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Toward the Conceptualization and Measurement of Caregiver Burden Among Pueblo Indian Family Caregivers

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Purpose: The purpose of this study was to evaluate burden experienced by a group of American Indian primary family caregivers and to determine if caregiver burden is a multidimensional concept. ***Design and Methods:*** This analysis is based on the results of a survey questionnaire administered to 169 Pueblo primary family caregivers in New Mexico. ***Results:*** Analysis of the items composing the Caregiver Burden scale indicated that caregiver burden is multidimensional and consists of several types of burden. Caregiver burden, as identified in this sample, is composed of four dimensions: role conflict, negative feelings, lack of caregiver efficacy, and guilt. Investigations of caregiver burden should consider the multidimensionality of this experience and evaluate burden accordingly. ***Implications:*** By identifying the specific type of burden that a caregiver experiences, interventions can be targeted more accurately to support family caregiving.

Key Words: Family caregiving, American Indians, Caregiver burden

Despite the growth of aging programs in the United States, family support networks continue to provide most long-term care services to functionally impaired elders. In fact, it has been recognized for some time that as an elder's impairment level increases, the value of services provided by the informal support network also increases (General Accounting Office, 1977). Subsequent research has further established the family as the primary provider of long-term care services (American Association of Retired Persons & Travelers Foundation, 1988; National Alliance for Caregiving & American Association of Retired Persons, 1997; Stone, Cafferata, & Sangl, 1987; Wood & Wan, 1993). Whether or not one endorses the notion that minority families provide more support to their elders than non-Hispanic White families, there is a general consensus that minority families are changing in ways that reduce the ability of the family to provide long-term care services (Antonucci & Cantor, 1991; Burton & Dilworth-Anderson, 1991; John, 1999).

Moreover, as evidenced by lower institutionalization rates (Himes, Hogan, & Eggebeen, 1996; John, 1995) and lower proportions of minority elders living alone (Angel & Hogan, 1991), minority families are even more salient as the providers of long-term care services than among non-Hispanic White elders. Because families are the principal providers of long-term care services to minority elders, it is vital to understand the context of family caregiving, especially the problems that threaten the caregiving system. Clearly, the persons who actually provide most of the care to impaired elders are the essential element in the family caregiving system, and whatever compromises their ability to provide care places the system in jeopardy. This fundamental insight has resulted in the development of one of the most active areas of gerontological research for nearly two decades.

Despite the inordinate amount of attention given to family caregiving issues during this time, knowledge of caregiving issues among American Indians—whose population age 65 and older increased 52% between 1980 and 1990 (Barresi & Stull, 1993)—is far less developed than similar research on other groups. In fact, only a handful of studies have investigated any caregiving issues in this population. Moreover, little is known about how the problems and stresses of caregiving are handled in light of American Indian cultural norms and expectations for elder care. Although the extended family structure and traditional values of American Indian tribes support and prescribe elder care (Red Horse, 1980),

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family caregivers—particularly those in reservation settings—can and do experience various difficulties associated with caregiving.

American Indian Caregiving Research

To date, most of the published research on American Indian family caregiving has been based on qualitative investigations. In a single, small-scale qualitative study that compared the perceptions of caregiving burden and coping among 10 Northwest Indian and 10 White caregivers matched on sex, income, and rural residence, Strong (1984) suggested that the experience of caretaking responsibilities and stresses differed between the two groups. In comparison to White caregivers, Strong found that the responses of the Indian caregivers suggested that they perceived themselves as having less control over the caregiving situation and that they also placed more emphasis on the positive dimensions of managing the needs of a dependent elder. Indian caregivers used a coping strategy that Strong characterized as "passive forbearance," that is, emphasizing acceptance of and adaptation to the caregiving situation rather than attempting to actively control it.

A second research project conducted on caregiving in American Indian families (Hobus, 1990) is a single case study that described the intermediary role played by a nurse in helping a family prepare to provide care to a frail Lakota elder during her periodic home visits away from an off-reservation Anglo nursing home. Hobus identified seven major problems that emerged during the family assessment process, including knowledge deficits in how to provide care to the elder, lack of knowledge about how to obtain outside help, lack of familiarity with the consumer rights of nursing home patients, guilt related to not providing care to the elder at home, fear about the eventual death of the elder in an alien surrounding, resentment toward previous health care providers, and concern for the health of the primary family caregiver during the elder's home visits. Because the family had provided in-home care to the elder before her placement in the nursing home, some of these problems were based on the experience of full-time, in-home caregiving, although these issues were not the explicit focus of Hobus's research.

A broader qualitative study of the situation and experiences of family caregivers among five tribes (Hennessy & John, 1995, 1996; Hennessy, John, & Anderson, 1999) identified a number of sources of burden among these caregivers. These Indian caregivers reported commonly experienced stresses such as competing responsibilities between caregiving and work or other family duties and perceived negative effects on family relationships and on personal health and well-being. These burdens were often produced or exacerbated by conditions encountered on these reservations, such as lack of indoor plumbing, the need to chop and haul wood for cooking and heating, or lack of availability of or access to comprehensive services.

