Family visits or contact to dementia elderly at long term care facilities

Sam Ndu Achor
FAMILY VISITS OR CONTACT TO DEMENTIA ELDERLY
AT LONG TERM CARE FACILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

By
Sam Ndu Achor
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September, 2000
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ABSTRACT

Very few studies have explicitly examined the roles of family members in institutionalized settings and how these roles affect the care of their loved ones with debilitating progressive diseases like dementia. The most widely used theoretical framework employed in studies that do exist is Litwak's structural-functionalist framework, a theory of shared functions and balances coordination. The theory is limited to the importance of both formal organizations and primary groups, but fails to provide understanding of the actual role of family members in long term care facilities. Therefore, an interactions approach which integrates concepts from the ecological perspective and the contextual framework for understanding the role of family members in long term care facilities was used in this study.

This study was conducted at Unit 700, dementia pod of California Veterans Home in Barstow. The sample frame was the agency staff that work directly with the dementia clients or residents (population under study). All available day care staff and social workers were interviewed or surveyed through a standardized
questionnaire to illicit their opinions on quality of family visits and the impact such visits make to treatment and adjustment level of elderly dementia clients.
ACKNOWLEDGMENTS

Many thanks to the administration of California State Veterans Home Barstow for allowing me to conduct this study in their facility. Much thanks to Bill Rigole (Deputy Administrator), Chris Crafton (Chief of Social Work) and the participating nurses (700 Unit dementia pod), all of Veterans Home Barstow for all their support. I would like to acknowledge Judy Rael for all her help and expert insights regarding dementia diseases and elderly clients who suffer from this unfortunate degenerative disease.

My gratitude and appreciation also goes to Scott Logan (PHD, intern DBH Rialto) for helping me read meaning to those computer jargons (data) and how to create tables. Also, to Dr. McCaslin (Professor of Social Work) for her wisdom, knowledge and patience in guiding me through this project. I would especially like to thank Betty Howard, (San Bernardino County Probation Department) for all her hard work in helping me with just a last minute notification, in typing almost all my reports, including this one. Finally, to my two little girls Kachi Gail (6 years old) and Nikki Obum (4 years old) and my son
Chukwuma Steven (17 years old) who showed their support by not disturbing Daddy when he was busy studying or writing reports.
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INTRODUCTION/PROBLEM STATEMENT

Dementia disease has often been defined as one of the characteristics of aging process. In fact in some cultures dementia is viewed as nothing but a normal aging process which afflicts a significant amount of old people. In those cultures no attempts are being made to diagnose or possibly find a cure for the disease. However just like in this culture, efforts are geared toward maintenance and management of the aged suffering from the disease to make sure that quality of life and dignity is maintained or preserved to the end. However, it is important to point out that dementia is not a normal part of the aging process. Dementia is caused by abnormal disease processes, and can affect both young and old persons (Cummings & Benson, 1983).

Caring for a demented member of a family can be a tortuous and painful exercise. Often times, the quality of care is reflective of the family relationship and communication dynamics prior to during the disease process. Once a decision is reached to place a family member in a long-term care facility or institution, families may or may not maintain meaningful support and caring interest with their demented member. The aim of this study was to focus
on quality of supportive caring by dementia family members in long term care facilities as it relates to the patients' adjustment to treatment. There have been numerous studies done on various aspects of dementia patients but little or none is specifically focused on treatment adjustment levels as it relates to family supports.

Dementia has been acknowledged to be the most devastating and debilitating condition affecting the aged. More than one million elderly suffer from dementia (Steiner and Clark, 1982). The condition is multifaceted, often involving the loss of certain intellectual abilities, which include but are not limited to memory, judgment, abstract thinking, and changes in personality. This disease can affect an individual's independent functioning, requiring that his or her every need be met by others. The degree of care required by the elderly person impaired by dementia is extensive. One half of all nursing home admissions are attributed to some type of mental impairment (Buckwalter and Hall, 1987). Specifically, in the case of impairment related directly to dementia, it is estimated that between 30% and 50% of all institutionalized elderly suffer from some type of dementia (Plum, 1979).
"Dementia is a syndrome characterized by acquired impairment in at least three of five neuropsychological and behavioral domains - memory, language/speech, visual ability, cognition (the ability to manipulate previously learned information), and mood/personality," (Cummings and Benson, 1992, as cited by Webster Ross et al. 1996).

Dementia is an umbrella term or general name commonly used to describe people clinically diagnosed with mental cognitive impairment. There are different types of dementia:

. **Alzheimer’s Disease** - This is the most commonly diagnosed dementia in the United States. The diagnosis of Alzheimer Disease requires that the course of memory impairment be gradually progressive, the onset is between the ages of 40 and 90, and there is no disturbance of consciousness and no other systemic disorders known to cause dementia (McKhann et al., 1984 cited by Webster Ross).

