

An Alzheimer Family Support Group Project*

HERBERT BERNSTEIN

Assistant Executive Director, Jewish Family Service of MetroWest, Millburn, New Jersey

In order to serve dementia patients and their families living in the community, family agencies have a responsibility to train social workers to work with this population. Social workers . . . in turn have an obligation to learn to function in this complex area.

Introduction

THIS paper will be a report of a two year experience in initiating and leading an Alzheimer Family Support Group as a pilot service program for a family agency. The author, trained as a social worker and psychologist, has had a 30 year interest in dementia of various origins. He has worked intensively with over 250 Alzheimer patients and their families in the community and an institutional setting, during the past 10 years.

The question may well be asked as to why the family agency should undertake such a task? Is not Alzheimer's disease a medical responsibility? The answer, in my experience, lies in the following considerations. Medical leadership is required in the diagnosis, treatment and management of the comprehensive medical aspects of the condition and its sequelae and other multi-organ diseases to which the patients are also subject. Periodic need for hospital care rarely requires more than a three week stay on average. Approximately five percent of the ill aged and ill non-aged are placed in long term institutions, e.g. chronic disease hospitals, health related facilities and skilled nursing home facilities.

Well over ninety percent of the Alzheimer population reside in the community with a wide variety of homecare

systems, ranging from the sophisticated to the sub-marginal. A substantial majority of patients are under the direct or indirect supervision of family caretakers. The need for service exists in the community at large, which the family agency is designed to serve. The only question, it seems, is whether we choose as professionals to avoid the challenge or plan to meet it. It is the clinical social worker in the family agency whose skills are needed to offer direct appropriate services to the affected patients and their family members, who are caught in a complex situation. This consists of being responsible for relatives with a disease involving progressive loss of intellectual capacity and later-stage loss of significant neuro-motor functions. The emotional impact on patients and families of the dysfunction and the stress related to ongoing care are sufficiently severe as to impair family functioning itself. Supportive and restitutive services are necessary to prevent family breakdown and to facilitate family capacity.

As to the incidence of Alzheimer's Disease in the general population, public health epidemiologists seem to be in general agreement about the following data: 1) The incidence of Early Stage Onset (occurring principally from 45 to 64 years) is approximately 3.5 to 4 percent per 1000 population; 2) The incidence of Late Stage Onset (occurring at age 65 or older) is approximately 2.5 to 3 percent per 1000 population. The above estimations do not include other

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types of non-reversible dementia such as those caused by multiple small strokes and reversible dementia caused by toxic drug effect, severe infectious or psychiatric disorders. If one considers that each Alzheimer patient (both early and late onsets) has an estimated average of two family members intimately connected in either caretaker or non-caretaker roles, then the magnitude of the patient and family population living in the general and Jewish communities becomes more evident. When one adds to the population the relatives of those patients residing in institutions, then the size of the community at risk, requiring professional supportive services, is by no means insubstantial.

In addition to the evidence substantiating patient and family need and the argument supporting the appropriateness of family agency involvement in service delivery, there are several relevant issues related to social worker attitudes and knowledge. Successful social work intervention with Alzheimer patients and their families requires a comprehensive acceptance and knowledge of the complex interaction of mind and body in assessing both functional and dysfunctional states. Further, there has to be reasonable knowledge and competence about the psycho-bio-social changes in people with Alzheimer's Disease plus the nature and range of family responses to the evolving dynamics. While we do not yet know how to prevent or cure Alzheimer's, we do know a great deal about how to help people in distress. Most importantly, to be truly effective, professionals must like such patients and their families and have a realistic acceptance of the nature of the condition. It is also necessary for us to be reasonably free of anxiety while working with family members who are frequently in torment, until the time they are helped to work out that level of adaptation of which they are capable.

Establishing the Program

The decision to undertake an Alzheimer Family Support Group was the product of several key factors. The author had both extensive experience and conviction about the desirability of such a program. The agency Executive Director was completely supportive throughout the process. The increasing incidence of community cases being diagnosed was observed. Federation and sister agencies agreed with the service premise. The media were beginning to pay substantial attention to the problem. Most importantly, when the recommendation for service was raised with the appropriate Board committees, there was thoughtful encouragement, culminating in policy approval for the project by the entire Board.