To some degree, the caregivers in this study (Hennessy & John, 1995, 1996; Hennessy, John, & Anderson, 1999) interpreted these burdens in a culturally distinct manner. For example, some family helpers viewed burden as being associated with those difficulties that negatively affected their ability to carry out their culturally endorsed role as care providers. Moreover, in contrast to findings reported for non-Hispanic White caregivers (e.g., Steinmetz, 1988), these American Indian caregivers emphasized the effects of caregiving strain on the group (i.e., family and tribe) rather than those that infringed on a caregiver's personal or individual needs (such as privacy or time for self).

In contrast to Strong's (1984) findings, Hennessy and John (1995) found that family caregivers were active in their attempt to enlist the support of others within both informal and formal support networks to create an effective caregiving routine (i.e., gaining mastery of the situation) and to seek information on potential resources to assist them with caregiving responsibilities. They found that caregivers in these five tribes accepted the caregiving situation, but not passively. Indeed, these caregivers also expressed some degree of resentment toward service providers and noncontributing family members for the lack of assistance with elder care. Overall, a salient finding was the pervasive sense of cultural obligation for caregiving that was expressed by these primary family caregivers. Hennessy and John (1996) concluded that this cultural norm underlies caregiving activities for this group of American Indians, with important policy and programming implications for the design and delivery of long-term care services.

These qualitative findings suggest that American Indian caregivers endorse certain burden concepts differently than their non-Hispanic White or other non-Indian counterparts. According to Biegel, Sales, and Schulz (1991, p. 51), because "the concept of burden lies at the heart of caregiving, it is essential that we achieve some clarity on the notion of burden at both the conceptual and measurement levels."

Caregiver Burden Research

Despite the fact that a widespread consensus has developed that the concept of caregiver burden is a central issue in any theoretical conceptualization of the caregiving process, a limited amount of previous research has investigated the multidimensionality of the concept of caregiver burden (Braithwaite, 1996; Greene, Smith, Gardiner, & Timbury, 1982; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Miller, McFall, & Montgomery, 1991; Montgomery, Gonyea, & Hooyman, 1985; Montgomery, Stull, & Borgatta, 1985; Zarit, 1992; Zarit & Zarit, 1990). Although researchers differ in the label they attach to this phenomenon (i.e., burden, strain, stress, or appraisal), everyone recognizes it as an important influence on caregiving outcomes, and it is important that the complexity of this concept be better understood. Without engaging in the dispute about which of these terms or labels best represents the phenomenon, we wish to determine if burden (the negative subjective appraisal of the caregiving situation) is multidimensional among American Indian caregivers and identify the types of burden American Indian caregivers experience.

As several researchers (Hernandez, 1991; Luborsky & Sankar, 1993; MaloneBeach & Zarit, 1991) have recognized, caregiving has different meanings and implications for different groups—including ethnic groups—and the lack of attention to group differences may obscure important findings about the experience of caregiving. In contrast to those who seek some universally valid conceptualization of what constitutes caregiver burden, Lawton and associates (1989) made the valid point that "some cross-sample variation in structure is probably the norm" (p. P70). Indeed, Lawton and colleagues ended their article by calling for additional measurement development and further examination of the generalizability of findings "across different subgroups of caregivers" (p. P71). To date, few studies have investigated the multidimensionality of caregiver burden, and no quantitative studies have investigated burden among American Indian caregivers. Therefore, the purpose of this study was to investigate caregiver burden among a sample of American Indian primary family caregivers and to identify important dimensions or types of perceived burden for this group.

Methods

This study was based on the results of a face-to-face survey of 169 Pueblo primary family caregivers. The data on the situation of American Indian primary family caregivers were collected between 1995 and 1997 as part of a National Institute on Aging–funded project (R01-AG11294; Robert John, principal investigator) in collaboration with American Indian aging programs in New Mexico. The broad purpose of the study was to investigate the family caregiving situation, including the identity of the caregiver, the tasks performed, the level and types of elder impairment, and a range of additional caregiving issues. A central concern of the research was to evaluate the level of perceived burden and identify the types of burden experienced by Pueblo caregivers. We hypothesized that, if the many critics of global measures of caregiver burden are correct (George, 1994; George & Gwyther, 1986; McKinlay, Crawford, & Tennstedt, 1995; Poulshock & Deimling, 1984; Schultz, 1990; Stull, Kosloski, & Kercher, 1994; Vitaliano, Young, & Russo, 1991), then caregiver burden should be multidimensional and the structure of caregiver burden should suggest how American Indian cultural values influence negative caregiving appraisals (Russo, Vitaliano, & Young, 1991).

The Burden Interview

The Caregiver Burden scale used in this study was based on an instrument adapted from the Burden Interview (BI) developed by Zarit, Reever, and Bach-Peterson (1980). The BI measures the extent to which caregivers perceive their emotional or physical health, social life, and financial status to be negatively affected as a result of their caregiving role and duties.

