The Family Stories Workshop (FSW) is a process through which family members and friends of persons with dementing disorders living in nursing homes develop stories of these residents' lives. The stories are meant to help staff members to develop a better, more deeply felt understanding of the lives of the residents, persons who can no longer tell their own stories. The workshop is product-oriented and is not meant as a support group and works best in organizations emphasizing individualized care. This article describes the process of the FSW as well as outcomes from preliminary implementation. It suggests ways of using elements of the process to more broadly accomplish the FSW purposes.

Key Words: Families, Dementia, Nursing homes, Empowerment

The Family Stories Workshop: Stories for Those Who Cannot Remember

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Nursing homes face a challenge to provide care that preserves the dignity, individuality, autonomy, and "shared humanity" (Evans, 1996) of residents. As "total institutions" (Goffman, 1961), nursing homes struggle against assigning residents roles devoid of individual life histories that strip them of their identities (Gubrium, 1991, 1994; Johnson & Grant, 1985). Dementia compounds the challenge. Because residents with dementing disorders are unable to interact competently, it is difficult for staff to conceive of them as the formerly able adults their family members still recall.

Family involvement for residents with dementia is integral to nursing home care, particularly in specialized dementia units (Gaston, 1994; Grant & Hill, in press; Hansen, Patterson, & Wilson, 1988; Spencer, 1991). The family can contribute substantially to the care of the person with dementia, particularly through family members' knowledge of the elder both as impaired and intact (Rowles & High, 1996). Family involvement can affect family satisfaction and resident adjustment (Montgomery, 1994). Assisting family caregivers to remain collaboratively engaged in care can allay feelings of grief, guilt, and alienation that often develop with placement (Austin & Hendrie, 1990; Cohen, 1989; Fopma-Loy & Austin, 1993; George & Gwyther, 1986).

This article describes the Family Stories Workshop (FSW), a program designed to provide an organizationally sanctioned role for family and friend caregivers of dementia residents to assist nursing home staff in personalizing resident care. The FSW provides a structured process through which these caregivers develop life stories of those residents and recount them to staff providing their care. The idea for the workshop grew from a number of research findings.

Improving family–nursing home staff relations is important. Strife between family members and the nursing staff, especially the nursing assistants, is not uncommon (Duncan & Morgan, 1994; Stephens, Kinney, & Ogrocki, 1991). Role ambiguity between family and staff in the subdivision of resident care tasks frequently undermines family involvement (Rubin & Shutlesworth, 1983; Shutlesworth, Rubin, & Duffy, 1982). Aides may resent families' intrusions into the technical aspects of care and they may also feel that families have abandoned their care of the patients (Litwak, 1981; Robinson, 1994).

Nursing assistants' perceptions can affect the care they provide. Staff members' orientation to patient care is positively affected when they believe patients are treatable, see patients as able to interact meaningfully, and construe the plan of care to be aimed at improving rather than maintaining patients' condition (Baker, 1984; Learman, Avorn, Everitt, & Rosenthal, 1990). Progressive deteriorating conditions such as dementia militate against such positive orientations. Training programs focused on special conditions affect care provision in positive ways (Linn, Linn, Stein, & Stein, 1989). More generally, the pre-
vailing organizational culture of patient care can affect nursing assistants’ perceptions (Brown, 1988).

Care providers’ knowledge about the personal and social history of patients results in more positive expectations and more fully individualized care (Happ, Williams, Strumpf, & Burger, 1996; Learman et al., 1990; Pietrukowicz & Johnson, 1991). Patients with dementing disorder are at risk for less positive expectations and more fully individualized care (Brown, 1988).

The stories entail substantial effort by the story-tellers. This effort signifies their continued involvement with their demented relative and a valuing of the work of the staff by attempting to make that work more personally rewarding for them. As a sanctioned activity of the nursing home, the workshop endorses a shared family–staff goal of person-centered care.

2. Help staff develop individualized perceptions of the elders. The histories are meant to convey the texture and detail of the life of the person who can no longer act as his or her own historian. This information may help to improve care through an improved understanding of the person.

3. Help families heal from the trauma and guilt of nursing-home placement. For the families of dementia patients, building the stories may prove beneficial in itself. Although FSW is unlikely to ameliorate the more profound impacts of caregiving such as stress or depression, story-building provides an opportunity to attain distance from the immediate situation and to affirm the whole life.

