

Why do some caregivers of disabled and frail elderly quit?

by Rachel F. Boaz and Charlotte F. Muller

In this study, the authors examine the extent to which the characteristics of caregivers or recipients determine the probability that caregivers stop being caregivers. We find that caregivers' characteristics such as working outside their homes, raising children, or having their own health problems do not increase this probability. Nor does the emotional distress of caregiving increase the

probability of quitting. However, caregivers are more likely to quit when recipients have six to seven disabilities in activities of daily living and need help on demand around the clock. This study also determines that assistive equipment, home modifications, and attendance at senior centers do not reduce the probability that caregivers quit.

Introduction

The rapid growth in the number of very old Americans has increased the number of elderly depending on others for the basic daily activities of personal care and household tasks. While living in the community, their main source of help is the informal care provided by relatives and friends, mostly immediate family members. According to Liu, Manton, and Liu (1985), in 1982, 73.9 percent relied solely on unpaid help, 20.6 percent had both paid and unpaid help, and 5.5 percent used paid help only. Stone, Cafferata, and Sangl (1987) show that, of all unpaid caregivers helping the most dependent elderly, 36 percent were spouses and 37 percent were daughters and sons.

By now it is well established that caregiving in the United States is stressful (Zarit, 1989). For example, according to Cantor (1983), whose findings are based on 111 caregivers in New York City, caregiving has a substantial effect on a caregiver's life, especially on job performance and on the time available for spending with other close relatives and friends or devoting to other leisure activities. Moreover, the closer the bond between caregiver and recipient, the greater the emotional strain for caregivers. Caring for frail and disabled elderly is stressful even in an optimal environment such as that offered in an Israeli kibbutz. The social structure of a kibbutz provides support for both caregiver and recipient and allows each to make choices about the mix of formal and informal care without being subject to exclusionary screening procedures and restrictions on eligibility for formal services, as is the norm in the United States. Next of kin can choose not to be caregivers because formal care is available on demand, and those who choose to be caregivers can receive work credit and other relief. Yet, as Holmes et al. (1989) show, based on a sample of 113 informal and 156 formal helpers in 53 kibbutzim, when informal caregivers feel overburdened, institutionalization is likely. Using the same data, Teresi et al. (1989) show

that caregivers' burden and low morale, due mainly to the recipient's mental status and incontinence, increase the risk of institutionalization notwithstanding the availability of paid help in the community.

Some caregivers quit although their care recipients continue to need help, as demonstrated by data from two linked national surveys undertaken by the Department of Health and Human Services in 1982. The National Long-Term Care Survey (NLTC) is based on a probability sample of the disabled and frail elderly living in the community (Office of the Assistant Secretary for Planning and Evaluation, 1986). Its companion survey, the National Informal Caregiver Survey (NICS), is based on a probability sample of the caregivers who helped these elderly with the basic daily activities of personal care. The average interval between the interviews conducted for both surveys was 3 months. Out of the 1,924 caregivers selected for the NICS sample, 298 who were caregivers at the time of the NLTC survey had become former caregivers at the time of the NICS survey. Of these, 145 had cared for 85 recipients who died during the interval and 27 had cared for 18 recipients who were reported not to need any more help. These represented approximately 97,000 disabled persons who died and 21,000 who recovered over a 3-month period. The remaining 126 former caregivers had 80 care recipients still needing help; they represented 95,000 disabled persons. The 1,620 current caregivers were helping 1,242 care recipients who represented 1,404,000 disabled persons.

