

A Support Group For Alzheimer's Caregivers: A View from the Inside Out and From the Outside In

The Native American admonition, "Do not criticize a person until you have walked a mile in his moccasins," addresses a profound and never-ending challenge to a professional helping person. We social workers must strive always to understand, comprehend, perceive what is going on in the minds and hearts of our clients without having experienced their experiences. As professionals we listen carefully and knowledgeably. We question informally and formally. We research quantitatively and qualitatively. We develop skill in communicating empathetically so that our clients can try to tell us. However within our clients, "inside the skin" that separates them from us, in the innermost self of each, there is always something more—a special and totally unique process of the self that is always changing and happening as the person moves through the helping experience.

by
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It is a personal journey in the context of a professional life that I am sharing, trusting that it will be of some use to social workers who work with groups. Indeed, the sharing will be clarifying to my own perception of what I have experienced in seeking and using help in a very painful period of my life.

The Native American admonition, "Do not criticize a person until you have walked a mile in his moccasins," addresses a profound and never-ending challenge to a professional helping person. We social workers must strive always to understand, comprehend, perceive what is going on in the minds and hearts of our clients without having experienced their experiences. As professionals, we listen carefully and knowledgeably. We question informally and formally. We research quantitatively and qualitatively. We develop skill in communicating empathetically so that our clients can try to tell us. However within our clients, "inside the skin" that separates

them from us—in the innermost self of each—there is always something more, a special and totally unique process of the self that is always changing and happening as the person moves through the helping experience.

As professional leaders of many kinds of support groups, made up of persons with realities in their lives that make profound and painful demands on their abilities to cope, we attend carefully to each person and to the growth of an interactional process with ourselves as workers and among the members. Using our knowledge and intervention skills, we watch for norms, bonds, roles and goals to emerge that will tell us that a collection of persons suffering with similar *tsouris* in their lives have created a group.

I will try to share with you, from the inside out, something of what transpires in the mind and life of a person who walks "in the moccasins" of a caregiver, who is a member of a support group for caregivers of Alzheimer's patients. This is the

journey of one who— along with the knowledge, experience, and skills of a group worker form the outside in— has been, and is there now, from the inside out as a member of a group.

Role Confusion: Professional Worker and Group Member

This has been an experience in role confusion. As a member of the group instead of the professional worker, this was a very personal dilemma. The special professional self which I kept private from the group rendered me feeling apart from the membership role. I had introduced myself as a retired social worker but not as one whose strong identity was teaching and writing about social group work. It was the group work connection that seemed to be the source of my uneasiness.

I told myself that I must move through the approach/avoidance dilemma relating to these strangers as my personal self without benefit of my professional mantle, which after fifty years of professional experience, is very much a part of my being. The common experience of having a loved one with Alzheimer's Disease, which I knew I shared with the others, was clouded in the beginning by my "secret" and very powerful other identity, that of knowing quite a bit about the professional role in such a group.

With my ethical head I determined not to compete with the worker and not to allow

myself to get stuck in "assessing" her way of functioning as group leader. Rather I was determined to experience the pain and possibilities of group life from the other side. But it was difficult to know what to do, how to be me, how much to share my fears for the future, my anger at my husband for having gotten this illness that was destroying his brain, my confusion, uncertainty, and ignorance about what was happening to me and my loved one. One of the group members told me several sessions later that she had thought I would not return! How I communicated my anxiety, I do not know, except that I said that my husband does not have Alzheimer's but Multi Infarct Dementia, undoubtedly denying the need to be there! I do know that somehow the social worker, with competence and clarity about her role, seemed not to be troubled by my uncertainty and helped me to be comfortable as a new member.

Despite the early experience, I did go back to struggle with the role confusion issues and all that I shared with the other members. We were all caregivers—as well as wives or husbands, daughters or sons, daughters-in-law, sons-in-law and all the possible kinship connections that are affected by this terrible disease that destroys the brain. That was the "commonality" which every group must have. It was a commonality which gave us all immense pain and made it possible for us to

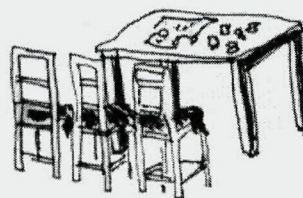
bond with each other. It also provided for each of us a rich source of knowledge about this dreadful disease.