The Family Stories Workshop Process and Structure

The FSW aims to help families develop narrative materials that will convey to the staff a sense of the unique personality of the resident for whom they provide care. Families work with facilitators to develop the narratives and then tell these stories to the care staff. The organization provides space (and coffee and cookies) for the workshop, recruits staff members to learn and carry on the workshop processes, organizes staff time so that those caring for the residents whose stories will be developed and told will be able to attend the presentation of the stories, and recruits families to take part in the workshops.

The FSW process takes place in six weekly two-hour sessions, held at the sponsoring nursing home at times convenient to participants. The workshop process entails a series of structured exercises, summarized in Table 1, built on “homework” that participants complete in the time between the sessions. These straightforward exercises are meant to help participants structure the task they have undertaken. Participants are encouraged to draw on all available resources (friends and relatives, family records, and other public records) to gather information and insight about the person.

<table>
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<th>Table 1. The Structure of the Family Stories Workshop</th>
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<td>Session</td>
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| 1. Orientation and first steps | • Introductions and icebreaking  
| | • Establish roles, ground rules, and expectations  
| | • Genogram exercise |
| 2. Time line and story elements | • Brainstorm: What makes a story a story  
| | • Review individual time-lines (done by participants as “homework”) |
| 3. Developmental history and story | • Read “Two Women of the Blue Ridge”  
| | • Review homework — expanded time-line from session 2 that identifies key moments and events in the person’s life and portrays them as vignettes |
| 4. Photo exercise | • Dyads review photos (gathered as homework) and select those most representative of person’s life and development  
| | • Individuals share selected photos and tell their stories to the group |
| 5. Themes exercise | • Participants identify person’s key life themes (as homework) and link them to key stories  
| | • Group coaching, editing, and authoring |
| 6. Rehearsal | • Participants present the developed stories (keeping within 15–20 minute limit)  
| | • Group coaching, editing, and authoring |

The orientation (session 1) establishes the FSW as a product-oriented work group — a class, not a support group. It alerts participants that they are to be active listeners and facilitators in their peers’ development of stories and to serve as audience and editors for each other in the story development process. This session reminds participants that an audience is waiting to receive the stories and assures them that the exercises will help them to succeed in their task. Session 1 examines the ethics of this biographical process, emphasizing that participants are in control of the narrative material. We urge participants to view the story-development process in the same way they view surrogate decision-making: They should tell the stories the person would tell; likewise, they should be comfortable keeping private those parts the person would keep private. Finally, the orientation draws attention to a difference between story and chronology and emphasizes that participants’ work will be to remember or put together small tales that reveal something not only about the events of the person’s life, but also about its meaning and about the character of the person. In this way, the product of the FSW differs from the social histories universally gathered in nursing home settings; they attempt to illuminate as well as report on a life.

During this first session, participants use a genogram exercise to identify who is in the resident’s...
family and how members are related to each other. The genogram puts the life of the subject in a larger generational, and frequently an international, context. Workshop participants are often surprised at how much information about family history becomes available through this minimally challenging warm-up exercise. Because other group members quickly respond and ask questions as each family tree unfolds, even those fearful that there may be nothing noteworthy about their family member discover that everyone’s life can be interesting. By examining the person’s family history, participants are often able to identify key moments (e.g., migration to America or to a large city) or themes (e.g., closeness with family, separation from family, solidarity with an ethnic group, economic hardship) that will recur and form the core of one or more stories. The exercise also identifies other living relatives whose knowledge of the person might contribute to the developing story.

In session 2, the family storyteller uses a time-line exercise to map the unadorned facts and events of the person’s life against the decades in which they occurred, identifying what he or she knows about the person’s life during each period (childhood years from one to 10; their teens, 20s, 30s, 40s, and so forth). The exercise helps the storyteller place facts in a historical context, examining, for example, what it might have been like to get one’s first job at age 12 when the Great Depression was in full swing. The key outcomes of this exercise are that storytellers begin to identify shaping or pivotal moments in their relative’s life (e.g., the death of the 12-year-old’s father, becoming the wife of the town’s doctor, the beginning of a career, the subtle patterns of parenting and housewifery, key trips) and to discern gaps in knowledge and possible ways to fill them (e.g., an adult offspring may decide to contact the parent’s siblings). Session 2 also initiates a deliberate effort to help participants become aware of the structure of stories and of storytelling as a craft. Through a brainstorming exercise, participants identify elements common to narrative (a central problem or plot, sequence, setting, mood and tone, character) and realize that character is typically revealed through the manner in which challenges are faced.

