

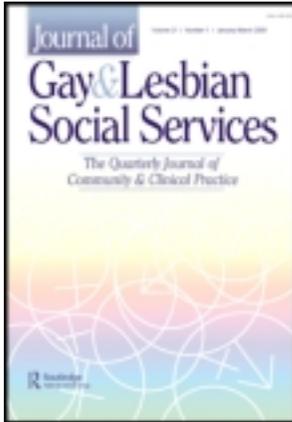
This article was downloaded by: [University of California, Los Angeles (UCLA)]

On: 13 February 2012, At: 11:52

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954

Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Gay & Lesbian Social Services

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/wgls20>

Caregiving Experiences Among American Indian Two-Spirit Men and Women

Teresa Evans-Campbell PhD^a, Karen I. Fredriksen-Goldsen PhD^b, Karina L. Walters PhD^c & Antony Stately PhD^d

^a Institute for Indigenous Health and Child Welfare Research, School of Social Work, University of Washington, 4101 15th Ave. NE, Seattle, WA, 98105, USA

^b Institute for Multigenerational Health, School of Social Work, University of Washington, Seattle, WA, USA

^c School of Social Work, and Director of the Institute for Indigenous Wellness Research at the University of Washington, USA

^d School of Social Work, University of Washington, USA

Available online: 25 Sep 2008

To cite this article: Teresa Evans-Campbell PhD, Karen I. Fredriksen-Goldsen PhD, Karina L. Walters PhD & Antony Stately PhD (2007): Caregiving Experiences Among American Indian Two-Spirit Men and Women, *Journal of Gay & Lesbian Social Services*, 18:3-4, 75-92

To link to this article: http://dx.doi.org/10.1300/J041v18n03_05

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.tandfonline.com/page/terms-and-conditions>

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

Caregiving Experiences Among American Indian Two-Spirit Men and Women: Contemporary and Historical Roles

Teresa Evans-Campbell
Karen I. Fredriksen-Goldsen
Karina L. Walters
Antony Stately

SUMMARY. Many Native men and women embrace the term *two-spirit* to capture their sexuality and gender expression. By analyzing the narratives of almost 70 two-spirit Native leaders from across the U.S., we explored contemporary experiences of caregiving among two-spirit people, historical two-spirit roles related to caregiving, and the implications of these roles for two-spirit and Native communities. The central role of

Teresa Evans-Campbell, PhD, is Assistant Professor and Director of the Institute for Indigenous Health and Child Welfare Research, School of Social Work, University of Washington, 4101 15th Ave. NE, Seattle, WA 98105 (E-mail: tecamp@u.washington.edu).

Karen I. Fredriksen-Goldsen, PhD, is Associate Professor and Director, Institute for Multigenerational Health, School of Social Work, University of Washington, Seattle, WA.

Karina L. Walters, PhD, is Associate Professor, School of Social Work, and Director of the Institute for Indigenous Wellness Research at the University of Washington.

Antony Stately, PhD, is Project Director of the HONOR Project, School of Social Work, University of Washington.

[Haworth co-indexing entry note]: "Caregiving Experiences Among American Indian Two-Spirit Men and Women: Contemporary and Historical Roles." Evans-Campbell, Teresa et al. Co-published simultaneously in *Journal of Gay & Lesbian Social Services* (The Haworth Press, Inc.) Vol. 18, No. 3/4, 2007, pp. 75-92; and: *Caregiving with Pride* (ed: Karen I. Fredriksen-Goldsen) The Haworth Press, Inc., 2007, pp. 75-92. Single or multiple copies of this article are available for a fee from The Haworth Document Delivery Service [1-800-HAWORTH, 9:00 a.m. - 5:00 p.m. (EST). E-mail address: docdelivery@haworthpress.com].

Available online at <http://jglss.haworthpress.com>
© 2007 by The Haworth Press, Inc. All rights reserved.
doi:10.1300/J041v18n03_05

caregiving among two-spirit people, related Native community expectations, the diversity of caregiving experiences across the lifespan, and the importance of caregiving in maintaining indigenous community ties emerged as key themes. doi:10.1300/J041v18n03_05 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2007 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. American Indian/Alaskan Native, GLBT spirituality, GLBT men and women of color, two-spirit, sexual orientation and discrimination, caregiving, parenting, qualitative research