I began to find myself experiencing that which I had learned often happens to new members of support groups. I experienced shock with the breadth and depth of the problem of being a caregiver of a patient with Alzheimer's Disease. I did not want to hear about it from so many dimensions. I remembered how social workers who do not understand group life use this as a reason for not advocating for group practice. This is one of the first lessons a group worker must be aware of when a new member joins a support group... and I was experiencing it! I was frightened by what I was hearing. I began,

however, to find that learning about so many aspects of Alzheimer's Disease and about what is ahead for both my husband

and me, though painful, was also helpful. The worker, an experienced professional, always seemed to notice unusual concern of any one of us and helped us to share our distress in order to neutralize the pain a bit. My courage was bolstered as I listened to others and others listened to me.

I found myself over-involved with some of the members and their problems. Again the professional self was awakened. For instance, I recognized the intensity of Marian's guilt about a nursing home solution to her impossible situation. Her



husband was removing the knobs off the doors and damaging the house in unbelievable ways in the unintentionality of his deteriorating mind. I participated with my whole self—professional and member—as we tried to help her work out a plan. I felt that this was a turning point for me since I no longer felt constrained to withhold my thoughts that had roots in my professional life.

The management of boundaries was an important experience for me. In a new way, I had to discipline myself to heed the worker's gentle admonition to all of us to speak for ourselves, take responsibility for our own thoughts and feelings, and be wary of telling others how they ought to feel. This was clearly one of the norms of the group to which I too must yield.

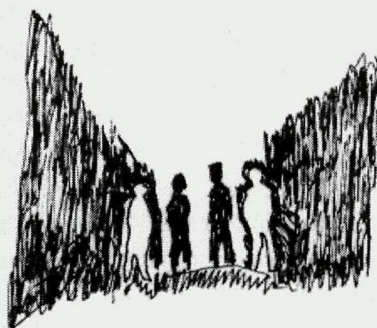
The group is open-ended. Members leave as their loved one dies or they no longer feel the need of the group. Attending a funeral helps to bring sad and relieved closure and we as members have shared the closure tenderly. There is something indeed profound in attending a funeral with fellow support group members.

When a new member was brought into the group, we, the members, reached out to whoever it might be. I found that I was no longer concerned with what the worker had done to prepare the newcomer. It was we, the members, who were very sensitive in assuming responsibility to welcome the newcomer, to share ourselves, and to help him/her to feel comfortable in sharing with us. This

was also a norm of the group. Thus, as members, we moved quickly to sustain the reality of the group.

Later on there were shared member situations that left me overwhelmed with the intensity of the group's experience. I found myself thinking "I am not certain that I would be able to handle this" and I was glad—and honored—that I was a group member and that we could share so much with each other.

I discovered a tremendous sense of respect and dependence on the worker. When we did, indeed, express and share profound and painful feelings in the group, we seemed to be safe. I often thought "How



can she bear so much pain that is being expressed? Each of us can defend ourselves in our own ways: denial, dissociation, etc. But she cannot. She must go on hearing the pain and helping us. She needs time off and a vacation from us!" Now I was detaching my professional self and allowing myself to thoroughly experience membership in this support group.

By acknowledging need, I was finally able to find my own personal way of relating to others in the group. My caring started slowly and grew. At one

point the part of my self that does not like to admit frailty was in trouble. My own health, in struggle with the stress in my life as caregiver, was at stake, and I apparently shared that I was ill. One member who was a nurse—and the worker—made certain that I would get to a doctor, even going with me if necessary. It was a profoundly important moment of dependence for me. With the proffered help, I was quickly able to return to my own level of involvement and independence and distance. I experienced in my self how a group member can play out his/her own psychological reality, psychic needs and patterns. For me it was also a moment of new level of recognition of how a worker and members can perceive one's internal issues—can tap into them—and help one to gain new awareness of self and new insight. I felt that it was really understood how difficult it was for me to ask for help, and I understood it better myself. Somehow, without really intending to do so, I had given some cues. Allowing myself to be a member, I had begun to participate in the group with needs as well as the ability to help others.

How does a professional use knowledge in the total reality of the self? One does not package up one's knowledge, tie it up with ribbons, and label the boxes (or bags!). In truth, our knowledge becomes a part of ourselves and we draw upon it always. Actually as I found myself relating to my friends and sharing my needs, I no longer debated the role "expectations."

I was a member with my whole self. Membership expectations were dominant. I no longer was trying to separate myself from my knowledge that comes from my profession—and age!

As an aside, at this point in my life, I know that a truly good professional will have integrated the professional self into the whole self. Professional role expectation contains the self—even as life continues to reveal and enlarge both the role and the self. This is the concept that is so familiar to social workers: "the use of the self" for helping. It is also the concept that is embedded in issues of self-disclosure and the professional ethic. Through membership in an Alzheimer's support group, I had experienced both professional growth and personal growth in a new degree.

