Objective: The purpose of the investigation was to identify factors influencing quality of visits with institutionalized patients suffering from dementia.

Study Design: Two focus groups of family members of patients residing on a Dementia Special Care Unit.

Setting: Dementia Special Care Unit in a Veterans Administration Hospital.

Participants: Spouses and adult children of institutionalized patients with dementia.

Intervention: During the focus group the family members were asked to identify factors that contribute to the quality of their visits with loved ones suffering from dementia. The group sessions were recorded and transcribed verbatim. Data obtained during the sessions were analyzed and specific factors affecting the visiting experience were identified.

Results: Numerous factors affecting the visiting experience were identified and were grouped into personal, interpersonal, and environmental domains.

Conclusions: The presence of visitors in the long-term care setting is very important. Visiting provides a link with the families and communities, and promotes the quality of life for patients with dementia. Satisfying experience during the visits helps the families to enjoy the interaction and promotes their involvement with their institutionalized relatives. Health care providers should make efforts to improve the quality of visits. (J Am Med Dir Assoc 2007; 8: 166–172)

Keywords: Visitors; dementia; long-term care
FVEP. Another program, Family Involvement in Care (FIC), was aimed at helping family caregivers of nursing home residents with dementia establish an effective partnership with the staff caregivers. The intervention consisted of 4 main components: orientation of the primary caregiver to the facility and proposed partnership, education about involvement in resident care, negotiation and agreement on the partnership, and finally, follow-up and the renegotiation of the agreement. Involvement ranged from simple provision of information to full participation in physical care and psychosocial interventions. The FIC findings showed less global deterioration of the residents although inappropriate behavior, cognition, and functional status remained unchanged.9 These data indicate that it is important to promote both frequency and quality of family visits with their demented relatives. It is likely that if the family members perceive that the visit was successful, they will be more likely to visit more frequently and the successful visit may have more impact on the demented relative. However, it is not clear what are the characteristics that define success in a visit from the family member’s point of view. Therefore, we performed a qualitative study that explored factors involved in successful visitation.

METHODS

Staff members from the 100-bed Dementia Special Care Unit identified family members of patients residing on this unit who were willing to participate in the study. The study was approved by the Institutional Review Board and informed consents were obtained prior to initiation of the study.

Over the course of several weeks we conducted 2 focus groups with 8 to 10 family members participating in each session. Each focus group was facilitated by 2 of the authors. Spouses and adult children of our patients took part in the focus group sessions. During the focus groups we asked group members their opinion on characteristics of a “good” visit with a family member afflicted with dementia. Additionally, focus group members were asked their opinion on the characteristics of an unsuccessful visit, and they were asked to express their thoughts about how the quality of visits can be improved. During the sessions, the facilitators helped group members clarify some points made by the participants.

Focus group sessions were recorded and subsequently transcribed verbatim. The transcripts were examined for emergent patterns and themes that reflected the meaning provided by group members in response to the main questions using the grounded theory.10 Data reduction involved coding and clustering of the data. Data reconstruction and synthesis involved the identification and verification of patterns and themes.

RESULTS

Family members were able to identify numerous factors that affected their experience during visits with their relatives suffering from cognitive impairment during the focus groups. Analysis of these factors indicated that these factors might be divided into personal, interpersonal, or environmental domains. Personal domain included factors associated with characteristics of the resident with dementia and his or her interaction with the family member. Interpersonal factors included interactions between residents and the staff, and between family members and the staff. Environmental factors included characteristics of the visiting space, the effect of other residents’ presence, and the availability of programs for residents (Table 1).

PERSONAL DOMAIN

On the personal level, establishing a special connection with their loved one during the interaction was viewed as an important task and, if accomplished, would give the visitors a sense of satisfaction.

“Some connection. Some interaction with . . . and recognition—. . . when he realizes maybe I am his wife, a family member, that means something.”

“I think for me . . . one thing that was a measure of a successful visit for me with my dad was some sort of recognition on his part that he might not remember my name, but he knew who I was . . . that recognition and that bonding with him if you will, that he knew we were there.”

Connection was not synonymous with recognition as the latter is frequently lost in the more advanced cases of dementia. Connection was rather associated with experiencing a special bond, which would differ depending on the stage of the illness.