The BI was selected for use because of its comparatively concrete phrasing and because of the greater face validity of items for this population than other candidate scales (Hennessy & John, 1995). All 22 items in this scale were measured at the ordinal level and were of the Likert scale format. Most of the adaptations made to the scale involved changing each question to elicit a temporal characterization of the experience by prefacing each question with the phrase "how often do you." Response categories to each item were never, rarely, sometimes, quite frequently, and nearly always. The other systematic change was to substitute *elder* for *your relative* so the interviewer could mention each care recipient by name or relationship (i.e., *your mother*).

Other than these format changes that did not change the original substantive issue of each question, three questions were modified to make them more appropriate to a broader population of caregivers. The original BI question that asked caregivers if they were stressed between caring for their relative and meeting other responsibilities to family or work was changed to *pulled* between these responsibilities. The question that asked whether caregivers feel like they have lost control of their lives "since your relative's illness" was changed to "since you've become a caregiver." The final change involved a wording change to the global measure of caregiver burden. In the original BI, this question was the only one that had a different response set (not at all, a little, moderately, quite a bit, extremely). We transformed the question to retain its meaning but elicit a response similar to the other items. Our wording, "Overall, how often do you feel burdened in caring for [elder]," made this question consistent with the other items in the scale. The exact wording of each question can be found in Table 1.

Additional Measures

The survey instrument assessed ability to perform activities of daily living (ADLs; five items) and instrumental activities of daily living (IADLs; eight items). Each item was measured on a 3-point scale (no help needed, some help needed, cannot perform the activity). The ADL and IADL scales were derived from Katz, Ford, Moskowitz, Jackson, and Jaffee (1963) and Lawton and Brody (1969), respectively, and had been used in the Michigan Caregiver Study (see Kosloski, Young, & Montgomery, 1999, for a description of the measures). One IADL item was changed from "buying/getting food/clothes" to "shopping for food or other essentials." To better reflect the caregiving context, another important IADL was added: dealing with government agencies and other organizations (e.g., filling out forms, arranging for services). The Cognitive Status scale (seven items) was based on a scale developed by Pearlin, Mullan, Semple, and Skaff (1990). On the basis of discussions

Table 1. Frequency Distribution of Caregivers Who Report Quite Frequently or Nearly Always to Caregiver Burden Measures

Scale Item	Frequency	%
How often do you feel that [elder] is dependent on you?	110	65.1
How often do you feel that [elder] seems to expect you to take care of him/her as if you were the only one he/she could depend on?	95	56.5
How often do you feel afraid of what the future holds for [elder]?	66	38.8
How often do you feel pulled between caring for [elder] and trying to meet other responsibilities for your family or work?	54	31.8
How often do you feel strained when you are around [elder]?	48	28.4
How often do you feel that because of the time you spend with [elder] that you don't have enough time for yourself?	48	28.2
How often do you feel that you don't have enough money to care for [elder] in addition to the rest of your expenses?	45	26.6
How often do you feel that [elder] asks for more help than he/she needs?	45	26.5
How often do you feel you should be doing more for [elder]?	30	18.1
How often do you feel that [elder] currently affects your relationship with other family members or friends in a negative way?	26	15.3
How often do you feel uncertain about what to do about [elder]?	26	15.5
How often do you feel you could do a better job in caring for [elder]?	25	14.9
Overall, how often do you feel burdened in caring for [elder]?	23	13.6
How often do you feel that you do not have as much privacy as you would like because you are caring for [elder]?	22	13.0
How often do you feel that your social life has suffered because you are caring for [elder]?	21	12.5
How often do you feel that you will be unable to take care of [elder] much longer?	20	12.0
How often do you feel angry when you are around [elder]?	13	7.6
How often do you feel your health has suffered because of your involvement with [elder]?	11	6.5
How often do you feel embarrassed over [elder's] behavior?	9	5.3
How often do you wish you could just leave the care of [elder] to someone else?	9	5.4
How often do you feel you have lost control of your life since you've become a caregiver?	7	4.2
How often do you feel uncomfortable about having friends over because of [elder]?	6	3.6

with Pueblo service providers, we modified the response set to measure each item on a 3-point scale (never a problem, occasionally a problem, always a problem). To make the scale more appropriate for Pueblo caregivers, we dropped one item (remembers home address) and modified one item from remembering "the day of the week" to remembering "what season it is." Both of these modifications made the item more appropriate to the Pueblo living environment (no house numbers or street addresses) and a temporal orientation more in tune with nature.

The Sample

The sample of individuals who participated in this study was composed of 169 primary caregivers who cared for functionally impaired family members. Selection criteria were based on care recipient characteristics, including being 55 years of age or older and requiring help with at least one physical ADL, or with at least two IADLs. In addition to the threshold of care, the Title VI program directors were instructed to interview the person who provided the most care to the elder.

