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## American Indian Family Caregivers' Experiences with Helping Elders

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### Abstract

Abstract In recent years, a vast literature has accumulated on the negative effects on family caregivers of providing care to elders, while relatively little research has explored caregiving as a positive experience. Only a handful of studies have examined any aspect of informal caregiving among American Indians. This mixed methods study explores the negative and positive aspects of providing elder care among 19 northern plains American Indian family members. These caregivers described low levels of burden and high levels of reward, attributable to cultural attitudes toward elders and caregiving, collective care provision, strong reciprocal relationships with elders, enjoyment of elders, and relatively low levels of care provision. Caregiving manifested as part of a complex exchange of assistance rather than a unidirectional provision of assistance from the family member to the elder. That caregiving emerged as such an overwhelmingly positive experience in a community faced with poverty, alcohol disorders, trauma, and cultural traumatization is testimony to the important roles that elders often continue to play in these communities.

### Keywords

American Indian; Caregiving; Elders; Family; Positive valuation of elders; Caregiving reward

### Introduction

Although the number of older American Indians has increased dramatically since the 1970s (John 1996; U.S. Department of Health and Human Services, 1997) and constitutes one of the fastest growing groups of nonwhite elderly in the United States, very little is known about informal caregiving in this population. This stands in stark contrast to the general caregiving field, where over the past few decades there has been a dramatic increase in the number of studies on this topic. The negative and burdensome aspects of caregiving, especially those associated with the stress-coping model (Pearlin *et al.* 1990), have received the bulk of attention in the literature (Cohen *et al.* 2002; Tarlow *et al.* 2004). Caregiver (CG)

burden has been defined in various ways, but generally denotes “the emotional, psychological, physical, and financial ‘load’ assumed by CGs, as well as their subjective appraisals of how task performance affects their lives” (Gaugler *et al.* 2000:323). Caregiving has been found to negatively affect financial wellbeing, physical and mental health, relationships with others, work, personal freedom (Faison *et al.* 1999), and even mortality (Schulz and Beach 1999). Greater caregiving burden has been linked to higher assistance provision with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Faison *et al.* 1999), as well as dementia caregiving (Schulz *et al.* 1995). Geographic location may also play a role, with burden and subsequent depression exacerbated in rural communities where isolation from social interactions, social support, and care services is common (Butler *et al.* 2005).

Despite the historic focus on burden in the caregiving literature, within the last decade researchers have increasingly explored the positive aspects of caregiving (Tarlow *et al.* 2004), with some studies finding that there is much that is rewarding about the caregiving experience (Butler *et al.* 2005). Caregiving reward may be related to interpersonal dynamics between the CG and care recipient, the intrapsychic orientation of the CG, or the desire to promote a positive outcome for the elder (Nolan *et al.* 1996). Caregiving satisfaction may be experienced in terms of interpersonal reciprocity or an increased sense of meaning gained from helping the elder (Butler *et al.* 2005; Noonan and Tennstedt 1997; Pearlin *et al.* 1990). Higher levels of caregiving satisfaction have been attributed to family support and positive family attitudes (Kaye and Applegate 1990).

Both positive and negative aspects of caregiving have been shown to manifest differently across various cultures, and it is crucial to consider these cultural factors (Aranda and Knight 1997; Dilworth-Anderson and Anderson 1994; Dilworth-Anderson *et al.* 2002; Lecovich 2008). In the U.S., most studies have compared whites and African American CGs, with a smaller number focused on Latinos and Asians. A metaanalysis of 116 empirical studies found that ethnic minority CGs had lower levels of income and education, were younger, and were less likely to be married than whites (Pinquart and Sorensen 2005). In addition, they provided more care and had more informal support than White CGs. With respect to health status, ethnic minority CGs overall had worse physical health than whites, but levels of burden and depression varied by specific ethnic group.