. **Cerebrovascular dementia** - This diagnosis depends on presence of a dementia syndrome and cerebrovacular disease that is sufficient to cause the dementia.

. **Frontal lobe degenerative dementia**.

. **Dementia** associated with Parkinson disease.
As the disease progresses to the late stages, the damage done becomes more pronounced and family members may find the afflicted relative increasingly difficult to manage. Maintenance in the home may become impossible and admission to a long-term care facility, the only alternative. Nursing home or other long-term care facility placements of an elder with dementia can create a whole new set of problems for the individual and his or her caregivers, thereby, straining and alienating the elderly individual from the loved ones and caregivers.

Some researchers have indicated that family members continue to have extensive contact and close emotional ties with their older adult relatives with dementia after institutionalization (Broddy, 1986; Moss and Kurland, 1979 as cited by Dupries and Soan, 1997) but quality and effect of those contacts are not known. Long-term care organizations should be able to depend on supports they receive from relatives of their residents suffering from these debilitating progressive diseases. Family members should be able to move towards considering themselves as vital members of the health care team, treating their elderly members.
Although our understanding of specific issues faced by community-based caregivers has been expanding rapidly over the past decade, very little is still known about the perceptions, activities, and experiences of familial caregivers after placement of a relative into a long-term care facility. In surveying over 40 textbooks on nursing home management and nursing home care, Safford (1989) discovered "an almost total lack of reference to the family." Also, it has been noted there has been some increased interest in institutional based caregivers over the past decade, but there continues to be a general lack of reference to research specifically focused on the roles of family members of institutionalized older adults.

This study attempted to answer the following questions: Could meaningful family support bring about much needed relief to both patients and nursing staff working with such patients? How important a role can frequent supportive family visits play in adjustment level and treatment interventions? Does the nursing staff view those visits or contacts as important in reducing the stress level of caring for dementia patients and helping in their adjustment level? Could there be any significant changes in clients' overall conditions (i.e. agitation level,
relaxation, restlessness, wondering, adjustment to treatment, etc.) before, during, and after visits? How do treatment adjustment levels of clients who receive visits compare with clients who do not receive visits? What family members (i.e. gender, spouse, and sibling) are more likely to visit and give quality supportive caring attitudes towards the dementia clients?
PROBLEM FOCUS

Family members should be an important part in the treatment and care of older family members with dementia placed in a long-term care facility. If the family is a functional, caring family prior to the sickness of a senior family member, the caring should not stop after that member was placed in a long-term care facility. Family members' roles should be uniquely and actively constructed and reconstructed over the caring of a family member placed in long-term care homes.

There is a need to look deeply into roles of family members in managing the care of their older members with the disease of Alzheimer's or other form of dementia in long-term care units. The resident or patient could adjust and respond better when family members are around, working together with the professional caregivers, especially, when the disease has not progressed to advanced stages.

Elderly people with irreversible cognitive decline diseases, such as Alzheimer's disease, make many demands on those who must care for them. When family members no longer have the capacity to meet these demands, a nursing home or other formal care facility becomes the only answer. This shift does not mean the end of family
care giving. Instead, the family’s care giving activities must be integrated with the ongoing efforts of the formal care staff. Not much is known about relationships between family caregivers and paid institutional staff. Too often, this lack of attention to the relationship between family caregivers and paid staff has stemmed from the assumption that families cease to play a major role in care giving once the move to formal care has occurred. This is known as the “myth of abandonment.” This assumption has now been criticized in several studies that documented the continuing involvement of family members in formal care setting (Bowers 1788; Chenowith and Spencer, 1986 as cited by Duncan and Morgan 1994).

Recognizing the patient-centered focus in formal care, Pratt (1987, has described the family caregivers of institutionalized dementia patients as “forgotten clients.” In addition, other ethnographic studies of nursing homes understandably place more emphasis on staff, as the major “players” in this setting, with correspondingly less attention to the role of family members (Gubrium, 1975; Savishinsky, 1991; Shields, 1988 as cited by Duncan and Morgan 1994).
Two approaches were used to conceptualize familial care giving roles similar to ones used in previous studies, based on Litwalk’s structural-functionalist framework called the “Theory of Shared Functions and Balanced Coordination.” Roles are conceptualized as a set of expectations and set tasks that the family is responsible for in relationship to the formal organization. Another approach is a qualitative inductive approach, which shows how the families view their roles in long-term care settings or relationship with staff (paid staff). The research questions regarding elderly with dementia in long-term care facilities and the role of family members in treatment and care which represent the general study were:

1. Will the active normative role of family members provide needed support to professional long-term care givers in managing the treatment and care of dementia clients? (2) Are their differences in adjustment level and treatment of dementia patients when family member take or do not take active role in their care? (3) Can treatment and intervention education of family members help family or patient adjust to their present situation?
CONTRIBUTION TO SOCIAL WORK PRACTICE

