Respite Care for Community Elderly

(family, self-care, home care, caregiver)

Betty Risteen Hasselkus  Margaret Brown

Respite care is planned, intermittent, short-term care designed to provide periodic relief to the family and the caregiver from 24-hour continuous care of a frail family member. The concept originated with the families of developmentally disabled children (1). More recently, it has been recognized that respite care programs for families of the frail elderly are needed (2-5). The high economic cost of institutionalization, the belief that community living best supports quality of life in old age, and the realization that it is the family unit that, in fact, the major health care provider for the elderly are all factors that have nudged health planners and providers toward the exploration of respite care.

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Occupational therapists and other health professionals in geriatrics are concerned with the promotion of wellness behavior, meaningful activity, and independence in activities of daily living (ADL) in older people (6). Respite care is a health care option that can prolong the frail older person's ability to remain in the community; thus, it promotes continuity of occupational behavior and quality of life in old age.

Respite care may be offered in the private home (for example, a trained volunteer or hospice worker may come in for short periods of daytime relief for the caregiver) or at a community day center (3, 7). The respite program of planned short-term hospitalization described here is modeled after the program described by Robertson, Griffiths, and Cosin (5). Although the general goal of the program remains consistent with all respite care models—to relieve the caregiver from continuous 24-hour care—the location of the respite in an acute care setting creates the need for therapeutic planning perhaps not otherwise required.

These authors, the occupational therapist and nurse practitioner on
an interdisciplinary geriatric health team, developed a respite care protocol that includes a pre-respite functional assessment of the client in his or her home, admission consultation with ward staff to provide information regarding the client's expected ADL abilities, interests, and special needs, and close contact of geriatric team members with the patient during the hospitalization to promote the wellness role, involvement in stimulating activity, and carry-over of self-care skills demonstrated at home. Descriptive data regarding reasons for respite, functional levels of the clients, and percentages of dysfunction in areas of self-care were gathered over a 3-year period. These data help to define the family's ability to care for its elderly members, to identify more precisely the types of dysfunction commonly represented in patients whose families request respite care, and to plan accurately for the development of community support services.

### Family Support Needs

Studies that describe and research the family as a support system for the frail elderly are increasingly represented in the gerontological literature. A 1972 national survey indicated that the immediate family of the older person is the major social support during illness. In fact, 80 percent of the necessary support is offered by the family. Eggert, et al. (9) in 1977 concluded that 65 percent of the variance contributing to decisions regarding institutionalization of elderly persons in their study was due to three factors—the older person's self-care skills, the physical and mental ability of the family to provide care, and the financial resources of the family to pay for at home services. Lindsey and Hughes (4) agreed that the family is the major support for its ill aged members and that institutions are used only when there is no family support system or when the family resources for care are exhausted. These and other authors concluded that older persons without family support are more likely to be institutionalized during illness than those with family support. The presence of a supportive family caregiver provides an alternative to institutionalization and enables a debilitated older person to remain at home.

The vast majority of caregivers for ill elderly are women—daughters, daughters-in-law, and wives. Davis raised issues related to the "femaleness" of this cadre of caregivers, such as the impact of the women's movement on women's roles and the new career and work focus of many middle-aged women today.

Fengler and Goodrich, in their 1979 study of the wives of elderly disabled men, stated that the impact of chronic illness is greater than the impact of acute illness on family supporters. Other researchers also described family feelings of anxiety over the constant nature of the required supervision, and feelings of being overwhelmed, angry, and socially isolated. Many caregivers had not had a holiday for years or an evening out for months. This was especially evident in studies of families caring for demented family members, where the wife was afraid to ever leave the patient alone for fear he would wander off and harm himself. Among Zarit's population of caregivers, feelings of burden correlated with the infrequency of family visits. The feeling of burden increased with perceived isolation and the lack of sharing care responsibilities.

Sanford, in a study of 46 older people who were admitted to a geriatric hospital in London, attempted to identify factors that led to their institutionalization. Significant " alleviation factors" (those that were poorly tolerated) were: sleep disturbances, fecal incontinence, dependence in transfer skills and toileting, dangerous irresponsibility, and worry about falls. Problems with ambulation, use of stairs, urinary incontinence, personal hygiene, and dressing were well tolerated.

On an issue closely related to caregiver burden, Block and Simnot concluded that a majority of their population of abused elders were dependent in self-care tasks. Types of abuse included frequent lack of personal care, misuse of money, verbal assault, and isolation. Overall, this exploratory study suggests that increased dependency is associated with increased risk of abuse.

