, outings etc…."
Time 3	"We believe that an excellent facility has been made even better. Needless to say we are pleased by the care and attitude of the staff."

Section V: Strengths and Limitations including barriers encountered and how they were over come

Strengths:

1. Community building

We have created an atmosphere of active participation among residents, staff, families as well as the greater community at large. During the first half of 2005, the facility's leadership designed a plan for full implementation of the community model, transitioning from the traditional nursing units to communities. We call them "Our Communities of Caring". We went from our two pilot communities to seven communities. All staff who work in community's report to Community Coordinators who have overall responsibility for their communities. Responsibilities shift from a decentralized traditional hierarchy to a centralized community model. For example, facility wide family association meetings will be held twice a year and families will be invited to attend the monthly community meetings, which are now led by Community Coordinators.

- We have had many positive comments about our club model, the strength-based approach to looking at our residents and the multi-disciplinary approach that all grew out of EDGE.
- New clubs are being formed that developed out of the EDGE model on a consistent basis, and the clubs that began at the beginning of the grant continue.

2. Environmental change

Environmental modifications helped to visualize our culture change efforts and group participation for everyone involved. Our greatest accomplishment in environmental changes has been the changes we have made in our dining services from tray service to restaurant-style dining. Since the summer of 2004 residents come to the dining room decorated with artwork selected to cue the residents to dining. The décor, furniture and plans were all selected by consensus of community members (staff, residents and families). Restaurant style dining became the impetus that really

brought the community together as a team and changed roles.

In addition, the spa renovation is complete and has made a great impact on improving the resident's quality of life. Residents that were hesitant to take showers now do so in a soothing, gentle environment.

3. Newsletters/Communication

- During the two years of the grant twelve newsletters were published. The newsletter became powerful means of communication, staff support, esteem promotion, recognition. From the first issue which was paid for by the grant, we had a distribution of 300 copies of a four page newsletter which was immediately published on the JHH website far ahead of our projected timeline for milestones in use of technology for enhanced communication. From the moment that the newsletter began appearing on the Internet we began receiving increased e-mails from family members far away and from interested professionals. Later issues added staff spotlights and a resident spotlight in every issue. We even began to get excitement among the staff to volunteer to write some of the articles, but it was only still four pages, later on distribution climbed to 500 copies per issue. New clubs were featured in the newsletter as well as culture change information. The residents were writing their own column for the newsletter and families and staff were beginning to take notice. This intervention resulted in increased utilization of technology in both e-mailing of photographs, comments and articles to include in the newsletter.

  The June 2004 issue increased to six pages and that is where they have been ever since. It was also a major step when the resident spotlight moved from the inside page to the front page. The "Magic Moment" column also has gone through a metamorphosis. Originally, it was a hodge-podge of one-line blurbs about good deeds that staff did, or wonderful things that staff saw that residents did. Later on, it evolved into a column containing human interest stories about relationships and people developing positive connections. Recently the distribution for the last issue increased to 700 copies due to the need for extra copies to give out at the EDGE, IAHSA, and Rockland Conferences and other events. In general, 500 copies seem to be the norm for what is needed for a general mailing and to give to staff and residents in the facility. There is a great amount of enthusiasm generated about the newsletter every time a new issue comes out.

4. Dissemination

- For the two year period of the grant we have continued to meet and communicate our culture change and EDGE goals with the Board of Trustees, Family Association, Department Heads, Clinical Leadership, Jewish Home and Hospital staff, Community Meetings, facility staff in Town Meetings, residents at resident council and community meetings, and volunteers.
- We have promoted the concept of culture change and EDGE among our staff, residents, families and community. In the past two years we have given approximately 400 presentations on culture change and EDGE to our staff, residents, families, trustees, volunteers and visiting staff from other facilities. The venue included round-the-clock Community Meetings, Town Meetings, Steering Committee Meetings, Family Association Meetings, Board Meetings, as well as individual tours and presentations.
- We have presented at outside meetings and speaking engagements in other facilities or at

conferences both near and far to present on culture change and EDGE and speak about what we have done at Sarah Neuman Center to disseminate the information we have learned about using EDGE to implement culture change.
- Many people and groups have asked for tours of our dementia communities and more information about Sarah Neuman as a result of the grant the work we have done in culture change.
- We completed the filming and production of the EDGE video and training manual which will be a resource for others who wish to help everyone who works in long term care to have the tools to create success from interactions with residents with dementia and have a 2-way relationship with the individual and look for the "spark of life" or the smile on a resident's face.
- The EDGE Training Manual and DVD, developed from our experiences and success using the EDGE model, has been mailed to all nursing home in NYS
- Sarah Neuman Center held its own EDGE Conference in May, 2005 to help disseminate the information learned during the course of the two years of the grant.

5. Training

- Education and training remains an active part of our program.
- We continue our relationship with 1199 SEIU and we have received a training grant to train our JHH Bronx and Manhattan facilities in EDGE through our success. Our EDGE Trainers will be the trainers and the grant continues through the end of March 2006.

II. Limitations

- The small sample size and high mortality rate were limitations of the present study. The deaths of research subjects are likely due to the fact that the study took place with mid- to late-stage dementia patients living in a LTC facility. However, one way we overcame this was to recruit new participants at all data collection points.
- Some staff members were illiterate and did not want to divulge this information. As a result, they did not participate in the study. This information itself is useful data and is helpful for considering different means of assessing staff satisfaction in future protocols.
- A primary barrier to participation in this study was family members' feelings of potential for no direct benefit. However, we sought to allay these concerns by quickly publicizing the concrete markers of change stemming from this project (e.g., environmental changes, the newsletter, etc).
- There was a delay in renewing the project with the IRB that was corrected but caused the time 3 data collection timeline to be shifted (but still completed).
- Collection of direct outcome indicators overall did not prove to be feasible during the three month data collection windows. Future paradigms will need to employ a research assistant dedicated solely to data collection.
- Perceived lack of control by facility staff during the culture change initiation and early intervention period.

Section VI: Conclusions

- What is the answer to the result question?
- Does the data support the hypothesis(es)?

The culture change intervention employed at our facility did lead to marked improvement in several aspects of resident quality of life. Affect overall substantially improved as did two crucial medical indicators, unplanned decline in ADLs and use of physical restraints. Furthermore, in instances where residents evidenced low base rates on an outcome measure (e.g., untreated depression), the intervention did not cause an increase in symptoms. This finding is important as it demonstrates the safety of implementing this intervention within a potentially vulnerable population. Positive family responses on both quantitative and qualitative measures throughout the study provide additional evidence that the goals of the intervention were to a great extent achieved.
Overall, the data suggest that staff did not experience culture change positively. This finding was not supported by the initial hypotheses. However, it is unclear if staff were responding to the process of changing itself rather than the specific changes, as staff likely were the most affected by changing. It is possible that if staff satisfaction was tracked in the long-term, responses would capture a reaction to culture change only and not be confounded by the difficulties associated with adjusting to a new system.

- What should happen next (including specific plans for dissemination)

The project has already been presented at regional, national and international conferences. In addition, Sarah Neuman Center held its own EDGE Conference to help disseminate the information learned during the course of the two years of the grant. In addition, we will write an article for publication in peer reviewed journals such as Alzheimer's disease Quarterly, Provider, Clinical Geriatrics or other journals frequently read by Nursing Home staff.
Representatives form other nursing homes continue to come and see and hear "culture change" at Sarah Neuman. The administrator is scheduled to speak in April, 2006 at the Westchester Administrators Educational meeting

Section VII: Final Budget Report

- QMR, section 3
    - All expenses applied to the budget