INTRODUCTION

To date relatively little is known about caregiving in racial and ethnic minority communities. Importantly, the limited scholarship available has identified ethnic and racial differences in caregiving values and norms (Dilworth-Anderson, Williams, & Gibson, 2002; Foley, Tung, & Mutran, 2002), informal social support networks (Ortiz, Simmons, & Hinton, 1999), access to caregiving services (Talamantes, Lawler, & Espino, 1995), and service utilization (Hinrichsen & Ramirez, 1992; Thornton, 1998). When controlling for the disability level of the care recipient, for example, ethnic minority caregivers tend to provide assistance for longer periods of time and use fewer formal supports than White caregivers (Dilworth-Anderson, Williams & Cooper, 1999; Fredriksen-Goldsen & Farwell, 2004; McCann, Hebert, Beckett, Morris, Scherr, & Evans, 2000; Peek, Coward, & Peek, 2000). Notably, the majority of existing studies compare the experiences of African American and White caregivers of elders (Fredman et al., 1995; Gitlin, et. al., 2001; Martin, 2000; Young & Kahana, 1995), and we know much less about the experiences and needs of American Indian/Alaska Native (hereafter referred to as Native) caregivers.

Studies examining informal caregiving in Native communities have focused primarily on the care of elders and factors associated with caregiver burden. Caregiver burden in Native communities has been described as multidimensional, incorporating role conflict, negative feelings, guilt and caregiver efficacy (John, Hennessey, Dyeson, & Garrett, 2001). Numerous factors related to Native caregiver burden have been identified and include: (1) distress and anxiety related to managing in-home medical care, (2) difficulties with psychosocial aspects of care, (3) stress on family relationships, and (4) negative impacts on the caregiver's health and

well-being (Hennessey & John, 1996). Hennessey and John (1995) found that many Native American caregivers respond to such demands by expanding their social support network and securing additional caregiving resources. It is also important to note that Native people tend to develop chronic health conditions at younger ages compared to those from other ethnic groups (Hennessey, John, & Anderson, 1999; Jervis & Manson, 2002) and, as a consequence, Native people may be more likely to serve as caregivers, they may provide care for relatively longer periods of time, and they may provide care for others while experiencing their own health concerns.

Although preliminary research among Native communities suggest that caregiver burden exists, there are considerable cultural differences in the expression of caregiver burden and how it is experienced in relation to cultural role expectations. Caregiving roles are valued and proscribed for individuals as they mature and reach elder status in many Native communities. In many cases, caregiving roles are not defined by illness or distress but rather by roles of nurturing and passing on of knowledge in relation to elder status. Thus, while the case of Native grandparents caring for grandchildren may be framed as a “burden” from a Western perspective, in many Native cultures intergenerational caregiving is a cultural expectation consistent with status responsibilities (familial, elder, and communal). Additionally, the challenges of Native caregiving are buffered with meaningful extended family ties and supports from significant others. As a consequence, the issue of “burden” in relation to caregiving for Native Peoples may have more to do with the level of unanticipated role stress or resource stress (e.g., lack of relatives for social support) than to the actual caregiving activity per se. An early study comparing caregiver burden among Caucasian and Native American caregivers, for example, found that Native caregivers tended to perceive less control over the care situation and were more likely to acknowledge benefits resulting from caregiving (Strong, 1984). Native caregivers may also be more likely to contextualize challenging caregiving situations within cultural norms and values. For example, in some tribes Western diagnosed dementia-related hallucinations represent an elder’s contact with the spirit world and are viewed as a source of strength rather than a sign of dysfunction (Henderson & Traphagan, 2005). Finally, Native caregivers view caregiving as a collective and holistic enterprise; and, as a result, experience caregiving at multiple levels—individual, familial, communal—rather than interpreting it solely from the perspective of their own individual lives (Hennessey & John, 1995, 1996; Hennessey et al., 1999).

TWO-SPIRIT PEOPLE IN INDIGENOUS COMMUNITIES

Although many Native people serve as caregivers at some point in their lives, Native LGBTQ-T-S (lesbian, gay, bi-sexual, transgender, queer, or two-spirit; hereafter referred to as two-spirit) people often have specific cultural roles and responsibilities tied to caregiving in indigenous communities (Jacobs, Thomas, & Lang, 1997; Walters, Evans-Campbell, Simoni, Bhuyan, & Ronquillo, 2006). Moreover, these roles are intimately tied to their identities as Native LGBTQ or “two-spirit” people. Many indigenous societies in North America have historically acknowledged and incorporated the existence of diverse gender and sexual identities among community members (Brown, 1997; Lang, 1998; Little Crow, Wright, & Brown, 1997). Although there were exceptions, these community members tended to be well integrated within Native communities and often occupied highly respected social and ceremonial roles which included caregiving (Lang, 1998). Over the past several centuries, however, colonization has dramatically influenced the acceptance and inclusivity of those with alternative gender or sexual identities (Tinker, 1993).

