Loosening the Tie That Binds: Residents in Long Term Care and Their Families*

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"It is important to note, however, that until gerontologists begin to view aging in an interactional manner, the myth that success can be achieved simply by the patient application of cures aimed at correcting deficits within the aging individual will be perpetuated."

Traditional interventions in work with the relatives of residents in long term care often fall short in reaching many family members; they are commonly children who suffer the greatest feelings of guilt about having to institutionalize a relative. They are often not the ones who ask for help or are even accepting of counseling service when it is offered.

In general, families have many mixed feelings about institutionalizing a relative. Feelings range from the relief felt by knowing that the relative will get needed medical and nursing care to the guilt which comes from feeling that the family should have made more of an effort to care for the relative in the community.

We have found that most families have exhausted themselves trying to care for a relative in the community and have sought long-term care only as a last resort. Families will try to maintain a relative in the relative's home with private duty nursing care, will place relatives in a convalescent home hoping the relative will be able to return home, or have even taken the relative into their own homes. When these arrangements take too much of an emotional, physical or financial toll on families, they seek long-term care—and then question whether they have extended themselves enough before having to seek placement.

The difficulty in accepting long-term care is felt by both the family and the relative. In most cases, the relative would prefer to remain in the community and not have to face the prospect of an old age home. The relative fears his own mortality, loss of independence and control, and loss of power/position in the family unit. He fears that his relationship with the family has changed and that he will be forgotten, since he is now out of the community and in an institution. Especially after admission to a long-term-care institution, the relative needs to test out his worth to the family and does so in a multitude of ways which are all designed to reassure himself that he is still cared about. The relative may feign illness, or actually become ill, or express many complaints about the institution or the care given. There may be validity to the relative's concerns but the family needs to be able to separate realistic concerns from concerns which are aimed to get the family more closely involved with the relative. This is especially true after admission to an institution when the resident is feeling the most insecure about his family relationships. The family needs to learn how to reassure the resident that they are as involved as ever so the resident doesn't have to play manipulative games to *get* the family

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involved.

At Menorah Park Jewish Home for Aged work is done with families prior to admission to help them anticipate the natural adjustment problems which will occur after admission to a long-term-care facility. However, some families are still unable to cope with their relative's adjustment period, even after much individual work has been done with them. These family members can be divided into two basic types: the bothersome, overly-involved, unrealistic, complaining family member and the "silent sufferer" who may visit often and take a guilt-provoking beating from the relative but not allow himself to be relieved in any way of this burden. Both types are frustrated by their feelings of impotence at being unable to help their relative but are too tied down by their guilt to be able to view alternative ways of coping with their relative and staff. Another impediment to the adjustment process for families and residents may be the long-standing, pathological family interactions which need to be overcome before any adjustment can take place.

We have developed a new approach to helping these families in a non-threatening group setting. The group setting was offered as a supplement to the ongoing individual work done by Menorah Park social workers with the families. It was chosen as a way to provide families with additional support from both social work staff and other families who were experiencing the same adjustment difficulties, as well as a chance for families to share their common experiences so that they no longer feel their situation to be unique and hopeless.

While those who work in long-term-care settings can clearly identify from their practice many cases of pathological family reactions to an elderly relative's decline, increased dependency and confinement, it is not until one has a conceptual understanding of the dynamics of the relationship and adaptations to it that one can begin to work effectively with it.

The characteristic patterns of how we relate to and deal with our aging relatives are set early. It is when stresses impinge upon these relationships that our own inherent ability to accommodate the change can be overwhelmed and rendered ineffective.

Losses which occur with advanced age—of loved ones, occupational role, economic security, or of physical and mental intactness—create increased dependency of the older person on his immediate environment to maintain his level of function, comfort and self-esteem. When the dependency is complicated by other factors which we will describe, then the chances for maintaining an equilibrium of individual and environment will be diminished.

Reference to some of the literature can provide a greater understanding of the environmental and psychodynamic factors which influence the ability of these human relationships to weather the impact of changes.

Arthur N. Schwartz presents[1] a picture of increased dependency needs of the older person which arise in the face of many real losses and those which reflect maladjustment and drain energy and emotion.

