

# Sample Bias in Caregiving Research

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*Data on subject selection biases in research with older adults are limited. We conducted two sample bias studies that assessed primary caregivers for dementia patients. The first study compared 46 caregivers, who required home interviews, with 63 caregivers willing to travel to the university hospital for assessment; all subjects had been offered free taxi service. Caregivers interviewed at home were helping more hours per day and were more depressed than those assessed at the university; in addition, the patients of caregivers assessed at home were more impaired and had greater personality changes. The second study compared available information from respite care users who chose to participate in our caregiver research project with those who chose not to participate. Nonparticipants provided care for more impaired patients. No demographic differences were found between groups in either study, and there were no differences in the chronicity of caregiving. The implications of these data for aging research are discussed.*

**B**IASSES resulting from selective research participation can have important implications for the generalizability of research data. Rosenthal and Rosnow (1975), reviewing evidence on research participation, noted that women participate more often than men, and participants are better educated and of higher socioeconomic status than nonparticipants. The latter finding has been reported elsewhere in mental health research (Bebbington, Hurry, Tennant, Sturt, & Wing, 1981).

In aging research, however, selection bias has received limited attention. For example, Hoyer, Raskind, and Abrahams (1984) reviewed the research practices of studies published in the *Journal of Gerontology* (Psychological Sciences Section) from 1975-1982. They found that only a small percentage of studies provided detailed information on sampling procedures. Similarly, in a review of sampling techniques in widowhood research, Gentry and Shulman (1985) noted that one third of the studies failed to detail the methods used for sampling. In general, little information is available on refusal to participate or the possible role of site of assessment as a selection factor.

This study addressed sample bias issues in caregiving research. Given the time involvement and concomitant decrease in mobility associated with providing care for a cognitively impaired family member (Kiecolt-Glaser, Dyer, & Shuttleworth, 1988; Schulz, Tompkins, & Rau, 1988; Zarit, Orr, & Zarit, 1985), participation in research may be problematic for many caregivers.

Excessive time demands are commonly cited as the most difficult component of caregiving (Select Committee on Aging, 1987), and competing time demands are a significant barrier to research participation (Rosenthal & Rosnow, 1975; Savitz, Hammon, Grace & Stroo, 1986). Thus, some samples might reflect the effects of selective participation due to the time demands and restricted mobility commonly associated with caregiving.

Similarly, mobility is often reduced in older adults. As such, caregivers capable of traveling to a central data collection center may not be representative of the larger popula-

tion. Because health problems and health-related disabilities are common impediments to travel, research that requires travel for participation may skew the sample toward more functional, healthier subjects.

We hypothesized that Alzheimer's disease (AD) caregivers assessed at home would be different than AD caregivers assessed at a university hospital site, with at-home assessed caregivers spending more time caregiving and caring for more impaired AD patients. We also predicted that at-home assessed caregivers would be more distressed than their university-assessed counterparts. In addition, nonparticipants were expected to provide greater amounts of care and to provide care for more impaired family members. No sex differences in participation were predicted. Given the preponderance of women as caregivers (Fitting, Rabins, Lucas, & Eastham, 1986), more females than males were expected among both participants and nonparticipants, and this was expected to override any effect gender might have had on volunteering.

## METHOD

The caregivers used in this study were part of a larger study of chronic stress and health in older adults. Primary caregivers who were providing at-home care were recruited from multiple sources including neurologists, hospital dementia evaluation units, dementia caregiver support groups, announcements in the Alzheimer's Disease Association monthly newsletter, respite care programs, and governmental caregiver support programs. Participation required completion of a variety of interview and self-report measures, as well as provision of a blood sample. All volunteers were paid \$30.

*Depression measures.* — The Hamilton Depression Rating Scale (HDRS; Guy, 1976) was used to assess current depressive symptomatology. The 24-item scale was rated by the interviewer based on observation and the subject's response to probes. Interrater reliability, assessed from ran-

domly selected audiotapes for 10% of the interviews, was .85.

The Brief Symptom Inventory (BSI; Derogatis & Spencer, 1982) was used to assess general psychological distress during the preceding week. This 53-item scale provides subscores on nine dimensions of psychopathology. Data from the six-item depression subscale served as a self-report depression measure in the present study.