While numerous scholars have explored the history and lived experience of indigenous peoples with diverse gender and sexual identities (Farrer, 1997), this work is almost exclusively focused on a bilinear Western model of gender with little or no insight into the complexity of gender identities and their intersectionality with sexual expressions. Accordingly, scholars have used limited labels such as *third gender*, *women-men*, and *men-women* (Lang, 1998) to describe Native people with multiple or alternative gender identities and/or sexual identities. Another commonly used term in gender scholarship, *berdache*, is considered offensive because of its colonial origins and purely sexual connotations: it is a non-Native term used to refer to male slaves who served as prostitutes (Jacobs, Thomas, & Lang, 1997; Thomas & Jacobs, 1999). In an attempt to capture the complex nature of indigenous gender and sexual identities, contemporary Native LGBT activists created a new term to define themselves—two-spirit. The word two-spirit derives from the Northern Algonquin word *niizh manitoag*, meaning *two-spirits*, and refers to an individual who embraces both feminine and masculine characteristics (Anguksuar, 1997). While not used by all Native LGBT people, this term is gaining acceptance and is increasingly used to define contemporary Native LGBT peoples. The term has important political and social implications for all Native people—two-spirit and other Natives—as it embraces the complexity of multi-gendered statuses and expressions,

and serves to reconnect contemporary Native people with traditional conceptions of sexuality and gender identity beyond Western dualistic notions of sexual and gender expression (Walters, Evans-Campbell, Simoni, et al., 2006).

One of the primary roles discussed in scholarship related to two-spirit identity is caretaking both historically and in contemporary times. In this paper, we present findings from a large qualitative study of two-spirit people to explore experiences, perceptions, and challenges related to caregiving. The data are part of a large-scale national study of two-spirit health (i.e., the HONOR Project) conducted in seven urban sites across the country from 2004-2006.

METHODS

As part of this larger study, HONOR Project staff worked with local, national, and regional two-spirit communities and Native agencies to complete 63 in-depth interviews with two-spirit leaders covering a range of topics including identity, resilience, and caregiving. In order to identify potential interviewees, we asked HONOR Project advisory board members as well as members of two-spirit organizations to suggest the names of those they considered to be two-spirit leaders. Individuals identified as leaders were then contacted and asked to be part of the study. To be eligible, participants had to meet six criteria: (a) be American Indian, Alaskan Native, First Nations, or Metis; (b) be self-identified as LGBTQT-S; (c) be age 18 or older; (d) be English-speaking; (e) not be psychotic or demented; and (f) reside in one of the seven national urban sites included in the study.

Using participatory action research methods, study investigators developed an interview guide that incorporated nine broad questions related to two-spirit identity, social support, health, and caregiving. We used narrative and indigenist research methods in our research, allowing the two-spirit leaders to give their *testimonios*, a type of oral history and life story as two-spirit leaders (Bishop, 2005; McMahon & Rogers, 1994; Tuhiwai Smith, 2005). Participants were encouraged to tell their stories with as little interruption as possible. Interviewers did not focus on uncovering minute historical information but instead explored how historical, cultural, and social events influence two-spirit identity, roles, and wellness. Embedded in the narratives are indigenist ways of knowing, worldviews, “deep metaphors,” and references to cultural traditions that connect individuals with ancestral ties as well as future generations

(Tuhiwai Smith, 2005). Participants had the option of reviewing their interview transcript and making changes if they desired.

For purposes of this paper, we conducted theoretical sampling from the qualitative interviews with 63 two-spirit activist leaders. Specifically, we read through the two-spirit interviews and selected 22 “cases” in which respondents explicitly talked about caregiving roles. As much as possible, we present the two-spirit leaders’ own words to illustrate similarities and differences in how Native two-spirit people “talk” or give testimony to their caregiving experiences. All interviews were audiotaped and generally took between two and three hours.

In terms of data analytic strategies, we used a modified form of a feminist interpretive method of narrative analysis called the Listening Guide, originated by Gilligan and colleagues (Gilligan, Spencer, Weinberg, & Bertsch, 2003). Each narrative was “listened to” by reading the transcripts multiple times, by multiple readers (including a two-spirit man) with the intention of “listening” to different aspects of a particular topic (e.g., caregiving), and then re-reading the transcripts to listen or focus on a different aspect of the topic of interest each time. Sections of the transcripts were color coded creating a visual map of the narratives’ layers in which identifiable, coherent “voices” could be heard. One of the authors “listened” by recording her thoughts simultaneous to color coding the transcripts, and thus, worked reflexively in interpreting the transcripts and coding the voices generating “themes” that relationally emerged across the transcripts.