Two examples of maladjustment are "neurotic dependencies" and "socially induced dependencies."[2]

> Neurotic dependencies as described by Goldfarb (1969) for example, may not reflect true dependency needs in the conventional sense. Neurotic dependencies rather represent behaviors which are calculated to manipulate and control others within an interpersonal context. That is to say, such behaviors essentially constitute emotional blackmail.[3]

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[1] Arthur N. Schwartz, "Psychological Dependency: An Emphasis on the Later Years," Pauline Ragan, ed., *Aging Parents*. Los Angeles: University of Southern California, p. 16.

[2] *Ibid*, p. 120.

Such behaviors relate to the need to "manipulate and control the behavior of others through fear and guilt (the fear of retaliation or not being loved, and the guilt over not being a "good child")."

Schwartz's example of socially induced dependency is the labeling by society of a significant portion of the aged population as "chronically ill" and thereby training them to accept the role of, and behave as, sick people. "This we know is a social role which can and usually does lead to the worst kinds of passivity, compliance, and eventually feelings of helplessness, depression, senility and death."[5]

While both of these aforementioned types of dependencies could be identified in the interactions of a confined elderly population, it is a third which Schwartz calls "mutual dependency"[6] which provides the primary target for work with the family group intervention. Some evidence even indicates that there may actually be more psychological dependency of children on parents than the reverse.[7]

The need on the part of children to receive approval and acceptance from their parents extends beyond the stage of development when physical maintenance of the child depends on the parent.

For the parent in turn there is the common injunction, "I don't want to be a burden to my children," which at face value asserts independence despite increasing odds. Upon further investigation, however, the expression very often reveals a feeling of love, approval and acceptance being the reward to children who invite the parents into their lives despite the injunction. In other words, this statement actually says that "if you are a good child, then you *will insist* that I should be a burden to you."

This significant mutual dependence is not easily diminished by geographical distance, other environmental variables or denial of its existence.

Howard Halpern gives children insight into this complex parent-child relationship:

> How you will react to your parent's becoming dependent on you will be a function of serveral factors. One of the most important of these is the relationship you have had with this parent in the years before his infirmity. Obviously if there have been loving closeness, mutual respect and friendship between you and your parent, you will be much more willing to shoulder some of the burden of the responsibility for his (her) welfare than if there have been years of antipathy, hostility and estrangement. Particularly important will be the kind of song and dance routines that have existed between you, and the progress you had made in modifying them, because most often the role played by the child within your parent will become more salient in a crisis of aging.[8]

In *every* parent-child relationship which is tested by the increasing losses of aging, not only the acutely disturbed ones, children have feelings of inadequacy when they feel they have not been able to prevent the negative forces in their parents' experiences. Intense feelings of guilt "seem to be a pervasive characteristic which contaminates the relationship between generations."[9]

To the extent that these feelings of guilt are denied by the children and not dealt with during the period of parents' decline necessitating long-term placement, they have been expressed in pathological family reactions following admission to the long-term care facility, and the pathology becomes intensified when complicated by poor communications within family systems.

One common, yet destructive, communication pattern prevalent in many family systems is the "double bind"

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[3] *Ibid.*

[4] *Ibid.*

[5] *Ibid,* p. 121.

[6] *Ibid.*

[7] *Ibid.*

[8] Howard Halpern, *Cuting Loose, An Adult Guide to Coming to Terms with your Parents.* p. 204.

[9] Arthur N. Schwartz, *op. cit.* p. 119.

originally described twenty years ago in relation to parents and children and which is "relevant to situations faced by today's elders and their families."[10]

An example of such a double bind or contradictory message to an aging relative who has realistically increasing dependency needs is, "I will help you to remain independent."[11] Can this relative really be independent if he will accept help? A realistic assessment of the needs and honest communication of mutual expectations would better serve the family member to maximize the aged individual's chances to function at a level of maximum independence. The importance of the quality of communication cannot be denied. "It is important to note, however, that until gerontologists begin to view many of the problems associated with aging in an interactional manner, the myth that success can be achieved simply by the patient application of cures aimed at correcting deficits within the aging individual will be perpetuated."[12]

This can be operationalized with examples taken from the family orientation group experience. A family member becoming enraged when told by a confined parent that "good nursing care is not being given in the Home," that the staff are "not nice," that "no one is around to help," might be most efficiently worked with through educating the family member to the faulty communication systems between that family member and his confined relative.