In session 3, participants examine the facts of the life in the context of developmental time (childhood, adolescence, early adulthood, etc.) and begin to search for patterns linking them. This examination, which focuses on the question of how events affect and shape a person, usually takes one of two directions. One direction involves participants’ recounting vivid but apparently discrete stories from different periods of a person’s life. Only later do they assign a name to the theme that links these stories. For example, one participant told three family stories about her grandmother — learning that not everyone spoke Swedish, leaving her small town, and being sent to a large city (and a famous doctor) to spend the last months of a difficult pregnancy and deliver her child. This granddaughter later realized that these and similar stories illustrated the depth and strength of family feeling that characterized her grandmother’s life. The second direction begins with participants identifying one or more key themes or characteristics of the person and then illustrating these with relevant stories. Thus, a wife of an emeritus professor linked together stories of her husband’s early childhood, adolescence, early adulthood, tracing his travels from his native Greece to Egypt, Chicago, and New York as a way to portray a theme she had earlier identified: his life-long pursuit of learning.

Session 3 continues the process of making explicit the craft of stories. We read a brief story, “Two Women of the Blue Ridge” (Garlichs, 1993), to exemplify many of the story principles the group had identified in session 2. The facilitators also begin to use story-board techniques to help participants structure and elaborate the preliminary narratives they are developing. This technique uses key words or phrases in a series of comic-strip-like panels to help the storyteller to see that his or her story does have structure and sequence. Story-boarding also graphically shows where connections could be strengthened, problems stated more clearly, or resolutions cast more fully, revealing more about the subject. Story-boarding is used for the rest of the workshop to help identify and solve compositional problems.

In the remaining three weeks of the workshop, participants engage in exercises designed to help them sift through the material they have gathered and to aggregate what they have selected into a set of three to five brief stories that will form the presentation to the nursing home staff. The photo exercise (session 4) allows participants to link visual representations to the developing narrative. Participants bring to the workshop things that show something about the person. Originally participants were instructed to search through old photos. However, group members began arriving with a wide variety of objects important to or illustrative of the person: paintings, woodwork, handwork, craft projects, published book reviews, collections of various kinds, awards, and even old clothing. In this session, participants work in teams to choose the half dozen or fewer photos or objects they feel best represent the person. They then link the chosen objects to the themes and stories begun in the first three sessions and make an impromptu multimedia presentation to the larger group. Such arrangements of representations and stories can bring home a characteristic or a theme with an immediacy not possible through words alone. A wife in one group, for example, wished the staff to appreciate what an optimistic her husband had been through his entire life. In examining the photos she brought in, group members quickly identified the bright smile and laughing eyes that showed in photos of the husband from ages 3, 19, 35, 65, and 80. As the spouse spoke of her husband’s positive view of life, she used photos to draw attention to “the smile” as a way for her audience to directly see and appreciate this optimism.
As a final structuring exercise (session 5), group members are asked to identify themes that serve as hubs around which stories and objects cluster and to name key characteristics or values that give continuity to a person’s life. As homework, we give participants a list of 20 abstract nouns that might describe, major themes in the person’s life (work, family, career, sports, art, religion, politics, etc.). We instruct participants to use these or other words to give added organization to the stories they have been developing. For one family, for example, a central theme was their father’s humor. Using this as the base, they built a presentation around stories of his quick wit and constant practical jokes and pictures of him dressed up in outrageous outfits for costume balls. At the presentation, staff resonated to these and responded with their own stories of flashes of wit from this very demented man. Commenting on a visiting daughter’s short stature, a nursing assistant, for example, recounted that she had once asked the man how such a tall person could have a daughter of such short stature; he reportedly answered that he had been tired at the time. Usually, participants have been using themes, at least implicitly, for the past two sessions, so this exercise serves to crystallize them. Occasionally, however, this exercise has served to bring a theme to light, providing unity for a number of vignettes. One participant, for example, had told many seemingly unconnected stories of her mother’s young adulthood in earlier sessions. Only when she identified the theme of “the immigrant” did these disjointed stories coalesce into a picture of a childhood straddling two cultures and the mother’s gradual Americanization.

