

# **Dementia Care in Nursing Homes**

## **Leading the way to Culture Change**

A guide to Cultivating Culture Change Catalysts  
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*In the challenging world of residential health care, there are exceptional people who when times demand, will rise above the expectations of the norm and create a special climate of caring.*

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# Cultivating Culture Change Catalysts

## **WHAT DID WE WANT TO STUDY?**

This study sought to answer the following questions:

- Can an indigenous catalyst to culture change be identified in a nursing home facility?
- Can this individual be trained in the precepts of a new culture of care?
- Can this individual be prepared to produce a series of innovative dementia programs at her or his facility?

Further, the study wanted to develop a profile of the individual who steps forward as a catalyst for culture change in the nursing home. Culture change programs were introduced in four New York City area facilities. Within the context of each unfolding program, the identification, emergence, development and performance of the individuals who filled the role of catalyst for culture change were observed, explored and evaluated using both qualitative and quantitative methods.

## **DID WE ACCOMPLISH OUR GOALS?**

The study objectives were accomplished. In each of the four facilities, culture change catalysts were identified and trained. In conjunction with their staff, catalysts for change in three of the four facilities prepared and established dementia group programs that resulted in a demonstrable improvement in the quality of participating residents' lives. In the fourth facility, a dementia group program was created with less than optimum results. This program contributed important insights into the catalyst for culture change's role in producing a successful dementia group program. In addition, the study sharpened our understanding of the personality traits that characterize the catalyst for change.

## **HOW DID WE GET STARTED? WHAT WAS THE RATIONALE FOR THE PROJECT?**

This project responds to the acute need for research that investigates ways to change the fundamental beliefs, values, attitudes and standards of behavior that currently shape the standard of care to nursing home residents with dementia.

## **WHAT HAD BEEN DONE BEFORE?**

Over the past decade, a significant amount of work has focused on improving the quality of care and the quality of life for long term care residents. The issue of the "culture of care" has become a focal point in attempts to reform nursing

home care for the elderly (Fagan, Williams and Burger 1997). It has become increasingly clear that factors which have a negative impact on the quality of life for nursing home residents generally exert a particularly disabling effect on residents with dementia due to their multiple cognitive and functional disabilities. Kitwood (1997) calls for a “re-thinking” of dementia care that will result in a “cultural transformation” in the institutions that offer dementia care. This new culture of care emphasizes the uniqueness, experience and accomplishments of both the individual with dementia and the person who gives him or her care, and the development of a personal, respectful, caring relationship between them.

Experience has demonstrated that if change in the culture of dementia care is to occur in the nursing home, a catalyst for change or a change agent must step forward to identify the new vision of care and to take responsibility on a continuing basis for the process of culture change in their facilities. (Fagan, Williams & Burger 1997; Coons 1992; Peppard 1991; Hiatt, Merlino and Ronch 1987). The change agent must be a leader, i.e. a person with interpersonal and intellectual resources, respected by co-workers, and who can inspire confidence and convey a sense of security in a changing workplace. The literature has identified a constellation of attributes that are regarded as most desirable in a culture change agent. They are:

- Ability to lead without being controlling
- Skilled at giving support and facilitating interaction
- Open to the ideas of others
- Able to assume full responsibility for her actions
- Willing and able to share knowledge
- Able to establish clear criteria for good job performance
- Assists staff to achieve personal work-related development
- Conveys that she regards this work “rewarding”
- Helps staff recognize both individual and team success
- Helps staff go beyond their job description to give quality care Is not discouraged by failure, but rather learns from it
- Communicates comfort with and excitement about trying new ideas
- Delegates responsibility, not just work
- Engages peoples’ unique personal gifts in addition to their professional abilities
- Treats team members as valued equals
- Has lots of creative energy
- Has a clear grasp of the new culture of dementia care and can communicate why it is important
- Is knowledgeable about long term care administration
- Has administrative and management experience
- Continues gerontological or geriatric training

The results of this study contribute important new knowledge about the catalyst for culture change in the nursing home, who the catalysts for change are, which of the many strengths and skills contribute most to the production of successful programming and what training and organizational support is most helpful for them.

## Description of Study

### **STUDY DESIGN**

Initiating, establishing, implementing and evaluating a culture change program for a dementia care unit in a nursing home—“getting a program up and running”—is a complex exercise, involving many people and many levels of participation. This study was designed to focus on one segment of this complex effort—the catalyst for cultural change. Within the naturalistic setting of culture change as it unfolds in a facility, this study examined and evaluated the development and performance of individuals who were identified in their facilities as catalysts for culture change.