Non-white CGs typically report less burden, even though they have lower income, provide greater amounts of care, and frequently have greater unmet care provision needs compared to their white counterparts (Navaie-Waliser *et al.* 2001). Many studies have shown that African Americans appraise caregiving as less burdensome and stressful than do white CGs, which has been related to their lower caregiving-related depression outcomes (Farran *et al.* 1997; Knight *et al.* 2002). This decreased sense of burden among African Americans has been attributed to their greater tendency to call on friends and neighbors to assist with caregiving tasks (Knight *et al.* 2002) and the greater likelihood of multiple CGs assisting with caregiving (Navaie-Waliser *et al.* 2001). Similarly, collective caregiving (caregiving by two or more individuals) and familism have been offered as explanations for decreased levels of burden among Latinos (Knight *et al.* 2002). Further, African American CGs have been shown to associate more positive feelings with caregiving and to find it more meaningful than whites (Farran *et al.* 1997; White *et al.* 2000). However, a recent study has found that higher levels of perceived stress and depression among African American caregivers was related to poor relationships with care recipients as well as “traditional caregiving beliefs” (e.g., the notion that they were chosen by their families as children to provide care to their families, that they never thought about doing anything else, that all of their life choices revolved around care provision, and that caregiving is expected by their families) (Rozario and DeRienzi 2008).

Few empirical studies have examined caregiving among American Indians, with most extant studies focusing on tribes in the Southwest. In one of the few available studies, focus groups with Pueblo CGs of elders with cognitive and physical decline highlighted the respect accorded to elders in tribal life as contrasted to the infantilization and resentment of elder participants believed to be common among white CGs (Hennessy and John 1995). Pueblo CGs sought to create harmony as a means of coping with family illness by emphasizing the collective well-being of the family over that of the individual. In focus groups with southwestern American Indian CGs of frail elders (Hennessy and John 1996), participants did experience considerable burden. This burden was attributed to managing medical conditions in the home, the provision of emotional support to the elder, the lack of assistance from other family members, and negative impacts on the CG's physical and mental health. A few satisfactions were also identified, including the successful routinization of care, the mobilization of family assistance, and the relief obtained from occasional breaks from caregiving.

Substantial caregiving burden was also identified in a survey of 73 Pueblo CGs of elders with physical and cognitive impairments, with burden much more common among those caring for cognitively impaired elders than those with physical impairments only (John *et al.* 1996). In a more recent article based on a survey of 169 Pueblo family caregivers to elders with relatively high levels of cognitive and/or behavioral impairment (John *et al.* 2001), burden was comprised of four dimensions: role conflict, negative feelings, lack of caregiver efficacy, and guilt, with guilt proving the most common form of burden in this sample. As this body of work suggests, both burden and positive elements may be part of the Native caregiving experience, with the multidimensionality of burden manifesting in unique ways, at least for American Indians in the southwest.

In this article, we explore caregiving among northern plains American Indians using a mixed methods approach. After examining responses to burden and satisfaction measures, we focus on CGs' descriptions of helping elders in ethnographic interviews. In doing so, we seek to place caregiving in this understudied group within its cultural context, and to gain a better sense of how caregiving manifests and is experienced.

## Method

This article reports on data collected as part of a larger study on cognitive assessment of community-dwelling Native elders. In the larger study, a culturally modified cognitive assessment was administered to 140 clients of an Administration-on-Aging funded senior nutrition center on a northern plains reservation (Jervis *et al.* 2007a, 2010). The reservation was quite rural, with a driving time of 6–7 hours to the nearest major metropolitan area and 1/2 hours to the nearest border town. It had a strikingly high poverty rate, with 46% of families living below the poverty level (U.S. Census Bureau 2002). The reservation was also plagued by high prevalences of trauma (Manson *et al.* 2005) and mental health problems, most notably alcohol disorders and post-traumatic stress disorder (Beals *et al.* 2005; Spicer *et al.* 2003). These were no doubt related to the cultural trauma the tribe had experienced since being colonized in the 19<sup>th</sup> century (Jervis and the AI-SUPERPFP team 2009; Jervis *et al.* 2003). No home health services were available on this reservation, although an Indian Health Services hospital was based on the reservation and the tribe owned a nursing home which was located in a nearby border town (Jervis 2006; Jervis *et al.* 2007b). Other chronic care services were in short supply, a situation not uncommon in reservation communities (Manson 1989, 1992).