Session 6 involves a rehearsal for the presentation. In this final run-through, we make sure each family’s stories will fit in a 15- to 20-minute framework. The rehearsal allows the facilitators and other group members a chance to offer final “editorial comment.” Usually the advice has to do with themes or material not yet included in the story. We also review the staging of the presentation — what props, photos, or objects the participant will display while making the presentation. During the session, we finalize arrangements for the presentation (time and place).

In these last three sessions, the group helps substantially to shape the final product. Participants have a keen memory for the material others present, and they are very enthusiastic in indicating details and story elements that they find particularly effective. They often strongly encourage storytellers to include particular stories, photos, or objects. For example, in an early session a spouse named Rose shared a story of her husband’s arranging to have their wedding bed filled with rose petals. When her plans for the final presentation failed to include this story, the group implored her to include it as an illustration of her spouse’s romance and affection. In another case, the group practically begged a husband to include their favorite story of his wife (then his “girl”) making him walk home 2 1/2 miles in the rain rather than stay overnight with her family lest the town should talk. The group helps to instill confidence in the goodness of the stories and to allay storytellers’ performance anxieties. On occasion, group members also provide assistance during the presentation itself. One woman, for example, forgot during her presentation to tell about her husband’s youth and their early courtship in New York in the 1920s and 1930s — until two members of her workshop reminded her to do so.

Results

Over the 3+ years of the project, we conducted 14 family workshop groups. Forty-four family members completed the groups, which varied in size from two to five attendees. In at least half the groups, staff from nursing home were present as facilitators-in-training. Three groups were led by nursing home staff (including two chaplains, a recreational therapist, and a social worker), and one group was scheduled to be led by two family members who had been participants in a prior group. Attendance at the six-week sessions was excellent. At least three-quarters of the participants attended all the workshop sessions, and no participant missed more than one session. Only three persons have not completed the workshop.

Workshop participants have included anyone who could legitimately represent the life story of a resident. The participants were primarily spouses (15) and daughters (23). Two granddaughters have taken part, as has one niece and three friends. We did not screen out anyone; willingness to become involved has proved an adequate inclusion criterion. Educational background did not appear to affect participation. Most of the older participants had no formal education beyond high school; most of the younger participants had two to four years of college. Nursing home staff who recruited for the FSW indicated that most of those whom they thought suitable but who declined to participate did so either because they could not commit the time or because they thought the experience might be too emotionally difficult.

Most workshop participants developed written stories that were left for the staff after being read in the presentation, but there were many other kinds of presentations. Several participants produced albums with thematically arranged photos accompanied by brief narratives (for example, a set of photos of one resident with the various cars he had owned and a brief text explaining that he had never bought the motorcycle he had always wanted because family responsibilities had interposed). One stage-frightened caregiver had herself videotaped presenting the life history (in the videotape she was wrapped in a quilt her mother, the subject of the story, had made). The daughter was present and available for questions as the videotape was shown to the staff. A friend storyteller of a resident who had been a high school French teacher provided a buffet of French foods with background music by
Edith Piaf as she recounted the life of her friend. A husband, while recounting the story of his wife’s life, wore the red baseball cap that she had worn while watching him pitch for his high school team. Many caregivers also brought to their presentations important creations or objects including paintings, sculptures, collectibles, and inventions of the person whose history was being told. We videotaped the presentations to allow staff from different shifts to see and hear the material. The videos were also used to orient new staff in working with particular residents. Copies were made for the family, providing them with a treasured celebration of the life of their demented elder.

Before and after the workshops, some of the storytellers (N = 40) used a 30-item semantic differential scale (Rosencranz & McNevin, 1969) to describe attributes of their relatives or friends (along dimensions such as ugly–attractive; generous–stingy; weak–strong; dependent–independent). As anticipated, most participants showed movement toward more positive descriptions, though the change did not achieve statistical significance. The change was consistent with experiences in group, indicating a valuing of the family member. We speculate that the process of developing a life presentation frees the family from the present, less positive reality of the demented elder and allows them a fuller and more balanced appraisal of the person over a lifetime.

