

Reaching Out to the Chronically Ill Homebound*

Fred E. Ochs

Supervisor, Jewish Community Services of Long Island, Rego Park, New York

Chronically ill persons are viewed as the more hopeless of our clients and are a threat to some of the omnipotent fantasies at times noted among professionals, which in some cases mask overwhelming feelings of helplessness.

"Quality of Life," a program for the chronically ill homebound, has been in existence for three and a half years. As of February, 1979 there were upwards of 215 active clients and their families, residents of Queens and Nassau counties in New York.

"Quality of Life" is designed to re-introduce the homebound client to life. Its aim is to create, insofar as possible, a community for the isolated homebound where they may be creative, feel useful and contribute to life, rather than remain passive recipients of what family or friends make available. Details of this unique program were outlined in a previous article.¹

The clients in this program are special in a number of ways. They are men and women ages 21-65 who could normally expect to be active and at the peak of their abilities. Instead, they find themselves homebound because of a chronic physical illness. They lack exposure to normal stimuli and have severely restricted access to community resources. These homebound clients are characterized by their isolation, loneliness and sense of abandonment. They are withdrawn, and most exhibit symptoms of reality based depression. An aura of hopelessness surrounds them. There exists no centralized spokesman for this particular group as with the larger category of the handicapped. They are truly forgotten, even by those lobbying for the special concerns of the handicapped. Our clients lack the energy, for the most part, for involvement in social action. It is not always clear how much

of their exhaustion is due to illness and how much is attributable to depression, but it is certain that the illness inhibits activity in a real way.

I propose discussing briefly some of the special problems encountered in reaching out to and working with this unique population. It is helpful in this connection to examine some of the attitudes and characteristics of the lay and professional community toward involvement with the chronically ill, as well as the attitudes and characteristics of the clients themselves and their families.

The Community at Large

In some respects the attitude of the community at large to the chronically ill is an exaggeration of similar responses aroused by involvement with the aging in our society. It is a mixture of sympathy with the plight of a less than adequately functioning person, and outright avoidance of more intimate involvement. There are differences, however, in the community's attitude towards the homebound chronically ill, from their response and commitment to other client-directed social services. It is most difficult for the able-bodied members of the community to imagine themselves in a chronically debilitating situation. The fear of such an occurrence is too frightening for many to contemplate and the reaction is often massive denial and repression. When consciousness is aroused, money is raised and services established to be staffed by "professionals" or "para-professionals." Rarely is there involvement on a person-to-person basis unless it is forced upon one by the illness of a close relative.

What is the bulk of services offered? They are generally on the order of institutions,

* Presented at the Annual Meeting of the Conference of Jewish Communal Service, Grosinger, New York, May 28, 1978.

¹ Fred Ochs and Jaclynn Faffer, *Journal of Jewish Communal Service*, (Fall, 1977), pp. 7-12.

special or segregated housing for a particular segment of the population, special centers for research, etc. The result, in effect, for the recipient of such services, is continued separation from the community at large while satisfaction is expressed by the community that "something was accomplished."

The lay person may find it easier to identify on some level with the needs of the aging, of children, or of the emotionally troubled and the disadvantaged. For most, aging does not present the same threat as chronic illness. Some of the reasons being that a growing percentage of our population is aging and there is increasing publicity about the elderly. In addition, active aging men and women are often in the public eye, many of them venerated and maintaining important roles in our society. Individuals are often part of families with aging relatives, a fact that cannot be ignored.

Children in our population receive much attention because of their dependency and because of some of the real challenges they present in terms of education, employment, crime, drug abuse, etc. Our children are often viewed as extensions of ourselves and are cherished because of the promise for the future that they hold.

It is also plausible in this era of pressure and anxiety, for many to imagine the possibility of falling prey to mental illness or of plunging into dire financial straits. This relative ease of identification is generally not true in regard to the homebound individuals we are discussing. Their numbers, while significant, are not overwhelming. Not every family experiences having a chronically ill homebound member. They are not viewed as a resource with a hope for the future. Indeed, they are not viewed as having a future. To an even greater extent than the mentally ill family member, the chronic physically ill person is viewed by the family and by themselves as a source of shame and literally hidden from the public view. Many chronically ill have severe impairments and disfigurements, misshapen bodies, lack of control of body function and speech and one avoids not only looking at them, but thinking

about them.