Our study focuses on caregivers' attrition rather than on their stress (the focus of other studies), and it is designed to understand the difference between current and former caregivers. Based on a nationally representative sample, caregivers who dropped out over a 3-month period in 1982 constituted 7.2 percent (126/1,746) of all caregivers whose recipients needed help with basic daily activities of personal care. If sustained, this would translate into an annual attrition rate of 28.8 percent for the subset of caregivers helping the most dependent elderly in the community.¹ The pivotal role of informal care in maintaining disabled persons in the community

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¹It should be noted that, though NICS is a nationally representative sample, it represents only a subset of caregivers, namely, those who helped with basic daily activities of personal care; but many of these caregivers also assisted with household tasks. However, the NICS does not include the caregivers who assisted "only" with household tasks.

suggests that it is important for public policy to know what distinguishes caregivers who continue from those who quit and understand why this source of care dries up. Equipped with this information, policymakers can decide about corrective measures and substitute services. This study contains this information. It examines which characteristics of caregivers and recipients are conducive to caregiver dropout and which are not; and, since this study is based on a national representative sample, the findings are applicable nationally. In the following sections, we will specify the likely determinants of caregiver attrition, estimate the characteristics of both caregivers and recipients which affect the probability that caregivers quit, and discuss the findings and their implications for public policy.

Determinants of caregiver attrition

A person who decides to be a caregiver has the option of quitting later. The utility derived from being a caregiver (denoted by U_1) is the satisfaction obtained from fulfilling a special role obligation and from helping a relative and friend with whom one has affectional ties. The disutility (denoted by U_2) of caregiving includes the time that is not available for other activities and the distress caused by seeing the decline of the care recipient. If $U_2 > U_1$, a person ceases to be a caregiver; if $U_2 \leq U_1$, the person continues. Since U_1 and U_2 are not observed, we define Y as an indicator of observed behavior, such that $Y = 1$ if $U_2 > U_1$ and $Y = 0$ if $U_2 \leq U_1$. The observed behavior depends on the personal characteristics of both caregivers and recipients (denoted by vectors X and Z respectively) and on the other resources available to the recipients to cope with disabilities (denoted by a vector Q). Hence,

$$Y = X_a + Z_b + Q_c + v,$$

$$v = 1 - (X_a + Z_b + Q_c) \text{ if } Y = 1,$$

$$v = -(X_a + Z_b + Q_c) \text{ if } Y = 0,$$

where

$$P(Y=0) = F(v) \text{ and } P(Y=1) = 1 - F(v).$$

The log likelihood function, which is to be maximized, is specified as follows:

$$\log L = \sum_{Y=0} F(v) + \sum_{Y=1} [1 - F(v)]$$

The caregiver characteristics that are expected to increase the probability of attrition are: work outside the home, raising minor children, and health problems. Boaz and Muller (1992) show that having a full-time job reduces substantially (by 20 hours a week in 1982) the time allocated to unpaid help; hence, it can be expected that full-time employment would also increase the probability of attrition. Further, younger caregivers (assisting their parents or grandparents) may also have the responsibility for raising minor children and are, therefore, more likely to quit; and older caregivers (assisting their spouses) may have health problems that lead them to give up caregiving.

The characteristics of care recipients that increase the probability of caregiver attrition are the degree of

dependence on others and the ensuing burden on caregivers. Katz et al. (1983 and earlier studies) demonstrate that the degree of dependence strongly correlates with the number of impaired functions in the basic daily activities of personal care. Boaz and Muller (1992) show that the number of such impairments is positively correlated with the number of weekly hours of unpaid help provided by each caregiver. The impaired functioning may impose a physical burden on a caregiver when the care recipient cannot be left alone and/or when the caregiver's sleep is frequently interrupted; and it may also impose an emotional burden when a caregiver is distressed by caregiving or has problems in the relationship with the care recipient. Additionally, because disabilities last many years, some persons who may serve as caregivers for several years may feel that they have contributed their share; therefore, the duration of caregiving may affect the probability of quitting.

The probability of quitting may be reduced when other resources available to the recipients to cope with disability and frailty ease the burden of caregiving. Among these are assistive equipment (e.g., a wheelchair), home modifications (e.g., ramps), and senior centers that provide meals, transportation, and health care services. Also, each caregiver's burden may be eased and time spent reduced when other individuals share in the tasks. Hence, mechanical devices, community facilities, and multiple caregivers are expected to reduce the probability of attrition.