Brody, et al. in their study of the family caring unit, concluded that "planners should be directed toward developing and providing support programs and services for families who provide home health care to their chronically ill/disabled relative. . . Support for the family caring unit should become a critical consideration that governs policy making in the field of long-term care." Lindsey and Hughes proposed that the creation of a program of respite care for an ill elderly person might increase a family's capability of maintaining its long-term support. In their study, the family members themselves identified the need for periodic and temporary relief from the continuous responsibility of care for the aged family member. A program of planned respite was called a "real unfulfilled need." Perhaps a most noteworthy sign of the times is
the report by Grossman, et al. (3) of a group of elderly caregiver wives who became their own advocates and persuaded local agency directors to assist in the development of a pilot respite project to meet their needs for periodic relief.

**Respite Care in an Acute Care Setting**

The Interdisciplinary Geriatric Training Project was a 7-year (1975-1982) University of Wisconsin student training program funded by the Veterans Administration and located at the Wm. S. Middleton Memorial Veterans Hospital in Madison, Wisconsin. The health care team included two Veterans Administration Geriatric Fellows, two nurse practitioners, a social worker, a clinical pharmacist, a dietitian, a physical therapist, and an occupational therapist. Veterans from the Madison area attended the geriatric outpatient clinic and received home visits or home assessments as needed. All the veterans were more than 60 years old, all but two were male, and all had multiple health problems requiring a team approach to their care.

Early in 1978 it became apparent that a mechanism for short-term hospital admissions was needed for selected geriatric outpatients to relieve the burden of care at home. A proposal for respite care at the Veterans Administration hospital was written by the occupational therapist and submitted to the hospital administration. The proposal, based loosely on the model described by Robertson, et al. (5), requested that two hospital beds be allocated for the use of respite admissions for patients in the geriatric program. The Respite Care Program proposal was accepted and initiated in June 1978.

Table 1 describes the respite admissions that occurred between June 1978 and September 1981. During that time period, 19 patients were admitted for respite care. All patients were men and had a mean age of 78.7 years (range 61-89). Sixteen of them lived with their wives, one lived with a niece, one with a daughter, and one lived alone but had a daughter-in-law caregiver nearby. All but one of these patients used one or more of the following community services: day care (5 patients), visiting nurse services (12 patients), special transportation arrangements outside the family (8 patients: only 2 of the 19 were still driving and those very little), special meal programs or home-delivered meals (5 patients), and home health services (6 patients). The one patient who used none of these services was a 61-year-old veteran who was terminally ill and whose relatively young wife was in good health.

The number of respite admissions per patient ranged from 1 to 16. The patient who was admitted 16 times had a schedule of pre-planned respite every few weeks. His wife was able to tolerate his demanding behavior and extensive care only by knowing that she could depend on frequent periods of relief. Almost 75 percent of the respite reasons were arranged to give the caregivers a rest; other reasons for respite were caregiver in the hospital, caregiver traveling, need for planned rehabilitative therapy, or patient moving.

Gradually, as the geriatric team, the patients, and the hospital staff began to experience respite admissions, the need for careful orchestration of this new kind of health care became obvious. The patient was at risk for regression into the sick role and unnecessary dependency, for rapid loss of strength and diminished mobility after long hours of inactivity in the hospital room, and for confusion from the relocation to unfamiliar people and physical surroundings. Hospital staff were puzzled; they were accustomed to a role geared to acute care and a system of prioritizing ward care to meet the needs of the most seriously ill. The geriatric team members were zealous in their expectations of involvement of busy ward personnel in the daily routine of each patient. Eventually, to optimize the benefits of respite care for the patient and his family and to assist the nursing staff.

<table>
<thead>
<tr>
<th>Reasons for Respite Admissions:</th>
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<tbody>
<tr>
<td>Rest for Caregiver:</td>
<td>29</td>
</tr>
<tr>
<td>Caregiver in Hospital:</td>
<td>8</td>
</tr>
<tr>
<td>Caregiver Travel:</td>
<td>2</td>
</tr>
<tr>
<td>Planned Rehabilitation:</td>
<td>1</td>
</tr>
<tr>
<td>During a Change in Residence:</td>
<td>1</td>
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### Table 1

<table>
<thead>
<tr>
<th>Patients Admitted for Respite</th>
<th>19</th>
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<tbody>
<tr>
<td>Total Number of Respite Admissions</td>
<td>41</td>
</tr>
<tr>
<td>Number of Respite Admissions per Patient</td>
<td>1-16</td>
</tr>
<tr>
<td>Number of Days per Respite Admission</td>
<td>4-20</td>
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in incorporating respite care into the ward routine, a three-part protocol was developed by the occupational therapist and nurse on the geriatric team: 1. Pre-respite planning, 2. Admission procedures, and 3. Implementation of the care plan during hospitalization.