The following case illustrates what is often typical of such situations and of the response of the "Quality of Life" program.

Mrs. Y., a 45-year-old, severely disabled woman, is homebound as a result of an advanced neuromuscular disease. This particular client has lost bowel and bladder control and has extremely limited use of her appendages. In addition, she has speech and eye impairments. She is considerably overweight and transfer from bed to wheelchair or vice-versa is an involved and taxing procedure. The client's husband works at three different jobs to maintain the family, the children are out of the home, (at college or living on their own) and seldom available. A live-in home attendant discouraged any possibility of socialization by refusing to take Mrs. Y. out in her wheelchair even on pleasant days and sabotaged efforts to introduce activities into the home. The client was terrified of contradicting the home attendant because she feared being left completely alone. In this case there was an apparent unspoken conspiracy between the husband, the children and the home attendant to maintain the client in an isolated position.

Family counseling was instituted in the client's home to help the various members come to terms with deep seated feelings of anger, guilt and embarrassment. A new home attendant was hired when the previous attendant proved unable to adjust to the changed attitude in the home and family. Activities in keeping with the client's abilities were introduced, e.g., music appreciation with a music therapist, talking books, as well as the writing of poetry with very personal themes in regular sessions with an art therapist. The new attendant now wheels the client outdoors on pleasant days. Contact was established with other clients in the program following publication of Mrs. Y.'s poems in the program's Newsletter, creating opportunities for ongoing contact with various members of the program.

This is not an unusual situation. For most homebound individuals however, access to services that can alleviate the severe isolation remains out of reach.

Community leaders work hard and effec-

tively for a variety of causes but rationalize that a service program for the homebound is not considered a financial priority. While lip service is paid to the need for work with the homebound, it is frequently quite another story when it comes to personal involvement and commitment, because of the complex psychological reactions already partially discussed. For these same reasons, it is more difficult to interest volunteers in direct work with such clients in any capacity.

The Professionals

As professionals, we are not immune to avoidance patterns and to feelings of anxiety, nor are we strangers to the art of denial and repression. How often have we come across a look of surprise and even pity, when our colleagues learn we are working with the aging or the chronically ill. We are told "they" could not work with this population. The underlying implication frequently is how can one maintain the role of therapist or "professional" working with such a clientele. Chronically ill persons are viewed as the more hopeless of our clients and are a threat to some of the omnipotent fantasies at times noted among professionals, which in some cases mask overwhelming feelings of helplessness. Many professionals find it extremely frightening to confront such feelings and subsequently set up strong defenses, particularly when faced with a client who is not expected to "get better."

An example of such attitudes would be in the case of Mr. T., a young man twenty-nine years-old diagnosed as having *Amyotrophic Lateral Sclerosis*, normally a terminal disease within three to five years of onset. The worker found herself extremely frustrated and anxious about continued home visits because of the impotence that she experienced at first. The client was completely bedridden, was no longer able to utilize either his arms or legs for even the simplest tasks. He needed to be fed, dressed, toileted etc. In some respects he was slightly more fortunate than others in his situation. He had a number of friends who continued to visit on occasions and under his guidance had set up a stereo system that could be operated by his toes. They also

equipped his bedside telephone with an amplifier that permitted his continued use of the telephone.

It took considerable time for the worker to recognize and come to terms with the value of her visits to the client. The client was able to make her understand that her visits as an "outsider" helped him deal with strong feelings of "unworthiness." The fact that someone aside from a few old friends was interested, helped him feel that he still was a meaningful human being.

As a result of a more relaxed attitude, the worker was able to arrange for talking books with speakers that could be attached to the client's pillow. In addition, a number of experiments were conducted over a period of months, to try to adapt a particular chess set, with the pieces to be moved by the client's head and mouth, (which were the only parts of his body that he could move at that time). It was hoped he could join the telephone chess group that met on a weekly basis. Although this effort eventually ended in failure, the ingenious attempts (most of them inspired by the engineering mind of the client) offered an interesting challenge. It productively utilized much of the time the client had remaining, giving him a sense of continued accomplishment and use. As he pointed out, even if he couldn't make use of the adaptations, perhaps someone else in a similar situation might benefit in the future.