The protocol for this study received approvals from the tribe's government, the University Institutional Review Board, and the regional Indian Health Service Institutional Review

Board. Elder participants were recruited from senior nutrition sites that served the vast majority of the reservation's older residents (83%), primarily excluding remote or uninterested elders. The vast majority (93%) of elders who were approached participated in the larger study; elders ranged in age from 60–89 with a mean age of 69.8 years. As part of the consent process, each of the 140 elders who participated in the larger study were asked for permission for the researcher to contact a family member who helped them in order to invite them to be interviewed. Fifty-three elders provided this permission. We sought to interview 20 family members of these elders; one interview was not retained for data analysis due to missing data, resulting in a final sample of 19 CGs. Of those we approached who did not ultimately participate, the majority (16) did not qualify for the study, mostly because they did not self-identify as family members and hence did not meet study criteria.

Of the remaining CGs, those whose elders either had low or discrepant cognitive scores on the Mini-Mental State Exam (MMSE) (Folstein *et al.* 1975) and the Mattis Dementia Rating Scale—Second Edition (DRS-2) (Jurica *et al.* 2001; Mattis 1976) were approached first. No statistically significant differences in cognitive scores were found between elders who had CGs participating in the study and those who didn't (MMSE=25.75 vs. 26.79,  $p>0.05$ , DRS-2=121.06 vs. 126.50,  $p=0.05$ ). With respect to the overall elder sample, however, performance on both measures identified many participants as cognitively impaired when compared with normative samples of predominantly non-Native populations with similar age and education levels (nearly 11% scored more than 2 standard deviation points below performance expectations on the MMSE; 27% on the DRS-2) (Jervis *et al.* 2007a, b).

The majority of CGs were female and under age 60 (Table 1). Approximately 3/4 had a high school education or higher, and most were married or living as married. As for work status, 38.9% of CGs were working full-time, with another 25% working part-time or occasionally; 31.3% were unemployed or laid-off. Mothers, grandmothers, and husbands were the most common care recipients. The majority of participants (81.3%) reported helping their elder for more than 3 years, with more than half (56.3%) stating that they had been helping the elder for more than 10 years. The remaining 3 CGs (15.8%) stated that they had helped the elder for 11 months or less. Nine (47.4%) of CGs co-resided with their respective elders, and of these, nearly half (4) began doing so in order to take care of the elder. Each CG participated in a structured interview, followed by a semi-structured audiorecorded ethnographic interview.

### Quantitative methods

In the structured interview component, functional status, caregiving burden, and caregiving reward were evaluated using measures employed in REACH II (Schulz *et al.* 2003), a multi-site intervention study of dementia caregiving. Functional status was assessed using a 14-item Activities of Daily Living and Instrumental Activities of Daily Living (ADL/IADL) measure based on the work of Katz and colleagues (Katz *et al.* 1963) and Lawton and Brody (Lawton and Brody 1969). The version used in this study was modified to include the wording “because you were sick or disabled” in order to exclude situations where task assistance was part of the customary household distribution of labor. Burden was measured using a 12-item version of the Burden Inventory (Bedard *et al.* 2001; Zarit *et al.* 1980). Caregiving satisfaction/reward was assessed using the 11-item Positive Aspects of Caregiving measure (Tarlow *et al.* 2004).

Due to small sample size, analyses were restricted to the percentages, range, mean, and standard deviation of CG responses to the IADL/ADL, burden, and positive aspects measures. We used t tests to compare the elders' mean MMSE and MDRS-2 scores.

## Qualitative methods

Following the structured interview component, CGs participated in a semi-structured ethnographic interview focused on their family lives, exchanges of assistance between the CG and the elder, problems helping the elder, and both the difficult and the positive aspects of caregiving. Ethnographic interviews were transcribed verbatim, following conventions established by DuBois and colleagues (DuBois *et al.* 1993). A coding scheme was created collaboratively by team members, who developed preliminary conceptual codes by reading interview transcripts, assigning evolving codes, and revising these codes until preliminary theoretical saturation was achieved (Strauss and Corbin 1990). Text was then coded using QSR Vivo 7 (NVivo 7) program (Qualitative Solutions and Research 2006). Once coded, interviews were examined for thematic clusters, using a modified grounded theory process (Glaser and Strauss 1967; Strauss and Corbin 1990). Emerging themes in the data were identified as transcripts were examined. This process continued until theoretical saturation was achieved, meaning that categorical development was dense, all paradigm elements were accounted for, and relationships between categories were well established (Strauss and Corbin 1990).

