

Family care giving for patients at life's end: Report from the Cultural Variations Study (CVAS)

ETIENNE PHIPPS, PH.D.,¹ LEONARD E. BRAITMAN, PH.D.,² GALA TRUE, PH.D.,³
DIANA HARRIS, M.A.,³ AND WILLIAM TESTER, M.D.⁴

¹Albert Einstein Healthcare Network, Center for Urban Health Policy and Research,
Thomas Jefferson University, Philadelphia, Pennsylvania

²Albert Einstein Healthcare Network, Office of Research and Technology, Philadelphia, Pennsylvania

³Albert Einstein Healthcare Network, Center for Urban Health Policy and Research, Philadelphia, Pennsylvania

⁴Albert Einstein Healthcare Network, Albert Einstein Cancer Center, Philadelphia, Pennsylvania

(RECEIVED March 6, 2003; ACCEPTED May 31, 2003)

ABSTRACT

Objective: To investigate differences between African American and White family caregivers in self-reported health, use of social support and external resources, and emotional and financial strain in the context of their care of a family member with advanced cancer.

Methods: Sixty-nine patient-designated family caregivers of patients with advanced lung or colon cancer interviewed between December 1999 and July 2001.

Results: Most African American and White family caregivers were able to identify someone else who was helping them in the care of their family member. Few caregivers used outside resources (e.g., home-based medical care, meal delivery, pastoral care, outside social support visitor) to assist in the support and care of the patient. At baseline, White caregivers were more likely to agree that caregiving caused work adjustments ($\rho = .28, p = .02$) and emotional difficulties ($\rho = .32, p = .008$) and that caregiving had been completely overwhelming ($\rho = .19, p = .12$) than were African American caregivers. At follow-up, among family caregivers of patients who had died, 44% reported having to quit work to provide personal care for the patient. Twenty-five percent of family caregivers reported using most or all of the family's saving in caring for the patient.

Significance of results: Caregivers of patients at end of life experience substantial emotional and financial difficulties related to caregiving. Family caregiving is a private undertaking with little use of outside resources to mitigate the burden.

KEYWORDS: Family caregiver and advanced cancer, End-of-life, Caregiver burden

INTRODUCTION

Family caregivers contribute to the quality of life and help support the autonomous functioning of the person with advanced cancer. As the disease progresses, family caregivers are often the ones who deal with the day-to-day realities of trans-

porting patients to and from medical appointments, arranging for nursing care, picking up medications, and providing for other needs. Indeed, caring for individuals with cancer who are receiving cancer treatment, whether for palliative or curative intent, requires an average of 10 hours of informal caregiving per week, and caring for cancer patients not receiving treatment requires an average of 6.8 hours per week (Hayman et al., 2001).

A family caregiver's ability to cope with the demands of caring for a loved one with advanced cancer is influenced by the presence or absence of

Corresponding author: Etienne Phipps, Einstein Center for Urban Health Policy and Research, Albert Einstein Healthcare Network-Germantown, 1 Penn. Blvd., Philadelphia, PA 19144.
E-mail: phippst@einstein.edu

personal, social, and spiritual supports as well as by knowledge and use of outside resources. Lifestyle interference, in which routines are broken and adjustments need to be made to address the needs of the unwell person, has been shown to predict emotional stress in family caregivers of patients with advanced cancer (Cameron et al., 2002; Goldstein et al., 2002).

Some researchers have written about differences in attitudes and behaviors of certain ethnic groups toward caring for a terminally ill family member compared with White caregivers. Aranda and Knight (1997) suggest that individuals from different ethnic and cultural traditions have different patterns of appraising stress and of coping with stress. White et al. (2000) found that African American adult women who become caregivers to their parent report less stress and more rewards from caregiving than do White women. Other researchers (Haley et al., 1995; Connell & Gibson, 1997) have reported that White caregivers are more susceptible to depression and emotional stress. In contrast, Williams (2000) reported African American and White caregivers to have similar estimates of distress and hardiness. These studies indicate that, although there appears to be variation in the experience of caregiving, the extent to which these represent ethnic differences is not entirely clear.