Using qualitative and quantitative methods, the subjective experience, professional development and performance, and personality attributes of the catalysts for culture change were studied. Initially, the study sample (i.e. the number of catalysts for change) was undetermined because it could not be predicted how many individuals would emerge as catalysts for culture change in the four facilities. As the study progressed a number of individuals functioned as catalysts, and their experiences, activities, actions and responses within the context of the ongoing programs were the data of the study.

The two-year study was conducted between January 1999 and December 2001.

### **WHO PARTICIPATED?**

Four facilities were involved in the study:

- The Dumont Masonic Home, located in New Rochelle, New York.
- St. Patrick’s Home in the Bronx
- Augustana Lutheran in Brooklyn
- Cabrini Center for Nursing and Rehabilitation located in Manhattan.

All participant homes are not-for-profit and have dedicated dementia care units with bed capacity between 37-44.

# The Catalyst for Culture Change

The first step in the process was the identification of change catalysts in each site. The discipline of each catalyst varied somewhat by site. They are referred to as catalyst agents or coordinators. In no case were new personnel lines added to the existing structure of each home. In two facilities the coordinators were Activities Assistant Directors, in another the Nursing In-service Coordinator assumed the role. In the last facility two individuals from two different disciplines shared the position. One was the Director of Activities and the other was Director of Social Services. In a very real sense, the catalysts to culture change were the “variables” to be “measured”. Their role within the context of the culture change program was multi-layered and pivotal. In addition to her routine responsibilities and schedule in her facility, the catalyst for culture change was required to commit three hours a week, at minimum, to program activities and responsibilities.

These included the following:

**In the initial phase of the project**, the catalytic leader worked jointly with facility administration and program consultant to identify a team of staff who were likely to work effectively together to develop and deliver a dementia group program; to identify a location within the nursing home where the dementia group program could be conducted; to identify and tailor a training program for the dementia group staff team; to design and plan a dementia group program that offered meaningful activities for residents and staff. In preparation for the role of catalyst for cultural change, the catalytic leader was trained in a variety of clinical and leadership issues.

Identified and potential catalytic leaders from each facility participated in four days of intensive training at the Alzheimer’s Association NYC chapter. As part of the training, catalytic leaders visited other facilities where successful dementia group programs were running to examine how such programs managed and provided services to participating residents with dementia. Site visits at other facilities continued throughout the period of the grant. Additional training sessions occurred at intervals during the first year of the project.

**Responsibilities for “staffing” the culture change program.** Implementing culture change necessitates redefining the priorities and re-assigning the responsibilities of some staff members. Catalytic leaders were responsible for coordinating such restructuring, and reported directly to the administrator in this capacity; for supporting and encouraging staff throughout the instability of the culture change process; for intervening with administration in support of staff and their needs; for identifying and developing appropriate back-up staff, and for developing a consistent schedule for staff; for spending some time with the dementia group leaders in the group program room.

**Responsibilities to residents participating in the program.** Catalytic leaders were required to “get to know” the residents personally, e.g. learning biographical details, assessing current interests and abilities; assessed and tried out residents for their appropriateness for the program; developed a core group of residents to “carry” the program; developed criteria for care and discharge plans; coordinated residents’ medical visits to prevent conflicts with their program participation; and for spending some time participating with residents in the group program room.

**Responsibilities to the program training process** continued throughout the project duration. Catalytic leaders met weekly with training consultants to develop a network for ongoing relationships with other leaders, to update each other on the progress of the programs under development, to discuss areas of concern and ongoing needs; to complete and process the quantitative evaluation measures on staff and residents participating in program activities.

## Residents Participating in the Group Program

Fifteen to twenty residents were selected for each dementia group program. Participating residents had a documented diagnosis of dementia, and the program was identified as clinically indicated and appropriate for them by the facility’s interdisciplinary care planning team. In all the facilities except one the groups were ethnically and gender mixed. In the fourth facility the unit identified for intervention by the staff was somewhat homogeneous. All were Caucasians, Catholic females (some Nuns) of Irish descent. Family involvement was particularly strong in this facility. Cognitive functioning of the individuals in each group program was varied in all facilities.

## Roles and Responsibilities

### **SUPPORT STAFF**

A unique feature of this research was the extensive and intimate onsite interaction between research project staff and the facility staff directly involved in the dementia group program development. The research project staff included the:

**Principal investigator**, who assumed overall responsibility for administering the grant; participated in training and seminars at designated points of the research.

**Program consultant** who developed initial relationships with each facility's administrator, department heads, supervisors and direct care staff; assessed the physical environment and general resident population to guide subsequent program development; facilitated selection of the individuals most qualified to become catalysts to culture change; organized and conducted initial and ongoing training and development of the change agents; worked with project training and research consultants to tailor programs to the specific needs of the nursing home; performed grant administrative duties.