#### *Dementia Assessment*

Family members can provide reliable data on dementia patients' characteristics (Reifler, Cox, & Hanley, 1981). In a sample of 82 elderly patients, the majority of whom had an AD diagnosis, there was a high degree of concordance between family and staff members regarding patient functioning (Reifler et al., 1981).

In order to help confirm the diagnosis of the impaired patient, caregivers were asked a number of questions concerning the assessment center, the year, and the types of assessment used to establish the dementia diagnosis. The great majority of the demented patients had received a diagnosis of AD at one of three city hospitals that used the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders recommended assessment battery (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984). Duration of caregiving was assessed by asking caregivers to specify, to the nearest month, the point in time at which assistance or supervision of the demented patient began.

The Blessed Dementia Scale (BDS; Blessed, Tomlinson, & Roth, 1968) was developed to measure negative changes in a demented person's abilities across daily living, self-care, and personality domains. Higher scores on this 22-item scale denote greater decrements in ability, with a potential range from 0 to 28. BDS scores correlate with senile plaque count during postmortem histological examination (Blessed et al., 1968; Erkinjuntti, Hokkanen, Sulkava, & Palo, 1988). In addition, the BDS correlates with neuropsychological testing and can be used to differentiate degree of dementia (Erkinjuntti et al., 1988). Caregivers completed the instrument using an interview format.

The Memory and Behavior Problem Checklist (MBPC; Zarit, Reever, & Bach-Peterson, 1980) measures behavioral excesses and deficits in dementia patients, and the caregiver's reaction to those problems. The 29 items include some of the problems most distressing to caregivers, e.g., the patient's inability to dress and feed him- or herself, incontinence, inability to communicate, hiding things, and inability to recognize familiar people. The scale provides three scores: a measure of the frequency of problem behaviors, a measure of associated caregiver distress, and a third score that combines frequency and reaction to produce a summary measure. The MBPC measures current symptoms and associated subjective caregiver distress, not impairment of the patient per se, as many behavior problems are most prevalent in the middle stages of dementia. The frequency of behavior problems served as a measure of current behavioral manifestations of dementia, greater frequency of problem behaviors being assumed a greater barrier to participation or travel due to an increased need for management.

The Global Deterioration Scale (GDS; Reisberg, Ferris, DeLeon, & Crook, 1982) provides a rating of dementia stage in patients who have been previously diagnosed with dementia. The scale has seven well-described anchor points, from 1 (no cognitive decline) to 7 (very severe cognitive decline). Ratings were based on caregivers' reports of the affected family members' history and current functioning. Scores on the GDS correlate with scores on 38 cognitive tasks and two physiological measures: ventricular and sulcal enlargement as measured by computerized tomographic (CT) scans, and glucose metabolism as measured by positron emission tomography (PET) scans (Reisberg et al., 1982). Interrater reliability using the GDS was assessed by comparing ratings made by the original interviewer with those of a clinical psychologist with geriatric assessment experience. The clinical psychologist, blind to the prior rating, based his ratings on information from the BDS and MBPC. Reliability was computed for a random sample of 22% of cases; the Pearson product moment correlation between the original and comparison GDS scores was excellent,  $r = .84$ .

*Study 1 procedure: Caregivers assessed at home vs at the university.* — After a caregiver agreed to participate, interviews were scheduled. When possible, in an effort to reduce project personnel time, caregivers were encouraged to come to the university clinic for assessment, and the availability of free taxi service paid by the project was discussed; those who said it would be difficult or impossible to come to the university were offered home interviews. The sample included 63 subjects assessed at the clinic (5 Black, 58 White) and 46 subjects assessed at home (3 Black, 43 White). In all cases dementia patients and caregivers shared residence. At-home assessed caregivers were compared to clinic-assessed caregivers on the depression and dementia-related level of impairment measures.

*Study 2 procedure: Participants versus nonparticipants recruited from respite program.* — One of the sites used to recruit caregivers was a government-funded respite care program for progressive dementia caregivers. All caregivers who used the service were sent a letter describing the study, and they were then contacted by phone to discuss participation.

