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ORIGINAL PAPER

Characteristics of American Indian Female Caregivers on a Southwest American Indian Reservation

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Abstract

American Indian (AI) caregivers have been excluded from national survey efforts. Drawing from a 2012 survey administered on the Hopi Reservation in northern Arizona, 20% of adults are caregivers. More information is needed to guide program development tailored to Hopi needs. In a University-Community collaboration, a 58 question survey was administered to self-identified caregivers of a family member about amount and type of care provided, difficulties, caregiver health, and desired support services. Characteristics of caregivers and their experiences were described. Forty-four (44) female Hopi caregivers were interviewed from June–October 2017, mean age of 59 years (± 12.6) with mean 5.5 year (± 4.4) history of providing care. Over 84% provided care to either a parent or grandparent. Most caregivers provided transportation (93.2%), housework (93.2%), and medical related care (72.7%). Caregivers stated they had difficulties with not having enough time for family and or friends (88.6%), financial burdens (75.0%), and not having enough time for themselves (61.4%). The most frequently identified difficulty was stress (45.5%). Caregivers would like additional services, with 76.7% asking for training. Over 77% would not consider placing their relative in an assisted living facility. Compared to national data, Hopi female caregivers are older, provide more care hours/week, more caregiving duties, and for a longer number of years. Stress is the most reported difficulty, although lower than national levels. As caregivers are resistant to placing the recipient in assisted living, educational efforts should focus on training caregivers to assist the care recipient and decreasing caregiver stress.

Keywords American Indian · Native American · Caregiving · Elder · Chronic disease

Introduction

In 2015, an estimated 39.8 million caregivers report providing care to an adult in the United States (U.S.) [1]. Little information is known about the caregiving experience of American Indian (AI) caregivers since they have been largely excluded from national surveys [1, 2]. The 2015 Report "Caregiving in the U.S" compiled by the National Alliance for Caregiving and American Association Retired Persons (AARP) Public Policy Institute only report percent of caregivers from a national sample of 1248 caregivers who are identified as White, Hispanic, African American and or Asian American [1]. A 2016 report from a random household interview of 500 Hopi men and women living on the Hopi Reservation in northern Arizona, estimated 20% of adult tribal members are caregivers, with more than half (56%) being female [3].

Limited published literature points to the caregiving experience of AIANs being mixed with both negative and

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positive experiences [4]. Understanding the ways that AI caregivers provide help (such as cooking, cleaning, transportation to medical appointments) and their challenges can inform community programs. This information may be especially pertinent in rural reservation communities where self-care services and health education are often limited. Through collecting more data on AI caregiver services desired and caregiver difficulties and concerns, support programs designed for caregivers can be locally relevant and culturally tailored.

The Hopi Tribe is a southwest American Indian Tribe located in northern Arizona. According to the Hopi Office of Tribal Membership, as of April 2018, tribal enrollment was 14,475 with 7815 living on the approximate 2.5 million acre reservation (M. Polacca, personal correspondence, April 2nd, 2018). Regional clinical health care services are provided by two health care centers: the Hopi Health Care Center located at Polacca, AZ on the eastern side of the Hopi Reservation, equipped with 24 h emergency services, hospital beds, an out-patient clinic, a 2-bed birthing unit, and a 4-bed medical and surgical unit supported by a staff of four physicians and 6 mid-level providers and a hospital located on the far west side of the Hopi reservation in Tuba City, AZ actually on the Navajo Reservation (approximately 53.2 miles from Kykotsmovi, AZ). On the Hopi Reservation, one "Hopi Assisted Living Facility" is located on Moenkopi, AZ that provides long term care [5].

To address the lack of information on American Indian (AI) caregiving on reservations and to expand on the work of the 2012 Hopi Cancer and Chronic Disease Survey [3], the 2017 Hopi Adult Caregiver Survey was developed and then administered to self-identified caregivers who were members of the Hopi Tribe about their responsibilities, difficulties, and needs.

Methods

Survey Development

A Community-University partnership between the Hopi Office of Aging and Adult Services (HOAAS) and the University of Arizona (UA) was formed to develop and implement the Hopi Adult Caregiver Survey (HACS). The first author, FC, an enrolled member of the Hopi Tribe and an a UA investigator, created the first draft, drawing on caregiving questions from the Hopi Cancer and Chronic Disease Survey [6]. The UA-HOASS team collaborated to refine the survey draft and reached consensus on a final version. The Hopi team members contributed to the community relevance of the survey and included questions they felt could inform HOAAS' future decision-making.