**Training consultants**, who providing initial and ongoing training to the catalysts for culture change and other staff directly involved in the dementia group programs. Topics included fundamental aspects of old and new cultures of dementia care, the effects of the care culture on residents and staff, basic group leadership skills, qualities of group leaders, group dynamics, problem solving, and so on; met weekly with catalysts to provide emotional support, monitor program development and problem-solve.

The training consultant wore many hats, including that of modeler, trainer, workshop designer, coordinator and facilitator, team builder and chronicler. For a period of 3 months, the training consultant worked intensively with the dementia group program co-leaders for approximately 12 hours a week, observing their programming and their interactions with residents and each other. When it was felt that trust had been established, modeling began to enhance the group leader's emotional attunement to residents and each other and in the process, help them to develop a sense of group cohesiveness. Through subtle adjustments in their tone and approach, she helped them gradually diminish aspects of their language and behavior that tended to infantilize the residents or minimize their abilities. Over time, she witnessed them alter many of their assumptions regarding residents' limitations and abilities and improve their connectedness to residents by reducing the degree to which they hid behind their roles, allowing more genuine connection to occur. One primary focus was in the area of emotional attunement. That is, based on their limiting view of the resident's capacity for an internal emotional life, the training consultant observed the group leaders ignore or minimize resident's expressions of feelings at times.

Consider the following scenario, summarized in one field note, observed one morning during a program:

*"At one point a male resident, known for his frequent wandering, got up. One of the group leaders questioned him and he replied, "I just wanted to look at the picture on the door. That's the only thing to do around here."*

The group leader, rather than responding to his statement and the feelings implied said, "I think Mr. X just wanted something to eat." Mr. X barked back, emphatically, "I didn't say anything about eating!" This botched interaction

underscored this group leader's dynamics with many of the residents: seemingly desperate to be liked, she made impulsive attempts to connect, missing deeper opportunities for genuine attunement.

In one of her brief meetings held after each observation, the training consultant engaged the same group leader in a conversation about the average age of the residents in the program (approximately 90 years), trying to point out the strengths demonstrated by residents at their advanced ages.

*“At one point I commented on the independence of one resident, listed as 99 but appearing much younger, livelier than most. I related some information the resident had told me about herself. The group leader was skeptical: “They often say things that aren’t true.” I suggested that, rather than focus on the veracity of the information, she assumes that it reveals some inner truth about the resident. The group leader listened quietly although I think she remained skeptical.*

Over time, the group leaders grew more open emotionally with the residents, a phenomenon that seemed to have a positive impact on both the residents and the staff. The following field note chronicles a discussion during a support group meeting with the training consultant:

*“During our meeting, I praised the group leader for having allowed herself to cry in front of the residents when moved by something, pointing out that it was good modeling for the residents. (Earlier, during the Christmas caroling, she had been moved to tears by one resident’s mood apparently stimulated by memories of Christmas) The group leader, embarrassed by the tears, had been self-denigrating during the program, referring to herself as a ‘baby’; a resident responded teasingly, “Bring out the baby carriage”) As I spoke in the support group, the group leader teared up again, cautioning that my talking about it was going to make her cry again. She said that she loves working with the residents but that she often feels overcome with sadness, adding ‘I want to take them home with me.’ I praised her for her sensitivity and nurturing but also suggested that she was attributing her feelings to them. i.e. that she should not assume that residents feel sorry for themselves just because she does...To her credit, the group leader has toned down her overly upbeat, cheerleader approach considerably, adopting a more open, genuine style of relating to residents.”*

The training consultants co-designed, coordinated, and facilitated workshops to build on basic knowledge and skills, enhance the staff's sensitivity to the emotional, social and physical needs of their resident and increase team work. The training included interviews with early stage persons and their caregivers, experiential exercises to enhance empathetic perspective toward residents and each other, concrete skills to improve their communication with residents and cope more effectively with challenging behavior. The training consultants

worked closely with the program coordinator to develop leadership program development skills. They attended weekly staff meeting to help air differences, reduce tensions, increase “buy in” of the interdisciplinary team and facilitate problem solving.

**Research consultant**, who was responsible for the overall research activities for the project’s duration, including research design, data collection and analysis strategies, and instruction to the catalysts for change about subject selection, appropriate program design, pre- and post-program measurement and data analysis activities.