## Findings

### Functional status, burden, and caregiving reward measures

Caregivers generally reported that participants needed relatively low levels of assistance in performing everyday tasks (Table 2), with most care falling into the IADL category. When participants endorsed helping with a task, they were asked “How much does helping with this bother or upset you?”. In the vast majority of cases, participants reported not being bothered or upset at all [not shown]. Family members also reported very low levels of burden on the Burden Interview (Bedard *et al.* 2001) (Table 3). The only burden-related items that were frequently endorsed were thoughts and feelings that the CG could do more or do a better job in caring for the elder. Interestingly, these same items proved highly salient in a study of burden among Pueblo CGs (John *et al.* 2001). In contrast to the burden findings, CGs reported very high levels of positive aspects of caregiving (Tarlow *et al.* 2004) (Table 4).

Most (69%) CGs reported that other individuals, nearly all of them family members, were also helping their elders. For these individuals, the average number of secondary CGs was nearly 3 per primary CG—meaning each of these elders had 4 people helping them on average. The most common additional helpers were the elders' daughters (9), sons (8), and granddaughters (5). The bulk of care provided by the other caregivers fell into the IADL category. The extent to which elder care was a family affair is illustrated by the following example, where in addition to the CG's assistance, the elder's son checked the elder's mail and took her to the store, the elder's daughter fixed her hair and did her laundry, the granddaughter did “little things” and helped the elder to the bathroom, while the grandson cleaned her room. This type of caregiving scenario was fairly typical.

### Expectations for caregiving and attitudes toward elders

The larger context upon which these findings should be interpreted is one where respect for elders has traditionally been held as a central cultural value. Respect for elders included visiting with them, listening to them, “serving” them, and taking care of them as needed. As 59-year-old Char noted, respect traditionally meant, “You took care of them. If they needed anything, you took care of it.” Sixty-seven year-old Tom attributed this emphasis on caring for elders to the larger Native culture: “I think it's the nature of the Indian people to take care of their own. We're such a family-oriented bunch of people anyway. We are all one huge

family.” Taking care of each other, according to Tom, was how American Indians managed to survive.

While all study participants provided at least some help to the elder, a few described helping several older community members in addition to their elder. For instance, 35-year old Deana provided assistance (e.g., cleaning, bathing, toileting, giving rides, babysitting) to both her mother and grandmother, as well as various aunts and male cousins within her community. This is a situation in which one might expect a CG to experience feelings of stress and burden, yet Deana did not report these kinds of feelings. Likewise, twenty-three-year-old Dug lived at his father's 20-plex (a residential complex with senior apartments attached to an Administration-on-Aging funded senior nutrition program) and helped (e.g., cleaning, shopping, cooking) all of the elders there. As a former gang member, it took a while for the elders to trust him, but he attributed his transformation to their wisdom: “If you want to know things, just sit there and listen and they'll tell you a lot. That's why I like kicking it with elderlies, because, see, my regular friends are too much hotheads or too much in the gang thing, always want to fight all the time.”

While respect for elders remained an important cultural ideal, most participants believed that this tradition had eroded considerably within the tribe as a whole. Many CGs believed that elders (although not *their* elders) frequently went without support or were disrespected. Lack of support meant that the elder lacked help, while disrespect might range from people not treating the elder properly to subjecting them to serious financial exploitation or worse. Participants generally attributed this change to culture loss, poverty, and/or alcohol abuse in the community. Caregivers in this study, then, were well aware of what they perceived to be a changing ethos with regard to respect for elders, with traditional norms dictating service to and care for elders, but more recent behavior among some community members violating this value system.