Rather than fruitlessly trying to document staff involvement, simply showing the manipulative nature of the remarks by the confined relative in a supportive and non-threatening manner can clue the family member to the game in which, because of his enormous feelings of guilt, he has become an unwilling pawn. When such an ideally enlightened relative goes back to his loved one, the next time he hears, "no one comes when I call," he may know that this actually means, "I need to keep you involved, I don't want you to be comfortable in the thought that you put me in a good place," and "I'm still trying to control you through your feelings." He can then begin to influence his relative's maximum potential for acceptance of, and integration into, the long-term care system.

The family orientation group at Menorah Park attempts to help families better understand and experience these concepts so that they can better cope with their relative's adjustment to a long-term care facility.

The format of the group is a three-session family orientation program for relatives of all newly admitted residents to Menorah Park. The goals of the group are: 1) to orient families to the Menorah Park systems as it affects them; 2) to assist families in working through their feelings of institutionalizing a relative and the changes that precipitated this move; 3) to anticipate and prepare families to cope with the adjustment reactions of the family member to living at Menorah Park and 4) to establish and continue a productive working relationship between families and Menorah Park via the social service staff.

In the groups held in 1980, two-thirds of the families invited to attend did participate. Reasons given for not attending were generally time conflicts or their feeling adequately oriented to Menorah Park and the anticipated adjustment problems. Each group had 8-12 members, with some groups having as many as 4 members from the same family. All groups were co-led by the two authors.

The first, and the most highly structured session of the three-session group is a slide

[10] John J. Herr, Ph.D. and John H. Weakland, "Communications Within Family Systems: Growing Older Within and With the Double Bind," *Aging Parents, op. cit.*, p. 145.

[11] *Ibid*, p. 147.

[12] *Ibid*, p. 152.

presentation and orientation to Menorah Park services and policies. During the slide presentation, group members begin to discuss their questions and concerns about institutional life. This highly structured session provides a non-threatening ground for group members to begin sharing feelings about their common experience of institutionalizing a relative.

A feeling of support has already developed among the group members when they reconvene for the second session. The small group size also enhances the felt support and the flow of communication in the group. In this session, the normal but difficult period of adjustment to admission for new residents and their families is focused upon. Using role plays which facilitate families' understanding of healthy versus pathological family interactions, leaders are able to get group members to begin to unburden themselves of the heavy feelings of guilt which they were not able to share in the first session.

One of the role plays used depicts the common but neurotic interaction between a manipulative, martyrish, guilt-provoking mother and the overly-involved guilt-laden daughter who comes to visit mother in the institution. Leaders over-dramatize the mother's facetious complaints and the daughter's reaction. Daughter feels she has to take care of all of mother's problems, even if this means calling the institution at 2:00 a.m. to make sure staff checks in on mother because mother says no one ever comes when she calls. This over-dramatization helps group members to identify themselves in the role play and be able to look at their own interactions with their relatives. After this role play about fictitious characters often comes the question, "How do you know my mother so well?" The ice is completely broken now. Members are reassured that they are not alone and that others suffer similar difficult relationships. They deal with each other's relationship problems and, with leaders' assistance, offer each other guidance.

It is interesting to note the developmental changes which occur in the nature of the group by the third session.

In contrast to the highly structured first and the more relaxed structure of the second session, by the third, momentum carries the group to an enthusiastic sharing of ideas. There is reinforcement of each other's coping with various shared personal experiences through almost no structured format outlined by the group leaders. With risk-taking on the part of the members occuring during the previous session, a solid group identity and support system are firmly established by the third session. While formality and structure have diminished, they have been replaced by the development of significant relationships between group members and the leaders and among various group members themselves. A number of family members have commented on how visiting their relatives was more pleasant since they were now acquainted with other visiting families and felt they were sharing similar experiences. Members of different families also begin to socialize, meet for coffee and to talk outside the group.

Some group members acknowledge that they now perceive the group leaders and other staff as people whom they might seek for help, and not as adversaries. The development of the leader-group member relationship also facilitated a number of referrals of family members for individual work with a social worker on various adjustment problems.

The theme of the third and final session is "we have prepared you for the adjustment period following your relative's admission to the Home but what might you expect after that?" Discussion is spontaneous, revealing, honest, and allows family members to share their feelings about their relative's declining, dying and continuing certain pathological patterns, that do not let these children fully turn over care of

their relatives to the institution.