## **INFORMED CONSENTS**

Informed consent forms were evaluated by the Sound Shore Medical Center’s Institutional Review Board and by the individual facility’s Ethics Committee and distributed to family members by each facility’s social service department. Eligible participants for the intervention were enrolled after their responsible parties had signed the consent form. Residents were also asked for their agreement to participate in the program. Residents’ verbal assent was carefully monitored. A pattern of refusal to participate in the intervention was construed as evidence of withdrawal of assent, and the appropriate clinical staff then evaluated possible medical or psychosocial causes for withdrawal. After a withdrawal, a resident was free to resume participation in the group at any time.

## **Data Collection and Analytic Methods**

Consistent with current dementia research practice, both qualitative and quantitative approaches were used in this study.

### **QUALITATIVE METHODS**

The study used two well-established qualitative methods to learn about and to explore the subjective experience of the catalysts for change as they moved through the culture change process:

**One-on-one interviews.** Formal and informal, directed and open-ended, face-to-face interviews to learn and explore participants’ experience of the dementia group programming. Catalysts and other relevant program staff were interviewed by research project staff at monthly intervals throughout the project to compile perceptions of participating resident’s experience throughout the intervention. Catalysts themselves conducted interviews with group programming staff to learn their perceptions of and reaction to the unfolding culture change process.

**Field notes.** Written, narrative statements about specific, concrete events that convey the content, sequence and feeling of an event from a variety of relevant participants in this study, taking field-notes was an ongoing process through out the life of the project. Training consultants took detailed descriptive notes on the training sessions with catalysts and on their on-site consultations with them. Program and research consultants documented their daily interactions with catalysts and other key staff at each facility. Some catalysts for change kept personal notes throughout their participation in the study, documenting their personal feelings, thoughts, and experiences as a catalyst for change. The interviews and field notes produced written texts that in turn served as data sources. They provided rich sources of insights into catalysts' changing experience of the dementia group program, personal growth and development in the role of catalyst for culture change, as well as important information about the program's effects on residents and staff. These documents were analyzed using established qualitative analytic methods of data inventory, coding and thematic analysis.

**Quantitative measures.** A variety of quantitative measures were used to assess catalyst performance and to evaluate the effects of the dementia group programming on participating residents.

**Catalysts for change** (and other staff ) participating in the training were assessed using the following instruments.

Change Catalyst Scale. Rates 20 catalytic change attributes identified on a 4-point scale (minimal, average, above average, exceptional).

Care giving Qualities Scale. Rate 12 care giving quality attributes on a 4-point scale.

The catalysts for change were rated variously by their administrator, staff peers, program consultant and themselves prior to the intervention, and at 6-month intervals throughout the project. Residents' cognitive and behavioral states were assessed using the following instruments to capture the effects of the programs.

- Folstein Mini-Mental State Exam measured cognitive status changes
- Cornell Scale for Depression measured depressive symptoms
- Cohen Mansfield Agitation Index measured agitation symptoms.
- Neuropsychiatric Inventory (Nursing Home version) captured behavioral disturbances.
- Nurses' Observation Scale for Geriatric Patients (II) measured functional levels.

These measures were collected before and after each group programming intervention.

## What Were the Interventions?

After the planning process, each home opted to create a day activities program for 15-20 residents. Following the team visits to several ongoing programs in a variety of sites each independently concluded that group structure had the most potential for success. This would create a more meaningful day for the most residents and a more fulfilling experience for the staff.

The programs schedule was similar, beginning after breakfast through the afternoon shift change 3:30. In some facilities the program eventually extended through supper. The group participated in a variety of similar traditional activities throughout the day. These included discussion, morning prayer, exercise, cooking, music and crafts. It is important to note verbal programming was generally scheduled in the morning, as most people are more alert. The physical environment for each day program was similar in nature. All program rooms were unit based and served as multipurpose activity and dining area. Efforts were made to decorate the room to be homelike and inviting. They could all be sealed off from the units themselves by the use of doors. Loudspeakers could be controlled from within the rooms.

It was established from the beginning that two staff people worked together as co-leaders at all times. The skills of the group leaders varied. In one facility the group leaders were both from activities, in the other sites CNAs were co-leading activity groups, many for the first time. Other challenges were language difficulties, turnover and staffing shortages. The following field notes from one of the training consultants gives a good snapshot of a typical day.