Empirical analysis

The regression analysis is designed to assess the extent to which the determinants of caregiver attrition change the probability of quitting. The data for this study are obtained from the NLTCs and NICS linked surveys previously mentioned.² The sample for this study consists of 1,746 caregivers whose care recipients were alive and needed help at the time of the NICS interview. By that time, 126 had quit and 1,620 remained active caregivers.

The NLTCs includes information on the characteristics of elderly care recipients living in the community and needing assistance with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). As represented in the NLTCs questionnaire, the ADLs are: bathing, dressing, getting around inside the house, getting in and out of bed, getting to the toilet, continence, and eating. The IADLs are housework, laundry, meal preparation, shopping for groceries, getting around outside the house, managing money, using the telephone, and taking oral medicine. Muller and Boaz (1991) show that almost all care recipients whose caregivers were interviewed for the NICS had both ADL and IADL impairments. The NLTCs also provides information on assistive equipment, home modifications, and attendance at day care or senior centers. The NICS includes the information on caregivers' characteristics and activities, such as the number of hours of unpaid help, their employment, minor children, and health problems. Caregivers were asked about the number of years of

²For a detailed description of these surveys see (Office of the Assistant Secretary for Planning and Evaluation, 1986).

Table 1
Differences in means between current and former caregivers, by variable: 1982

Variable ¹	Caregivers		Statistically significant difference (t)
	Current (N=1,620)	Former (N=126)	
	Mean		
Caregiver's personal characteristics			
Paid work:			
No work ²	.698	.706	.149
Part-time	.094	.079	-.411
Full-time	.209	.214	.106
Having minor children:			
No children ²	.918	.865	-1.210
Only under 6 years of age	.014	.016	.104
Only 6-17 years of age	.055	.095	1.076
All ages under 18	.013	.024	.559
Health problems which interfere with functioning:			
None ²	.907	.937	.927
1	.053	.016	** -2.135
2	.028	.024	-1.69
3 or more	.013	.024	.559
Birth decade ² :			
Before 1910 ²	.190	.127	-1.444
1910-19	.273	.214	-1.107
1920-29	.228	.190	-.742
1930-39	.141	.103	-.943
1940-49	.080	.142	1.416
1950-59	.048	.087	1.105
1960-68	.039	.135	**2.226
Female	.720	.683	-.588
Minorities	.158	.254	*1.721
Disabilities and their associated characteristics			
ADL limitations:			
Less than 3 ²	.446	.214	***-4.295
3 to 5	.307	.357	.814
6 to 7	.247	.428	***2.860
Unpaid help by each caregiver (weekly hours)	24.020	31.106	*1.732
Years of caregiving:			
11 or more ²	.206	.183	-.459
6 to 10	.235	.167	-1.405
3 to 5	.326	.278	-.827
2	.123	.151	.607
1	.100	.198	*1.936
Physical burden	.534	.730	***3.382
Emotional burden	.749	.841	*1.914

See footnotes at end of table.

caregiving, whether caregiving results in frequent sleep interruptions, whether the recipients can be left alone, whether caregivers are distressed by caregiving, and how well they get along with the recipients.

Table 1 compares the differences between current and former caregivers. The personal characteristics of the two groups are similar; that is, there are no statistically significant differences between them except that the youngest caregivers (between ages 14 and 22 in 1982) are more likely than older ones to quit.³ Statistically significant differences between current and former caregivers are found for the disabilities of their care recipients and the characteristics that are associated with caring for the most dependent persons. Thus, caregivers of persons with six to seven ADL disabilities are more

likely to quit than caregivers of persons with fewer ADL disabilities. Similarly, the difference in the physical burden between the two groups is statistically significant. Further, active caregivers are more likely to quit if other persons share in the tasks and less likely to do so if they are the sole source of help. When recipients have paid help, their caregivers are more likely to quit than if they have no paid help.