The results of this study will help social workers as well as other health professionals to formulate effective treatment plans and intervention approaches in handling dementia patients in long term care homes or facilities. It will help social workers to understand the dynamics of family systems or roles in designing better treatment intervention plans. If it is proven that meaningful supportive family contacts to the elderly dementia residents (patients) have some positive effects in their adjustment level to treatment and living conditions, then it would be relieving to caregivers and much more practical to involve such family members in treatment planning team. The results of this study would enhance the knowledge and education of social workers, nursing professionals, and others who work with or care for patients with progressive diseases like dementia. It will particularly give insights in the morbidity of dementia and how to care for the patients. Families could be encouraged or discouraged through education to play a major role in the care of their loved ones. It would open up and foster relationship between professional caregivers, social workers and
families. It would also lead to other areas of study that will enhance social work practices.

Social work practice with dementia patients and their families illustrates the necessity for an ecological - family centered practice. This is based on the assumption that people can be understood and helped only in the context of the intimate and powerful systems of which they are a part (Hartman and Laird, 1982). Family members can provide useful supplementary data and contextual interpretation documenting the presence and degree of cognitive dysfunction of a patient which can help the caregivers, social workers, and doctors to formulate a better care plan for the patient. Families also have the capacity to effect changes in their relatives that professional can only guide.

The research questions for this study were based on the hypothesis that frequent supportive family contact with their older dementia patients in long-term care facilities would increase the patient’s adjustment to treatment, intervention and care. Therefore, the research question was as follows:
(1) Could meaningful supportive family visits or contacts to elderly dementia patients benefit their adjustment level to treatment.
LITERATURE REVIEW

Relationships between caregivers, family members and their relatives who suffer from dementia are important to treatment and care of dementia patient. One study shows the effect of three social work treatments to improve the relationship between the parties affected by dementia through a study using a pretest - posttest control group experimental design. The interventions provided for family members were an educational approach, a supportive approach, and a combined approach. Relationship satisfaction was measured by a modified version of the child's attitude towards mother/father scale. Literature and research in the area of dementia patients and their relatives in long-term care have been limited. Dziegelewski (1991) of Florida State University conducted a study, which showed that whether or not the relative is in a nursing home, family members are stressed by the condition of dementia. This is in support of earlier studies by Brubaker and Brubaker (1984), Buckwalter and Hall (1987) and Pratt, Wright, and Schmatt (1987), that institutionalization does not relieve the stress of family members. Although, the participants in the study felt that they were agonized and stressed by the illness, the study
did stress the closeness of the relationship and how deeply involved family were in the treatment and care of their relative (Dziegielwski, 1991).

Health and well being of family members, regardless of whether they are direct care givers or not, are affected by having a demented elder in the home. Descriptions of caregivers and family stress, burden, and coping problems reported in the literature by Zarit, Orr, and Zarit (1985) and Haley, Levine, Berry and Hughes (1987), among others as cited by Lindsey-Davis, (1996), have provided the impetus for numerous dementia care giving studies over the last decade. Negative family caregiving outcomes associated with long-term home care for a cognitively impaired elder are well documented in literature. Family caregivers often experience a decline in physical health and well being. These negative outcomes have provided the impetus for various caregiver and family interventions, (Davis, 1996).

Although supportive interventions that focus on caregivers, affect, stress, and burden have been well received by caregivers, these types of interventions have limitations if used in isolation. Zarit, Anthony, and Boutsello (1987) noted that dementia caregivers ultimately become dissatisfied with interventions that focus
exclusively on their feelings, responses, and reactions. Caregivers of impaired elders also want interventions that help them reduce or manage the behavioral aggressiveness, wandering, and physical self-neglect that result, from cognitive impairment of their clients or relatives (Lindsey-Davis, 1996).

Citing the work of Teri and Gallagher-Thompson (1991) with dementia, caregivers, it was concluded that in early-stages of dementia, both Alzheimer (AD) patients and their caregivers benefit more from cognitive interventions (i.e., interventions that help them identify and reframe their negative thoughts and feelings). In later stage dementia, behavioral management skill training (e.g., training in those skills that help caregivers alter noxious environmental stimuli and restructure the AD patient's daily activities) is needed (Lindsey-Davis, 1996).

Group versus individual interventions over the past decade, and interventions with informal caregivers have focused primarily on the one individual who provides all or the majority of care for the impaired person. Interventions with groups of these individual caregivers primarily have been either psycho-therapeutic (focused on group discussion of relationships and interactions to
improve affect or provide support) or educational in nature, i.e., increasing knowledge or learning new skills, strategies or techniques. Results of care giving studies from the past decade indicate group interventions to be more useful than individual level interventions for certain kinds of dementia problems (Davis, 1996).