“What makes a satisfactory visit is, a really satisfactory visit when he looks up at me and his eyes brighten and he smiles and he reaches out.”

Table 1. Domains and Factors of Visit Satisfaction

<table>
<thead>
<tr>
<th>Domains</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal</td>
<td>Connection with the resident</td>
</tr>
<tr>
<td></td>
<td>Recognition by the resident</td>
</tr>
<tr>
<td></td>
<td>Ability to communicate</td>
</tr>
<tr>
<td></td>
<td>Emotional expression</td>
</tr>
<tr>
<td></td>
<td>Involvement in activities during visit</td>
</tr>
<tr>
<td></td>
<td>Knowledge that resident is being well taken care of</td>
</tr>
<tr>
<td></td>
<td>Appearance of the resident</td>
</tr>
<tr>
<td></td>
<td>Ease of leaving</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Knowledge that the resident is attached to staff members</td>
</tr>
<tr>
<td></td>
<td>Information about resident from the staff</td>
</tr>
<tr>
<td></td>
<td>Confidence in caregivers</td>
</tr>
<tr>
<td></td>
<td>Staff help in initiating and ending the visit</td>
</tr>
<tr>
<td></td>
<td>Learning from the staff how to interact with the resident</td>
</tr>
<tr>
<td></td>
<td>Help from staff before and during the visit</td>
</tr>
<tr>
<td>Environmental</td>
<td>Peaceful, homey surrounding</td>
</tr>
<tr>
<td></td>
<td>Clean environment</td>
</tr>
<tr>
<td></td>
<td>Cleanliness of other residents</td>
</tr>
<tr>
<td></td>
<td>Change of milieu</td>
</tr>
<tr>
<td></td>
<td>Availability of activities and activity supplies</td>
</tr>
</tbody>
</table>
On the other hand, the lack of ability to connect and display emotional expression plus the inability to communicate because of severe deficit were considered to be obstacles to successful visits.

“... the hardest thing for us is that we can’t communicate.”

“It’s the blank look that’s really hard.”

Visitors pointed out that once the resident reaches the stage of advanced dementia and there is seemingly no interaction with the outside world, they continue to come and find fulfillment in knowing that their loved ones are being well taken care of.

“I don’t know whether X knows me or not, but it doesn’t matter. I come in with a smile on my face and tell him what I have done and what I had for lunch and what’s on my grocery list and I try to somehow to bring back the past ... I just feel he is well taken care of and clean, so I just hold onto that because I know I don’t get anything really, no satisfaction at all ...”

Group participants found that noticing positive emotions on their relatives’ faces and observing the residents’ involvement in activities was indicative of the resident’s overall content with the program, appropriate adjustment to the environment, and provided the visitors with a sense of relief and gratification.

“I think a good visit is when my husband is happy.”

“He’ll smile, he’ll participate in different things. He plays cards. He reads newspaper. He does that, I feel happy.”

“I do appreciate the visit when my husband is content, not ill at ease.”

Family members also talked about the importance of organizing visits around specific tasks. Family members who had an established agenda felt that it provided them with a notion of having a concrete purpose for their visit. The agenda tended to ease the anxiety associated with the visit and if the task were accomplished, it helped the visitor to experience gratification. For example, visiting during meal times helped visitors to take pleasure in the feeling of “nurturing” their loved ones, plus it provided the notion of being “helpful” to the staff and gave a subjective feeling of being “useful.”

“We would try to visit my wife during mealtime so we could assist in her being fed and this way we felt good that she was getting ... one meal that was good and the other thing in part of our reason was to show the staff that we were there to assist them so down deep we felt well maybe they’ll help her in the future because we are helping them now.”

For some relatives coming for visits during mealtimes provided them with the only opportunity to “sit down” with their institutionalized elder, especially when the latter is a pacer.

“He’s continually in perpetual motion, practically the only time he does sit is at mealtime and that’s how I can sort of watch or visit with him when he’s eating.”

Some visitors were able to gain pleasure from every visit as they became proactive in reaching out to their loved ones through various means and adjusted to their level of cognitive functioning. Some believed that incorporating touch through massage during the visit allowed them to achieve a special level of connection, which became manifest by nonverbal expression of pleasure and content on the part of their dementia-afflicted relative.