Table 2 presents the regression coefficients; these indicate the direction of change in the probability of caregiver attrition effected by each factor when all other variables are held constant. Equation 4 includes all explanatory variables. Paid help and the number of caregivers sharing in the tasks have statistically significant coefficients. The probability of dropout increases when a care recipient had paid help in place before the caregiver quit. Sole caregivers are less likely

³Some young caregivers might have left the households that their parents shared with the care recipients.

Table 1—Continued
Differences in means between current and former caregivers, by variable: 1982

Variable ¹	Caregivers		Statistically significant difference (t)
	Current (N=1,620)	Former (N=126)	
	Mean		
Other resources to cope with disabilities			
Assistive equipment for:			
ADL disabilities ⁴	.653	.595	-.912
IADL disabilities ⁴	.492	.333	***-2.587
Home modifications	.361	.310	.859
Day care or senior centers	.041	.063	.729
Paid help	.187	.317	**2.188
Number of caregivers helping a recipient:			
1	.607	.349	***-4.116
2	.235	.270	.616
3	.100	.127	.630
4 or more ²	.059	.254	***3.558
Caregiver and recipient living together	.751	.674	-1.270

* Statistically significant at .10 level.
 ** Statistically significant at .05 level.
 *** Statistically significant at .01 level.

¹The standard errors (not shown) are multiplied by a factor of 1.4 to adjust for the sample design effect and for the fact that a care recipient can have more than 1 caregiver.

²Reference category is the regression equations of Table 2.

³The public-use tape provides information on the birth decade but not on the birth year. Caregivers under age 14 were excluded from the National Informal Caregiver Survey by the survey design. (The youngest caregiver in 1982 was born in 1968.)

⁴Assistive equipment for ADL disabilities is a binary variable and so is equipment for IADL disabilities. There is some overlap because some persons have such equipment for both ADL and IADL disabilities.

NOTES: t statistic, "former" is compared with "current". ADL is activities of daily living. IADL is instrumental activities of daily living. For any variable, totals may not add to 1 because "no response" category is not shown.

SOURCES: (Office of Assistant Secretary for Planning and Evaluation, 1986) and with to specific reference to footnote¹: Tourangeau, R.: Informal Caregivers: Report on Sampling. *Long-Term Care Survey and National Survey of Informal Caregivers, 1982: Report on Methods and Procedures Used in Surveys, Part 2, Documentation*, National Technical Information Service PB86-161791. 1986.

to quit than caregivers whose recipients have several (four or more) caregivers. Because of multicollinearity, the coefficients of ADL disabilities, weekly hours of help, and burden of caregiving are not statistically significant in equation 4. But each is statistically significant in an equation that includes only one of these three variables. Equation 1 includes only ADL disabilities, equation 2 includes only weekly hours, and equation 3 includes only the caregiver's physical burden; their respective coefficients are statistically significant at 5 percent. When care recipients have six to seven ADL disabilities or when caregivers are burdened by frequent sleep interruption and/or cannot leave the care recipient unattended, the probability of quitting increases. This probability also increases with the number of weekly hours of informal help provided by each caregiver. Neither the caregiver's personal characteristics and the emotional burden of caregiving, nor the recipient's assistive equipment, home modifications, and attendance at a senior center have an effect on caregiver attrition.

For the statistically significant factors, Table 3 shows the percent change in the probability of quitting within a 3-month interval. Partial derivatives (converted into percents) measure the magnitudes of the effects that can be attributed to each factor. A substantial level of disability, as indicated by six to seven ADL limitations, increases the probability of quitting by 3 percent; and, the

physical burden of caregiving also increases this probability by 3 percent. An increase in the weekly hours of help has only a negligible effect. When care recipients have paid help, the probability of attrition increases by 3 percent compared with caregivers whose recipients do not have such help. Further, the probability of quitting is reduced by 8-9 percent when sole caregivers are compared with four or more caregivers sharing the tasks. These findings suggest that caregiver attrition does not result in abandonment of their care recipients although, because of caregiver dropout, former recipients may have fewer hours of help than similar recipients of active caregivers.