Participants were recruited by staff from local American Indian senior service (Title VI) programs who were familiar with families caring for an impaired relative in their community. Although our sample was purposely selected, our goal was to survey the universe of primary family caregivers who were dealing with situations that met the selection criteria. Because of the nature of relatively small American Indian communities (including tribal bureaucratic procedures such as the maintenance of a tribal roll, annual documentation of the size of the elderly service population for purposes of federal funding, and the deep nexus of family interconnections of historical proportion), the situation of each elder in the community is known, especially to service providers charged with their care. Because of this and our attempt to identify and interview all caregivers who met the selection criteria, we are confident in the representativeness of the sample.

The primary caregiver was interviewed in person by an indigenous service provider who was trained by us in administration of the instrument. Interviews took place in the caregiver's home or another mutually acceptable location where respondent privacy could be assured. The interviewer read each of the survey questions to the respondent because this more conversational mode of conducting the survey is more culturally appropriate than self-administration by the respondent and because, among elderly caregivers in particular, literacy in English might be limited.

Caregiver Characteristics

The sample of primary family caregivers was 86% female. The most frequently represented caregiver was a daughter (54%), followed by a wife (11%), son (6%), granddaughter (5%), husband (4%), sister (4%), and daughter-in-law (2%). The remaining caregivers (15%) were other family members (grandson, niece, nephew, or son-in-law) or others (friend, live-in partner).

The caregivers ranged in age from 16 to 90 years with a median age of 49 years. Most of the caregivers in the sample were married (47%), followed by a significant portion who had never married (36%); 13% were widowed, and 4% were divorced or separated. Approximately three quarters (74%) of the caregivers were living with the care recipient, and a solid majority of caregivers (57%) had responsibilities for the care of one or more dependent children within their household.

Care Recipient Characteristics

The median age of the care recipients was 81 years (ranging from 55 to 103 years old), and 66% were female. Half of the caregivers (50%) said that the elder was very dependent on others for help with daily tasks, and another 34% said that the elder was somewhat dependent. The remainder of the elders were not very dependent (8%) or not dependent at all (9%).

Caregiver reports of the elder's functional and cognitive impairments and problem behaviors revealed that the typical care recipient was highly impaired. On the basis of the caregiver's assessment, most elders had substantial problems with IADLs such as using the telephone, using transportation, preparing meals, taking medicine, doing housework, managing money, or dealing with government agencies. Approximately two thirds of the care recipients needed some assistance with all of these activities. Although fewer elders had difficulties with physical ADLs (including bathing, using the toilet, dressing, transferring from bed and chairs, or eating), fully one quarter (25%) of these care recipients needed some assistance with all five ADL tasks.

Caregivers claimed that cognitive impairment or difficult behaviors were also a problem. When asked how frequently the elder exhibited seven specific cognitive deficits (remember recent events, the season, words, understand simple instructions, find way around the house, speak sentences, or recognize people), more than one quarter (28%) of these care recipients displayed five or more of these problems at least occasionally. To make matters worse, approximately 9 in 10 (92%) of the care recipients had exhibited one or more of the following problem behaviors during the past month: wandering or getting lost, being constantly restless, being nervous or agitated, engaging in potentially dangerous activities, or being incontinent. In fact, incontinence was a problem either occasionally (40%) or frequently (13%) for more than half of the care recipients. Because of these high levels of impairment, close to one half (48%) of the caregivers reported that the care recipient could not be left alone for more than an hour.

Factor Analytic Techniques

To examine the underlying dimensions of caregiver burden among this American Indian sample, we analyzed the data using exploratory factor analysis. Exploratory factor analysis is a construct validation method "aimed at assessing the validity of treating a set of indicators as reflecting the same construct" (Pedhazur & Schmelkin, 1991, p. 65). In other words, this method analyzes how responses to questions group together to provide some meaning about the relationships between them. We used principal-axis factoring, the most widely used method of factor extraction (Pedhazur & Schmelkin, 1991). This method of extraction was chosen for its utility in analyzing individual items for construct validity. Other techniques used in the factor analysis were listwise deletion of missing values and oblique rotation of the factor solution. The criterion for acceptance of factors was set at a minimum eigenvalue of 1.0. Items with a communality and a factor loading of 0.40 or more were retained. Reliability of the factors, or subscales, was evaluated by using Cronbach's alpha.

Findings

Overall, the data indicate that Pueblo caregivers reported substantial levels of perceived burden. Table 1 indicates the percentage of respondents who said they quite frequently or nearly always felt a particular type of burden. Results of a reliability analysis of the entire caregiver burden scale yielded an alpha of .91, a finding consistent with results reported by others (Gallagher et al., 1985; Zarit & Zarit, 1990).

Exploratory Factor Analysis

Table 2 presents the zero-order correlations, means, and standard deviations for the items retained in the factor analysis. In general, the zero-order correlations were consistently high among items contained within the same factor and lower among items that were found to load in different factors. The means and standard deviations were reasonable given the caregiving context and content of the items. Although not included in Table 2, the skew and kurtosis values showed that the items were normally distributed.