### Opposition to nursing home placement

Many participants expressed negative ideas about nursing homes. Thirty-five-year-old Elaine exemplified this perspective: “I don't like nursing homes. I never want my mom to go there.” After her mother's recent health episode, Elaine's mother's doctors suggested nursing home placement. Elaine's mother initially agreed to enter the nursing home, since Elaine had 9 children living in a 3-bedroom house. Elaine, however, didn't see her family situation as a barrier to caregiving, stating, “If I can take care of 9 of my kids, I can take care of her too.” Several participants believed that they could care for the elder just as well at home as a nursing home could. Annie typified this viewpoint: “I don't think that I would ever want to put my grandma in a nursing home, because I feel that whatever they can do for them in a nursing home, we can do just as good at home for her. And I'd rather have her be, you know, in her own house and around her family and stuff.” Caregivers generally believed elders should be cared for at home rather than by nursing homes, despite obstacles presented by socioeconomic hardships or competing caregiving obligations (such as childrearing) that were common on this reservation.

### Reciprocity

Participants frequently approached caregiving as an opportunity to give back to elders. Twenty-nine-year-old Elaine lived with her grandmother on and off from a very young age and exemplified this attitude: “The way I see it is my grandma took care of us all of her life and now it's our turn to give what she gave to us back to her. She taught us a lot.” Indeed, Annie's grandmother was a refuge for her growing up:

I kind of feel whenever I was growing up, my grandma was always there for me and I always remember my grandma telling me that she loved me and buying me

stuff and taking me wherever she went...and like if I would be mad at my mom or whatever, I could go and stay with my grandma and I'd go to sleep with her and [laughs], so I just feel like she did all that for me and she loved me enough to take me in wherever my mom was going to school and stuff, and I kind of feel—I don't feel like I owe it to her—I just feel like I can give her something in return now that she's older and stuff.

On occasion, reciprocity was oriented more toward the future than toward the past. Dug, for instance, stated, “I don't mind giving my time to these old guys because I'm going to be old sooner or later too. Might as well help them out. They do need help.”

## Burden

Family members generally described little difficulty or burden with helping elders. There were likely several contributors to this lack of difficulty. First, 3 of the 19 CGs consistently stated that they did not help their elder a great deal, which would likely be associated with less burden. Proximity to the elder was also identified as easing caregiving burden. Tom contrasted the difference between Indian and non-Indian “society,” based on his own experience with living off of the reservation. In his view, a non-Indian might think, “God, I worry about my brother. I can't get away. I really, really worry about my brother or sister or whatever, but geez, they're clear down in Texas and economically, I can't leave here. I've got to stay here'... Well, with Indian people, they're so much contained on a reservation that usually their relations are all here...They're able to be with each other more so than they are out there in the white society, because [that] society doesn't allow it.”

Sometimes lack of competing interests was cited as facilitating caregiving. Annie, for instance, stated that she didn't have that much to do other than care for her grandmother, despite the fact that she worked full-time and had several children to care for. Similarly, 45-year-old Sandra, who was simultaneously helping her mother, grandmother, and husband, reported that although she was doing a lot, it “wasn't that bad” because she was unemployed.

Another factor that might have eased caregiving burden was multiple CGs. Besides the participant, the elder's other children or grandchildren often provided considerable help to the elder. None of the family members in this study described caring for the elder as a solo venture. This is likely related to the normativeness of extended families on the reservation (John 1988; Red Horse 1983).

In summary, CGs expressed little burden associated with helping elders, which they attributed to the physical closeness of Indian families, a perception of lack of competing priorities, and a tendency toward collective—rather than individualistic—caregiving.

## Positive aspects of caregiving

Consistent with the findings from the structured interview component, participants were generally quite positive about the caregiving experience. A sense of emotional reward was clear in Annie's statement: “There's a lot of good things about helping my grandma. I feel like when I help my grandma it makes me feel good. I mean, it makes me feel depended on and it makes me feel like I'm doing good for her.”