The objective of The Cultural Variations Study (CVAS), a prospective study of African American and White advanced cancer patients (stage III-B or IV lung cancer or Stage IV colon cancer) and their family caregivers, is to investigate differences in attitudes, preferences, and behaviors related to end of life. In this report, we examine differences in caregiver health, emotional and financial strain, and use of family and outside resources to assist in the care and support of the patient, at baseline and again 8 months later.

METHODS

The rationale and design of CVAS have been presented elsewhere (Phipps et al., 2003). The research was carried out in Philadelphia, Pennsylvania. Family caregivers were identified by the study patient as the person most involved in their care. Family caregiver interviews were conducted separately from the patient, at baseline, and at 8-month follow-up. Baseline interviews were conducted in the home of the caregiver or in the Albert Einstein Cancer Center. Follow-up interviews were conducted over the telephone. We utilized ethnic matching of interviewers with interviewees to promote comfort and honest disclosure (Weeks & Moore, 1981).

Family caregiver interviews addressed caregiver health, family and social support, use of outside resources to support and care for the patient, and caregiver emotional and financial strain. Outside resources were defined as: medical and home-based nursing care, social support (such as the use of a buddy or visitor from an organization such as the Red Cross), pastoral care, and meal delivery as well as any other resource identified by the caregiver as providing support and/or care for the patient. We adapted questions from the "Caregiver Strain Index" (Robinson, 1983) to focus on specific areas of strain: (1) adjustments at work, (2) emotional strain, and (3) financial strain. We also asked the caregiver to identify all relevant persons who were helping them in the care of the patient (SUPPORT, 1995; Teno, 1999). Caregivers rated their overall health on a five-point ordinal scale from excellent to poor using Ware's (1993) measure of global health status, known to be highly predictive of future objectively measured health outcomes.

Follow-up interviews assessed any changes in family caregiver self-reported health, use of resources, and emotional and financial strain. For family caregivers of patients who had died, we additionally recorded the site of the patient's death, whether or not the patient was enrolled in hospice at the time of death, and whether advance directives played a role in medical decision making at end of life (Teno, 1999).

The study was approved by the Institutional Review Board of the Albert Einstein Healthcare Network in Philadelphia. Written informed consent was obtained from all participants.

Statistical Analysis

We compared dichotomous variables by Fisher's exact test. All *p* values are two tailed. Associations involving ordinal level variables were assessed using the Spearman's rank correlation, ρ (rho). Caregiver self-reported health at follow-up was compared to health at baseline using the sign test. Statistical analyses were performed using Stata 7.0 (College Station, TX).

RESULTS

We report results on 69 family caregivers (Table 1). The median age of caregivers was 53 years. Thirty-six percent of family caregivers were spouses or partners of the patient and 35% were children of the patient. A greater percentage of African American caregivers were female (92% vs. 69%). Fifty-four percent of African American patients and 65%

Table 1. Characteristics of caregiver sample

	African American (<i>N</i> = 37), <i>n</i> (%)	White (<i>N</i> = 32), <i>n</i> (%)
Female gender	34 (92)	22 (69)
Age (median, range)	54 (25 to 85)	53 (53 to 87)
Married/living with partner	20 (54)	20 (63)
High school graduate or above	34 (90)	28 (88)
Religious affiliation		
Protestant	27 (73)	7 (22)
Catholic	4 (11)	15 (47)
Jewish	0	9 (28)
Other	5 (14)	1 (3)
None	1 (3)	0
Relationship to patient		
Partner/spouse	12 (32)	13 (41)
Sibling	1 (3)	3 (9)
Parent	2 (5)	0
Child	13 (35)	11 (34)
Other related	4 (11)	2 (6)
Other nonrelated	5 (13.5)	3 (9)
Uninsured	3 (8)	3 (9)

of White patients in the study were female (Phipps et al., 2003).

Family Caregiver Health

At the beginning of the study, 25% of family caregivers reported their health as fair or poor. More African American family caregivers reported that they were in fair or poor health compared with Whites (32% vs. 16%, $p = .16$).