The head of the respite care program, a nurse with geriatric training and extensive experience with AD patients, completed data sheets detailing demographic characteristics of the caregivers who declined to participate in our study and severity ratings of the affected family member, using the instruments described above. Information for nonparticipant respite users was gathered during an extensive interview of the caregiver at entry into the respite program. Impairment ratings on the GDS and BDS were discussed by the nurse and senior author on a case by case basis, with the nurse's ongoing contact with the demented patient serving as data upon which ratings were based.

Of the 46 subjects contacted, complete information was attainable on 18 who participated and 18 who did not. Adequate information was not available for 10 nonpartici-

Table 1. Demographic Characteristics by Study

	Study 1				Study 2			
	At-home Assessed		Clinic Assessed		Participant		Nonparticipant	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sex								
Male	11	24%	22	35%	4	22%	8	44%
Female	35	76%	41	65%	14	78%	10	56%
Income (\$)								
<10,000	4	89%	4	6%	3	17%	3	17%
10–14,999	5	11%	8	13%	3	17%	3	17%
15–19,999	9	19%	10	16%	3	17%	3	17%
20–29,999	12	26%	17	27%	6	33%	4	22%
30–39,999	6	13%	8	13%	1	5%	1	5%
40,000 +	10	22%	16	25%	2	11%	4	22%
Age	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )
	59.90	(15.02)	61.02	(11.60)	65.11	(12.51)	70.28	(9.81)

pants due to limited recent contact with the respite provider; therefore they were excluded from the study.

## RESULTS

### Study 1

Demographic comparison of clinic versus at-home assessed caregivers (Table 1) showed no significant differences between groups on sex, income, education, relationship of patient to caregiver, and age. Caregivers assessed at home included 28 spouses and 18 adult children; clinic-assessed caregivers were 40 spouses and 23 adult children.

Stage of dementia rating (GDS) was compared using analysis of variance (ANOVA), and at-home assessed caregivers were found to be caring for more impaired family members  $F(1,102) = 4.93, p < .03$ . Daily living, self-care, and personality scales of the BDS were compared using multivariate analysis of variance (MANOVA), and a significant group effect was found  $F(3,100) = 2.56, p < .05$ . Subsequent ANOVAs found at-home assessed caregivers reported significantly greater personality changes,  $F(1,102) = 5.33, p < .02$ . No significant group effects were found on the daily living,  $F(1,102) = 2.70, p < .10$ , or self-care,  $F(1,102) = 1.46, p < .23$ , scales. Similarly, at-home assessed caregivers also reported a significantly greater frequency of problem behaviors on the MBPC  $F(1,102) = 5.36, p < .02$ .

Comparison of at-home versus clinic-assessed caregivers on the average hours of care provided per day showed that at-home assessed caregivers provided significantly more daily care,  $F(1,96) = 5.35, p < .02$ . Length of time since onset of caregiving was compared using an ANOVA, and no significant difference was found,  $F < 1$ .

A MANOVA assessing group differences on the two distress measures, HDRS and the BSI Depression Subscale, was significant (Wilks  $F(2,103) = 3.84, p < .03$ ). Subsequent ANOVAs found significantly higher HDRS scores in home-assessed caregivers,  $F(1,104) = 5.37, p < .02$ , but no

Table 2. Study 1: Means and Standard Deviations for Caregiving and AD Patient Variables by Site of Assessment

	At-home		Clinic	
Months spent caregiving	67.71	(145.93)	52.54	(48.78)
Average hours caregiving daily*	10.85	( 5.79)	8.11	( 5.60)
MBPC frequency*	55.16	( 17.29)	46.43	(20.64)
Hamilton Depression Rating Scale*	9.28	( 6.90)	6.54	( 6.08)
BSI Depression	57.00	( 9.43)	56.15	(10.09)
AD patient information				
Blessed Dementia Scale				
Daily living	5.70	( 1.90)	5.00	( 2.33)
Self-care	3.91	( 2.88)	3.25	( 2.65)
Personality*	6.82	( 2.67)	5.68	( 2.37)
Global Deterioration Scale*	5.48	( 1.17)	4.90	( 1.34)

\* $p < .05$ .

significant differences were found on BSI Depression subscale scores,  $F < 1$ . These data are presented in Table 2.