Several participants noted that their elder appreciated what was done for them. For instance, 35-year-old Elaine stated that when she gave food to her mother or helped her dial the telephone, “She just gets all happy and really says, ‘Thank you.’ You know, she appreciates everything I do for her.” Similarly, Sandra asserted that helping her mother “makes [her] feel good, and she's really thankful when we get done helping her. Or she always says, ‘I

know you guys care,' you know, or 'I enjoy your company or [I enjoy the company of] the grandkids,' which makes everybody all the way around feel good."

Another positive aspect of providing care was taking pleasure in spending time with or helping the elder. Sometimes this was discussed in terms of enjoying older people in general. Dug reflected, "I just like to help old people because they're pretty cool to listen to. They're more understandable." Likewise, 35-year old Elaine said that, unlike most people, she liked taking care of elderly people: "They're funny. They get funny after a while, get goofy, make you laugh. It gets fun." In other cases, comments were specific to their particular elder. Annie, for instance, stated: "I like to spend time with my grandma. I like to talk to her. And I like to visit with her, and she does some crazy stuff. I mean some funny stuff."

At times the emotionally close relationship between the CG and the elder was emphasized. Twenty-seven year-old Dana reflected that she had a very close relationship with her father growing up, which continued into the present day. "Knowing that my dad's there, he just gives me some kind of—I don't know what you call it—he's like my strength, my confidence, my everything, you know. Just knowing that he's there and alive and well, and I have him to go visit and see every day, it's like I can just go and face the world without any doubts."

Elders were said to give a lot to CGs, sometimes in the form of advice or wisdom. Annie observed, "I think a lot of good comes out of me spending time with my grandma and me doing things for my grandma because she teaches me a lot and she teaches my kids a lot and stuff, and I just like to be around her." Similarly, Dug reflected,

I always listen to all these old people. It changed my life. Because to me, I thought there was no life out there for me, but they always say, "Why you going that way? There is a life out there for you." So I took their advice and I went the other way... But if it wasn't for the old people, for the elderlies, I probably wouldn't be here because the way I was going, I was going to end up joining them [gang fighting with his friends], throw my life away.

The help that Dug provided to older people, then, was compensated for by the life-transforming advice they provided.

Elders were also described by a number of participants as providing CGs with money when needed. This was typically characterized as part of a mutually reciprocal relationship, with each party helping out the other as necessary.

Elaine described her mother: "She'll just like ask me if I need something. She'll ask me how much I need or pay my light bill or get me propane or something." Sometimes the help that the elder provided to the CG was quite considerable. For instance, Caren's mother was raising several of her children.

In sum, CGs in this study expressed a number of positive feelings regarding the caregiving experience, often described as "feeling good," being appreciated, or enjoying the elder. Reciprocity once again comes into focus, with elders perceived as giving CGs a lot, whether that be in the form of advice, wisdom, or financial assistance.

## Discussion

Across structured and semi-structured interviews, family members in this study reported low levels of caregiving burden and high levels of reward. CGs overall reported a low-intermediate frequency of helping their elder due to illness/disability, with most care falling



into the IADL category. However, an examination of the study's qualitative data suggests that CGs were likely providing more care than suggested by the structured component, with the bulk of this care also falling into the IADL category. An important consideration is the addition of the wording "because you were sick or disabled" to all items in the ADL/IADL measure. This likely produced a conservative estimate of the amount of help elders were provided, since tasks undertaken as part of customary household divisions of labor would have been excluded.

Multiple factors may explain the findings of low burden and high reward. First, elders in this study were not perceived as requiring high levels of care, which is generally associated with higher levels of burden (Faison *et al.* 1999; Sales 2003; Sherwood *et al.* 2005). Second, the traditional emphasis on respect for elders (Red Horse 1980) and the cultural value placed on keeping them out of nursing homes (Hennessy and John 1995) likely informed caregiving expectations. Third, family members did not provide care in isolation; on the contrary, several family members typically shared caregiving tasks, which may have eased burden. Forth, the belief of some CGs that they didn't have much else to do but help the elder may have been helpful. It is worth noting, however, the subjective nature of these perceptions, since fully 65% of these participants were employed, and many had significant childcare and/or additional eldercare responsibilities.