Caregivers with psychological problems benefited most from individual counseling and reported the greatest reduction in psychiatric symptoms. Caregivers who participated in a support group reported greater knowledge of existing community resources and improved ability in using those resources. Greene and Monahan (1989) as cited by Davis (1996), also assessed support group effectiveness for caregiver skill training. In this study, “Caregivers (N=244) who participated in group activities successfully mastered personal relaxation techniques that helped them to manage negative feelings and perceived care giving burden” (Davis, 1998).

The literature review indicated that when dementia becomes reality, caregivers benefit more from behavioral skill training interventions that help them manage those specific deficits manifested by the impaired elder. Findings also indicate that dementia caregivers benefit
more from different types of assistance at different points in time.

Family involvement in elderly patient care, especially those diagnosed with irreversible dementia in skill nursing, long-term care units cannot be overemphasized. A search of the current literature, however, revealed a lack of reliable and valid instruments designed to measure the perceived needs of caregivers of institutionalized geriatric (dementia) patients and their families. The importance of family involvement in an elderly dementia patient care and the impact of the sickness to the family support system lack thorough studies. The mental health field, in exploring methods of improving treatment of inpatients with schizophrenia and other psychiatric disorders, has developed and discussed the benefits of programs that actively educate and involve families in patient care (Glynn et al. 1993; Cummings, 1998). In addition, attention has also been focused on the importance of medical personnel involving family members when treating an Alzheimer's disease patient (Eisdorfer, 1991, Fortinsky and Hathaway, 1990; Miler et al. 1992 as cited by Cummings et al. 1998). These studies showed how important family
members could be, in treatment and wellness of their sick members.

However, little attention has been directed towards the complex needs of families taking more responsible active roles in the treatment interventions of their loved ones. Family members of elderly demented patients in long term care facilities should deal not only with the acute challenge related to nursing home placements but often must do so within the larger context of ongoing care giving responsibilities.

Gilhooly et al. (1994), in their study of family care of the dementia elderly asked some of the following questions: (1) Is caring for a dementia person stressful? (2) Is caring for someone with dementia more stressful than caring for someone with some other disorder? (3) What role do other family members apart from the main caregiver play? (4) What are the predictors of the break down of family care? The answers to these questions were not clear but demonstrated the need for more studies. The first two questions showed high stress levels among the caregivers of dementia patients. The questions about roles family members play imply that when Granny or Dad becomes demented, the whole family pulls its resources to help out.
Unfortunately, almost all the research shows that caregiving is primarily a female role and that, on the whole, only one member of the family takes responsibility (Hunt, 1978 as cited by Gilhooly). A fairly consistent finding is that men and women caring for a dementia relative react differently, men coping better than women (Gilleard et al., 1984 b; Levin et al., 1984 as cited by Gilhooly, 1994).

Zarit et al. (1980) found that what contribute to levels of burden among main caregivers was the frequency of family visits, more visits being associated with lower reported burden. This was contrasted by Scott et al., (1986) who found that high burden was reported both by caregivers who had been rated as not receiving enough family support, and by those rated as receiving more than enough support. Interestingly, and perhaps related to the suggestion, some studies have indicated that it is not the amount of help given to the primary carer that matters, but how satisfied the carer is with the help given (Gilhooly, 1984). As Gilhooly cited, what determines the type of support given by family members are often the pre-morbid relationship between the dementia member and the family.
RESEARCH METHODS

The purpose of this study was to gain understanding of the dynamics of family role (contact) in the day to day care and adjustment level of their senior member with dementia placed in long term care facilities, at Veterans Home Barstow. It is important to know if frequent family contacts with their elderly demented members placed in such facilities would have a positive or negative effect on their treatment adjustment levels and adaptation to treatment. It is also important to note how meaningful and supportive those contacts would be to the overall care and intervention with clients (patients) and their relationship to the care-giving staff of the facility. Satisfying and unsatisfying experiences of family contacts will be elicited through survey of nursing staff that cares for the dementia patients at Veterans Home, Barstow. The nurses and nurses aids were polled through a standardized 15 item questionnaires.
Sampling

Due to financial and time constrain, the sample size and population frame under this study was limited to surveying the nursing staff at dementia pod of unit 700 of skill nursing unit at Veterans Home, Barstow. All available daycare staff (i.e. RNs, CNAS, LVNS etc.) who showed interest was surveyed through a standardized questionnaire using a quantitative research approach. In order to carry on with this survey, permission was obtained from the deputy director of the facility, chief of social workers and the administration of the facility. A formal letter of consent was sent to them and others concerned prior to the actual research, explaining the study and asking permission to conduct the study with the facility staff. The participating nursing staff were debriefed and assured confidentiality of their responses, as there was no tracking device in effect. The nursing staff was chosen as participants or sample frame in this study due to the fact, they are the ones that maintain close contacts to the residents (patients) and their families. The nursing staff especially, is responsible for day to day care of the residents, and they are the ones that supervise or monitor such visits.
Data Collection