### **“A DAY IN THE LIFE.”**

November 4, 1999

*T*

*Today was my first day, but staff didn't know this, T had taken the day off, and P was in a meeting. I went to the unit. V considered running the program with half the residents, stating that they were short staffed. I suggested that we run the program together with the full group. She was very receptive to this and grateful*

*The residents trickled into the room and were seated at the tables. I introduced myself to them one by one, explaining that I would be there two mornings a week helping out. I sat near one resident (seated at one end) who was agitated, perhaps by my presence, and negative re participating. I offered reassurance re my helping the regular staff and slowly moved my chair closer to the middle of the room to grant her space but remained engaged with her. Within time she grew calmer and eventually seemed relaxed, able to enjoy herself more and accepting of my presence. V introduced me to the group, and then did a short piece on the date, day etc. This was followed by a picture identification activity.*

Simple drawings of everyday objects were presented and residents were asked, one by one (selected by V) to identify the objects? What is this? At times her Spanish accent was difficult for me, but I'm not sure for the residents, who know her better. An interesting moment occurred when one of the men was presented with a picture of a car. He replied "roadster". V didn't understand this and was in the process of correcting him gently. I intervened and suggested that roadster was in fact a colloquial term for a car, used by the older generation. She was very responsive to this, appreciative of the help and of the opportunity to smooth things for the resident and the activity in general. From my perspective, it felt like a lovely bonding moment. Later during our debriefing she was self-effacing about her English. I reassured her that her English was good enough and that her Spanish offered something special to the program e.g. the moment, which occurred earlier. During the activity I noticed that her pictures were largely those of kitchen objects and that she was focusing on the female residents. I wondered aloud if some of the men might not also have had some experience with such objects. (my feminist bias) As if on cue, one male resident next to me volunteered that he had been a baker. This seemed to be a revelation to V, and she seemed very receptive to this approach. Later a female resident struggled with the word when presented with a picture of a colander. She used her hands to gesture and V was nicely responsive to this. When the others couldn't V offered strainer and I offered colander and we had a nice moment of praising the resident for her accurate gesture. V hadn't known the word colander but wasn't thrown, offering the easier synonym strainer which others more readily recognized. A rhythm activity followed. Residents were offered various rhythm instruments/objects to be used with a series of songs, many from the 50's. Some residents were very hesitant to participate. There was a lot of focus on using the instruments. One resident would use one for a moment and then put it down. When encouraged she would try another instrument, only to put that one down too. V indicated that this was her m.o. I suggested that maybe J wasn't sure she wanted to participate. J nodded in agreement. Another resident eschewed the instruments altogether, using instead his drink as a kind of conductor's wand. Still others avoided the instruments but could be seen subtly moving their feet or hands to the rhythm. I pointed this out to V and the residents to foster a sense of sharing the activity.

Throughout the morning there were numerous interruptions, with staff flowing in and out of the room freely to give medications, ambulate the residents, toilet them, etc. One family member arrived and stayed for some time. V seemed irked by the interruptions but did nothing to stop them. Later, during our debriefing, I noted the fluid boundaries. She replied that a previous co-leader had been very strict, harsh about the boundaries noting that she repeatedly mentions the problem in staff meetings. We discussed ways to shape staff behavior without alienating, by focusing not on their bad behavior, but on the need to help the program remain focused, etc. We discussed using a sign on the door requesting that the program not be disturbed.

*disruptions, she seemed more ambivalent about the value of tight boundaries, drawing a distinction between “interruptions” and “disruptions”, and suggesting that the eventual goal after restructuring the unit was to have a more casual atmosphere, where residents and program out of the room with ease. After V and I took a walk to discuss how the morning had gone, I stayed for part of the afternoon program. During our talk, V was warm and seemed eager to hear my observations. I gave her a lot of positive feedback re her warmth and caring, and her ideas for activities. In the afternoon program she chose an autumnal scene for coloring. Some residents were not initially participating and eventually got involved minimally after mild directions, e.g. explaining, delineating details for them on the picture, and helping them to choose colors. I chose to sit with them and color a picture myself, trying to present the activity as an interesting one. I gave positive feedback where I could i.e. their choice of colors and neatness. While I tried to talk about the theme a bit in retrospect I could have done more.*

*Overall, the group was calm and I think very accepting of my presence and of V and I as a team. I think we worked well etc at lunch. She seemed relieved, I think, that I deferred to her as the leader and that we clicked.*

*When P later asked how things had gone, I discussed my observations about the disruptions with her. Her initial response was annoyance at the staff, who “should know better”. However, the next day, when I commented to her that there had been fewer staff could, indeed, flow in and together. I tried to be helpful to her, helping with aprons, cutlery. We discussed ways to by focusing not on their bad behavior, help the program remain focused*

## Problem Solving

Predictably, each facility had its own unique experienced related to accepting, organizing and developing the culture change program. Consequently, each facility progressed at different speeds in initiating and implementing the culture change project. Several important developments related to implementing the project arose. These were:

### **REASSESSMENT AND REPLACEMENT OF TWO FACILITIES.**

Two facilities (names deleted) were originally slated to participate in the study. However, several months into the research it became clear that these facilities lacked a strong enough administrative backing and commitment of resources to participate fully in the study. They were subsequently dropped from the study and replaced by Augustana Lutheran Home and Cabrini Center. The late entry of the latter two facilities into the project timeline required additional time for staff orientation and program development.

