

A STUDY OF CAREGIVING SYSTEMS IN ONE COMMUNITY:

When and Why Elders Enter a Nursing Home

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An older person is more likely to enter a nursing home when he or she is very old, lacks financial and/or social supports, suffers from multiple physical disabilities, and is disoriented and incontinent. Families surveyed in this study made great efforts to care for their impaired elderly relatives in the community, seeing placement in a nursing home as a last resort. It is suggested that excessive caregiving burdens on family members are more likely to lead to nursing home placement than the actual health problems of the older relative.

The purpose of this study was to examine the use of long-term care resources among applicants to a nursing home sponsored by the Jewish community. It explored the functional capacities of older adults, the caregiving patterns of families, and the use of a range of long-term care services that addressed the health, social, and personal care needs of individuals who were lacking some capacity for self-care. These services included community-based care, as well as residential facilities.

The degree to which adequate long-term care services are provided depends, in part, upon the unique history and thrust of a particular community's caregiving institutions. These services must also be examined from the point of view of those involved directly in care (Daatland, 1983). Daatland has proposed that family caregiving is best viewed as a form of social organization that involves the structuring of interpersonal relationships and the division of practical tasks. He suggested that community-based "home care is a truly collective action, depending upon direct and indirect contributions from a number of actors, including the cared-for-himself" (Daatland, 1983, p. 1). This point of view set the context for

the study, allowing for a cross-sectional examination of caregiving systems and how such care is affected by (1) family membership, (2) service issues, and (3) sense of community/ethnicity.

STUDY SETTING

This study was conducted in the Washington, D.C. area, a large metropolitan area in which the Jewish community comprises 7 to 8% of the 1 million population. Jewish communal services for the aged included a recreational center, transportation, financial aid, employment referral, nutrition programs, individual and family counseling, residential apartments, friendly visiting, meals-on-wheels, group homes, house-keeping services, day care, home health care, hospice, and a nursing home—the Hebrew Home of Greater Washington.

The Hebrew Home of Greater Washington (HHGW), where the study took place, is a 500-bed nursing home for elderly individuals needing a number of levels of supervision and care. The study was undertaken when a new building was completed at the facility and new residents were to be admitted from the waiting list (a list of

those who had inquired about the HHGW over the past years). At the time of final application, the prospective residents were assessed to determine their appropriateness for admission. The researchers broadened the scope of the assessment to include more information on use of long-term care resources and family involvement in caregiving. The intent was to gain a better understanding of why families initially inquired about the HHGW and what factors may have led to institutionalization of particular older adults on the waiting list.

STUDY METHOD

Each elderly person who participated in this study had his or her physical and mental functioning assessed by a professional social worker using the Hebrew Home Functional Scale (HHFS) (Table 1). The purpose was to ascertain whether two groups of elderly

persons, those living in the community ($n = 23$) and those entering the HHGW ($n = 39$), exhibited significant differences in functioning. The study explored the influence of the older adult's physical, social, and mental functional level and family caregiving situation on the need for institutionalization.

The community sample was randomly drawn from the HHGW's waiting list, which consisted of isolated frail elderly or "at risk" individuals. Only five families drawn from the waiting list refused to participate. Those in the institutionally based sample were the first 39 residents accepted into a newly built part of the facility.

The Hebrew Home Functional Scale (HHFS) was developed by an interdisciplinary team of physicians, nurses, and social workers. It measures activities of daily living, nursing care required, mental functioning, continence, and general behavior.

Table 1.
HEBREW HOME FUNCTIONAL SCALE (HHFS)

To accurately use the number as a shorthand of communication, the functional categories were defined as follows: 1 = high, 2 = moderate, 3 = low.