Factor analysis indicated that caregiver burden among Pueblo primary family caregivers is multidimensional and consists of several components or types of burden. Results of the exploratory factor analysis indicated four factors or latent variables that were composed of items that were highly correlated with each other but were not highly correlated with other factors, supporting the multidimensionality of caregiver burden among this group of American Indians. Evidence of the construct validity and reliability of the subscales was provided by the high factor loadings, communalities, and by the Cronbach's alpha coefficients. Table 3 identifies each subscale and its constituent burden items.

Factor 1 was composed of eight scale items: How often do you feel (a) that because of the time you spend with [elder] that you do not have enough time for yourself, (b) that [elder] is dependent on you, (c) pulled between caring for [elder] and trying to meet other responsibilities for your family or work, (d) that [elder] seems to expect you to take care of him/her as if you were the only one he/she could depend on, (e) that you do not have as much privacy as you would like because you are caring for [elder], (f) strained when you are around [elder], (g) your health has suffered because of your involvement with [elder], and (h) that your social life has suffered because you are caring for [elder]? These items measure the degree to which caregiving interferes with other roles or interpersonal relationships or stems from diver-

Table 2. Mean, Standard Deviation, and Correlations Among Caregiver Burden Scale Items

Item	*M*	*SD*	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Not enough time for self	2.9	1.20	—																	
2. Competing responsibilities	2.9	1.21	.75	—																
3. Embarrassed by elder's behavior	1.7	0.95	.21	.21	—															
4. Angry when around elder	2.0	1.01	.27	.27	.62	—														
5. Negatively affects other relationships	2.2	1.18	.39	.43	.49	.54	—													
6. Elder dependent on respondent	3.7	1.12	.52	.42	.06	.16	.24	—												
7. Feels strained around elder	2.7	1.28	.51	.42	.30	.56	.50	.44	—											
8. Health has suffered	1.9	0.95	.51	.51	.39	.42	.42	.35	.67	—										
9. Not as much privacy as desired	2.2	1.20	.59	.57	.28	.44	.54	.37	.56	.57	—									
10. Social life has suffered	2.3	1.14	.49	.47	.28	.40	.57	.31	.48	.50	.66	—								
11. Uncomfortable having friends over	1.6	0.85	.32	.30	.62	.60	.56	.13	.38	.43	.53	.51	—							
12. Feels like only one elder can depend on	3.5	1.33	.50	.45	.09	.25	.30	.58	.35	.30	.38	.46	.23	—						
13. Unable to care for elder much longer	2.0	1.10	.40	.42	.39	.30	.39	.15	.38	.39	.35	.34	.47	.22	—					
14. Lost control of life	1.7	0.93	.48	.48	.43	.41	.52	.16	.39	.50	.61	.60	.57	.24	.56	—				
15. Wants to leave care to someone else	1.8	0.97	.41	.41	.43	.41	.52	.13	.42	.34	.42	.39	.47	.19	.58	.59	—			
16. Uncertain what to do about elder	2.2	1.09	.28	.23	.35	.33	.40	.15	.28	.28	.25	.37	.40	.25	.57	.49	.54	—		
17. Should do more for elder	2.8	1.00	−.04	−.06	−.11	.06	−.04	.12	.07	.00	.12	−.05	.03	−.05	−.03	−.02	.08	−.05	—	
18. Could do a better job	2.6	1.03	−.04	−.05	−.07	.09	.01	.09	.06	.05	.13	.02	.04	.01	.02	.05	.03	.08	.65	—

gent role expectations, and the factor was, therefore, identified as Role Conflict. The construct validity of this factor was supported by the communalities ranging from .409 to .719 and the factor loadings ranging from .45 to .77. The alpha coefficient (.88) indicates the high degree of reliability of this subscale.

Factor 2 was composed of four items: How often do you feel (a) angry when you are around [elder], (b) embarrassed over [elder]'s behavior, (c) uncomfortable about having friends over because of [elder], and (d) that [elder] currently affects your relationship with other family members or friends in a negative way? These items measured the degree of negative feelings about the caregiving situation that caregivers acknowledged. Negative feelings toward the elder and perceived disruption of interpersonal

Table 3. Pattern Matrix of Factor Structure, Commonalities (U^2), and Reliabilities of Caregiver Burden Subscales