At 8-month follow-up, caregiver health was similar to health at baseline among caregivers of patients who were still alive (those patients hereafter referred to as survivors; $p = .50$) and among caregivers of patients who died ($p = .61$).

Context of Caregiving

At the beginning of the study, 38 of 69 family caregivers (55%) provided care for a family member who was receiving either palliative radiotherapy or palliative chemotherapy. A greater percentage of African American caregivers were providing care for family members receiving one of these palliative therapies (63% of African American caregivers vs. 45% of White caregivers, $p = .15$). Three family caregivers had patients who were enrolled in hospice at the beginning of the study.

At follow-up, 36 family caregivers (52%) had a family member who was still alive. Of these, 3 (8%) had a family member enrolled in hospice.

At follow-up, in cases where the patient had died, 18 (64%) of those families used hospice services

(83% of Whites and 50% of African American family caregivers, $p = .58$). Ten patients (36%) died in either a hospital or a nursing home. Living wills (LW) were completed by patients of 3 African American family caregivers (20%) and 12 (92%) White family caregivers ($p < .001$). Two (14%) African American caregivers and 9 (70%) White family caregivers had patients who had a signed durable power of attorney (DPOA; $p = .006$). Three (21%) African American caregivers and 7 (58%) White caregivers discussed the patient's directions in the LW or discussed the proxy appointment of the DPOA with the patient who died ($p = .11$).

Help in Caring for the Patient

At the beginning of the study, 23% of family caregivers had no one in their family or extended social support system helping them in the care of the patient. African American caregivers were alone in caring for the patient in 38% of the cases and White caregivers in 26% of the cases ($p = .31$).

At follow-up, 35% of family caregivers of survivors reported that no one else was helping them in the care of the patient (42% of Whites and 28% of African Americans, $p = .50$).

Almost all family caregivers of patients who died reported having help caring for the patient in the last two weeks of life (93% of African Americans and 100% of Whites). In addition, most family caregivers reported daily contact with the patient in the last week of the patient's life (87% of African Americans and 92% of Whites).

Use of Outside Resources

At baseline, few caregivers used outside resources to support the care of the patient. Seven (10%) family caregivers used pastoral care to attend to the patient; 6 (9%) had home-based medical or nursing care; 5 (7%) had an outside social support visitor (e.g., cancer buddy support); 4 (6%) caregivers reported the use of other kinds of resources to provide care for the patient (i.e., other friends and hospice worker); 1 caregiver used home-meal delivery. African American and White family caregivers were similar in their use of most outside resources at baseline. However, home-based medical or nursing care was used more by White family caregivers than African American family caregivers (16% vs. 3%, $p = .085$).

There was little increase in the use of outside resources among family caregivers of survivors compared with baseline. Five (14%) family caregivers of survivors had home-based medical or nursing care; 1 (3%) had home meal delivery; 7 (19%) used pastoral care; 5 (14%) had an outside social support visitor; and 2 (5%) used other sources of support (i.e., pharmacy delivery, and paratransit). None of the caregivers of survivors had meal delivery.

African American and White family caregivers of survivors were similar in the use of meal delivery and home-based medical or nursing care. Pastoral care was used by 28% of African American caregivers and 11% of White caregivers ($p = .23$), social support visitors by 22% of African American caregivers and 5% of White caregivers ($p = .18$), and other resources (as identified above) by 11% of African American caregivers and no White caregivers ($p = .23$).

In the last week in the patient's life, home-based medical or nursing care was used by 47% of African Americans and 69% of Whites ($p = .28$), pastoral care was used by 21% of African Americans and 46% of Whites ($p = .24$), and social support visitors by 7% (or 1) of African Americans and 23% of Whites ($p = .31$).

Emotional Strain

At the beginning of the study, 31 (56%) caregivers reported that caregiving caused emotional difficulties; 25 (37%) reported that caregiving had been completely overwhelming. White caregivers were more likely to report that caregiving caused work adjustments ($\rho = .28$, $p = .02$), that caregiving caused emotional difficulties ($\rho = .32$, $p = .008$), and that caregiving had been completely overwhelming ($\rho = .19$, $p = .12$) than were African American caregivers. Educational level of caregivers was not

associated with caregiving being completely overwhelming nor with agreement that caregiving caused emotional difficulties (data not shown).