“I consider every visit successful because I always get a response from him physically. They are like babies, what they know is touch. I always leave feeling so good and he feels so good because I can see it in his body. He is moaning and groaning and it’s wonderful.”

Others discovered that simple touch by holding hands, washing their loved one’s face, or brushing their teeth with a battery-operated toothbrush helped their relatives to become calm, content, and relaxed. Visitors left the unit again with a notion that their time was spent successfully.

“Every night before I go home, I wash my husband’s face and I don’t think it’s dirty.”

“I bet he’s relaxed.” “I take a battery-operated toothbrush and I brush his teeth, I think the vibration stimulates him.”

Appropriate hygiene of their loved ones was viewed as an absolute requirement for a successful visit. Some family members expressed their particular sensitivity about the selection of clothes and reported getting substantially distracted and upset if their loved ones were wearing mismatched clothes or parts of the outfit that did not belong to them. They argued that before the development of dementia their husbands/wives were very meticulous about their appearance, therefore all the efforts should be done to ensure such even after the institutionalization.

“It is so upsetting to a new family to come in and see their loved one who had always been dressed beautifully and clean ... to have somebody else’s shirt on.”

“Sometimes when there’s somebody new on, they’re not exactly sure whose clothes are whose and I know the roommate that’s in my husband’s room, he sometimes comes out with my husband’s clothes and my husband comes out with his clothes on.”

Family members additionally indicated that even the most successful visit might be changed into an unsuccessful one if the end of the visit was difficult. Getting into a struggle during the “good-bye” times left the family members with a profound sense of blame and culpability. The feeling persisted long after the visit was over.

“When X doesn’t cry when I leave and ask me to take him home. That’s a good visit.”

“If he was happy when I’m leaving, I would say it was a good visit.”

“He’d follow me down and I’d have to get someone to take him away from me and then I’d be in a real mess ...”
On the other hand, when the ending of the visit was peaceful, visitors were more likely to experience contentment with the entire visit. Some of the relatives of our residents were able to develop certain strategies to minimize the painful aspects of saying good-bye at the end of the visit.

“I would sit with X and generally in front of the fish tank and then she’d fall asleep and then I’d leave.”

“That’s a happy visit when they fall asleep and you leave.”

“I put him to bed at 3:00. I’ll give him a kiss on the forehead, rub his head, put him in and within seconds he goes out like a light. I stand up here and look.”

Study participants also talked about feeling of guilt associated with having their loved ones placed in an institutionalized setting. They often concluded that if that guilt was exacerbated during the visit then the visit was considered unsuccessful.

“An unsuccessful visit is when I go home with a guilt trip. My husband said once, I think I’m in jail. So you can imagine what a guilt trip I had and it happens almost every day.”

From the personal perspective, the family members stated that they frequently found comfort in realizing that their loved ones do have significant memory impairment that ultimately makes them more immune to the anguish of separation from their families. Knowing that shortly after the visit the memory of having that interaction will likely fade, put the visitors at ease and helped them to overcome guilty feelings associated with leaving.

“I find it a blessing that they don’t remember . . . because I feel like, I hope he doesn’t know what’s going on because it makes me sad to think that he would think that I would put him in somewhere, that I wouldn’t take care of him myself.”

“That gave me a little better feeling that when I left, even though he was trying to get back to me, I know that 5 minutes later he was going to forget I was there.”

Some family members shared their special intimate ways of maintaining a connection with their institutionalized elder after the visit.

“I always left with music on which he happened to love and so that it always made me feel good and I put the same music on driving away. So it was a nice way to leave.”

INTERPERSONAL DOMAIN

Factors influencing the quality of visits can also be of an interpersonal nature. An effective relationship between the residents and the staff members, as well as interactions and communication between staff members and the families were considered to be very important aspects affecting the visiting experience. Members of the focus groups pointed out that they were reassured when they observed their loved one’s positive contacts with staff members. They viewed the “connection” between the residents and the workers as a confirmation that their relatives were treated with care and respect.

“I can sit there and just turn pages of magazines with him as long as I know he is having good interaction with his caregivers, which I do see, yes very much so and that makes me happy.”

Additionally, a great sense of relief was associated with the notion that the residents over time become attached to the hospital staff, which to family members indirectly indicated that appropriate care was provided also in their absence.