Subscales With Items	U^2	RC	NF	CE	G
Role Conflict (RC)					
Not enough time for self	.719	**.77**	−.12	.22	−.12
Elder dependent on respondent	.481	**.74**	−.38	−.15	.09
Competing responsibilities	.619	**.67**	−.10	.28	−.10
Feels like only one elder can depend on	.409	**.65**	−.00	−.02	−.04
Not as much privacy as desired	.623	**.54**	.29	.13	.12
Feels strained around elder	.556	**.50**	.41	−.03	.06
Health has suffered	.506	**.47**	.34	.07	.00
Social life has suffered	.523	**.45**	.26	.19	−.03
Negative Feelings (NF)					
Angry when around elder	.685	.06	**.84**	−.07	.06
Embarrassed by elder's behavior	.581	−.16	**.68**	.19	−.13
Uncomfortable having friends over	.623	.00	**.60**	.28	.02
Negatively affects other relationships	.545	.21	**.47**	.23	−.03
Caregiver Efficacy (CE)					
Unable to care for elder much longer	.585	.04	−.05	**.77**	.00
Wants to leave care to someone else	.596	.02	.10	**.70**	.07
Uncertain what to do about elder	.441	−.03	.04	**.66**	.02
Lost control of life	.633	.16	.16	**.61**	.01
Guilt (G)					
Should do more for elder	.761	−.01	−.03	.02	**.87**
Could do better job	.554	−.02	−.01	.07	**.75**
Eigenvalue		7.23	1.95	1.72	1.15
% variance explained		40.15	10.83	9.55	6.39
Reliability Coefficient (α)		0.88	0.83	0.82	0.79

relationships brought about by the caregiving situation were evident in this subscale. The results for this factor showed that the communalities ranged from .545 to .685, and the factor loadings ranged from .47 to .84. The reliability of this subscale was assessed (α = .83), indicating a high degree of internal consistency.

The third factor was composed of four items: How often do you feel (a) that you will be unable to take care of [elder] much longer, (b) wish you could just leave the care of [elder] to someone else, (c) feel uncertain about what to do about [the elder], and (d) feel you have lost control of your life since you've become a caregiver? The communalities for this factor ranged from .441 to .633, and the factor loadings ranged from .61 to .77. The alpha coefficient of .82 indicated the high degree of reliability of this subscale. We labeled this type of burden *Caregiver Efficacy* because it reflects an assessment of the caregiver's capability to provide care to the elder. It indicates the degree to which the caregiver is experiencing serious questions about whether or for how long they will be able to care for the elder. A high score on this type of burden suggests that the caregiving situation is at a critical point that may place the elder at risk of not receiving care adequate to meet his or her needs. This type of burden may well be the precursor of neglect, institutionalization, or a shift of caregiving to others.

Factor 4 was composed of two items: How often do you feel (a) you should be doing more for [elder] and (b) you could do a better job in caring for [elder]? The communalities for this factor were .761 and .554, and the factor loadings were .87 and .75. The reliability of this index was satisfactory (α = .79). These items measured the perceived degree of guilt indicated by the caregivers about the caregiving situation. Higher scores on this index indicated feelings of inadequacy by the caregivers concerning the extent and effectiveness of their caregiving activities.

As seen in Table 4, the first three types of burden were moderately related to each other, which was consistent with the only other study to report such findings (Novak & Guest, 1989). However, the fourth factor—guilt—was not related to any of the other types of burden.

Four burden interview items were excluded from the factor solution: How often do you feel (a) that [elder] asks for more help than he/she needs, (b) afraid of what the future holds for [elder], (c) that you don't have enough money to care for [elder] in addition to the rest of your expenses, and (d) overall, how often do you feel burdened in caring for [elder]?

Table 4. Correlations Between Types of Burden

Factor	1	2	3	4
1. Role Conflict				
2. Negative Feelings	.36	—		
3. Caregiver Efficacy	.42	.56	—	
4. Guilt	.05	.03	−.04	—

Discussion

We tested the 22 items composing the Caregiver Burden scale on a sample of 169 American Indian primary family caregivers. Analysis indicated that caregiver burden is multidimensional and consists of several types of burden. We believe, therefore, that investigations into the level of perceived caregiver burden among American Indians should consider the multidimensionality of this experience and evaluate burden accordingly.

Perceived caregiver burden is composed of four dimensions, or types, of burden and four separate unscaled items: (a) role conflict, (b) negative feelings, (c) caregiver efficacy, and (d) guilt and the unscaled items of feeling that elder asks for more help than he/she needs, afraid of what the future holds for the elder, that they do not have enough money to care for the elder in addition to the rest of their expenses, and overall feeling burdened in caring for the elder.

Role Conflict

The type of burden we labeled role conflict is classic caregiver burden (containing elements that most, if not all, caregivers experience). It signifies the multiple impacts of caregiving on the life of the caregiver from personal impacts (time for self, lack of privacy, health has suffered) and disruption of other roles (pulled between elder and other responsibilities, social life has suffered) to features of the changing relationship with the care recipient (elder dependent, only one elder can depend on, strained around elder).