Fifth, reciprocity was a crucial factor, with the caregiving relationship embedded in long-term relationships where elders were believed to have given a great deal to the CG and where the CG now wished to "return the favor." In this tribe, as in many other American Indian groups, it is culturally normative for grandparents to help raise grandchildren who, in turn, are expected to provide companionship and care for the grandparent when they are older (Schweitzer 1999). According to Red Horse, providing eldercare is not only a matter of reciprocity, but a way of demonstrating respect for elders' wisdom (Red Horse 1980). However, in this study immediate reciprocity proved equally important, since many elders continued to provide advice and money to families, as well as care for children in the family. This is an extremely important consideration, as elders were perceived as continuing to give to CGs, rather than merely taking. And lastly, CGs often enjoyed elders, which manifested either in feeling that they learned much from them or that they had fun with them. Enjoyment may have served to mitigate or compensate for some of the more onerous aspects of caregiving.

The findings of this exploratory study should be viewed with caution, as the study took place with only one tribe, employed a purposive sample, and had a small sample size. Also, the study excluded caregivers who were not self-defined family members, an omission that future studies might wish to address. Nonetheless, it is possible that some of these findings may extend to other American Indians, given that the traits described here are common to many American Indian cultures. For instance, traditional family structures in Native groups frequently emphasize the extended family, interdependence, task assistance, and respect for elders (Hennessy and John 1995; John 1988; John *et al.* 2001; John *et al.* 1996; Red Horse 1983). Moreover, it is not unusual for elders to act as economic providers, as well as sources of wisdom and guidance to family members (John *et al.* 1996). These factors may indeed facilitate positive experiences of caregiving like those identified here.

This study's findings show some similarities to those found among other ethnic minorities, especially the tendency toward collective caregiving and the propensity to perceive it in positive terms (Farran *et al.* 1997; Knight *et al.* 2002; White *et al.* 2000). This study's participants expressed far less burden than that described previously among southwestern Indians (Hennessy and John 1996; John *et al.* 2001; John *et al.* 1996), which may be attributable either to cultural differences between tribes and/or to differences in care needs

among their respective study participants. Another striking finding is that, despite the reservation's extreme rurality, CGs in this study experienced less burden than one might expect for CGs who live in rural areas (Butler *et al.* 2005). It may be that although they lacked access to services such as home health care, CGs in this study did not perceive themselves to be socially isolated or without social support.

## Conclusion

Within the extensive literature on elder caregiving, the negative aspects of caregiving predominate. In this study of American Indian CGs, providing care was associated with high levels of reward rather than burden. This suggests that several aspects of the American Indian caregiving experience deserve increased attention, particularly the sense that providing care is part of a long-term relationship where the elder has provided much to the CG. Moreover, elders often remain active contributors, helping out the CG with advice, money, and/or child care. In this sense, caregiving is part of a larger, mutual exchange of familial assistance, rather than merely a unidirectional provision of care from the CG to the elder. Another striking finding is the emphasis on enjoyment in the caregiving relationship, especially humor and fun, something that is rarely, if ever, found in the general caregiving literature. The rarity of this finding begs the question of whether humor and fun in the caregiving experience is specific to this cultural group, or whether more research emphasizing these aspects of care provision is called for in other populations as well.

The fact that assisting an elder was viewed in such positive terms among participants who live in a rural community struggling with poverty, trauma, high levels of alcohol disorders, and cultural traumatization may seem surprising. It may be that it is precisely these factors that strengthen and intensify elder-CG relationships. Perhaps adverse circumstances such as these—and elders' roles in providing respite from such difficulties—combine with cultural expectations for caregiving, traditional positive attitudes towards elders, and the normative interdependence of the Native family to produce a desire to reciprocate to elders who are perceived as giving so much to their families both in the past and present.