And so the program was launched. A series of prominently featured notices was published in the weekly Jewish community newspaper. A six week Family Support Group series at the agency was announced initially for the purpose of supporting healthy caretaker relatives through weekly group discussions thus helping maintain Alzheimer patients living in the community. Interested persons were asked to call the group leader for further information. Nine families responded by telephone. Following brief phone discussion geared to determining some data about the patient's condition, the relatives' interest and availability and the group purposes, all interested parties agreed to attend. A convenient weekly meeting time was mutually decided. The first group consisted of four spouses and 6 adult children (two sisters). Their age range was from 22 years to 83 years and all told there were 7 women and 3 men. They described their patients at home as being equally divided between Early Onset Alzheimer's (age range 52 to 63 years) and Late

Onset Alzheimer's (age range 65 to 82 years), 6 were women, 3 were men. The age, gender and onset distribution for relatives and patients reported above were characteristic of both a second ten week-series group of twelve families (six returned) and the current open-ended group of fifteen families (four returned) which has been meeting weekly for sixteen months except for holiday periods and summer vacations (over fifty sessions to date). Each series has had at least two families with multiple members attending in various combinations e.g. well parent/adult child; siblings; adult child/spouse; adult child/grandchild. The ground rules established by common agreement were that members are free to attend for as long as they wish, with responsibility to inform the group when they wish to terminate contact. By custom and expectation members notified the group or leader when they were unable to attend a session. In practice, members attended with great regularity and had a strong sense of responsibility to each other and the leader.

Program Dynamics

Some comments are in order about the dynamics of membership in a support group. Unlike therapy patients who attribute their pain to faults they see within themselves or other family members, support group members view themselves as normal people caught in a life cycle situation beyond their control. As a result of this view, they quickly bond with other group members similarly affected. They are usually non-defensive, empathic with others and fairly open to examining personal and family variables and options. This is not to deny that each has his/her characteristic method of understanding and coping. Since the support group experience encourages participants to exam-

ine each idea on its merits, members always seem to retain the feeling that they are in charge of their own decisions and choices. These reactions seem to apply even when unhelpful attitudes towards self, ill relatives or alternate options are discussed. Additionally, major movement on crucial issues often occurs fairly rapidly (e.g. often in ten week cycles). Examples include becoming more realistic about relatives' disability, acknowledging their own contribution to family problems, making changes in responsibility for home care arrangements, and resolving conflicts about relatives' institutionalization. One sees also shifts in family complementarity and acceptance of role changes previously rejected.

The support group process, including the leader's contribution, has three major elements; education, support and therapy. All the elements combine somehow to make the group process a therapeutic one, even though it is a variant of more traditional forms. The support group is unquestionably a major force for change. It is another important reminder that significant personal change can come about in myriad ways, especially during periods of prolonged stress when individuals seem to be more open to readaptation. The experience of an Alzheimer support group is also a tribute to the human spirit. Both ordinary and gifted people faced with the responsibility act with grace for the most part, while in touch with their personal anguish, loss and anger over the progressive deterioration of an important family member.

Some observations about the role of group leader are needed. The group needs very much to trust the leader. In order to give that trust, the group members expect of him/her a sound clinical knowledge of the nature of Alzheimer's Disease, through its four grades or stages. The group needs reassurance

also that the leader understands the nature and dynamics of family reactions and can understand the specific findings for each grade, (stage or phase).

Four Stages of the Disease

Grade I: (Early Stage)

- Subjective complaints of memory deficit.
- Self awareness that something is different.
- Decreased functioning in complex situations at work and on social occasions.
- Beginning anomia (word loss) and, or concentration deficit.
- Deficit in handling money and numbers.
- Diminished comprehension and reaction.
- Some anxiety, depression and denial.
- Increased irritability.
- Avoidance of the unfamiliar.