- A. Activities of Daily Living
 1. Not requiring help in dressing, ambulation, or feeding and only supervision in bathing.
 2. Regularly requiring some assistance in dressing, feeding, bathing or ambulation.
 3. Unable to dress, feed, ambulate or bathe him/herself.
- B. Nursing Care
 1. Only requiring nominal assistance such as help with taking medication or having blood pressure checked.
 2. Requiring nursing care but not needing to be placed in a wing for skilled nursing. Skilled observation needed for medical conditions, such as hypertension, diabetes and cardiac problems.
 3. Medical condition requiring skilled nursing care. Observation and care for medical conditions, such as gastrostomies, intravenous or nasal-gastric feedings.
- C. Mental Functioning
 1. Alert and oriented, allowing for recognized forgetfulness.
 2. Moderately disoriented and occasionally not alert.
 3. Severely disoriented; not alert.
- D. Continence
 1. Completely continent or able to care for minor incontinence problem by him/herself.
 2. Occasional accidents requiring self-help.
 3. Incontinent.
- E. General Behavior
 1. Appropriate; emotionally stable; able to communicate and relate to others.
 2. Occasional inappropriate behaviors; emotional instability.
 3. Inappropriate behavior; uncooperative; withdrawn, or any behavior requiring special attention.

Individuals are evaluated in each area on a scale of one to three. One is the highest level of functioning (requiring minimal assistance), two is moderate, and three indicates the lowest level of functioning (requiring the most care).

The study data were collected through the use of questionnaires developed by the researchers and given in person to the subjects. (Five family members were interviewed by telephone.) Information was gathered on demographic factors, levels of mental and physical functioning, patterns of family involvement, use of community resources, social and economic supports, and types of services required and used. Each interview lasted an average of 90 minutes.

The data were analyzed through cross-tabulations and Chi-square analysis at the .05 confidence level to ascertain whether there were any statistically significant differences between the HHGW resident group and the community group. Cross-tabulations were run comparing the four scale items assessed by the HHFS. Significant differences were found for three of the five variables discussed below and are presented in Table 2.

STUDY FINDINGS

Comparison of HHGW's Residents' and Community Members' Functional Abilities

Of the 39 older adults who were members of the first group of newly admitted residents to the HHGW, most (85%) were aware of the original inquiry made by their families to the Home. Ninety-seven percent were female; the average age was 81 years. A majority did not live alone in the community before admission. Ten percent lived with their children, and 68% had at one point required temporary nursing home care. Major health concerns included heart disease, arthritis, cancer, and hearing or visual loss.

Of the 23 older adults living in the community, most (61%) were aware of the original inquiry to the Home made on their

Table 2.
FUNCTIONING OF COMMUNITY MEMBERS AND
HEBREW HOME RESIDENTS

	Level of Functioning		
	1 (High)	2 (Mod)	3 (Low)
Activities of Daily Living			
Community members	52.5%	21.7%	26.1%
HHGW residents	25.6%	48.7%	25.6%
Nursing			
Community members	73.9%	13.0%	13.0%
HHGW residents	46.2%	41.0%	12.8%
Mental*			
Community members	82.6%	8.7%	8.7%
HHGW residents	46.2%	35.9%	17.9%
Continence*			
Community members	91.3%	8.7%	—
HHGW residents	64.1%	23.1%	12.8%
General Behavior*			
Community members	87.0%	8.7%	4.3%
HHGW residents	56.4%	35.9%	7.7%

*Statistically significant.

behalf. Eighty-five percent were female; the average age was also 81. Close to half (48%) were able to live alone, most (80%) were widows, and 52% lived with a family member. Almost half (48%) were said to have a form of organic brain disease at the initial time of inquiry. As in the case of the institutionalized older adults, major health problems among the community-based group included heart disease, arthritis, cancer, and hearing or visual loss.

The statistical analysis revealed no significant differences in activities of daily living or in skilled nursing care required between those who were institutionalized and the community-based adults. However, there were two major areas of functional capacity in which the two groups differed: continence ($X^2 = 6.0$) and mental functioning ($X^2 = 8.2$). One hundred percent of individuals experiencing "total" incontinence entered the Home. This finding supports the well-documented view that urinary incontinence may alter the physical, psychological, and socioeconomic aspects

of an individual's life and may lead to premature institutionalization (Baigis-Smith et al., 1989; Brink et al., 1983; Ouslander et al., 1985). In the other area of functional capacity, 82% of individuals with the highest level of mental functioning remained in the community, whereas 77% of those with the lowest level of mental functioning entered the Home. These admissions may be related to the substantial burden that the care of an Alzheimer-diagnosed member, whose deteriorating memory and concomitant behavior problems, places on families (Quayhagen & Quayhagen, 1988; Rabins et al., 1982; Zarit et al., 1985).