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**Table 1**

## Caregiver demographics

	n	%
Gender		
Male	5	26.3%
Female	14	73.7%
Age		
19–24	5	26.3%
25–39	5	26.3%
40–59	6	31.6%
60+	2	10.5%
Education		
<High school	5	26.3%
Graduated high school	10	52.6%
Some college	4	21.1%
Marital status		
Married	8	42.1%
Living as married	5	26.3%
Never married	5	26.3%
Widowed	1	5.3%
Person CG is Assisting		
Mother	6	31.6%
Grandmother	4	21.1%
Husband	4	21.1%
Father	2	10.5%
Sister	2	10.5%
Wife	1	5.3%

**Table 2**Caregivers' ratings of elders' past week disability-related ADL and IADL needs ( $n=19$ )

	<b>n</b>	<b>%</b>
IADLs		
Housekeeping	8	42.1%
Food preparation	7	36.8%
Shopping	7	36.8%
Traveling by car	7	36.8%
Doing laundry	6	31.6%
Using telephone	4	21.1%
Taking medications	3	15.8%
Handling money	0	0.0%
ADLs		
Getting into or out of bed	2	10.5%
Grooming	2	10.5%
Dressing from waist down	1	5.3%
Eating meals	0	0.0%
Bathing	0	0.0%
Using toilet	0	0.0%
	<b>Mean</b>	<b>SD</b>
IADL Score <sup>a</sup>	2.21	2.12
ADL Score <sup>a</sup>	0.26	0.56
Total Score <sup>a</sup>	2.47	2.39

<sup>a</sup>Higher values indicate more frequently endorsed items

**Table 3**

Caregiving burden (n=16)

	Nearly always		frequently		Sometimes		Rarely		Never	
	n	%	n	%	n	%	n	%	n	%
Health has suffered because of involvement with elder	0	0%	0	0%	0	0%	0	0%	16	100%
Lost control of his/her life since elder's illness	0	0%	0	0%	0	0%	1	6%	15	94%
Feels strained when around elder	0	0%	0	0%	1	6%	1	6%	14	88%
Social life has suffered because of caring for elder	0	0%	0	0%	2	13%	0	0	14	88%
Angry when around elder	0	0%	0	0%	2	13%	1	6%	13	81%
Caregiving negatively affects relationship with family members/friends	0	0%	0	0%	0	0	0	0	0	0%
Doesn't have as much privacy as he/she would like	0	0%	0	0%	2	13%	2	13%	12	75%
Doesn't have enough time for self due to caregiving	0	0%	0	0%	3	19%	2	13%	11	69%
Is uncertain about what to do about elder	0	0%	0	0%	4	25%	1	6%	11	69%
Stressed between caring for elder and other responsibilities	0	0%	0	0%	5	31%	3	19%	8	50%
Feels he/she could do a better job of caring for elder	5	31%	2	13%	6	38%	1	6%	2	13%
Feels he/she should be doing more for elder	5	31%	2	13%	7	44%	1	6%	1	6%

Excludes 3 participants whose elders reportedly required minimal to no care



Table 4

Positive aspects of caregiving (n=16)

	Agree a lot		Agree a little		Neither agree nor disagree		Disagree a little		Disagree a lot	
	n	%	n	%	n	%	n	%	n	%
Made him/her feel needed	16	100%	0	0%	0	0%	0	0%	0	0%
Enabled him/her to appreciate life more	16	100%	0	0%	0	0%	0	0%	0	0%
Made him/her feel good about self	15	94%	1	6%	0	0%	0	0%	0	0%
Made him/her feel strong & confident	15	94%	1	6%	0	0%	0	0%	0	0%
Made him/her feel more useful	14	88%	2	13%	0	0%	0	0%	0	0%
Made him/her feel appreciated	13	81%	3	19%	0	0%	0	0%	0	0%
Made him/her feel important	13	81%	1	6%	2	13%	0	0%	0	0%
Given more meaning to life	13	81%	2	13%	1	6%	0	0%	0	0%
Enabled him/her to develop more positive attitude	12	75%	4	25%	0	0%	0	0%	0	0%
Strengthened relationship with others	12	75%	4	25%	0	0%	0	0%	0	0%
Enabled him/her to learn new skills	11	69%	4	25%	1	6%	0	0%	0	0%

Excludes 3 participants whose elders reportedly required minimal to no care