Approvals

Before study initiation, Hopi Tribal Council reviewed and approved the survey and the research protocol. Approval was obtained from the Institutional Review Board (IRB) of the UA Office of Human Subject Research Compliance. All research team members and field team members completed the CITI training prior to beginning the participant consent and survey processes [7].

Recruitment and Eligibility

Participants were recruited from the HOAAS' list of caregivers that receive local services and through responses to an article placed in tribe's weekly newspaper, the Hopi Tutuveni. Inclusion criteria included: ≥ 8 years of age or older, providing care to a family member with any one of the following: cancer, other chronic disease/health condition (such as diabetes, Alzheimer's), disabled or elderly, and being a Hopi tribal member living on the Hopi reservation. Exclusion criteria included: less than 18 years of age, non-Hopi tribal enrollment, non-reservation residence and providers of care for healthy children. Status as a caregiver was determined by response to the following question: *People may provide regular care or assistance to a friend or family member who has a disease or disability. During the past month did you provide any such care? (Excludes care provided to young healthy children at home).*" Participants who responded "Yes" to this question were considered caregivers.

Survey Components

The 58 item survey included demographics questions: age, gender, marital status, education level, and employment, as well as current health status, exercise habits and eating habits. Specific questions related to caregiving included the types of care provided, amount of time providing caregiving, reasons for being a caregiver, caregiver difficulties, and services desired. Questions about the care recipient (as reported by the caregiver) included: age, relationship to caregiver, and health conditions.

Data Collection

Data collection occurred between June and October 2017. HOAAS provided a contact list that contained the phone number of caregivers who had registered at their offices. A maximum of five contact attempts via phone or in person were made by a trained Hopi interviewer. For consistency in administration, the interviewer used a computerized script when contacting and setting up participant interview meeting dates. Once contact was made, the interviewer read the consent form aloud to the potential participant, answered questions about the research, and obtained written consent; participants were given a copy of their signed consent form. After providing consent, participants completed the survey questions verbally administered by the interviewers. Participants had the option of having the interview conducted in English or Hopi. Interviews were conducted at the Hopi Nutrition Center in Kykotmsovi, AZ, as well as in participant homes to accommodate those without transportation or a caregiver replacement. Participants received either $20 gift card or $20 cash as compensation for their time.

Data Analysis

The survey was built in Windows version 7 of Epi Info and transferred to the Epi Info app for entry by the Hopi interviewer [8]. Survey data then were transferred to Stata 13 for analysis [9]. Frequencies and percentages were calculated for categorical variables for all questions and mean and standard deviations for continuous variables. Per the Hopi Tribe approval requirements, only group-specific sample sizes greater than or equal to five were reported.

Results

From the list provided by HOAAS and those self-identified caregivers recruited from the newspaper, 46 of 64 potentially eligible caregivers were recruited (71.9% response rate). Those that did not participate were either never reached by phone or not rescheduled after not appearing at their survey appointment time. Of the 46 caregivers who provided consent and interviewed, all but two were female. The subjects of this report will be the 44 female caregivers. Average time of survey completion was 45 min. None of the participants requested to have the interview conducted in Hopi, all interviews were conducted in English.

Caregiver Characteristics

These female Hopi caregivers ranged from 23 to 77 years, mean age of 57 ± 12.6 years. Fifty-nine percent reported they had children under the age of 18 in their home and all reported they had at least one other adult over the age of 18 residing in their home (Table 1). The largest percentage of caregivers (34.1%) lived in separate homes from their care recipient, and 29.6% moved into the home of the caregiver to provide caregiving. Eight caregivers were already living with their care recipient prior to their needing caregiving and seven recipients moved into the home of their caregiver. Almost half (45.5%) of all caregivers reported that they provided more than 40 h/week of caregiving, 25.0% provided 8 h or less/week, 15.9% provided 9–20 h/week and 13.6% provided 21–40 h/week (Table 1).

Participation in traditional medicine and ceremonies were found to be important to these caregivers (Table 1). More caregivers reported having been to a traditional healer within the past 5 years (54.5%) than those that did not (45.5%). A large percentage of caregivers (84.1%) reported that they take part in cultural ceremonies as a regular practice.