Most participants were able to understand the workshop’s intent and to produce stories that represented the life and character of the person. Four of the authors (KH, WC, ML, SO) independently reviewed the products of 27 workshop participants with whom more than one of us had worked. The products were rated on two dimensions: participants’ understanding of the process and intent of the FSW and the narrative quality of the final product. The very few rating discrepancies were resolved through conversation. Most stories were of good narrative quality: 9 of the 27 stories were very high-quality narrative, portraying much of the character of the person; another 6 had flashes of illumination embedded in a chronological presentation. Nine participants produced material that could be characterized primarily as a chronological report of staff participation — where it reflected the prevailing culture of the organization. In those facilities in which top management embraced the workshop as consonant with an existing vision and mission, more staff members participated more enthusiastically in the workshop and at the presentations. Where the workshop was championed by someone not in top management (e.g., a chaplain or social worker who had heard of it through the grapevine) and where the culture of individualization was not preeminent, it was more difficult to secure staff participation at presentations. Although the workshop might provide leverage in a process of culture change, it is unlikely to be powerful enough to bring about a culture change in an organization. Such change must occur from within — and from attendance has been modest, including one or two members of the professional staff, and one or two nonprofessional staff members.

Discussion

The workshop appears to have succeeded in involving its participants in a process that integrates them into the life of the institution, produces good narrative material, and in some cases provides unexpected benefits to themselves. Although not intended as a psychological intervention, the FSW process enabled some to break free of a disease–saturated narrative and to regain a fuller sense of the meaning and accomplishments of the person’s life and also to deal with the impact of the dementing illness. About a third of the storytellers discovered something positive they had not understood or known about the person or the nature of their relationship with him or her; for others it was a time of grieving but also of healing framed within a celebration of the elder and his or her life. For example, a son, through research about his mother’s teenage years, saw a frivolous side to her otherwise very structured life. A niece, studying a photo of her always imperious 96-year-old aunt as a beautiful 4-year-old, came to appreciate why her aunt might justifiably be vain about her looks and came to admire her more in the process.

We did not systematically gather information on the effect of the histories on staff members. We heard that staff enjoyed knowing more about the patients and that, in some cases, the information directly affected the kind of care that people receive. The history gives the staff points of reference with which to reminisce with patients. Greater understanding and appreciation of the resident as a person who has lived a life, raised a family, enjoyed recreation, and had a career may have resulted in more sensitive, empathic, and respectful interactions. Thus, for one person, whom the staff can’t understand and who was a meticulous dresser all through her life, activity of daily living (ADL) care is now embedded in verbal reinforcements of how attractive she looks and also in a reportedly higher staff attention to her dress throughout the day.

The workshop worked best — especially in terms of staff participation — where it reflected the prevailing culture of the organization. In those facilities in which top management embraced the workshop as consonant with an existing vision and mission, more staff members participated more enthusiastically in the workshop and at the presentations. Where the workshop was championed by someone not in top management (e.g., a chaplain or social worker who had heard of it through the grapevine) and where the culture of individualization was not preeminent, it was more difficult to secure staff participation at presentations. Although the workshop might provide leverage in a process of culture change, it is unlikely to be powerful enough to bring about a culture change in an organization. Such change must occur from within — and from
the top — before the environment can be most conducive for the workshop.

The workshop demonstrates the multiple benefits of involving family members, but it is a lengthy process, one from which many shied away. In an environment in which the workshop is more a part of care and more reflective of the larger culture, perhaps more families could be more readily involved in the workshop. For example, an integrated care continuum might begin working with dementia patients and their families long before institutionalization. The capturing and celebration of the person’s history and individuality would become a guiding element in these long-range activities just as determining advance directives and establishing long-range financial plans would be. In addition to staff-led workshops, other methods could be employed to develop these stories. Facilities and systems of care might articulate clearer and more involved in the workshop. For example, an integrated care continuum might begin working with dementia patients. In particular, nursing homes might adopt a more ambitious strategy for and broader understanding of the social history now gathered at admission. Elements of the family workshop (e.g., the genogram, time-line, and themes exercises) could be incorporated into interviews with the family by various disciplines. Structured guides or exercises (e.g., the workshop’s photo exercise or a self-completed family guide such as that suggested by Burger et al., 1996) could be completed independently by families, with encouragement by staff. Although such techniques might not provide the group benefits and the sense of accomplishment that participants derived from the workshop, they would emphasize to families the value the institution places on the individual and they would provide staff with rich historical information.

As a final suggestion, leadership of FSW groups presents a wonderful opportunity for involvement by family councils. Leadership (including recruiting, facilitation, and organizing presentations) could be integrated into the way the family council draws new residents’ families into the life of the facility. In general, we envision this as a way to encourage families to understand that the nursing home is a living community, that it provides them with important opportunities for continuity of the care they have been providing, and it acknowledges the importance of the information that they have for care-providing staff.

References


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