Role Confusion: Alzheimer's Caregiver and Self

This was a personal struggle with professional self as member of a support group. But what about the commonality that I shared with all the members of the group? I was a caregiver of a beloved person whose brilliant brain was dying, causing loss of his memory, confusion in his behavior (for example, trying to eat his meal with his knife), helplessness (for example, incontinence), disinhibition. As knowledge of the disease of Alzheimer's became more understandable to me, I could share and clarify and cope.

An earliest struggle was

with anger. Peace had to be made with the reality that it was not his fault—nor my fault. We could not possibly have prepared for this illness in this stage of our life together. However, the behavior of an Alzheimer's patient is very hard to bear. One does not understand what is happening to one's partner and there is the progressive nature of the illness that one neither recognizes nor expects. I found myself so very angry all the time—until I finally could face the reality of Alzheimer's, both in his life and in mine.

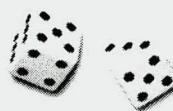
The proverbial self debate that is present in most lasting marriages (ours lasted fifty-six years), an occasional wondering how one got oneself into this, was no longer relevant. There was no abandoning. This was my life. This was our life, even with the terrible frustration and loss for both of us. It was not Benj's fault that I was so angry.

One day a group member, whose husband also is in a nursing home, mentioned to me that she has found spending time with her husband in the nursing home to be more loving because she is free of the impatience and anger of the caretaking days at home. That idea has been very important to me and I have passed it along to others whenever the moment seemed right. It has helped me to treasure the little time each day that I have spent with Benj—with greater acceptance of our predicament.

A next struggle seemed

to be with the seductiveness of the illness—looking constantly for evidence that it is not what it really is. In the nursing home, I was continually looking for evidence that he could be on a higher functioning floor, that he would not need the skilled nursing care. I kept looking for others on the ward who might be healthier, expecting confidently that he would be able to relate. The adjustment to the nursing home was long and slow—but longer and slower for me. I cringed from the realization that he was adjusting to being there and that he could not socialize. When friends asked how Benj is doing, I would draw back from answering. Then I might say, "He is adjusting very well to the nursing home and that is good but bitter," and then change the subject.

Of course there was the struggle with guilt. This played out early on around hiring nursing aides so he would not be home alone. Guilt arose when I went away and left him with aides. It was difficult to allow myself to need assistance in the caregiving. Were the professional parts of my life and all my interests so important? Why should I not become the full-time caregiver like those gallant souls about whom I occasionally heard? Was it so important for me to rescue myself from the selfishness of that role? Some people continue to adjust to the care of their loved one, why shouldn't I? My support group friends kept re-



minding me of *The 36 Hour Day* (Mace and Rabins, 1984), and the fact that one person cannot do it alone.

Guilt took on new and intense colors as the nursing home decision was slowly worked on. It was my own feelings of vulnerability that made the decision bearable. I could die before Benj does. Then who would take care of him? There was the guilt of having "done it to him" since the illness rendered him unable to participate in the nursing home plan or in the execution of it. I had to work out the plan, without his agreement and without his knowing what was happening to him. (I was blessed by the presence and support of our grown children—and the Agency—and my group.)

There was the guilt of leaving him there each day. In order to leave, I found myself always saying "I'll see you tomorrow." Even after three years that feeling remains...

The impact of the finality of the nursing home move was overwhelming for me. I was leaving my husband there for life! He would not be getting well. How long it would be I could not know. Alzheimer's disease is not a killer. It simply

steadily and persistently destroys the quality of life until death can rescue him and/or me.

Death is an issue that the members of the support group have been able to talk about, cautiously but honestly, because of the trust of each other and the strength of the group worker. I think I may have been the member of the group who finally was able to say it. I do not remember what I said but I recall the emotional impact of that session and the importance to me of finally addressing it.

In Conclusion

Stress and illness, loss without death, loss with death, and the emotions of anger, denial and guilt—these are powerful, human issues for a caregiver whose loved one has Alzheimer's Disease. Without a support group with whom to share the experience, it would have been and still would be very difficult for me. The group has made it possible for me to cope with my reality, to reflect without too much rage or panic or despair, and to use these years of my life experience for learning and growth, rather

than being destroyed by the pain. I have learned anew the power of the group through being a member.

My life long love affair with the human group has been reinforced by this new and unpredicted and unwanted experience. I have learned also in an unexpected way how precious is the role of the professional group worker—though never easy. The helping component in a group is elusive and can be released through the skills of the worker.

I opened this paper with a proverb from Native American Indians. Let me close with another one that has meaning for me and my fellow group members:

"The soul would have no rainbows if the eyes had no tears." □

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(1916-1998)

REFERENCE

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(1984). *The thirty-six hour day*. Baltimore: Johns Hopkins University Press

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