The data was gathered from 28 nursing staff through standardized survey questionnaire. The questionnaire was specially designed to elicit staff opinions on their observations of quality of family visits or contacts. Data under review and collection were specifically focused on client weekly adjustment/adaptation levels. Independent Variables: Supportive family visit, level of interest and frequency of visits, level of concerns, gender of visitors. Dependent Variable: Adjustment/adaptation level of client, quality of care, relationship with caregivers, changes in adaptation/adjustment prior and after family visit, e.g., agitation level, changes in skin coloration, violence episodes, assault to staff/self, eating/sleeping habits etc. A look at frequency of visits, lack of visits and duration of visits and how the nursing staff saw or perceives it was important to this study. The study included the following elements or attributes: observation of family interactions with client, including assisted grooming, touching, tone of conversations; client reactions and responses; family interactions with staff, complaints, gratitude’s; phone contacts by family to client and staff; and staff perception and opinion of family contacts. The
study was strictly quantitative, incorporating Likert-type scales, using ordinal measurement. Attached in the Appendix # A is the questionnaire for the study.

Procedure

As mentioned earlier, data for this study were gathered through a survey of 28 nursing staff who work with the dementia residents. A fifteen-item questionnaire was specifically designed to seek opinions of the nurses regarding observation of family visits and contacts. The questionnaire was given to the head nurse of the unit to distribute to the willingly participating nurses. They were given one week to complete the questionnaire and place it in a designated mailbox at the mailroom. The response was very low after a one-week period, thereby forcing the researcher to singularly lobby the staff to participate in the study. After another week almost all-available nursing staff in the dementia pod at Unit 700 responded to the questionnaires and placed them back in the appropriate designated box. The participating nurses were assured confidentiality of their responses, as there are no tracking devices in effect. The participating nurses were
given a letter of consent and debriefing statement (Appendixes C and D).

The respondents were asked not to identify themselves and clients by name. All participants were granted anonymity.

**Data Analysis**

This study was specifically quantitative and a Likert type scale was used to measure variables under study. The observation of staff and, or his or her opinion of the quality of family member visits or contacts were measured through carefully worded questions.

The analysis was comprised of running frequencies and correlations for the following variables: gender (sex) of visitors, frequency of concerns raised, observed changes in client or adjustment level, and family-staff interactions. This entailed computing the standard deviation, range, mean, median and mode of the associations. Also, the analysis computed bivariate correlations among the variables used for measurement.
RESULTS

Of the 28 nurses and nurses aids polled in this survey the following are the frequency distribution of their responses.

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<th>Table I. Adjustment Level After Visits (N=28)</th>
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How do you rate adjustment level of dementia residents after visit by their family members?

The majority of the nurses (64.3%) surveyed reported "some" (39.3%) and "much changes" (25%). The remaining
nurses (35.7%) reported "no" (7.1%) and "little changes" (28.6%). (See Table 1)

How do you rate adjustment level of dementia residents during visit?

The majority of the nurses (82.1%) reported "some" (57.1%) and "Much changes" (25%), while the remaining of nurses (17.9%) reported "little changes" (See Table 2).

Do family members show some appreciation to the caregivers?

The majority of the nurses (82.2%) reported "a little bit" (17.9%), "somewhat" (46.4%), and "a lot" (17.9%). The remaining nurses reported "None" (10.7%) and "very much" (7.1%).

Do families consult with the nursing staff during visits regarding resident's conditions?

The majority of nurses (85.7%) reported "a little bit" (17.9%), "somewhat" (35.7%) and "a lot" (32.1%). The remaining nurses (14.3%) reported "None" (3.6%) and "very much" (10.7%).

How often do family members visit dementia residents?

The majority of the nurses (64.3%) reported monthly (39.3%) and every six months (25%). The remaining nurses
reported "Weekly" (14.3%), "bi-weekly" (7.1%), and "yearly" (14.3%).

Percentages of dementia residents that receive visits from family members?

The majority of nurses reported 10% or less range (46.4%). The remaining nurses reported in the 20% range (21.4%) and 30% range (32.1%).

How do you rate quality of caring shown by family members during visits?

The majority of the nurses (71.4%) reported "somewhat" (50%) and "a lot" (21.4%). The remaining respondents reported "none" (3.6%), "a little" (14.3%) and "very much" (10.7).

Do family members relate to nursing staff in a friendly manner?