Some of the most exciting and rewarding help for group members in understanding aging and in adapting to the changes that come with aging occurs in the third session. By this session, group members are able to deal with the real issues of aging which they aren't able to deal with in the initial two sessions. They are able to confront the fact that their relatives would likely deteriorate while in the institution and talk about the effect it would have on them. There are even some group members who are able to begin to discuss their feelings about their own aging process, possible decline, and death.

As the group members expand upon their feelings about their own aging, they begin to talk about the relationships with their own children and similar problems they anticipate coming up in their own futures. Group members unanimously want to have better relationships with their own children than they feel they have with their relatives who are presently in the institution. They talk about taking home what they've learned about communication patterns in the group, hoping to better handle the situations that presently exist. During the process of unburdening themselves about their difficulty in dealing with their own relatives' aging and decline, the group members point up the existence of another whole subgroup. This subgroup is having great difficulty coping with the problems already identified by the group members; that is, the grandchildren of the residents of the institution. Group members share experiences of having sons and daughters who can not even enter the building to visit their grandparents and who disappoint their parents in not fulfillng the minimal obligation of perhaps one visit a year to the nursing home to see their aged grandparents. The group helped many members see this not just as a rebelliousness on the part of the youthful grandchildren, but rather as conflict and difficulty in accepting the changes in their aged grandparents. Some of these conflicts identified by the group members could then be confronted by family members or by professional intervention with the grandchildren in a supportive and direct way to help them resolve some of the conflicted feelings about their aged relatives.

At the end of each series, evaluation forms are sent out to all family members who had been invited to attend the groups, whether or not they had actually attended. Everyone who attended the group reports it to be helpful in his dealings with this relative. Most indicate that because they now have a better understanding of normal adjustment reactions, they can be more tolerant and feel less guilty about their relatives' complaints. They also feel better equipped to separate their relatives' real from manipulative complaints and to be able to reassure the relatives of their concern in a healthy, non-manipulated way. All express gratitude for the peer support and many ask for a group reunion.

Single-session reunion groups have been held for each of the completed series. While initiated at the request of the group members through their response to evaluation forms, each reunion was co-led by the initial group leaders and set up in a very free-form structure. Even though, in some cases, a year had elapsed since the original series met, the members of the reunion group immediately found the support which they had shared during the earlier sessions and were anxious to get together and talk about how each other hand handled the first year with the relatives in the Home. The feeling of mutual support was very evident during the reunion group. Members felt visiting was easier because they saw other family members present in the institution whom they had known to have shared similar experiences to their own, which they feel helped them handle their own relatives better at times. One noticeable change during the year which had

elapsed is that the tone of the group members had significantly changed. While initially, following admission, everyone was anxious to know what to expect from their relative's adjustment to the Home, most group members seemed to have settled into some kind of adjustment. The issues of their concerns were different at this time, however. The overwhelming preoccupation was on the rate of decline to be expected in their relatives. A couple of observations about the reunion group included the more relaxed atmosphere for discussion of some of the moral dilemmas to emerge. Group members were able to talk about the questions they had about quality of life for their older, deteriorated relative and were able to question the value they had for life without the same feelings of guilt which they had shown previously. Furthermore, they questioned duties, obligations and responsibilities which they had for each other and which children have for parents. They expressed conflicted feelings that they who were coming needed to fulfill some minimum responsiblity of obligation to their parents, yet very often saying they expected nothing from their own children in this role. It was interesting to observe the transition many group members experienced who had initially come to the group presenting a lot of concrete complaints and grievances against the institution. They came to understand these grievances as often the result of demanding, manipulative behaviors on their relatives' part. The most fascinating piece of this enlightenment was the group members' own reaction to these manipulations. They tried to compensate for those behaviors exhibited by their aged relatives by insisting that they would not be as demanding and manipulative when they grow old. They said that they in turn would expect nothing from their own children or from anyone else when they would begin to decline.

Overall, it has been found that working with family members in the group setting has enabled staff to work more productively with them on an individual basis. Families in turn feel freer to come to discuss problems with their social worker. Both floor staff and administrative personnel feel that their relationships with the potentially most difficult family members and their relatives at Menorah Park have improved. The feeling is that the family members' experiences in the group have had a positive effect on their relatives' adjustment to a long-term care faciltiy.

Additional Bibliography

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