“X is more attached to the hospital staff than to me, but they are all so kind to him that I do appreciate that.”

Group participants commented on the fact that staff members’ particular attention to residents’ privacy and dignity observed during their stay on the units was particularly reassuring. They were subsequently able to enjoy peace of mind that their loved ones were going to be treated with similar respect.

“They are very private people.”

“They still have dignity left.”

Focus group members also stated that they valued staff members’ feedback on how the resident was doing outside of the visit. Family members voiced that receiving reliable information on their loved one’s status, attitudes, and interactions between the visits was considered to be an important interpersonal factor compounding the quality of the visits. On the other hand, getting conflicting reports from the staff members resulted in families losing confidence in caregivers who interfered with their ability to concentrate on the visit.

“If they got a reason they would sometimes get three different reasons and then you’d lose confidence and then you’re not concentrating on the visit.”

Another important point of interpersonal connotation was that family members appreciated staff members’ involvement in initiating and ending the visit. A cordial smile, a friendly greeting, or a warm eye contact with staff members upon arrival to the unit reportedly helped visitors begin their visit with their loved one on a positive note plus it made them feel welcomed in the facility.

“I think the biggest thing is to help you to get in because sometimes you can come and say hello or have a big smile on your face and you don’t get a response from a staff person.”

Similarly, staff members’ involvement was appreciated at the end of the visit especially when staff had proven to be skillful in distracting the resident or shifting focus off the family member so the good-bye time with the family member was less stressful. Family members concluded that they would be interested in learning skills and strategies from the staff members so they could ultimately become more self-sufficient in easing their loved one’s frustration or agitation.

“I think staff has been very good at easing that (resistance) or changing the focus and redirecting it, but it’s not always a skill that I feel I have, I need some help with that. I mean we’ve all picked up these little tricks in watching the staff.”
Visitors voiced that sometimes they felt that they lacked the necessary expertise to decide whether their involvement or ideas as how to organize the visit actually contributed to escalating behavior of their loved ones. In situations like that they would not mind having the staff directly telling them that change in approach might ease the interaction.

“A little stronger suggestion is all right.”

An additional issue that was brought up during the group sessions was that poor communication between the families and the staff members resulted in unnecessary anger, frustration, and inability to enjoy visits. Some relatives pointed out that they expected their loved one to be “ready” for a visit; meaning “all dressed and out of bed.” If for whatever reason these conditions were not met, the visit was doomed to be unsuccessful. A helpful resolution to this type of conflict would be for the family member to talk with the staff and inform them about the specific time of the visit.

“It takes a lot of my visit just waiting for them to put him in a wheelchair . . . that makes for a very frustrating visit.”

At times family members became frustrated with the caregivers if the staff members recommended some intervention that had proven to be calming for their loved ones, yet the staff showed reluctance in implementing the advice.

“I had it put right on his radio: ‘He loves classical 102.5.’ For awhile it was on, but I don’t think it’s on now.”

Additionally, the discussants stated that behavioral or psychotic symptoms that frequently occurred in residents suffering from dementia were a source of significant stress for them. Adequate control of these symptoms with medications eased their stress, diminished their loved one’s suffering and consequently provided for a better visit.

“An unsuccessful visit is when he fears people around him . . . and when he has to constantly be in a certain position against the wall so that he can see the oncoming threats or whatever. He also fantasizes about my sexual activity. He fears that I’m with someone else because he can’t be. He fears that his children have been hurt and they’re not telling him.”

Yet another interpersonal dimension that was important for the quality of visits was support that the visitors gained from their institutionalized elders, they develop a sense of camaraderie, but also provide each other with concrete guidance with respect to visits and “monitor” the quality of care that was provided to other residents.

“Now I will sit with few other women and let him go down the hall an he does.”

“I think on the X floor, it’s pretty accomplished because we encircle . . . It’s really very inclusive and I think the wives try to invite anybody new into it. So they learn some of the ropes from each other. There’s a lot of support from the others . . . we discuss some of these things with new people and it helps.”

**ENVIRONMENTAL DOMAIN**

The environmental factors were also viewed as an important prerequisite for a pleasurable experience during the visit. Peaceful surroundings, clean environment, and cleanliness of other residents on the unit were viewed as very significant factors contributing to the visiting experience.