The two-spirit voices reflected in these interviews represent considerable tribal, cultural, and geographic diversity. Respondents ranged in age from their early 20s through late 60s and all were considered leaders in their respective communities. To protect confidentiality, pseudonyms are used and identifying information such as tribal affiliation or site specific information about a particular community incident to which they could be linked were all deleted from their narratives. When necessary, quotes were edited to ensure readability and clarity.

RESPONSIBILITY TO THE COMMUNITY

Many of the two-spirit people we spoke with had served as caregivers at some point in their lives or anticipated taking on this role in the future. Those we interviewed often alluded to caregiving as a primary role and responsibility of a two-spirit person. Indeed, a number of respondents

felt that caretaking connected them to their historical roles, at individual and community levels.

The two-spirits, we were responsible for the village. We were the ones who took care of the infirmed. We were the ones who raised the children, not because they were unwanted, or abandoned or, we were in text godparents. We were the ones who stayed behind, and protected the village; we're the last form of defense against, protecting the women, the children, and the village.

–Terri

That's what our role was in previous times [caretaking] and then so many of the people that I knew in the community . . . were kind of in a caretaking role, and then coincidentally I've met all these people who are either in the medical field or they did other things in the community to kind of bridge different parts of the communities . . . I don't think it's a coincidence that my life has gone in that direction. I dunno, I'm just really drawn to it, I really am and I felt like since I was young, you know, I always felt like for some reason I needed to be a caretaker.

–Roberta

I just feel like I have this responsibility to the community that I have to fulfill and that's just a part of me . . . I feel like I would be being irresponsible if I didn't do certain things I'm trying to do in the community.

–Jackie

There is a correlation between maybe our traditional role as I see it as two-spirited people and our relevance in healthcare . . . I mean we find our way into this nurturing society role and that we should really look at that as more of a traditional way to contribute to a society. Just like when we were home slaughtering buffalo and because we were the strong winkle [a tribally-specific term for two-spirit], we were cutting up the meat from the bone, from disconnecting the back leg of the buffalo and pulling it off and giving it to grandma to actually cut into smaller pieces you know? It's that concrete.

–Mary

**A PRIMARY TWO-SPIRIT ROLE—
CARETAKING OF SICK AND ELDERLY PEOPLE**

Through the interviews we learned that many of the respondents had cared for sick family, friends or elders. Although challenging, caregiving was commonly viewed as an accepted and even anticipated role for these two-spirit leaders. Further, caregiving was referenced as a larger Native community expectation of two-spirit people which they took pride in fulfilling.

Caregiving is totally important, it's totally important to our two-spirit self, who we are . . . We had this wonderful guy in the community [that had been terribly abused as a child by his parents]. And then I watched him take care of those parents. And they had—I'm telling you, there's like 12 kids, but he is the one—and he's the two-spirited one, he's the only one. So he is taking care of those parents that were abusive to him, but yet because that is in our DNA as two-spirited people that we love our people. That he, despite all that happened to him, took care of that mother. I'm telling you, he was there. When she said frog, he jumped. Because he wanted to take care—and he took care of her up until the very end. And I went to the funeral when she passed and he wailed. And he hurt so bad. And now the father's still alive and he's taking care of him. It blows me away, it blows me away that tenderness, that love for each other.

—Mary

A dear friend of mine from my tribe is taking care of his grandmother. Nobody else will. So our people are constantly, constantly the ones that are relied upon. And I kept thinking, why is it just us—the two-spirits? Why is it not somebody else? And it was like Creator and the old ones told me it's because you all have such the love and the passion for people and the people see it. And we have such caringness, and that we love our people, that's why. It's just part of who we are. And I see it constantly. I look around the room, and I see everyone of our guys having one or the other part of caregiving in their family. Yeah, it's amazing. Totally.

—Mary

I took care of my grandmothers, my great-grandmother . . . I mean they constantly wanted me to be with them. They constantly wanted me to take care of them. And I was constantly at my grandmother's house, and I was doing cooking, helping, being with her, making her laugh, my grandmother, my great-grandmother. It was so awesome to be able to know my great-grandmother. And I would sit on the porch with her and she would be churning butter the old fashioned way and I was the one and I think back, I was the only one that they called upon. And as they got older because my great-grandmother lived to be 98 and my grandmother lived to be 97, and up until the end they were calling for me . . . And it was just that, it was just that, oh it makes me teary. Because I miss them. Because we had such a bond together. And such a relationship. And I'd love to take care of them. I loved taking care of them [sniffs].