Summary and policy implications

Informal care is the major source of in-home help for the most dependent elderly living in the community. Consequently, caregiver dropout is a major concern for public policy. Based on these national surveys, 7.2 percent of these caregivers quit during an average 3-month period in 1982. Of these, one-half had their care recipients placed in a nursing home or in another (unspecified) institution and the remaining one-half had recipients who continued to live in the community. Former care recipients who were institutionalized were more likely to have six to seven ADL limitations and

Table 2
Probability of change from caregiver to non-caregiver, by variable: 1982¹

Variable ²	Equation 1	Equation 2	Equation 3	Equation 4
Caregiver's personal characteristics				
Paid work:				
Part-time	-.574	-.554	-.600	-.527
Full-time	-.266	-.205	-.296	-.155
Having minor children:				
Only under 6 years of age	-.307	-.517	-.556	-.447
Only 6-17 years of age	.000	.082	.042	-.024
All ages under 18	.339	.575	.463	.377
Health problems which interfere with functioning:				
1	-1.200	-1.164	-1.112	-1.176
2	-.252	-.233	-.258	-.254
3 or more	.673	.661	.717	.759
Birth decade ³ :				
1910-19	.009	.067	.001	.026
1920-29	-.143	-.127	-.167	-.158
1930-39	-.352	-.358	-.354	-.342
1940-49	.499	.477	.447	.515
1950-59	.240	.332	.244	.306
1960-68	.964	.980	.834	1.045
Female	-.205	-.151	-.149	-.175
Minorities	.181	.194	.205	.160
Disabilities and their associated characteristics				
ADL limitations:				
3-5	*.713	—	—	.578
6-7	**800	—	—	.558
Unpaid help by each caregiver (weekly hours)	—	**009	—	.006
Years of caregiving:				
6-10	-.295	-.298	-.313	-.312
3-5	-.437	-.419	-.456	-.448
2	.267	.229	.291	.217
1	.613	.651	.707	.650
Physical burden	—	—	**711	.503
Emotional burden	.633	.653	.499	.467
Other resources to cope with disabilities				
Assistive equipment for:				
ADL disabilities ⁴	-.152	-.115	-.073	-.142
IADL disabilities ⁴	-.252	-.309	-.279	-.219
Home modifications	-.350	-.356	-.379	-.386
Day care or senior centers	.130	.249	.182	.163
Paid help	**695	**821	**756	**675
Number of caregivers helping a recipient:				
1	***-1.737	***-1.954	***-1.865	***-1.741
2	***-1.165	***-1.204	***-1.211	***-1.119
3	***-1.442	***-1.472	***-1.429	***-1.401
Caregiver and recipient living together	-.119	-.117	-.141	-.253
Intercept	**1.807	*1.558	*1.620	**2.015
$\hat{P} = \exp(\bar{X}b)/1 + \exp(\bar{X}b)^5$.049	.048	.047	.045
Chi-squared	132	129	131	142
N = 1,746				

* Statistically significant at .10 level.

** Statistically significant at .05 level.

*** Statistically significant at .01 level.

¹Maximum likelihood logit regression coefficients.

²The standard errors (not shown) are multiplied by a factor of 1.4 to adjust for the sample design effect and for the fact that a care recipient can have more than one caregiver.

³The public-use tape provides information on the birth decade but not on the birth year. Caregivers under age 14 were excluded from the National Informal Caregiver Survey by the survey design. (The youngest caregiver in 1982 was born in 1968.)

⁴Assistive equipment for ADL disabilities in a binary variable and so is equipment for IADL disabilities. There is some overlap because some persons have such equipment for both ADL and IADL disabilities.

⁵Predicted mean probability.