Grade II: (Middle Stage)

- Evident retardation of comprehension and expression.
- Marked difficulty in calculation and a concentration deficit.
- Substantial problem with decision making and planning.
- Inability to perform complex tasks.
- Flattened affect and significant denial.
- Marked self absorption and insensitivity to other's feelings.
- Avoidant of any challenging situation.
- Periodic confusion and episodic disorientation to time and place.
- Lose thread of conversation.

Grade III: (Middle Stage)

- Marked personality and behavioral changes (variable) e.g. delusional and/or accusatory behavior, marked anxiety, agitation, etc.
- Misidentification of people.
- Marked memory deficit for recent events.
- Substantial loss of orientation to time and place.
- Marked deficit with numbers or in identifying objects, body parts, etc.
- Confused by changes in routine and location.
- Neuro-motor loss evident (variable) e.g. gait, balance, locomotion swallowing disorders.
- Incontinence of bladder and bowel (variable)
- Difficulty with activities of daily living e.g. eating, dressing, bathing, etc.
- Loss of purposive behavior and willpower due to inability to retain a thought long enough to complete an action.

Grade IV: (Late Stage)

- Marked apathy.
- Recent and remote memory poor to absent.
- Loss of intelligible speech.
- Marked confusion and disorientation.
- Complete loss bladder and or bowel control.
- Requires assistance with ambulation, eating and other activities of daily living.
- Marked perseveration of words and actions.
- Startle reactions evident.

Patient and Family Management

Discussion with family members about the management of the patient at home covered both basic situations encountered plus pre-existing conflicts heightened by the stress of an Alzheimer patient within the family. Families were cued about the characteristic patient reactions in early stages of Alzheimer's of avoidance, substitution and withdrawal in situations they were having difficulty, e.g. names, places, faces, etc. The patient's sense of loss, vulnerability and lack of confidence can be overcome in part by a down-to-earth family attitude in which reminder, simple repetition, consistency and calmness conveyed in a quiet voice are most helpful. The simplification of daily routines and the reduction of available choices frequently prevent unnecessary stress.

Reality orientation with patients on a daily basis is vital, especially in combination with simple intellectual stimulation. I recommend always the installation of small blackboard or corkboard on the kitchen wall. The day, date and time of all major daily events should be noted and repeated frequently. Familiar objects, e.g. newspaper, magazines, should be retained in the same location. Photographs of family, friends should be looked at together frequently with reminders of names, faces and places. A large clock and a large calendar, marked off daily, should be wall mounted and referred to often.

Bathing, grooming and changes of clean clothing are often daily functions to which patients object. Since cleanliness and presentability are important for good hygiene and self-esteem, it is important that patients be reminded daily of the reasons these things are necessary. The procedures should be simplified and consistent to make patient's participation easier and more acceptable.

As patient comprehension lessens, family members frequently respond by reducing their interaction with their relative. This often takes the form of no longer talking with the patient but *at* him/her. It is painful to lower one's expectation of a disabled relative with whom one has a significant relationship, but it must be done when encountering Alzheimer's Disease. To avoid stress family should not insist or explain that the patient do something he/she is no longer capable of understanding. A good substitute method is to show literally what is expected, reinforced by gestures, and any easily graspable method that conveys meaning other than verbal explanation. The principle is that the care taker must develop new means of interacting with the patient, based on an acceptance of the realistic limitation.

Assuring competent and interested medical care for Alzheimer patients is often problematic. Many physicians, as do many social workers, and others walk away from patients with dementia. This is not because physicians or social workers are bad people, but because many professionals have highly personal reactions to deteriorating conditions they cannot change. The fact remains that Alzheimer patients require medical management of their condition, coupled with the need for care for other conditions they develop, all complicated by their difficulty in reporting symptoms. My recommendation to families is that

they have frank face-to-face discussion with their present or prospective physician outlining their concerns about both patient and their own needs for professional leadership. If a physician elects not to be the primary care physician then it is unwise to try to convince him/her otherwise. It is preferable to obtain the services of a doctor who is comfortable with treating such patients and families as demonstrated by both personal agreement and availability when called.