Differences in general behavior, the ability to interact with others, were also found to be statistically significant ($X^2 = 6.3$). Those who displayed inappropriate behaviors, such as throwing food, having violent outbursts, or taking off their clothing, would, if admitted, need to be placed in a more structured environment. Those older adults who were assessed as more emotionally stable—that is, better able to communicate and relate to others—were more likely to stay in the community.

Residents' and Community Members' Use of Community Resources

There were striking differences between the two groups—newly admitted residents and those remaining in the community—in the types of services required and used. Over half (55%) of the community-based sample reported no great financial difficulty and were able to purchase services, such as homemakers or meals-on-wheels. However, the 45% that did experience financial difficulty did receive some aid from their families. Many (35%) were known to the other Jewish agencies, but few (less than 10%) required day care or group home services. However, many (48%) reported psychological problems, such as depression or “periods of upset.”

In contrast, more than 25% of the newly admitted nursing home residents were

having financial difficulties purchasing adequate services before admission. A large majority (67%) were known to public and other Jewish agencies, one-third (33%) had used day care, and one-third had lived in group homes. In short, the community-based sample appeared to have been better able to purchase appropriate services, whereas the institutionalized sample had more financial difficulties and needed more intensive services, such as day care or group homes.

Family Involvement

The adult children/relatives who had originally made an inquiry to the Home on behalf of their older relatives were surveyed. These contact persons were daughters (50%), daughters-in-law (32%), sons (9.1%), or other family members (9%). Most relatives called the Home as a result of a perceived crisis in the life of the older family member, such as a stroke or other medical emergency, the death of a spouse, or a severe depressive episode. The initial calls of inquiry were made when the relative felt “helpless” or “overwhelmed” by the demands for care and was seeking additional service for the older adult. Most often they were referred to other community agencies.

Family members of both community-based older adults and those who were eventually institutionalized followed a similar pattern of activity to assist parents while in the community. Such family assistance/involvement included visits (received by about 70%), shopping (approximately 50%), and financial support (near 25%).

In general, families of community-based older adults said they were able to provide the necessary assistance that permitted the older relative to remain in the community. Yet, statements of concern over the possible progressive deterioration of the relative were expressed by most adult children (93%) in the community-based sample. Relatives particularly feared mental deterioration and/or incontinence in the older

person. At the same time, the community-based sample appears to have had less financial difficulty and were able to supplement their involvement by purchasing appropriate services.

In agreement with the findings of studies of family support systems, which have shown a "persistence of attitudes of filial obligation among adult children" (Finley et al., 1988), interviews with the family members whose relative still remained in the community revealed such filial concern. Family members often stated that they "took for granted" that their role as adult child required them to assume responsibility for their infirm relative. When asked "how they came to have major responsibility for helping the older person," most respondents (82%) replied simply, "I am the son" or "I am the daughter." When asked about sharing this responsibility with other siblings or family members, close to half of the respondents (47%) indicated that the responsibility came to them "naturally." They expressed strong statements related to feelings of filial responsibility, including "She can't really live independently without me" or "It's my help that allows her to live independently." This feeling of obligation is in keeping with Jewish law, which expects grown children whose parents are aged and needy to take the responsibility to clothe, feed, shelter, and care for them in a gracious, nongrudging manner (Donin, 1972).

Adult children of those older adults who were institutionalized expressed similar feelings of filial concern. They spoke of their long-standing efforts to keep their parents in the community and expressed disappointment that the difficulties that resulted from such problems as incontinence and dementia had prevented the maintenance of the older adult in the community. In addition, the Home was seen as a "positive place" where more comprehensive services could be obtained after the plan to keep their parent in the community was no longer viable. Many families

also welcomed the economic support that might result, such as Medicaid benefits.

Community and Ethnic Involvement

It has been suggested that ethnicity is an important variable to assess in the provision of social services (Gelfand & Fandetti, 1986). The study subjects, both adult children and older adults, presented information about their initial inquiries and expectations of the HHGW that supports these contentions. An overwhelming majority's (82%) subjective perception of the HHGW was one of strong community affiliation. That is, they viewed it as a personal resource, source of support, or "their Home."