“I found the environment very important to the successful visit in that if I were sitting in the dayroom and there was a strong odor or some men not being paid attention to, it was very distracting and it just ruined the whole visit. I mean you just couldn’t concentrate on being with your loved one.”

Frequently a simple change in the routine or a mild modification of the milieu could have a very powerful impact on the interaction with a dementia-suffering relative.

“Wonderful visits . . . were when we would all be sitting under the tree outside and with a group of patients and their wives and friends.”

Family members enjoyed an opportunity to bring their loved ones outside, which ultimately provided them with the “necessary break” from the “atmosphere” of the long-term care facility. It also allowed the visitors to engage the residents in activities that were not available on the unit, eg, walking, enjoying nature, and so forth.

“I feel good in the summer because we’ve been getting outside and the grounds are so beautiful and there’s so much space to walk around in the summer. You can kind of get away from the atmosphere of the unit for a while . . . I mean inside you see a lot of sad things.”

The visitors expressed also their attentiveness to the cleanliness of the surroundings. Family members stated that the lack of appropriate housekeeping services resulting in inadequate neatness of their immediate environment provided unwanted distraction and ultimately inability to enjoy visiting.

“Have the furniture cleaned, so we’re not playing musical chairs.”

“I used to take the chairs and turn them around and put them up against the wall so nobody would sit on them . . . that was very offensive for a bad visit . . . And those are things that you notice.”

The participants also pointed out that arranging the surroundings into a more homelike environment helped them...
and their loved ones to experience feelings of comfort and intimacy.

“Last winter there were several of us who went down on a weekend to day care and just more homely surroundings I think induced a very nice visit.”

“There was just something about the whole atmosphere... I think my husband felt like he was having friends in his own home and he enjoyed that a great deal.”

The availability of a kitchen for the families’ use, along with basic appliances, was viewed by visitors as a nice addendum to the milieu that ultimately opened a new avenue for taking care of their loved ones, involving them in simple everyday activities and enjoying company of other families and residents.

“I like the coffee machine that we have because X always liked coffee and now it’s so available... he gets such pleasure out of that. Also I like the microwave because I bring him food in. So that’s a nice thing.”

“I get a chance to make him stew that he likes so much... I like the kitchen.”

The discussants additionally talked about the importance of adequate stimulation of residents of our special care unit. They expressed their frustration when there was a lack of resident involvement in activities. They talked about becoming significantly distracted during their visit when other residents were not being attended to or not enough effort was being put into having them occupied. They pointed out the importance of hiring enough staff or attracting additional volunteers to secure adequate stimulation and attention to each and every resident on the unit regardless of family involvement.

“I try to keep him awake but the stimulation isn’t there and I see so many patients who are up in the chair and they’re either in the corner or against the wall and just kind of staring into space. If only they could give them something to keep in their hands to stimulate them.”

“The thing that really aggravates me is when I come in and I find my husband sitting all by himself facing a wall and maybe 2 or 3 other men asleep. No, that’s not always the case, but my visit, when I see that... I get extremely upset.”

“Expanded recreation and expanded attention to the men means additional staff...”

“The volunteers who come on floor and encourage the men to play cards if they can and to do different things and I think it’s very helpful too.”

Family members made special suggestions regarding modifications in the activities that would, in their opinion, improve the quality of life of their relatives on the unit and permit both parties to enjoy visiting more fully. They emphasized the importance of having easy availability of music, movies, and magazines that could be incorporated into the visit. Ultimately, these items would make the visits more interesting and variable. They also indicated that having children and pets visit the unit more frequently would serve as a great addendum to the setting and subsequently provide the residents with a very pleasurable experience.

“Well the Golden Oldies, I think they all love that and the old campfire songs. X always responds to the sing-along type and the dancing music.”

“My dad still loves just to look at the pictures in magazines.”

“I wish they had more interesting tapes to play for entertainment.”

“They love to see children.”

“My family feels that if you encourage young children to visit. Everybody seems to have a positive reaction to the youngsters.”

“And pets.”