## **STAFF TURNOVER**

Several of the nursing homes experience key staff turnover at crucial junctures in the research. Such turnovers represented a setback for staff and residents, particularly during the transition period when new staff was being hired and trained to participate in the culture change programming. Continued inadequate and inappropriate staffing for proposed dementia group programs frustrated catalysts for change and their staff, and adversely affected the development of a trusting relationship between administration and the culture change staff at one facility. However, at another facility, unexpected opportunities arose from the setbacks caused by staff turnover. For example, rather than becoming discouraged by inadequate staffing, catalysts for change and their team rallied together, “pitching in” to conduct group programs while new staff was being hired and trained. Although the programs themselves did not run as smoothly as desired during this period, the team’s response to this situation considerably solidified their sense of commitment to each other, and enhanced their feelings of “ownership” of the program.

## **INCOMPLETE QUANTITATIVE DATA COLLECTION**

The project experienced considerable difficulty in enlisting reliable and consistent staff cooperation in completing the Change Catalyst Scale and the Caregiving Quality Scales. This was due variously to the confusion caused by staff turnover, staff uncertainty about whose responsibility it was to complete ratings, staff reluctance to evaluate self and co-workers, poor follow-through on the part of some catalysts for change, and staff resistance to “taking on more paperwork”. Repeated efforts to reorient staff responsible for proper ratings completion were unsuccessful. Consequently, it was not possible to produce a quantitative analysis of the characteristics of catalyst for change measured by these scales. This represents the most serious limitations of the study.

## **Findings of the Study**

The study offers the following key findings.

### **A. The research demonstrates that a catalyst for culture change can be identified in a nursing home.**

This individual—or team of individuals—can be trained and prepared to produce an intervention that demonstrably improves the quality of life for the participating residents. As a result of this training, catalysts for culture change mounted successful dementia group programs in 3 or the 4 participating facilities.

### **B. The research reveals two overarching key traits that characterize the catalyst for culture change; first, a strong personal sense of urgent need**

**for culture change and second, the ability to coordinate the efforts of many people to effect culture change in the institution.**

The individuals in the study identified as catalysts for change feel a strong personal belief in the humanistic or altruistic need for culture change in dementia care. They experience this belief as an “urgent need”, and want to begin “making change happen now”. In this respect, they are “visionary”. Catalysts are able to communicate their passionate commitment to culture change. Through their actions and words, they convey to others that they regard this work as “valuable” and “rewarding” at many levels. In addition, they can identify and meet the needs of the people involved in the culture change process while at the same time forging these individuals into a “team” that can “work together to win”, i.e. mount a successful dementia group program. In this capacity, they are like an athletic team’s “coach”.

**C. The key traits of *sense of urgent need* and *coordinating ability* are expressed in various ways in two complementary sets of attributes.**

On the one hand, the humanistic or altruistic impulse of catalysts for change typically leads them to have open, personal relationships with others, whether resident or co-worker. They “personalize” their relationship with residents, often referring to them protectively as “my residents”. They care about their residents personally, and clearly want “to make life better” for those under their care. Similarly, catalysts also personalize their relationships with staff, referring to them protectively as “my staff” yet interacting with them in a non-hierarchical way, supporting their development by delegating to them not only work but also responsibilities, and trusting their discretion in taking initiatives in dementia group program work.

On the other hand, catalysts for change are also good managers. They are typically knowledgeable about long term care administration and have management experience within that context. They take full responsibility for their actions, but are also willing to delegate responsibility to others. They are effective in communicating expectations and criteria about job performance, and are fair in performance evaluations. They are adept at identifying and utilizing their co-workers’ complementary skills. In sum, the catalyst for change is typically an individual with a clear and committed vision about the new culture of dementia care, the ability to interact with staff and residents in the context of the new culture of care, and who possesses strong managerial skills to coordinate and achieve change.

It was anticipated that these attributes would meld in a single individual in the nursing home, who would then step forward as the catalyst for cultural change in the facility. However, this was not to be the case.