–Jackie

When I spoke earlier about sitting down with this elder woman and her just saying you know like, oh you're winkte [tribally specific word for two-spirit] and you can be a caregiver . . . and that's related to how I feel about our survival as a community you know . . . Maybe that's why I'm trying to return professionally to provide support to help people survive. So it's nurturing in that way.

–Al

I can't think of [any two-spirit person] that isn't, you know, that's not taking care of at least one, maybe two people.

–Marc

CAREGIVING FOR CHILDREN

It was even more common among respondents to have parented children and/or served as primary caregivers of children at some point. This was often viewed as an integral part of both their Native identities and their two-spirit identities.

And like we have a family model in our reservation which is extended, we don't have one mother, we have many mothers, many

fathers, any uncle can be a father, any aunt can be a mother. It's very (enmeshed) and this makes my non-Native friends very uncomfortable when I go home and like we're sitting there and then an uncle will come in and just say hello and make himself at home like it's his house. So, those kinds of things traditionally, tribal living, kind of looking at that, but I really think we have to look at our role nationally in the larger picture because I think it will validate what we know traditionally.

—Mary

I think especially like older lesbians, we all have children, because we did what we thought was available . . . and those of us who didn't ended up taking care of other kids anyway . . .

—Roberta

A number of the respondents had been asked by family members to help raise children.

In terms of children, I was sterilized when I was seventeen. I wanted to have children, even though I knew I was a lesbian. By the government, I didn't know what was happening at the time, like a lot of young Native women. And um, I've helped raise my nephew and niece.

—Marie

My oldest sister was having problems, health problems and alcohol problems, and just a lot of marital problems and things, and she had two children and she was expecting a third one and she called me and she said, "You know, I can't take care of the kids. Would you be willing to take this new one that I'm going to have?" And I was kind of surprised and . . . I said "Yeah, but you have to remember, you have to understand, you know, my life too that I'm gay." And she said, "Oh, (JR)," she said, "I love you and I know you—we all love you." She says, "Don't worry about that. That's not a problem, just take care of him." . . . And I've had him since then . . . [At first I] stayed with my mom three weeks and she showed me how to take care of him and how to wrap him and change him and bathe him and all these things . . . I had a hard time sleeping at night 'cause you know there was crib death and all that stuff to think

about, and I would nudge him and keep him awake. I cradle wrapped him all the time, for two years he was cradle wrapped. And uh, I'm surprised he's alive today! (laughs). He's 16, going to be 17.

–JR

And I actually a couple years ago, actually four or five years ago we [*my partner and I*] took my sister and I think she was like nine at the time, she came and I got custody of her for awhile. My mom was so supportive of it because she knew it was a good opportunity for her. So we had her come out here and she stayed with us for awhile and you know it's a huge responsibility for us but we were up for it and you know we moved into a bigger house so we could accommodate the extra body in the house. So she stayed with us for like eight months.

–Matt

My partner D. and I served as foster parents for a friend of ours. And so he lived with us for like three years. There isn't anything official there's no paperwork involved I mean, D. could walk in and say I'd like my son back, and we'd have to go okay, but to the extent she put up with it and, and, and he benefited from it, it worked.

–Camille

Notably, there was a sense in the interviews that raising children and helping to raise children was beneficial to the two-spirit community as a whole.

I know a lot of two-spirit people are parents or are taking on relatives' children, you know taking on cousins and raising children and that has an impact on them and that's changing the base of our (two-spirit) community for the good, I think.

–Terri

When we care for the children, we are a part of the heart of the community. Central to the whole Native community and that's helping us regain our traditional roles.

–Mary

MESSAGES RECEIVED ABOUT PARENTING/CAREGIVING

Respondents were asked about the messages they had received either explicitly or implicitly about being gay and being a parent—from family, from the Native community, from the LGBT community, or any other communities. Throughout the interviews, respondents highlighted the positive messages about being caregivers from family or Native community members.

I mean growing up I never heard anything but when we were going to take my sister on everybody was so supportive because they knew we were so responsible and together that they knew she would have a really good opportunity here. But everybody was so supportive. And then we took in my sister's baby and everybody again was pushing to have me get involved and get the baby 'cause they knew we could do it. And you know for me that was a good feeling 'cause I was like, wow people aren't even thinking of anything, in a positive or negative way . . . It was just kind of—it's just the way it should be and they're accepting of it.