The majority of nurses (75%) reported "somewhat" (50%) and "a lot" (25%). The remaining nurses (17.8%) reported "none" to "a little bit" and (7.1%) "very much."
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<td>During Visits</td>
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<td>.10</td>
<td>-.18</td>
<td>.46*</td>
<td>.37*</td>
<td>.33</td>
<td>-.17</td>
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<td>After Visits</td>
<td>.25</td>
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<td>-.16</td>
<td>-.19</td>
<td>-.28</td>
<td>-.25</td>
<td>.07</td>
<td>-.03</td>
<td>.55*</td>
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</table>

Note: *The correlations are significant at the 0.05 level (2-tail). ^The correlations are approaching significance at the 0.05 level (2 tail).
Comparing the tables, it is important to note that two of the respondents who reported no significant changes "after" family visits did not do so while answering the question if there were changes in adjustment level "during" family visits. The two tables showed the highest responses in five points Likert scales in "Some changes" category. The frequencies in "much changes" remained constant in both tables while the "no changes" and little changes reflected some variability in frequencies.

The mean responses in the fifteen questions, using Likert five-point scale range from 1.9 - 3.9, which was indicative of little variation in opinions.

Bivariate correlations were calculated among all the opinion items. In order to show all correlations on a single table, the items or questions that did not have significant statistical correlations are not reported (e.g. Items number 1, 2, and 6.) The item numbers in the table correspond to the items or question numbers in the survey questionnaire. Brief descriptions of each item are listed in the left column of the table with matching numbers as it shown in the survey questionnaire (See Appendix E). The numbers in each row and column show Pearson correlates in relation to matching items.
It is important to note as Table III showed, that items in column #4 (do family members speak to residents with respect and love) showed the greatest number of significant statistical correlations with other questionnaire items (e.g. it was correlated with items # 5 (touch and hold hands), #8 (relate to nursing staff in a positive way), #9 (take residents for a walk), #11 (show some appreciation to caregivers), #13 (how do you rate quality of care during visit), and #12 (help full suggestion). However, the degree of the significant correlations were in the low to moderate range for question #4 (do family members speak to residents with respect and love). Item #4 (speak to residents with respect and love) and item #13 (quality of caring) showed the highest degree of correlation at .71, which means the respondents see a strong relation between the two items.

Columns #9 (take residents for a walk)) and #10 (family feed the residents) showed negative statistical significant correlations with item row #14 (how do you rate the adjustment level of clients "during" visits). Also, it is important to note that item # 15 (adjustment after visits) showed only one significant statistical correlation (with item 14).
Item #4 (do family speak to residents with respect and love), showed a significant correlation with #3 (what members of a family visit most frequently).

Item #5 (touch and hold residents hands) was significantly correlated with items # (members of family that visit frequently) and item #4 (do family speak to residents with respect and love).

Item #8 (family relationship with nursing staff) was significantly related to items #4 (family speak to residents with respect and love) #5 (family touch and hold), and #7 (family consult with staff about concerns).

Item #9 (family take resident for a walk) was significantly correlated to #4 (speak with respect), #5 (touch and hold resident hands), #8 (relate to staff in a friendly manner).

Item #11 (family show appreciation to staff) was positively and significantly correlated to #4 (speak to #4 (speak to residents with respect), and #8 (relate to staff in a friendly way).

Item #12 (family give helpful suggestions regarding residents ADL) was positively correlated with #5 (touch and hold residents), #7 (consult with staff regarding
residents), and #8 (family relate to nursing staff in a friendly manner).

Item #13 (quality of caring shown by family members during visits) was positively and significantly correlated with items #3 (members of a family that visit most frequently), #4 (speak with respect), #9 (take resident for a walk), and #11 (show appreciation to staff).

Item #14 (adjustment during visit) was only significantly correlated with item #9 (take resident for a walk).

Item #15 (adjustment after visit) was also only significantly correlated to item #14 (adjustment during visit).
DISCUSSION

This study investigated the relationship of family members with their elderly demented relatives placed in such retirement facilities. The study also, examined if there might have been a difference between frequent family contacts and meaningful supportive family contacts.

The hypothesis that supportive family visits and contact with elderly dementia residents in long-term care facilities will help adjustment level and adaptation to treatment interventions was weakly or mildly supported by this survey study which polled 28 nurses at the dementia pod of Unit 700 Veterans Home Barstow. All twenty-eight nurses reported some or little changes in adjustment level of residents during family visits. Furthermore twenty-six out of twenty eight (or 93%) of the nurses reported some changes in adjustment level after family visits. The only possible explanation for the two significant negative correlations (between item take resident for a walk and adjustment during visit and between family feed residents and adjustment during visit are that the nursing staff may have perceived the family members’ involvement in these areas as a threat to their professional care-giving. The nurses may have seen it as an encroachment on their
effectiveness in caring for the residents or it could just be a mere inconvenience to the nursing staff to accommodate wishes of family members. The meaning behind these two negative correlations would be interesting to investigate further in future research.

Factors that may affect staff views of resident’s adjustment process include the following:

1. Staff appeared at times to be reluctant to offer candid opinions about residents. Job security issues and the desire for approval by administration may have caused CNA & RN staff to moderate their opinions and observations.

2. Staff appeared to be under time constraints during interviews. Although they had administration’s permission to cooperate with this research project, they had many tasks to complete during their shift.