**D. Contrary to expectations, the research reveals that the catalyst for culture change is not likely to be a single individual, but rather to be a team involving 2 or 3 individuals.**

In the four participating facilities, no single individual emerged as the catalyst for culture change. For example, at the Dumont Masonic Home, the catalyst for change role was filled by two people; the Director For Development and the Director Of Recreation. At St. Patrick's Home, the catalyst role was also filled by two people; the charge nurse on the dementia unit and the in-service director. At Augustana Lutheran Home, the catalyst for change role was filled by three people; the nursing home Administrator, the Director Of Recreation and the Director Of Social Services. At the Cabrini Center, the catalytic change agent's role was compromised due to her assuming the dual roles and responsibilities of change agent and group leader.

This empirical reality leads to an important refinement of the catalyst for culture change concept. Henceforth, catalyst for culture change might best be regarded as a category that comprises (at least) two additional roles, namely a change agent and a coordinator for change. The change agent is an individual who feels the urgent need for change, who "has the vision for change", who is "hooked on the idea", who "has to have it". This is the individual whose vision and desire for change introduces the change concept to the facility and pushes it forward—"fights for it"—in a variety of ways. The coordinator for change is the individual who takes responsibility for translating and implementing the change agent's visionary agenda. The coordinator for change is, in effect, the manager responsible for organizing the pragmatic aspects of introducing the change and implementing it. Thus, the change agent and the coordinator for change are not necessarily—indeed are not likely to be—the same person. Together, the change agent and the coordinator for change may be considered as a catalytic team.

It was anticipated that where the catalyst role would be divided between two (or more) people, the result would be a fragmented, disconnected and ultimately unsuccessful intervention. However, this proved not to be the case.

**E. Again, contrary to expectations, the research demonstrates that a catalytic team can be effective in producing culture change.**

While each facility experienced its own unique development in terms of organization, processing and accepting the program, and progressed at different speeds in initiating and implementing the culture change project, three of the four facilities mounted successful dementia group programs using the catalyst team model. At the Dumont Masonic Home, the program was called "The Living Room". At St. Patrick's Home, the program was called "The Parlor". At Augustana Lutheran Home, the program was named "K(indness) E(mpowerment) E(ducation) P(rogram) K.E.E.P." Additional important insights into the nature of the catalyst for culture change model follow from these unexpected findings.

**F. The change agent and the change coordinator can achieve an effective dementia group program even where they have different degrees of commitment to the culture change process.**

Change agents who are highly motivated by their sense of urgent need may nevertheless decline the title or responsibility of coordinator for pragmatic reasons. For example, several altruistically motivated change agents refused to accept the coordinator's role, arguing that their current job commitments made it impossible to accept additional responsibilities. However, they remained deeply influential in developing and implementing the program, facilitating, inspiring, and in fact often coordinating efforts behind the scenes despite their protestations to the contrary.

Similarly, while some change coordinators do share a sense of urgent need for culture change with the change agent, others accept this role for less altruistic reasons. Chief among these reasons is the desire for enhanced job responsibility, a more visible role in the facility's administration, or to further personal career objectives. Coordinators for change may also accept the role out of personal regard for or allegiance to the change agent. And in still other cases, the change coordinator is simply appointed by a senior administrator to fulfill the role. Irrespective of their personal sense of vision and urgent need, coordinators for change can operate professionally to do what is necessary to effectively organize, coordinate and promote the process of culture change. However, it should be noted that pragmatically motivated or appointed coordinators' sense of urgency and vision was enhanced and increased as they witnessed first hand the benefits of the dementia group program to residents and participating staff. Site visits to other successful dementia group programs proved to be particularly persuasive to such coordinators for change.

**G. Unsuccessful catalysts for change appear most likely to involve a single person who fills both change agent and change coordinator roles.**

While the causes for a less successful program are complex, and not the subject of the present research, causes germane to the culture change catalyst can be mentioned briefly. They offer important opportunities for understanding how successful catalysts for culture change function.

For example, in one facility, no clear individual catalyst or catalytic team emerged or was sufficiently empowered and consequently, the dementia program that was previously in place did not flourish. In this facility, a single individual filled both group leader and change coordinator roles.

Similarly, in another facility, a single individual stepped forward who appeared to feel the need for culture change and to have the coordinating abilities necessary to initiate and implement a program. But as the program unfolded, it became clear that her organizational decisions favored the needs of her own department and she was unable to enlist support from co-workers in other disciplines. The program did not flounder, however. As an "insider" in the

facility, this individual had “local knowledge” of other staff who also embodied the values and skills necessary to effective culture change. She identified these persons, and the responsibilities of change agent and change coordinator gradually shifted to them as they receded from her.