A related problem is the frequency with which Alzheimer patients develop toxic drug effects when their medication intake is not carefully monitored. This occurs when there are several physicians prescribing, none of whom assumes medical leadership, when patient's take their own medicine or when a well family member does not take responsibility for dispensing medicine directly to the patient. Toxic drug effects may occur in the presence of careful monitoring, but is less likely to occur and can be corrected more readily when intake is supervised. A major problem any physician faces in titrating drug dosages and in evaluating drug effects is the unreliability or inability of the patient to describe changes, symptoms, drug reactions, etc. A physician must carefully monitor clinical symptoms of Alzheimer patients since these disabled people are not reliable informants.

Over the years I have learned a number of important lessons from Alzheimer patients and their families. As people, they react to the disease and its manifestations in the characteristic fashion with which they have dealt with problems and crises all their lives. Basic personality perception and adaptation continue to operate as before. Pre-existing personal and family conflicts continue to play their accustomed role in their approach and solutions to human problems. Only as the familiar

adaptations fail to work in the new situation do people experience the stress and pain which may open them up to better solutions. Many families begin to look at themselves more introspectively in response to the pain and some begin to move towards qualitatively improved relationships. Others, of course, do not. Of the thirty-one families I worked with extensively during the course of this two-year project, eight families sought individual and family consultation for various unresolved problems. Such supplemental contact lasted from several weeks to many months. Of the eight families, I incorporated five patients within family sessions. The other three patients were unavailable by virtue of living at the time with other adult children or spouses in distant states.

The nature of complex family situations discussed in the support group and in supplemental family treatment were wide ranging.

Case Illustrations

1. *A Death-Bed Promise—The V Family:*

An anxious 25 year-old pregnant woman, mother of a hyperactive toddler was an active member of the first and second support groups. The presenting problem was in connection with providing adequate care for her 73 year-old widower father, diagnosed several years earlier as having Alzheimer's Disease. Her only sibling was a 22 year-old sister more recently married than she, with a small infant. The two sisters, who were in disagreement about the severity of the father's disability, had been caring for him alternately in their own homes for six week periods at a time until recently. Following an argument, the older sister insisted on placing the father in a senior citizens' hotel outside New York City. This failed after two weeks due to the patient's disorientation and toxic drug reaction from a lanoxin (heart medicine) overdose requiring hospitalization and restabilization. When the hotel refused to readmit the father as unsuitable the sister in the group took him into her own home again.

The family has had much trauma. The parents had been in a concentration camp as

Holocaust victims where each had lost their previous spouses and children. They emigrated to the United States after the war, subsequently met and married, and had both daughters in their middle age. The father, a retired kosher butcher, was described as a rigid, cold, agitated person, out of control. The younger sister accepted my invitation to join the group and she travelled in from Brooklyn regularly, infant and all. Discussion revealed that the daughters had the more meaningful relationship with their mother who developed cancer when they were teenagers. They nursed their mother at home for the last two years of her life. The older daughter could never forgive her father for his childlike dependence on the mother and his unavailability to them all their lives. His total helplessness during the mother's last years was especially galling. The mother extracted a death bed promise from the older daughter, who hated her father thoroughly, that she would care for him after the mother's death to which the daughter agreed.

Several family interviews, incorporating the father, revealed a frightened, rigid, childlike man with Grade II Alzheimer's Disease, mildly confused, disoriented and overwhelmed. The angry older daughter was feeling trapped by her promise to her mother and a continuing rage toward the father which she could barely contain. The younger daughter was trying unsuccessfully to mediate an impossible situation. Group and family sessions succeeded in conveying to the family that regardless of hurtful family history, the daughters were dealing with a sick, old man incapable of change or restitution, who required family leadership in obtaining a supervised environment where he could feel safe and be cared for more adequately.

The older daughter tempered her rage sufficiently to allow her sister to play a more prominent role. The sister obtained admission for her father to an acceptable health related facility near her own home in Brooklyn, where the father made a more adequate adjustment for the first time in many years. The older sister finally was able to acknowledge that her angry behavior towards her father was her method of punishing him for his misdeeds, of which she had been hitherto unaware. She found some peace at last and the sisters then continued the support group through the 12th (final) session of the second series.