Pre-respite Planning. Admission staff were notified several days in advance to expect a respite admission on a specified date. The patient’s hospital records were pulled and the geriatric physician entered a note that included the rationale for the respite admission, a summary of the patient’s present medical problems, and an update of current medications and on-going treatments.

The occupational therapist visited the patient and caregiver at home to discuss the upcoming respite, to clarify expected procedures, allay undue fears and anxiety, establish a wellness focus for the hospitalization, and emphasize expectations for independent function where appropriate. During the home visit, the occupational therapist evaluated the patient’s current functional ability in basic living skills in order to be able to formulate accurate and reasonable objective of care with the family and the hospital staff.

Admission Procedures. Upon arrival at the hospital, the patient was accompanied through the admission process to the assigned ward by a member of the geriatric team. The team member stayed with the patient long enough to assist with orientation to the ward staff and to the physical layout of the unit. At this time, special requests—such as ascertainment of a room near the bathroom—were conveyed to the head nurse. Sometimes environmental modifications were implemented—for example, the use of bright yellow marking tape on the door to maximize orientation for a visually impaired patient. Hospital policies regarding smoking and use of television, and the location of areas such as the day room and library, were discussed, and the request was made that the patient be allowed to wear street clothes.

Probably the heart of the admissions procedure was a written care plan entered in the nursing Kardex. The Kardex was used instead of the medical chart because it was the primary mechanism for communication during change-of-shift reports and team conferences, and it enabled the unit staff to make quick references to such parameters as diet and activity.

A sample care plan for a Respite Care Admission might include:

1. Pertinent social history:
2. Present status of basic living skills, a. Independence/dependence in self-care skills; physical assistance needed; assistive devices used; sensory impairments, aids, b. Mental status, c. Meaningful leisure activities and interests, d. Diet-modifications and preferences, e. Outline of “typical” day.

Implementation of Care Plan. During the short-term respite hospitalization, members of the interdisciplinary geriatric team and students had daily contact with the patient. This provided the older person with a consistently familiar figure and also afforded regular opportunities for the team to consult with the nursing staff regarding the implementation of the care plan. The daily visits by the team member/student were used to provide simulation and purposeful activity for the patient—ambulation in the hallway or to the canteen or library, reading aloud from the daily newspaper, assistance in writing a letter, interviewing for a Project newsletter article, setting up for a handicraft hobby, active listening and reminiscing, or reading through scrapbooks brought from home. Sometimes the team member would act as “surrogate” caregiver by assisting every day with self-care tasks such as dressing and shaving to ensure that the older person maintained as nearly normal a routine as possible without overburdening the ward personnel with time-consuming chores.

For some respite patients, arrangements were made by the geriatric team for them to continue to participate in their usual community activities such as attendance at a day center or walking with a group in a shopping mall.

Occasionally, the respite period was used to provide specialized rehabilitative programming for the patient, either by the in-house staff or by the therapists on the geriatric team. Daily attendance at speech, physical, or occupational therapy to improve upon or maintain normal functional levels or to assess perplexing problems was planned; or the respite was used to pursue diagnostic dilemmas with x-ray studies, ultrasound, or C-T scanners.

Table 2

<table>
<thead>
<tr>
<th>Patient Population</th>
<th>No.</th>
<th>Mean Score</th>
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<tbody>
<tr>
<td>Geriatric Clinic</td>
<td>111</td>
<td>81.67</td>
</tr>
<tr>
<td>Living Alone</td>
<td>38</td>
<td>93.16</td>
</tr>
<tr>
<td>Living with Others</td>
<td>73</td>
<td>76.30</td>
</tr>
<tr>
<td>On Respite Care</td>
<td>19</td>
<td>65.79</td>
</tr>
<tr>
<td>At Nursing Home Placement</td>
<td>18</td>
<td>85.55</td>
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Figure
Comparison of percentages of respite population and clinic population dysfunction in self-care areas

Functional Status of the Respite Population

The need for respite care implied that these patients were more functionally impaired than the geriatric clinic patients as a whole. It was presumed that one of the reasons that respite was requested was because greater perceived care responsibilities existed at home. Basic descriptive data were gathered to help define and identify the functional status of patients who requested respite care so that the needs and responsibilities of the caregivers might be better understood.