Negative Feelings

The second factor represents the caregiver's negative feelings toward the care recipient. This factor closely resembles one of three factors reported by Greene and colleagues (1982) and one of five factors identified by Novak and Guest (1989). Although Greene and colleagues used a different instrument on a small sample (N = 38) among caregivers of demented elders, three of the four items they identified (feel embarrassed, prevented from having visitors, gets cross and angry) are quite similar to three of the items in our factor. Novak and Guest also used a different instrument on a sample of 107 caregivers of cognitively impaired elders, half of whom resided in an institution. They also found a five-item factor that contained three variables (feel embarrassed, uncomfortable having friends over, angry about interactions with care receiver) that are similar to ones identified in our analysis. Novak and Guest labeled this factor *Emotional Burden* but described it as negative feelings that they attributed to behavioral problems that often accompany cognitive impairment.

Our findings suggest that negative feelings are a type of burden American Indian caregivers also experience. Although our previous research (Hennessy & John, 1995) found some degree of denial about negative feelings and emotions during focus group discussions, at the time we speculated that a group discussion may not be conducive to an admission of negative sentiments because it would be a public acknowledgement of a norm violation. There can be little doubt that feeling anger, embarrassment, social discomfort, and social limitations are inconsistent with how Indian caregivers are supposed to feel about caregiving. Yet this constellation of negative feelings was present among these caregivers when they did not have to admit publicly that they had such feelings.

Caregiver Efficacy

We labeled the third factor Caregiver Efficacy because the items in this factor cast doubt on the ability to sustain caregiving. Unfortunately, the items that compose this factor are quite ominous and even suggest a certain amount of desperation. Feeling unable to care much longer, wishing they could just leave care to someone else, feeling that they have lost control of their life and are uncertain about what to do *all* suggest caregiver breakdown.

Guilt

The fourth factor (could do a better job and should be doing more) represents caregiver guilt. The distribution of responses to these two items suggests that guilt is the most common form of caregiver burden among Pueblo caregivers. Most of the responses to both of these items were consistent. For example, around one fifth (22%) never or rarely felt guilty, approximately one third (36%) experienced both feelings sometimes, and 22% experienced one or both feeling more frequently. The remaining caregivers (19%) were somewhat inconsistent about whether they could or should do more.

From a cultural perspective, guilt is extremely important because it is independent of the other factors, having little to do with role conflict, negative feelings, or caregiver efficacy (see Tables 3 and 4). The existence of this factor confirms one of the major problems identified by Hobus (1990) in her study of an Indian family that had placed an elder in a non-Indian nursing home. Given American Indian cultural values, their guilt is understandable. However, our findings suggest that guilt is a form of caregiver burden that exists even when performing a culturally prescribed role.

The findings of this study suggest that Pueblo Indian family caregivers experience guilt more intensely than the other three types of burden. This being the case, service providers should initially determine whether guilt is warranted. If the elder is not being cared for adequately, then additional caregiving support services should be procured for the family. If the elder is being adequately cared for, but the guilt feelings of the caregiver are based on faulty perceptions, then services should be tailored to provide education and affirmation to the caregiver. This might be delivered in the form of counseling sessions with a medical social worker or other health-related professional or in a group setting such as a caregiver support group.

Other Burden Issues

It is interesting to speculate about possible substantive reasons that four items did not scale well. The first item, feeling that elder asks for more help than he/she needs, was endorsed by approximately one quarter of the caregivers. We believe that there are several possible reasons that this appraisal was not systematically related to any of the factors. Because of the high level of impairment and dependence that was recognized by these caregivers, it is possible that the caregivers do not consider most requests for assistance made by the care recipient as unreasonable. Alternately, it could be that most care recipients are not very demanding regardless of the type or level of need for assistance, a behavioral characteristic that is quite consistent with American Indian cultural norms. Either of these occurrences would constrain the relationship between unreasonable demands for assistance and a sense of role conflict, negative feelings, lack of efficacy, or guilt.

The second item, feeling afraid of the elder's future, is a feeling that was endorsed by a substantial proportion of the caregivers (39%). This assessment is not unreasonable in any caregiving circumstance because a decline in the elder's condition is expected at some point in the future regardless of the elder's current condition. Moreover, as seen in the description of the sample, the typical elderly care recipient was highly impaired and dependent on the caregiver. Our previous research with Pueblo family caregivers likewise confirmed the anxiety that these caregivers frequently experienced given the perceived lack of adequate information about the nature and expected course of the elder's medical condition and/or psychological problems (Hennessy & John, 1995, 1996; Hennessy, John, & Anderson, 1999).

However, the third item—not having enough money—needs to be interpreted more squarely within the Pueblo cultural framework. Our previous work (Hennessy & John, 1995) documented a number of Pueblo cultural norms that influence the interpretation or meaning assigned to the caregiving situation. Primary caregivers in these focus group discussions tended to endorse family caregiving at all costs (personal as well as financial) and were less likely to view financial problems associated with caregiving as an important determinant of their caregiving behaviors. Moreover, from a socioeconomic perspective, many of these families lack financial resources and experience financial difficulties on a continuing basis, so that the financial difficulties associated with caregiving are not as salient as among Anglo families. Among many Pueblo families, the financial difficulties associated with caring for an elder are simply part of a broader mix of financial pressures and concerns. In addition, one aspect of the cultural ethos regarding older tribal members expressed in the focus groups (Hennessy & John, 1995) may have relevance to the lack of emphasis on the monetary costs of elder care. This is the view of elders as repositories of cultural knowledge, wisdom, and language, on whom a monetary value cannot be placed. From this vantage point, caregiving was seen as part of the larger fabric of nurturance and preservation of Pueblo culture, and the death of an elder was regarded as an inestimable loss to the Pueblo cultural legacy.