**DISCUSSION**

Older adults suffering from dementia and residing in long-term care facilities receive physical and emotional benefit from family members and friends. Prior research suggests that pleasurable social experiences decreased behavioral problems among residents, ultimately easing the burden on staff members.9 Visiting of spouses in a nursing home is mostly associated with feelings of satisfaction (in 80% of visitors) and enjoyment (67%) but a majority of visitors also experience guilt, sadness, and depression (53%). It is very likely that these negative feelings are evoked more frequently if the visit is perceived as unsuccessful.

Previous studies examined the variables affecting the frequency of family visits but did not address quality of visits. Barriers hindering continuous family involvement in resident care include resistance to institutional change, family members' fear and hesitation, institutional rules and protocols, lack of institutional encouragement of family involvement, insufficient programs and activities addressing the social and emotional needs of the family, and ineffective communication between the staff and families.11 Frequency of visits after nursing home admission is increased by close relationship with the resident, existence of social support for the caregiver and if the resident is white, but it is decreased if the resident suffers from dementia.12 Frequent long visits are related to the caregiver being a spouse, having lower education, being against the placement, and living close to the nursing home.13 Visit frequency is decreased by transportation problems and poor relationship with staff but it is increased if the caregiver is anxious.14

Much less is known about how the visits are perceived by family members and what makes the visits enjoyable. Our study aimed to explore factors that contribute to a successful or an unsuccessful visit as perceived by visitors. Numerous factors affecting the visiting experience have been identified and grouped into 3 main domains: personal, interpersonal, and environmental (Table 1). Our study was not designed to determine the relative importance of these 3 domains and their relationship; however, the personal domain accounted for most of the discussion in the focus groups and is probably the most important. Factors included in other domains may increase or decrease the degree of the visit’s success but may not be the most important for its outcome.
Some of the factors that we identified are targeted in quantitative studies investigating satisfaction with care but our qualitative approach illustrated specific issues that families are encountering during visits. Results of our study may be used as a basis for development of a quantitative measure that could be used for evaluation of quality of family visits. Availability of such a measure would be useful for studies that investigate the effect of family education on family visitation.

Our study has several limitations. Participants in the focus groups were suggested by the staff members and therefore may not represent all family opinions. However, our second focus group did not bring new concepts that were not mentioned by the first group and our informal contact with other family caregivers did not uncover any additional factors. We did not differentiate between responses of spouses and adult children in our study; however, our impression was that both of these groups had the same concerns when visiting with the family relatives.

The presence of visitors in the long-term care setting is very important. Visiting provides a link with the families and communities, and promotes the quality of life for patients with dementia. Having a satisfying experience during the visits helps the families to enjoy the interaction, ease the sense of guilt, and promote their involvement in taking care of their institutionalized relatives. Health care providers should make every effort possible to improve the quality of family visits for their residents with dementia.

Group participants posted several suggestions that, in their opinion, would make the visiting experience more successful (Table 2). They pointed out that improving their communication with staff members, receiving more education and practical support, and obtaining constructive feedback from the caregivers on the unit would allow them to make necessary adjustments to improve the quality of their visits. The families also suggested that inviting young children and pets to the unit, as well as making the environment cleaner and more private and cozy would certainly have a positive impact on the visiting experience. Additionally, involving the residents in appropriate activities and entertainment, attracting more volunteers, and expanding the attention given to the residents would be a great addition to the milieu when family members are not visiting. Another improvement would be having available videophones that would eliminate some of the barriers related to transportation. Analysis of videophone use for communication with a resident with dementia indicated that the conversations using a videophone were in some cases more focused and better quality than face-to-face conversations. 14,15

Table 2. Suggestions for System Changes That Would Improve Quality of Family Visits

<table>
<thead>
<tr>
<th>Suggestions for System Changes That Would Improve Quality of Family Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve communication with families</td>
</tr>
<tr>
<td>Enhance family education</td>
</tr>
<tr>
<td>Increase practical support during visits</td>
</tr>
<tr>
<td>Provide constructive feedback to family members who visit</td>
</tr>
<tr>
<td>Invite children and pets to the unit</td>
</tr>
<tr>
<td>Ensure a clean and homely environment</td>
</tr>
<tr>
<td>Provide wider range of activities and entertainment for the residents</td>
</tr>
<tr>
<td>Increase number of volunteers willing to spend time with residents</td>
</tr>
<tr>
<td>Allow videophones to improve communication with families</td>
</tr>
</tbody>
</table>

REFERENCES