—JR

[People from my tribe] would be so supportive . . . I just went back last weekend to see my grandma 'cause she's in the hospital. So when I came back she called and she was like, do you want to adopt a kid [interviewer laughs] because one of our cousins had her baby too young and blah blah blah and I'm like, no, you know I just can't think of that now, if I'm going to take the kid it's going to be for, you know, my niece. But you know, they're already trying to push kids off on me, so I know that they would be very supportive [both laugh].

—Martin

I think [my family] would love it. I think they would adore that. They might not be comfortable with the situation [laughs] surrounding me having kids at first, but they would definitely come around. They better come around. [researcher laughs] . . . My dad might think it's a little crazy at first but he would be like whatever, that's great. I'm happy for you.

Interviewer: Okay, and how do you think you'd be received in the broader community?

Respondent: In the broader Native community that's what would matter, in the non-Native community it wouldn't matter but in the broader Native community, I would hope that they would be supportive and understanding and happy. I would hope that that's the response I would get. I'm sure they would. I think everybody, at least my friends in the Native community would be very happy for me.

Interviewer: So you wouldn't be impacted too much by what the non-Native community thought?

Respondent: No. Not one bit. Not one bit.

–Thomas

CAREGIVING SUPPORT FROM TWO-SPIRIT COMMUNITY

Some respondents discussed the challenges of caregiving and talked about the support they had received in this role. It was clear through the interviews that other two-spirit people played a primary role in easing the burdens related to caregiving.

I was a teen parent and without, without that I would not have been able to be an effective parent, um [clears throat] the resources and support that I was able to access were directly a result of my relationships with two-spirited Natives where I was living, you know, just I mean literally from feeding me and my kids for a year, standing in food lines for me, just you know everything you can think of, not being able to afford medicine and having them take care of that, um, just everything, and now it's interesting because my middle daughter is two-spirited and very uncomfortable with it, and so watching her struggle through that is something that I couldn't have done without having the two-spirit community around me in the first place to be able to support her through it. And then my older daughter, is a butterfly spirit and she has to be treated very tenderly and gingerly and she finds that with her two-spirited

uncles and aunts. She just finds that nurturing, she can, she cannot access that in all of her communities, but she can when she's a (young kid) and wants to put her head in somebody's lap, that's the only place that she can go. That's it. And she's met other youth that have two-spirited parents or family members so that now she can be open and feel comfortable.

–Viv

My granddaughter has been with me now for the last six years and if it wasn't for the two-spirit community, I don't know if I would be alive.

–Terri

[My granddaughter] knows there's not just grandma, she's got aunts and men who care whatever happens to her. Everyone has her best intentions at heart . . . and so she's definitely a child that's being raised by the community.

–Roberta

DISCUSSION

The narratives in this study illustrate the critical role of two-spirits in providing caregiving across the lifespan to extended family members and kin within their communities. Caregiving is perceived as an important and integral role of two-spirit people, and it is clear that many two-spirit people already engage in caregiving or expect to provide care for others at some point during their lifetime. Importantly, the findings of this study demonstrate significant variability in the types of caregiving relationships that exist among two-spirit caregivers and their loved ones. Based on culturally proscribed roles, two-spirit people may be asked to care for the elderly, relatives, or children. In some communities, they may be asked to care for the community as a whole as they take on specific social or ceremonial responsibilities. In general, the people we interviewed spoke with pride about their caregiving responsibilities and a few noted how serving as a caregiver tied them to the Native community in an immediate and central way, particularly when they cared for children.

While much of the general caregiving literature focuses on caregiver burden, the people we interviewed often viewed caretaking as a

challenging but central part of their two-spirit identity and role expectation. They literally would not be who they are as two-spirit people if separated from their caregiving roles. Yet, there are clearly also extra social, emotional, and financial burdens that accompany caregiving responsibilities and, as illustrated in the interviews, two-spirit people may take on caregiving roles at multiple levels (eg. individual and community) simultaneously.

Consistent with indigenous worldviews related to kinship systems and collective systems of care, several participants stressed the critical role of community support in assisting two-spirit caregivers and spoke to the need for more support; in particular, cultural systems of support (e.g., connection to extended family systems and other kinship structures of support). To insure that two-spirit individuals have access to appropriate support services, service providers must modify as necessary the accessibility and cultural relevance of community-based services assisting caregivers and their families (Fredriksen-Goldsen & Farwell, 2004). Negative experiences with health and social service systems and the absence of staff of similar cultural backgrounds (Cox & Monk, 1996; Gordon, 1995; Ortiz et al., 1999; Talamantes et al., 1995) need to be addressed to increase access to and utilization of services.