2. *A Case of Role Reversal—The Q Family:*

A 58 year-old gentle, bright, successful business man joined the support group two years

ago and has continued active participation to date. His 55 year-old wife whom he loves dearly had been diagnosed several years earlier as having Alzheimer's Disease. He was deeply troubled by her angry denial that she had Alzheimer's, by his inability to please her in any way and by the burden and anger he felt at having to take care of everything, a job previously carried very well by his wife. Several joint evaluatory sessions with the couple confirmed a relationship that was loving and an angry, denying and avoidant wife, with Alzheimer's dementia, grades I—II. Several additional joint sessions devoted to dealing openly with the reality of the wife's condition led to her reluctant acknowledgement, thereby diminishing her fear somewhat and the husband's concern that he could never deal with this issue.

The husband's participation in the support group over the months has been thoughtful, reflecting the great pain he felt at the turn his life has taken. Periodic discussion of his concerns revealed the following additional dilemmas. He is basically dependent at home, was trained to depend on the woman of the house, has always had difficulty sharing his feelings with his children, expects himself to be able to come up with solutions for all troubling family matters, without informing anyone about his worries. Over a period of months, he began to experience the group as a supportive place where he could talk openly, with acceptance, about his concerns.

He was subsequently helped to resolve the following issues. He discussed with their three sons who lived out of state, particularly the oldest son and daughter-in-law, his need for assurance that in the event of his death, the children would administer the estate in a manner designed to provide home care and institutional care when needed for their mother. The children's ready assent and personal expression of concern for both their mother and himself was most reassuring. Next, he was helped to hire a part-time home health aide and companion for his wife over her objections to assist in both homemaker and socialization functions. He became somewhat more comfortable in living with his wife's disapproval of anything which confirmed that she had a problem. He accepted gradually that as the responsible caretaker, he had to do what he believed was genuinely in her best interest. As her condition progressed over the next year-and-a-half, the husband introduced a trained recreation worker two days a week to provide exercise, intellectual stimulation and socializa-

tion, especially important now that she had fewer activities and friendships than before.

The most difficult task for the husband to accept is the role of family planner, social secretary and sole decision maker, though he informs his wife sensitively of all that is going on. A major hurdle is his feeling that this is woman's work and that he feels his manhood diminished thereby. I have taken the tack that he is fully justified in his feeling by virtue of his training and our cultural values. The dilemma which he must accept, though he is not required to like it, is that the task is his by default. His only choice is whether to do it or to leave it undone. Since he is essentially such an orderly, responsible person he elects to do it, albeit reluctantly and sometimes tardily. Of greatest importance is that the husband continues to function well as both husband and wage earner under difficult circumstances. His relationship with his children continues to improve and become closer. He feels less alone with his family and within himself. He is managing a difficult task with dignity, courage and caring and with less pain. The Support Group has played a helpful role in his improved functioning.

3. *The Angry Wife—The F Family:*

An attractive, assertive and very angry 73 year-old woman joined our open-ended family support group in January 1984. Her 74 year-old husband was diagnosed last fall as having Senile Dementia of unknown origin. The wife's description of the event centered on the argument she had with the consulting neurologist who suggested that her husband's dementia was probably Alzheimer's, but he could not confirm this in the absence of a CAT scan (computerized axial tomography) to demonstrate loss of brain mass. In the group, we ascertained that her great anger was related to blaming her husband for becoming ill, thereby making the rest of her life forever different and harder. She acknowledged the unreasonableness of her thinking, but found it hard to control her outbursts. She decided to come to the group because she knew she was frightened and needed both knowledge and the ability to control herself better.