3. The stage of progression of the disease may affect results. For instance, the early stages of dementia are marked by anxiety and confusion. Residents may become agitated by visits from even very supportive family members due to inability to process the experience and to understand why family does not take the resident home with them. Staff may view the
interaction with family as negative and detrimental to adjustment. On the other hand, a person in the later stages of the disease may be unresponsive entirely to family. He/she may no longer recognize or remember spouse or children. Again, staff may view the visit as essentially without effect.

4. Staff may have an unacknowledged bias in their reporting, based on their own relationship with the resident. A staff person who develops a warm and positive attachment to a resident may have exceptional skills which family does not possess. Very often staff members who have mastered behavioral management skills, or who are intuitively capable or relating positively with a resident with dementia, are able to be very successful at gaining the compliance of the dementia person. That staff person may thus view a troubled family visit negatively, perhaps in order to reinforce his or her own view of him or herself as a seasoned and skilled professional.

5. CNAs and RNs in a skilled nursing facility such as the California State Veterans Home Barstow are frequently transferred from unit to unit and shift to shift.
There is also rapid staff turnover. They may not have had the opportunity to gain a perspective on an individual and his or her family relationships over time. Their survey responses may then be based on isolated events they have observed.

6. The veteran population at the California State Home is unique in that there is a large number of residents with histories of alcohol abuse and unstable family relationships. Many residents' visitors are second and third degree relatives, or ex-wives, stepchildren, or formerly estranged children. As such, these family members may inadvertently expose the veteran to memories and emotion of past painful experiences and events. This emotional content can negatively affect a demented person's experience of family visits.

7. California State Veteran Hospital Barstow is situated in a geographically isolated location. Very few residents have family members who live in the immediate area. Therefore, families find it difficult to visit frequently or regularly. Demented person benefits from a consistent and structured routine and may become agitated and unmanageable when
presented with infrequent visits from families. The loss of normal routine and the inability to grasp the reasons for the appearance and disappearance of family members as well as the inability to remember when families are scheduled to visit will often create an unsuccessful visit.
CONCLUSION

Greater understanding of the role of family members of elderly dementia patients in long term care facilities would expand our knowledge and comprehension of staff experiences and may enable care planners to bring about intervention approaches focused towards better adaptation and adjustment.

As literature has acknowledged that dementia is the most devastating and a debilitating condition ever affecting the aged the impact of the disease on family can be equally devastating. As the disease progresses and the deficits of it become more pronounced, family members endure the painful ordeal as the afflicted relative becomes increasingly difficult to manage. Chances are, there may be different level of reactions toward the disease by different members of the family. The degree of reaction may affect the adaptation or adjustment level of such elderly patients in the long-term care facility. Also, family perception of the disease coupled with their reactions might impact quality of care given to the patient.
Caring for an elderly family member with dementia can be a burdensome exercise and eventually the decision is made to place that family member in a long-term care facility like Veterans Home Barstow. The caring should not stop but should continue to assure a good adjustment and adaptation to treatment and to the new environment by the client. The role of family members could be important to insure those clients or residents are better cared for by the professional caregiver. These roles could be redefined as a dimension that determines how caregivers relate and aid patients or residents.

It was the goal of this study to examine the effect of family visits to their loved ones diagnosed with dementia in long-term care facilities. How these contacts and visits affect the adjustment to treatment of the residents and adaptation to their new environment are not known. The results of the study provided weak support of the hypothesis that supportive and meaningful family contacts do help the adjustment level of population understudy. The degree of adjustment to treatment during and after family visit is also not known. However, a majority of the nurses reported some adjustment by clients or residents. Whether
those adjustments were in behavior characteristics or attitude to treatment, the survey did not say.

Family members' roles could not simply be differentiated by the types of task and contact performed by role expectations. Family members' roles, instead are based on the meaning and purpose that a family member ascribes to her or his caring role which in turn, both influences and is influenced by relationship with the demented member before or during the sickness. An interpersonal factor such as family history and the nature and quality of relationships between the elderly family member and others within the immediate family setting determines the quality of caring. It is proven that family contact do help dementia patients adjust to treatment and their new environment.
APPENDIX A

SURVEY ON FAMILY VISITS TO DEMENTIA RESIDENTS

Circle or check only one answer in each question

1. What percentages of dementia residents receive visits from family members in a month?
   1. 10% or less
   2. 20%
   3. 30%
   4. 40%
   5. 50% or more

2. How often do most family members visits dementia residents?
   1. Weekly
   2. BI- weekly
   3. Monthly
   4. Every six months
   5. Yearly

3. What members of a family visit most frequently?
   1. Male spouses
   2. Female spouses
   3. Male children
   4. Female children
   5. Other family members

Please use the following scale to answer questions about supporting, caring and nurturing attitude towards dementia residents with a:

   1. None
   2. A little bit
   3. Somewhat
   4. A lot
   5. Very much

4. Do family members speak to residents with respect and love?
   1 2 3 4 5

41
5. Do family members touch and hold resident's hands while talking with them?