Functional ability was measured with the Barthel Self-care Index (17). (The use of this scale with community elderly has been described elsewhere (18).) The Barthel Index is a 10-item scale that includes the following: feeding, transfer skills, toileting, bathing, ambulation, dressing, use of stairs, personal hygiene, continence of bowel, and continence of bladder. Each item is rated and the Index has a total "score" that may range from zero to 100 (dependence to independence in the ten self-care items). The scale is preferentially weighted for mobility and continence, which seems clinically appropriate. Also, it is adaptable to the community setting.

Barthel scores for this respite care population of 19 patients ranged from 25 to 100. A score of 25 is a very low score for a home care patient (18). The one patient who received this score was dependent in all ten Barthel items though he achieved partial scores in feeding, continence, transfer skills, and toileting.

The figure illustrates how this respite population compared to the geriatric clinic population as a whole on the Barthel self-care items. Greater percentages of the respite population demonstrated dysfunction in every self-care skill on the scale. It is interesting that the profile across self-care items is very much the same for both populations. Almost 80 percent of the respite population demonstrated dysfunction in the "big three"—bathing, ambulation, and use of stairs. Fecal incontinence and assistance with transfer skills and toileting had the lowest percentages in both populations.

The mean Barthel scores for the clinic population, the patients on respite care, and other clinic subpopulations are presented in Table 2. As might be predicted, those patients who lived alone had a higher mean Barthel score than those who lived with others. The respite care mean score of 65.79 is very close to the mean score of geriatric patients at time of nursing home placement (65.55). Both of these scores are close to what Granger called the "pivotal score of 60," the point at which patients move from independence to dependence and become less able to live in a community environment (19). In fact, 12 percent of the respite population were eventually placed in nursing homes compared to 16 percent of the clinic population as a whole. Patients on respite care were indeed living on the brink of institutionalization.

The data from this population of patients agree with many of the findings of previous studies on family care of the elderly. All of the caregivers in the respite population were female. For the gentleman who lived alone, it was not his son to whom he turned for care but to his daughter-in-law. The social expectation of women in the caregiving role is so strong that blood relationships will apparently be ignored to fulfill this. Those clinic patients who lived alone were more independent in self-care skills than those who lived with others: patients who are less competent are less likely to be able to live in the community.

In the clinic and respite populations, the high percentages of dysfunction in ambulation, use of
stairs, and bathing are in the same areas of care that Sanford suggested were well tolerated by caregivers (15). People can adapt to dependence in these tasks, and community living is not seriously threatened by impairment in these skills. The areas of personal care that Sanford identified as poorly tolerated by caregivers—fear, incontinence, transfer skills, and toileting—were the Barthel items with the least percentages of dysfunction in the clinic population. Perhaps this suggests that patients with these dependencies are no longer at home—they are in institutions. The marked increase in bowel dysfunction and transfer dysfunction in the respite population implies a greater caregiver burden for these patients and a greater risk for institutionalization.

It seems clear that dependence in self-care tasks, though severe in its impact on the family's ability to provide care, is strongly related to independent living in the community. As competence decreases, the burden of the caregiver, the risk of elder abuse, and the risk of institutionalization increases. Periodic relief from constant care responsibilities, offered through a respite care program, is one option for increasing the family's capacity to sustain its care burden over long periods of time. It should be obvious that health providers must also direct their efforts toward maximizing the older person's self-care abilities through adapted ADL techniques, assistive devices, and health education for the patient and caregiver.

Conclusions
Respite care offers a new health care option to frail older people that may be able to prolong their ability to live in the community. There is need for future research to measure the impact of respite care on the incidence of institutionalization. Occupational therapists and other health providers need to understand the concept of respite care and be sensitive to the potential for the development of such programs in a variety of settings and models. Careful therapeutic programming must take place to counteract the potential negative impact of respite care in an acute care setting. The respite care must not only provide intermittent caregiver relief, but must also provide a temporary placement that promotes health maintenance and wellness for the frail older person. Coupled with a program of therapy to maximize the older person's competence in activities of daily living, respite care can be a powerful mechanism for supporting meaningful community life in old age.

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