I saw the couple jointly for evaluation and saw evidence of Senile Dementia, probable Alzheimer type, Grades II-III. The husband is a pleasant, passive man with good social affect, who at the time was fearful, apprehensive and almost non-communicative. He responded well to reassurance and physical touch. He had a medical history of surgery twice in the past five years for excision of a slow growing prostate

malignancy. He had recently begun again to dribble urine daytime and to be incontinent at night. A urological consultation was suggested, since the wife had not followed up on the symptom. Her attitude towards her husband was clearly ambivalent. She described a good marriage based on his passivity and her dominance. There was obvious affection, but it was mixed with her marked irritability towards the patient. She acknowledged yelling at him constantly.

During the next four months in weekly group meetings, the wife showed herself to be open to learning about the nature and progress of dementia, the diminished capacity of the patient to comprehend and perform and to identify her own reactions and dilemmas to a frightening situation. The patient had less and less stimulus, she was working harder to care for him, e.g., bathe him twice daily, wash bed linen and all his clothing changes daily, had less time for her own activities, felt trapped and wanted to run. With discussion, the first major change was a diminished anger, within herself and towards patient. She followed up on my suggestion that she consider enrolling her husband in the Day Care Center operated by the Geriatric Center.

Patient began attending three days a week, giving the wife respite from 8:30 A.M. to 3:00 P.M. for her own activities. The patient made a good adjustment and has begun to paint again, an activity he gave up many years ago. His fear has certainly diminished. He has recently begun to lose bowel control and this needs to be evaluated medically. The wife is now able to inform their two sons, both of whom are concerned, that she is less overwhelmed and will need their support when she eventually must move their father into nursing home placement. The family will support that move whenever the mother feels she can no longer care for father. She has just arranged for a practical nurse, with experience in the field, to help out at home during the hours before and after the patient is at Day Care. At a recent session, she announced that the nurse has agreed to care for the patient during the entire week in June that the Senior Citizens Club at the YM-YWHA will be away on an early vacation at their summer camp. Thus, she will have her first respite alone in more than four years.

Staff Training

In order to serve dementia patients and their families living in the commu-

nity, family agencies have a responsibility to train social workers to work with this population. Social workers likely to work with this population in turn have an obligation to learn to function in this complex area. In addition, social workers like myself who have had an exposure to this population and who have developed special knowledge and competence in this field, have an obligation to transmit the knowledge and prepare the next generation of clinicians to work with clients who need these services.

As part of the Alzheimer Family Support Group Project, I attempted to meet the training obligation, by inviting five interested colleagues to participate with me over the two year period. The training aspect consisted of each colleague sitting in seriatim for six to twelve weekly sessions. This was followed by individual conferences each week that person was the observer—participant. The conference dealt with all material including colleagues' observations about the group process, the leader's role and any issues needing clarification regarding Alzheimer's Disease and its implications. All colleagues expressed positive reactions to the exposure to Alzheimer patients/families and felt better prepared to serve them. Over the two-year period several staff members served such clients on their caseloads with positive results.

Two family agencies in other parts of the state, one a sister Jewish family and children's service, each sent a social worker to us for consultation in setting up Alzheimer family support groups. The consultations covered the issues discussed in this paper. No data are available yet on those new programs, but they represent a beginning effort.

Summary

This paper has described the programmatic planning, community out-

reach and structuring of a two year pilot Alzheimer Family Support Group Project. Included has been commentary on typical concerns of members about the nature and progression of the disease, the evolution of the group process and its rationale and the group leader's role. Typical concerns about management of the patient at home have been summarized as well as several case illustrations of the resolution of pre-existing personal and family conflict situations. Finally, the family agency responsibility for training staff to serve this population was discussed and the training method used in the project was described.

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25 Years Ago

It is interesting to note some of the findings reported by Rabbi Alfred Jospe, in a pilot study initiated in 1954 on the Jewish attitudes and beliefs of a whole class of incoming freshmen at Hillel Foundations at three universities in three different geographic areas. He finds that the Jewish student today is very "polite" to his religion. There is a high regard for the synagogue. Yet only 5% testify that they attend services with any degree of regularity. Nevertheless two-thirds of the respondents assert that one needs religious belief in order to attain a mature philosophy of life and the same proportion thinks that religion has had at least a moderate influence on their upbringing.

Miriam Ephraim
this *Journal*, Fall, 1959