   1   2   3   4   5

6. Do family members help dementia residents with grooming and hygiene while visiting?

   1   2   3   4   5

7. Do family members consult with Nursing Staff during visits regarding dementia resident's conditions?

   1   2   3   4   5

8. Do family members relate to Nursing Staff in a friendly way?

   1   2   3   4   5

9. Do family members take residents for a walk?

   1   2   3   4   5

10. Do family members attempt to feed the residents requiring assistance?

     1   2   3   4   5

11. Do family members show some appreciation to the caregivers (nursing staff etc.)?

     1   2   3   4   5

12. Do family members give some helpful suggestions regarding residents activities in daily living (ADL)?

     1   2   3   4   5

13. How do you rate the quality of caring shown by family members during visits?

     1   2   3   4   5

   ADJUSTMENT LEVEL

14. How do you rate the adjustment level of clients during visit from scale of one to five

   1. no changes
   2. little changes
   3. some changes
   4. much changes
   5. much more changes
15. How do you rate the adjustment level of client after visits?

1. No change
2. Little change
3. Some changes
4. Much changes
9. PARTICIPANT RECRUITMENT

The participants of this study will be nursing staff, clerks, and social workers assigned or that work at dementia pod of unit 700 at Veterans Home, Barstow. Selection would be based on convenience and availability of staff, targeting at least twenty to thirty-five (20-35) staff and supervisors. The questionnaire would be placed on each staff mailbox or via the unit supervisors. The participants or respondents would comprise of different ethnic background, sex, age and status (RNs, CNAs, Clerks, Supervisor, and Social Workers).

10. PROJECT DESCRIPTION

This study would be seeking staff subjective opinions and perspectives through a quantitative and, or, qualitative research methodology, about their experiences and observations of family contacts and effect to clients (residents) (treatment adjustment). The hypothesis for the study is as follows: a frequent and meaningful family supports (contacts or visits) will positively effect client treatment adjustment levels. Data would be collected through survey using simple standardize questionnaires. A Likert type scale would be used to measure variables.

11. CONFIDENTIALITY OF DATA

Each respondent would be assured confidentiality of their responses by applying the following measures: questionnaire would be placed in staff mailboxes, completed questionnaires would be placed at designated social workers mailbox in the unit or mailroom. Staff would be asked not to identify their names or that of clients in question, there would be no tracking records to identify respondents, and total anonymity would be granted.
12. **RISKS AND BENEFITS**

There would be no risk factors whatsoever associated to this study. Any risk or anticipated risks would be eliminated through confidentiality machine. The purpose of this study is directed towards finding a better way to reduce client, staff, and family stress factors associated with caring for a patient with dementia. If anything, the result of this research would benefit the participants through a better understanding of family roles in treatment intervention. It would also benefit all the professions that work with this population, especially the social work and nursing profession.

13. **INFORMED CONSENT**

Copy of informed consent would be attached in this packet. Although, the agency administration and chief of social work have been orally approached for this research project, they would also need letters of informed consent explaining the purpose of the study and confidentiality issue. (See attached Informed Consent)

14. **DEBRIEFING STATEMENT**

(See attached debriefing statement)
Veteran's home nursing staff and social workers will be asked to share their observations of Contacts between family members and dementia residents. The information gathered, which involves a survey of staff, will be used to learn how to effectively incorporate family members in treatments. Information gathered will be included in the final report of this project, in-group forms only, so that anonymity of the participant is preserved.

Sam Achor, MSW student, under the supervision of his faculty advisor is conducting this study. Questions regarding this study can be directed to Dr. McCaslin, Professor of social work, California State University, San Bernardino at (909) 880-5507 or Bill Rigole, Deputy Administrator of Veterans Home Barstow. The Department of Social Work Sub-Committee of the Institutional Review Board, California State University San Bernardino has approved the project.

My mark below indicates I consent to participate in this survey and to the release of information gathered for the final report of this project.

Participant’s Mark

Date

Researcher’s Signature

Date
Thank you for your time and input in the survey. If there is anything you would like to know about this survey, please feel to contact me at (760) 246-9303, or contact my faculty and research advisor, Dr. Rosemary McCaslin at California State University, San Bernardino School of Social Work.

This study is being conducted as a fulfillment of a partial requirement of a Masters Degree in Social Work at California State University, San Bernardino. The result of the study will be available at California State University, San Bernardino by June 17, 2000.

Thank you so much for your participation in this research project.

RESEARCHER:

Sam Achor
MSW Student
(760) 246-9303

FACULTY CONTACT PERSON

Dr. Rosemary McCaslin
Professor of Social Work CSUSBD
(909) 880-5501
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