Among family caregivers of survivors, 14 (38%) reported that caregiving had been completely overwhelming and 22 (59%) that caregiving caused emotional difficulties. Similar percentages of African Americans and Whites of surviving patients agreed that caregiving was completely overwhelming; Whites more strongly agreed with the statements that caregiving caused emotional difficulties ($\rho = .37$, $p = .03$).

Financial Strain

At the beginning of the study, 27 (49%) family caregivers reported that caregiving caused work adjustments. Twelve (18%) reported that care had been a financial strain.

Financial strain was similar in White and African American caregivers ($p = .88$). In terms of financial stress, the more highly educated the caregivers were, the more likely they were to report that caregiving necessitated work adjustments ($\rho = .33$, $p = .006$).

At follow-up, among caregivers of survivors, 13 (35%) reported that caregiving necessitated work adjustments and 8 (22%) said that caregiving caused financial strain. Similar percentages of African Americans and Whites of surviving patients agreed that caregiving caused financial strain.

Among family caregivers of patients who had died, 44% reported having to quit work to provide personal care for the patient. The need to use most or all of the family's savings in response to the patient's illness was reported by 25% of all family caregivers. Thirteen percent of African American caregivers and 23% of White caregivers of deceased patients reported problems with the patient's health insurance during or after the patient's death.

DISCUSSION

Family caregivers play a major role in supporting and assisting the patient at end of life and in contributing to that patient's quality of life. Substantial emotional and financial adjustments were experienced by caregivers regardless of ethnic background or educational status. Our findings are similar to those reported in SUPPORT by Covinsky et al. (1994) where, in 20% of the families of (2,661 seriously ill) patients, a family member had to quit work or make another major life change to provide care for the patient and 31% reported loss of most or all of the family savings. We also found that the

initial process of emotional adjustment to caregiving appeared to be more difficult for Whites than for African Americans.

Overall, our findings support a view of a private and often isolated world of family caregiving that is confirmed in other studies reporting low use of outside support-related resources by families caring for terminally ill family members (Stetz & Hanson, 1992; Horwitz & Reinhard, 1995; Aranda & Knight, 1997; Navaie-Waliser et al., 2001).

One limitation of our study was the decreasing sample size over the course of the study, which limited our ability to draw definitive conclusions about the subgroups of family caregivers of patients who were still alive and of family caregivers of patients who died. Still, there appear to be a number of potentially important differences between African American and White caregivers that require a larger sample size to confirm.

In some ways, there appears to be heightened vulnerability of African American family caregivers. Their self-reported health was worse than their White counterparts. They used less home-based medical or nursing care for the patient over the course of the study. Fewer of the patient family members of African American caregivers had advanced directives or durable powers of attorney. Similarly, fewer African American caregivers reported discussing the patient's directions in the LW or DPOA in cases where the patient subsequently died. And fewer African American patients died with hospice care compared with Whites. This difference could also contribute to the vulnerability, as hospice care is geared to provide support to both the patient and family at end of life.

On the other hand, White family caregivers appear to have a more difficult adjustment to the emotional and financial strains of caregiving or are at least more forthcoming in their responses to the interview questions. Both White and African American family caregivers were similar in their minimal use of outside resources except in the areas identified above. White family caregivers may give voice to the substantial emotional and financial effects of caring for a dying family member.

Overall, family caregiving is, in many ways, a private undertaking. Because of the numerous medical, psychosocial, and practical needs of the patient at end of life, this work cannot be easily sustained without the help of others. Indeed, although many family caregivers eventually have someone else helping them in the care of the patient, they are not likely to have all the required skills to care for patients at end of life. With the minimally reported outside help they get, family caregivers are likely to be underprepared for this difficult time. An im-

portant goal of end of life care today should be to provide more support to these family members.

Two additional limitations merit mention. Interviewing caregivers separately from patients enabled caregivers to speak more honestly about their views. However, our analyses are limited by not considering multiple family caregivers for a patient and by relying on the perspective of an individual family caregiver.