Several other features of the caregiving context may also influence the independence of financial concerns from the identified types of burden. First, American Indians in this study have access to a socialized medical system through care provided by the Indian Health Service. The Indian Health Service provides acute inpatient and ambulatory patient care through hospitals and clinics and delivers or funds modest community-based health care services. Although the services provided by the Indian Health Service do not have a geriatric focus and existing programs are underfunded, the services that are available do not require out-of-pocket expenses. Therefore, one source of financial concern (mounting medical expenses) does not exist for these caregivers.

Second, the Indian Health Service does not fund institutional long-term care, and only one tribe in New Mexico operates a nursing home. Therefore, the kind of financial concern associated with nursing home placement probably does not influence caregiver perceptions of burden. Typically, nursing home placement would mean placement in a non-Indian nursing home. For most families, the financial cost of such care would be prohibitive, but the cultural cost (removing the elder from Pueblo culture and violating a cultural norm to provide care within the family) would be the salient consideration.

The final item that was not retained in the factor analysis was the measure of the overall feeling of burden. As a global indication of caregiver burden, it is good that this item did not uniquely load on any single factor. In fact, this item was the most complex of the variables and was associated with the first three factors to a modest degree. Guilt was the only type of burden to which this sense of overall burden was not related.

Comparison With Previous Research

Our findings differ substantially from previous investigations of the multidimensionality of caregiver burden in two important respects: (a) in the factor structure of the individual items that compose each type of burden and (b) the latent concept revealed by the factor analytic technique. Perhaps this is to be expected, as most of these studies used, at best, only a few items that were the same or similar to those in this study. However, our results are quite different from the limited results reported by Zarit and Zarit (1990). They identified two factors that they labeled *Role Strain* and *Personal Strain*, along with the burden items of each factor. In contrast to their findings, our results suggest a more complicated factor structure. Because so little has been published about the dimensions of caregiver burden, it is difficult to speculate about the reasons for these differences. One possibility is simply that their results were based on a different group whose characteristics were not reported but probably did not contain any American Indian respondents. Another possibility is that the factor structure is more complex than what was reported by Zarit and Zarit (1990), as other studies that have investigated the factor structure of caregiver burden have generally reported more than two factors to represent the factor structure (Braithwaite, 1996; Greene et al., 1982; Kosberg, Cairl, & Keller, 1990; Lawton et al., 1989; Niederehe & Fruge, 1984; Novak & Guest, 1989; cf. Miller, McFall, & Montgomery, 1991; Poulshock & Deimling, 1984).

Practical Implications

The identification of a more complex conceptualization of burden has a number of practical benefits. In the first instance, by identifying the specific type of burden that a caregiver predominantly experiences, interventions can be targeted more accurately. For example, if a caregiver mainly experiences the type of burden we have labeled negative feelings, then a support group or individual counseling might be a more appropriate intervention than, say, respite services. Such targeted interventions open a new avenue for applied research that could provide aging service providers with a more sophisticated approach to diagnosing need and providing services to family caregivers and care recipients.

The secondary benefit of having a more precise conceptualization of burden is that it would allow researchers and service providers to examine how the sense of burden changes and whether or how caregivers change in response to the experience of burden. Additional studies are also needed to identify whether certain types of burden are more common during particular stages of the caregiving experience or whether a specific type of burden is associated with particular caregiving situations (i.e., dementia care). With this kind of information, some types of burden may be anticipated (and considered normative), and other types of burden may represent a pathological state that endangers the caregiver or care recipient.

Conclusion

Although the findings reported here are limited to this sample of Pueblo caregivers, this study suggests the importance of continued research in the area of caregiver burden. Ideally, additional research would investigate the multidimensionality of caregiver burden among other ethnic groups, as well as other groups of American Indians. There is every reason to believe that the factor structure of burden will vary between groups based on differences in cultural values and the existence of resources (including financial resources and help received from formal service providers). Ultimately, by identifying the types of burden a particular caregiver experiences or perceives, service providers may provide support better targeted to the specific needs of the burgeoning caregiving population. Although better methods of targeting support services should save money by reducing receipt of unnecessary or unwanted services, the true value of this approach will be realized by strengthening caregiving within families. More important, this method of tailoring service support to the areas of greatest perceived burden would potentially reduce perceived burden and thereby improve the overall caregiving situation in the family and forestall neglect, family turmoil, or a variety of adverse outcomes for the impaired elder.

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