NOTES: ADL is activities of daily living. IADL is instrumental activities of daily living.

SOURCES: (Office of the Assistant Secretary for Planning and Evaluation, 1986) and with specific reference to footnote²: Tourangeau, R.: Informal Caregivers: Report on Sampling. *Long-Term Care Survey and National Survey of Informal Caregivers, 1982; Report on Methods and Procedures Used in Surveys, Part 2, Documentation*, National Technical Information Service PB86-161791. 1986.

Table 3

Percent change in the probability of becoming a former caregiver within a 3-month period: 1982

Variables with statistically significant coefficients	Equation 1	Equation 2	Equation 3	Equation 4
ADL ¹ limitations:		Percent change		
3 to 5	3.2	—	—	2.5
6 to 7	3.6	—	—	2.4
Unpaid help by each caregiver (weekly hours)	—	.4	—	.3
Physical burden	—	—	3.2	2.2
Paid help	3.1	3.8	3.4	2.9
Number of caregivers helping a recipient:				
1	-7.8	-8.9	-8.4	-7.5
2	-5.2	-5.5	-5.4	-4.8
3	-6.5	-6.7	-6.4	-6.0

¹The magnitude is computed as the partial derivative of the *k*th variable evaluated at the mean of all explanatory variables and converted into percents: $(\partial P/\partial x_k)100 = b_k \bar{P} (1-\bar{P}) 100$.

NOTE: ADL is activities of daily living.

SOURCE: (Office of the Assistant Secretary for Planning and Evaluation, 1986).

imposed a greater physical burden on their caregivers than former recipients who stayed in the community.

The major determinants of caregiver attrition are the degree of dependence of the frail and disabled persons on others and the burden that this dependence imposes on their caregivers. When an elderly individual has six to seven ADL disabilities, help has to be available on demand because such a person cannot get out of bed or to the toilet without assistance. Under such circumstances, the caregiver's entire daily schedule may be tied to the needs of the care recipient; a helper has to be around all the time because the disabled person cannot be left alone and, at night, the caregiver's sleep may be interrupted. This routine is likely to lead to nursing home placement, where 24-hour availability does not devolve on a single individual. To ease the burden on caregivers and to avoid the financial and emotional cost of institutionalization, some care recipients have paid help to supplement their unpaid help (Liu, Manton, and Liu, 1985). This study demonstrates that either the number of ADL disabilities or the physical burden reported by caregivers can serve as an indicator that some sources of informal help will dry up.

Further, the study ascertains the characteristics that have no effect on caregiver attrition. It shows that work outside the home does not lead active caregivers to withdraw from caregiving, although full-time employment reduces the number of hours of help they provide. Raising children does not affect caregivers' decision to quit. Nor does the emotional distress cause attrition. Also, neither the demographic characteristics of caregivers, nor assistive equipment or home modifications that might improve the functioning of the disabled elderly, nor their attendance at senior centers have any effect on the decision to quit caregiving.

Many studies examined the stressfulness of caregiving, but stress does not necessarily result in quitting. This particular study goes a step further to determine which factors increase the probability that caregivers drop out. The signal is clear: quitting is more likely to occur when the care recipient has many ADL limitations and needs help on demand. Equipped with this knowledge, policymakers may implement measures that provide for

substitute services. Some disabled persons may have to be placed in an institutional setting where the personnel are available to provide help around the clock; others may be able to remain in the community if their disabilities are manageable and paid help at home is not more costly than institutional care. Maintenance in the community and minimization of long stays in nursing homes will have to be considered an important goal of public policy in view of the expected increase in the number of very old persons and their preferences for continued living in the community as long as feasible (Sherwood, Morris, and Ruchlin, 1986). Rivlin et al. (1988) show that public and private insurance programs could be designed to assure affordable paid help in the community, which might substantially ease the difficulties of the disabled elderly and their caregivers. The implementation of such programs is a major issue for public policy in the 1990s.

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