Last, our results may not be applicable to family caregivers dealing with diseases that have different end of life trajectories, such as coronary heart failure, chronic obstructive pulmonary disease, AIDS, and Alzheimer's dementia. Patients and families dealing with these other chronic terminal illnesses might have different experiences than those in our sample. Thus, generalizations to other family caregiver groups should be made cautiously.

ACKNOWLEDGMENTS

Funding/Support: Preparation of this article was supported by Grant R21-NR05112-02 (Phipps, PI) from the National Institute of Nursing Research. Author contribution: Study concept and design: Phipps, True, Braitman. Acquisition of data: Harris, Phipps, True, Tester. Analysis and interpretation of data: Phipps, Braitman, True. Drafting of manuscript: Phipps, Braitman, True. Critical revision of manuscript for important intellectual content: Phipps, Braitman, True, Tester, Harris. Statistical expertise: Braitman. Obtained funding: Phipps, True, Braitman. In addition, we would like to thank Natalie Brown for the data management and technical assistance for this project and Joanne Ackler, B.S.N., for her support throughout the research and for her helpful comments on earlier drafts of the manuscript.

REFERENCES

- Aranda, M.P. & Knight, B.G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *Gerontologist*, 37(3), 342–354.
- Cameron, J., Franche, R., Cheung, A., & Stewart, D. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, 94, 521–527.
- Connell, C.M. & Gibson, G.D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *Gerontologist*, 37(3), 355–364.
- Covinsky, K.E., Goldman, L., Cook, E., Oye, R., Desbiens, N., Reding, D., Fulkerson, W., Connors, A., Lynn, J., & Phillips, R. (1994). The impact of serious illness on patients' families. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Medical Association*, 272(23), 1839–1844.
- Goldstein, N., Concato, J., Fried, T., Cherlin, E., Kasl, S., & Bradley, E. (2002). Factors associated with caregiver burden among caregivers of patients with cancer in a hospice setting. *Journal of Clinical Epidemiology*, 55(6), 628.

- Haley, W.E., West, C.A., Wadley, V.G., Ford, G.R., White, F.A., Barret, J.J., Harrell, L.E., & Roth, D.L. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. *Psychology and Aging, 10*(4), 540–552.
- Hayman, J., Langa, K.M., Kabeto, M.U., Katz, S.I., DeMonner, S.M., Chernew, M.E., Slavin, M.B., & Fendrick, A.M. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology, 1*(19), 3219–3225.
- Horwitz, A. & Reinhard, S. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior, 36*(2), 138–150.
- Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C., Kuerbis, A.N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. *Gerontologist, 41*(6), 733–741.
- Phipps, E., True, G., Harris, D., Chong, U., Tester, W., Chavin, S.I., & Braitman, L.E. (2003). Approaching the end of life: A comparative study of attitudes and behaviors of African American and White patients and their family caregivers. *Journal of Clinical Oncology, 21*(3), 549–554.
- Robinson, B.C. (1983). Validation of a Caregiver Strain Index. *Gerontologist, 38*(3), 344–348.
- Stetz, K. & Hanson, W. (1992). Alterations in perceptions of caregiving demands in advanced cancer during and after the experience. *Hospital Journal, 8*(3), 21–34.
- SUPPORT. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association, 274*, 1591–1598.
- Teno, J. (1999). Afterdeath interview for Rhoda Island State Mortality Followback Survey, Version 6. In *Toolkit of Instruments to Measure End of Life*.
- Ware, J. (1993). SF-36 Health Status Questionnaire. In *Medical Outcomes Trust*.
- Weeks, M. & Moore, R. (1981). Ethnicity of interviewer effects on ethnic respondents. *Public Opinion Quarterly, 45*, 245–249.
- White, T.M., Townsend, A.L., & Stephens, M.A. (2000). Comparisons of African American and White women in the parent care role. *Gerontologist, 40*(6), 718–728.
- Williams, A.M. (2000). Distress and hardiness: A comparison of African-American and white caregivers. *Journal of the National Black Nurses Association, 11*(1), 21–26.