It is also important that service providers are cognizant of the tremendous tribal and cultural diversity reflected in the two-spirit population. When assessing needs, for example, providers must consider intra-cultural as well as intercultural differences related to help-seeking. Given the extent of caregiving and the range of caretaking activities discussed by respondents, concerted awareness programs are called for to educate organizations and agencies that support two-spirit people. Further, as so many of those interviewed were quite active in their Native communities, it is critical that organizations work with Native agencies in their efforts to reach out to two-spirit people and provide culturally meaningful services.

Many existing caregiver support programs and policies also reflect a cultural bias by only assisting caregivers who are providing support to elderly and immediate family members. Our findings suggest that two-spirit people may be more likely than others to parent or care for children or for non-relative community members. Indeed, caring for children or community needs may be an accepted and anticipated role for two-spirit people. Educating caregiver support programs on these practices is critical.

Finally, additional research is needed to more fully understand the needs and experiences of two-spirit as well as other caregivers in Native American communities. Often, two-spirit and other Native people are not

included in caregiving research, limiting what we know about caregiving responsibilities in Native communities and related challenges. Indigenous worldviews regarding caregiving roles in relation to collective responsibility and systems of care need to be further developed in the caregiving literature to fully theorize and respond to issues related to caregiving burden and distress. Additionally, to build our knowledge base in this area, scholars and researchers must make concerted efforts to include two-spirit and Native people in their research and outreach efforts. Such a knowledge base will be critical in enabling family practitioners to more fully understand the range of experiences among ethnically diverse caregivers and to tailor services and policies to assist them and their families. Finally, expanding the caregiving knowledge base to include collective systems of care and indigenist worldviews will undoubtedly strengthen caregiving intervention development for diverse communities.

REFERENCES

- Anguksuar [LaFortune, R]. (1997). A postcolonial perspective on Western [mis]conceptions of the cosmos and the restoration of indigenous taxonomies. In S. E. Jacobs, W. Thomas & S. Lang (Eds.), *Two-spirit people: Native American gender identity, sexuality, and spirituality* (pp. 217-222). Chicago: University of Illinois Press.
- Bishop, R. (2005). Freeing ourselves from neocolonial domination in research: A Kaupapa Maori approach to creating knowledge. In N. Denzin and Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research, 3rd edition*, (pp. 109-138). Thousand Oaks, CA: Sage.
- Brown, L. B. (1997). Women and men, not-men and not-women, lesbians and gays: American Indian gender style alternatives. *Journal of Gay and Lesbian Social Services*, 6(2), 5-20.
- Cox, C., & Monk, A. (1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. *International Journal of Aging and Human Development*, 43(2), 93-106
- Dilworth-Anderson, P., Williams, S.W., & Cooper, T. (1999). Family caregiving to elderly African Americans: Caregiver types and structures. *Journal of Gerontology: Social Sciences*, 54B, 237-241
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *Gerontologist*, 42(2), 237-272
- Farrer, C. A. (1997). Dealing with homophobia in everyday life. In S. E. Jacobs, W. T. Thomas, & S. Lang (Eds.), *Two-spirit people: Native American gender identity, sexuality, and spirituality* (pp.297-317).Chicago: University of Illinois Press.