### Study 2

Demographic characteristics of the second sample are presented in Table 1. All caregivers were providing assistance to their spouse at home. Comparison of participants and nonparticipants on demographic variables showed no significant differences between groups. Similarly, no significant differences between groups were found in ANOVAs used to compare participants and nonparticipants on number of hours spent caregiving,  $F_s < 1$ .

Daily living, self-care, and personality scales of the BDS were compared using a MANOVA, and a significant group difference was found,  $F(3,32) = 5.61, p < .003$ . Subsequent ANOVAs showed that nonparticipants reported significantly greater personality changes,  $F(1,34) = 17.64, p < .0002$ . No significant group effects appeared on daily activity or self-care,  $F < 1$ . Comparisons of family members' stage of dementia revealed significantly higher GDS scores

for the affected family members in the nonparticipant group,  $F(1,34) = 6.48, p < .02$ . Caregiver and AD patient variable values are presented in Table 3.

## DISCUSSION

At-home assessed caregivers spent more hours per day in caregiving activities than their clinic-assessed counterparts, had to cope with more problem behaviors, and provided care for more impaired family members who had experienced greater personality changes. At-home assessed caregivers also appeared more depressed than their clinic-assessed counterparts; this latter finding must be interpreted cautiously due to the lack of convergence between self- and other-rated depression measures, as discussed below. In contrast, no differences between groups appeared on sex, age, education, income, or chronicity of caregiving. These data suggest that caregiver studies that limit participation to those able and willing to travel to a central assessment site may bias their samples toward less depressed caregivers who provide care for less impaired family members with fewer dementia-related personality manifestations.

The finding that the 6-item BSI depression subscale was not significantly different between groups, in contrast to the HDRS, may be a function of the truncated range of the BSI subscale. The HDRS is likely a more sensitive measure, given its specificity of design and the broader sampling of depressive symptoms provided by a range of 24 items. Additionally, caregivers' tendency to minimize personal distress, thus lowering self-report on depression scales, has been previously noted in the literature (Becker & Morrissey, 1988).

Differences in caregiving variables between participants and nonparticipants were found in the expected direction. Nonparticipants' family members were more impaired and had experienced more personality changes, although daily living and self-care abilities were comparable. A case can be made that caregivers who do not participate may represent a more burdened, hidden, subpopulation of caregivers (but due to restricted sample size this should be done cautiously).

Both participant and nonparticipant respite care users had extreme values on caregiving variables. Mean daily time spent providing care exceeded 9.5 hours for both groups. It appears likely that respite care users, both participants and nonparticipants, represented a highly involved group of caregivers. Previous research exploring patterns of respite use supports this contention, suggesting that caregivers use supportive services only after reaching the limits of their personal endurance (Bass & Noelker, 1987). Even so, nonparticipants cared for more impaired family members.

These data may have broader implications for aging research, especially when research subjects are recruited from service sites. Other research has suggested that it is more difficult to accrue elderly controls than younger controls (e.g., Olsen & Mandel, 1988). Moreover, the same factors that are related to initial nonparticipation can also play a longer-term role in selective attrition from longitudinal studies (Cooney, Schaie, & Willis, 1988). Studies addressing dysphoria in older populations should ideally offer home-assessment of subjects as one option in order to provide the

Table 3. Study 2: Means and Standard Deviations for Respite Care Users Who Participated in the Caregiver Research Project

	Participants		Nonparticipants	
Months spent caregiving	54.27	(55.21)	32.34	(16.09)
Average hours caregiving daily	9.63	(6.40)	9.51	(9.31)
AD patient information				
Blessed Dementia Scale				
Daily Living	7.22	(1.05)	7.17	(1.21)
Self-care	5.56	(3.03)	5.33	(2.72)
Personality**	7.50	(2.26)	10.11	(1.36)
Global Deterioration Scale*	6.38	(0.70)	5.61	(1.09)

\* $p < .05$ ; \*\* $p < .001$ .

most representative data and maximize longitudinal participation.

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