Many (41%) adult children expressed the sentiment that the HHGW was *the* place to inquire about the life-change events affecting their parent's well-being. As many as 20% indicated they had "earned" the HHGW's support because they were active members of the Jewish community, participating in synagogue activities and volunteer organizations. Particularly when the cost of community-based care and dementing illness was of concern, adult children said that they "hoped the HHGW would be there for them." A segment of the sample (17%) also expressed the view that other non-Jewish nursing homes would not be acceptable to them.

Two-thirds of the new residents of the HHGW were of Eastern European background. The environment of the Home, which centers around shared religious symbols and rituals, was said to be an important factor in the selection of the facility. Community members indicated that they saw the Home as a place to call in time of crisis. A majority (80%) indicated that they had placed their relative's name on the waiting list as a type of insurance policy or "just in case they needed it." In short, family members in this study appeared to view the Home as a community-sponsored extension of the family support system. This finding is congruent with the growing

body of evidence that suggests that formal services supplement, not substitute for, informal care (Edelman & Hughes, 1990).

PRACTICE IMPLICATIONS

Many adult children in this study made their initial inquiry to the HHGW during a crisis that caused concern and/or a disruption in the family caregiving functioning. This finding underscores the importance of viewing an inquiry to the Home as a first service contact. It is during such a crisis that a client's "felt needs" are often expressed, thus providing an opportunity for a professional intake worker to discuss family caregiving issues and to make referrals to an appropriate agency.

The study supports the view discussed in the literature that even families who make considerable effort to maintain their older relatives in the community find it difficult to manage when incontinence and severe cognitive impairment are involved. There is growing recognition that special programs need to be targeted for both the impaired individual and his or her caregivers (Toseland & Zarit, 1989). Family life education programs offer opportunities for families to learn preventive techniques and caregiving skills. Support groups also are being used with increasing frequency to help caregivers cope with the stress of caregiving. Providing an opportunity to share feelings, reducing isolation and loneliness, universalizing experiences, and providing support, understanding, affirmation, and validation of feelings are among the possible benefits of such groups (Toseland & Rossiter, 1989).

The study findings also provide insights into the need to provide information about alternative care arrangements available in the community before a crisis occurs. There is evidence that families may not seek help until they reach a crisis point (Montgomery & Borgotta, 1989). For families who may be reluctant to take preventive measures, family life education programs that offer

information about caregiver strategies may prevent undue strain.

The financial difficulties experienced by a sizable portion of the study sample also raises practice-policy issues. Inasmuch as Medicaid may not cover many community-based services, there can be a bias toward institutionalization. That is, some families with functionally impaired older adults may find that it is easier to manage financially by arranging for institutionalization of the Medicaid-eligible older adult. In addition, each Jewish community decides whether and how much each program it provides will be subsidized and the amount of its sliding scale fees. From this perspective, all long-term care options may not be equally available to all families, conceivably contributing in some situations to caregiving stress.

CONCLUSIONS

At a time of increased demands for service and limited resources, the study provides additional information on how long-term care options are used. The findings, when taken with other accumulated research, indicate that an older individual is more likely to enter a nursing home when he or she is very old, lacks financial and/or social supports, suffers from multiple physical disabilities, and is to some degree disoriented and is incontinent (Palmore, 1976; Smyer, 1980). At the same time, research on the risk of institutionalization has documented that individuals along the full impairment continuum, ranging from moderate to completely bedridden, live both in nursing homes and in the community (Doty, 1986; Newman et al., 1990). This ironic phenomenon is often accounted for by the availability and viability of informal support systems.

Research continues to document that the aged and their families wish to have options in long-term care resources and appear to prefer home-based services. In addition, the results of this study tend to

concur with other studies that suggest that families make great efforts to care for impaired elderly in the community (Zaret et al., 1980). Families are actively involved in meeting the day-to-day needs of their older relatives, sometimes sharing this responsibility with the service industry. Excessive burdens on family members, such as mental deterioration of the older adult and the confinement of caretaking, are more likely to lead them to seek nursing home admissions for their relative than actual health problems per se. Relocation usually occurs only after a lengthy period of the older parent's deterioration and the concomitant stress on the child (Brody et al., 1978). Placement of an older family member in a nursing home usually is a "last resort after other alternatives have been exhausted and family members have endured severe stress (Brody et al., 1990).

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