- Foley, K. L., Tung, H. J., Mutran, E. J. (2002). Self-gain and self-loss among African American and white caregivers. *Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 57(1), 14-22.
- Fredman, L., Daly, M. P. & Lazur, A. M. (1995). Burden among White and Black caregivers to elderly adults. *Journal of Gerontology*, 50B(2), 110-118.
- Fredriksen-Goldsen, K. I., & Farwell, N. (2004). Dual responsibilities among Black, Hispanic, Asian and White caregivers: Implications for social work practice. *Journal of Gerontological Social Work*, 4(43), 25-44.
- Gilligan, C., Spencer, R., Weinberg, M. K., & Bertsch, T. (2003). On the listening guide: A voice-centered relational method. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 157-172). Washington, DC: American Psychological Association.
- Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *Gerontologist*, 41(1), 4-14.
- Gordon, A. K. (1995). Deterrents to access and service for Blacks and Hispanics: The Medicare Hospice Benefit, healthcare utilization, and cultural barriers. *Hospice Journal*, 10(2), 65-83.
- Henderson, J. N., & Traphagan, J. W. (2005). Cultural factors in dementia: Perspectives from the anthropology of aging. *Alzheimer's Disease and Associated Disorders*, 19(4), 272-274.
- Hennessy, C. H., & John, R. (1995). The interpretation of burden among Pueblo Indian caregivers. *Journal of Aging Studies*, 9(3), 215-229.
- Hennessy, C. H., & John, R. (1996). American Indian family caregivers' perceptions of burden and needed support. *Journal of Applied Gerontology*, 15(3), 275-294.
- Hennessy, C. H., John, R., & Anderson, L. A. (1999). Diabetes education needs of family members caring for American Indian elders. *The Diabetes Educator*, 25, 747-754.
- Hinrichsen, G. A. & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of adaptation, adjustment and service utilization. *The Gerontologist*, 32(3), 375-381.
- Jacobs, S.E., Thomas, W., & Lang, S. (1997). Introduction. In S. E. Jacobs, W. Thomas & S. Lang (Eds.), *Two-spirit people: Native American gender identity, sexuality, and spirituality* (pp. 1-18). Chicago: University of Illinois Press.
- Jervis, L. L., & Manson, S. M. (2002). American Indians/Alaska Natives and dementia. *Alzheimer Disease and Associated Disorders*, 16(2), S89-95.
- John, R., Hennessy, C. H., Dyeson, T., & Garrett, M. D. (2001). Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *The Gerontologist*, 41(2), 410-419.
- Lang, S. (1998). *Men as women, women as men: Changing gender in Native American cultures* (J. L. Vantine, Trans.). Austin: University of Texas Press.
- Little Crow, Wright, J. A., & Brown, L. A. (1997). Gender selection in two American Indian tribes. *Journal of Gay and Lesbian Social Services*, 6(2), 21-28.
- Martin, C.D. (2000). More than the work: Race and gender differences in caregiving burden. *Journal of Family Issues*, 21(8), 986-1005.

- McCann, J. J., Hebert, L. E., Beckett, L. A., Morris, M. C., Scherr, P. A., & Evans, D. A. (2000). Comparison of informal caregiving by Black and White older adults in a community population. *Journal of the American Geriatrics Society*, 48(12), 1612-1679.
- McMahon, E., & Rogers, K. L. (Eds.) (1994). *Interactive oral history interviewing*. Hillsdale, NJ: Lawrence Erlbaum.
- Ortiz, A., Simmons, J., & Hinton, W. L. (1999). Locations of remorse and homelands of resilience: Notes on grief and sense of loss of place of Latino and Irish-American caregivers of demented elders. *Culture, Medicine and Psychiatry*, 23(4), 477-500.
- Peck, M. K., Coward, R. T., Peck, C. W. (2000). Race, aging and care. *Research on Aging*, 22(2), 117-143.
- Strong, C. (1984). Stress and caring for elderly relatives: Interpretations and coping strategies in an American Indian and White sample. *The Gerontologist*, 24, 251-256.
- Talamantes, M., Lawler, W. R., & Espino, D. V. (1995). Hispanic American elders: Caregiving norms surrounding dying and the use of hospice services. *Hospice Journal*, 10(2), 35-49.
- Thomas, W., & Jacobs, S. E. (1999). “. . . And we are still here”: From *berdache* to two-spirit people. *American Indian Culture and Research Journal*, 23(2), 91-107.
- Thornton, M. C. (1998). Indigenous resources and strategies of resistance: Informal caregiving and racial socialization in Black communities. In H. I. McCubbin (Ed), *Resiliency in African American families*. Resiliency in Families Series, Vol. 3. (49-66). Thousand Oaks, Ca: Sage Publications.
- Tinker, G. E. (1993). *Missionary conquest: The gospel and Native American cultural genocide*. Minneapolis: Fortress Press.
- Tuhiwai Smith, L. (2005). On tricky ground: Researching the Native in the age of uncertainty. In N. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research, 3rd edition*, (pp. 85-107). Thousand Oaks, CA: Sage.
- Walters, K., Evans-Campbell, T., Simoni, J., Ronquillo, T., & Bhuyan, R. (2006). “My Spirit in My Heart”: Identity experiences and challenges among American Indian Two-Spirit Women. *Journal of Lesbian Studies*, 10(1/2), 125-149.
- Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 54B(1), 12-23.
- Young, R. F., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. *The Gerontologist*, 35(2), 225-232.

doi:10.1300/J041v18n03_05