Finally, the worker arranged for the purchase of a specially adapted T.V. that could be operated by a slight movement of the big toe which the client took with him when he finally had to be placed in a chronic care facility.

Precious time passed while the worker struggled with conflicting feelings about her contact with this severely disabled client. Once she understood her feelings of anxiety, helplessness, fear, anger and sympathy, the relationship with the client became much more productive.

Some professionals have sufficient insight to recognize the torrent of feelings unleashed in such circumstances. Others have been able to overcome some of these same attitudes, as well as feel secure enough in their self-image, not to be overwhelmed by such involvement. They

see the need and the possibilities that exist. While it is frustrating to deal with the lay community in overcoming such deep-seated attitudes, it is even more frustrating and upsetting to try to cope with the prejudices of professionals and to break through their well-developed defenses.

The Client and Family

The resistance encountered among the lay and professional communities is often overshadowed by the roadblocks thrown up by the clients themselves and sometimes their well-meaning relatives. Many clients very openly do not want to be identified as belonging to a group of chronically ill homebound individuals. Often they and their family resort to magical thinking in the belief that if one does not acknowledge the condition it really does not exist. They are able to do this for long periods of time despite numerous symptoms that erupt as a result and which are often of greater discomfort than the condition itself. Two examples follow:

Mrs. F., 49 years old, with a diagnosis of terminal cancer, was transported regularly to the hospital for chemotherapy. Despite having all the classic symptoms, Mrs. F. insisted she did not have cancer, she was not like the "others" and her doctor "didn't really know what he was talking about." She could not consider becoming part of a chronically ill program because she had "nothing in common with chronically ill individuals."

Miss K., a 37-year-old homebound client with multiple sclerosis has been told of her diagnosis. Her family insists Miss K. is unaware of her true illness and reassure her that it is a neurological condition that will improve on the special diet recommended by a nutritionist. Miss K. outwardly accepts this explanation and refuses to consider joining a telephone socialization group to help her cope with her isolation, because she is not "chronically ill like the others" and "they need the service more than I."

In both instances the caseworker's patience and continued involvement over an extended period helped develop feelings of trust that permitted the client to acknowledge the reality

of her chronic illness and begin efforts at learning how to live with it.

Many clients in this category have been so traumatized by their illness, by their sense of loss, and often by what is actual or perceived abandonment by their family and friends, that they withdraw completely from life. They become so distrustful that they appear almost impossible to reach. Since they are not active in the community, they are, of course, hard to find. Outreach workers cannot be sent to a local school, playground, hangout, or senior citizens center and "Y" to look for such clients. Somewhat surprising to us at first, there is little or no return in canvassing the medical profession and the local hospitals. This client population exists within their own four walls, many with no ties, even to ongoing medical care. There is often little the hospital or doctor can do for them in any case, except perhaps dispense a pill or two, and this does not require extensive attention.

With great difficulty the "Quality of Life" program succeeded in breaking through this isolation to find the client. This was accomplished through a variety of media approaches and with the aid of communal agencies. Serious problems however, remained. What was then needed was a slow process of winning the trust of the client and the family. We have at times maintained a carefully orchestrated contact with clients for periods of up to a year or more via telephone, newsletters and occasional home visits before we could in all honesty say there was a meaningful involvement in the program.

Summary

An extraordinary outlay of monies is not required to reach successfully and provide adequate service to the homebound. What is required is cooperation of the clients, their families, the professionals and the community-at-large. Human beings are unquestionably social animals and recognition from others is essential for the self-esteem of all. Meaningful human contact is absolutely vital for those confined to an existence which condemns them to unbearably long hours in which they can

only interact with inanimate objects.

Overcoming the prejudice, anxieties and unreal fantasies regarding the chronically ill is, without a doubt, a major hurdle in helping this

group realize their social potential. The lay community, the professionals and the clients themselves bear this responsibility in equal amounts.