**H. The research demonstrates that the most effective training for catalyst teams (or individuals) addresses the two central problems of staff resistance and limited resources.**

Catalyst teams or individuals are faced with two central problems. First, they often face resistance from other staff who may view them as a threat, an annoyance, or who do not comprehend the vision—“who don’t get it.” Consequently, catalytic teams must draw heavily on their humanistic and managerial resources to overcome interpersonal resistance to the change process. Second, catalyst teams or individuals who are not supported from the onset by Administration are not likely to be given extra time or extra money by their facilities to “get the programs up and running”. Typically, they must work within the context of their facilities’ financial and institutional resources to achieve their goal. Training and preparation that surmounts, or at least mitigates, the effects of resistance and limited resources is the most beneficial and productive for catalytic teams.

**I. The research identifies outside site visits, interaction with training consultants and peer support groups as central vehicles for effective training.** An important means for exciting the catalytic team’s sense of urgent need is to expose them to successful dementia group programming at other facilities. The catalytic teams represented in this research agreed that observation and participation in outside facilities’ dementia programs energized and inspired them, enhanced their “got to have it” feelings, and helped crystallize for them “what it is exactly that we’ve got to have.”

The catalytic teams represented in this study agreed that the availability of training consultants to work individually on-site with them was crucial to their developing problem-solving skills. They also valued the professional and emotional support the training consultants offered them.

Peer group meetings took several forms (e.g. focus groups, informal discussion, directed discussion, peer support discussions) and provided an important source of practical learning and emotional support for catalytic teams. Catalytic team members’ evaluations of their training were positive overall. The catalysts represented in this research highly valued the regular opportunity to meet with their counterparts in similar interventions. In these day-long meetings conducted by process consultants, the change agents and change coordinators learned that despite their unique circumstances, their own situations shared many elements in common with those of others. Thus, these meetings offered the practical benefits of idea and strategy exchange, and of in-depth problem-solving discussion. These meetings also offer the intangible

benefits of validating catalysts' perceptions of the benefits of the dementia group experience for participating residents and staff and affirming their understanding of the end result each catalytic team is trying to achieve. Finally, the catalysts represented in this study agreed that the peer meetings offered them a desirable and necessary avenue to express the positive and the negative feelings generated in them in the course of the work they regard as "pioneering" and "visionary". The training consultants who conducted the groups agreed that the training was positive overall, but felt that smaller group sizes would promote stronger connections between individuals in the group.

**J. The research shows that three of the four facilities witnessed positive changes in participating residents' general functional capacity and disruptive behaviors.** As early as 6 months into the first program, catalytic teams and other program staff reported positive changes in the behavior of participating residents. For example, some residents who were tube-fed prior to participating in the program became self-feeding as their participation in the program progressed. Residents identified as "aimless wanderers" were observed to participate more readily and completely in activities than they had previously done. Each facility reported an overall increase in the amount and degree of social interaction between participating residents.

These qualitative observations are supported by quantitative measures aimed at assessing participating residents' cognitive, psychological, social and behavioral states. In the three facilities where a successful program was mounted, there was a decrease in negative affect and behavior related to residents' program participation. In the facility which had an unsuccessful program, residents' scores on these affect and behavioral measures did not change. (See Appendix IV for additional material).

**K. The research suggests that family members also perceived an overall improvement in their relatives' cognitive function and behavior which they attributed to program participation.**

Letters from family members in one facility offer important, although anecdotal, insights into the perceived benefits of the dementia group for participating residents and staff. Family members perceived that their relative improved since beginning to participate in the program. Cited most often are their relatives' decreased agitation, increased alertness, and overall sense of enhanced well-being. Family members themselves were heartened and encouraged by these improvements. Importantly, family members also observed positive benefits for staff members participating in the program, for example a sense of being less pressured and an increased willingness to talk personally with residents and family members. Family members typically commented on the "new positive energy" that characterized the dementia unit since the inception of the program.

## Discussion and Conclusion

### **WHAT ARE THE IMPLICATIONS FOR DEMENTIA CARE?**

A common intervention in all facilities was the utilization of a group modality to effect the quality of life for the largest number of residents. Not only is this cost effective but there seems to be a special magic that happens when cohesive groups become formed. We need to understand the magic better. What is it about the group experience that helps people with dementia sustain “normal functioning”? What are the skills necessary for group leaders to develop more meaningful group experiences? How can we go beyond task? How can we connect to the emotions of the individual and thereby validate and sustain their sense of self? Successful programs require ongoing administrative support and team building. Now, our challenge is not in identifying culture change catalysts and teams but in sustaining them. What can nursing homes do?

### Recommendations for Other Nursing Homes

- Develop peer networks among dementia staff within and outside the facility
- Advocate for increased reimbursement for dementia specific care
- Redefine nursing home roles in dementia care
- Empower and expand the role of the CNA through education and career ladders
- Create and identify a new discipline of Dementia Group Workers

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