Caregiver Personal Health

Table 1 also shows self-reported perceptions about the caregivers' personal health behaviors. Overall, 61.4% of the caregivers reported that being a caregiver had no impact on their personal health. Rating their health on a scale of poor, fair, very good, to excellent, 56.8% of caregivers reported their health as "Fair," 34.1% reported their health as "very good." More than 50% of the caregivers reported no changes to their eating habits since becoming a caregiver; while 23.3% participants reported eating healthier and 23.3% reported eating less healthy. When asked if their exercise habits had changed, the majority of caregivers (47.7%) reported exercising less, with 38.6% reporting no change and 13.6% reported they exercised more.

Formal Versus Informal Support for Caregivers

Almost one-third (31.8%) of caregivers reported they received formal (paid) caregiving assistance from aides or housekeepers, and 75% of caregivers reported informal (unpaid) assistance provided by other family members over the age of 18 (Table 1). Adult children and siblings provided the most informal help. Less than half (43.2%) of caregivers received informal caregiving assistance from family members under the age of 18. The majority of this assistance came from grandchildren (27.3%), and children (20.5%) (Table 1).

Characteristics of Care Recipients

Care recipients ranged from 39 to 98 years, with the mean age being 83.6 years ± 12.05 (Table 2). The majority of care recipients were parents of the caregivers (70.5%), followed by grandparents (13.6%). Caregivers were asked to identify the main health condition of their care recipient. The majority of caregivers provided care to a relative with a chronic disease, with the most mentioned conditions being "dementia" (27.3%), cardiac related problems (18.2%), cancer (18.2%), and diabetes (13.6%). Caregivers were asked reasons their care recipient needed care, specifically physical health condition long term, physical health condition short term, old age, emotional or mental health issues, behavioral health issues, learning disability, ad/or mental disability/

Table 1 Characteristics of Hopi caregivers (June–October 2017)

	Caregivers [N (%)]
Total	44
Age (years)	
< 49	10 (22.7)
50–59	10 (22.7)
60–69	18 (40.9)
70+	6 (13.6)
Average ± SD	57 years ± 12.6
Education[b]	
High school graduate/GED or less	13 (30.2)
Trade, technical, vocational beyond High school	5 (11.6)
Some college but no degree	16 (37.2)
2 year degree or more	9 (20.9)
Marital status	
Single	15 (34.1)
Married (cohabitating/common law/married traditional)	14 (31.8)
Widowed	6 (13.6)
Separated, divorced	9 (20.5)
Number of adults living in home	
One	7 (15.9)
Two	13 (29.6)
Three	13 (29.6)
Four or more	11 (25)
Number of children living in home[b]	
None	18 (41.9)
One or more	25(58.1)
Language speak at home mostly[a]	
English	36 (81.8)
Hopi	23 (52.3)
Within the past 5 years how often have you used services from a traditional healer or medicine person?	
No times	20 (45.5)
1–5 times	23 (52.3)
6–10 times	< 5
Do you take part in cultural ceremonies?	
Yes	37 (84.1)
No	7 (15.9)
Years caregiving	
> 1 year	5 (11.4)
More than 1 year–3 years	14 (31.8)
3 + years–6 years	14 (31.8)
More than 6 years	11 (25)
Hours/week spent caregiving	
8 h or less	11 (25)
9–20 h	7 (15.91)
21–40 h	6 (13.64)
More than 40 h	20 (45.45)
Caregiver perceived health	
How would you describe your own health?	
Excellent	< 5
Very good	15 (34.1)
Fair	25 (56.8)
Poor	< 5

Table 1 (continued)

	Caregivers [N (%)]
How would you say taking care of your relative has affected your health?[b]	
No impact	27 (61.4)
Made it better	< 5
Made it worse	13 (29.5)
How have your personal eating habits changed since becoming a caregiver?[b]	
No change	23 (53.5)
Healthier	10 (23.3)
Less healthy	10 (23.3)
How have your personal exercise habits been affected since becoming a caregiver?	
No change	17 (38.6)
Exercise more	6 (13.6)
Exercise less	21 (47.7)
About how many days per week do you usually exercise?	
0 days	8 (18.2)
1–2 days	7 (15.9)
3–4 days	17 (38.6)
5–7 days	12 (27.3)
Formal and informal support received[a]	
Informal-family over 18 years of age	33 (75)
Daughter(s)	20 (60.6)
Son(s)	12 (36.4)
Sister(s)	10 (30.3)
Brother(s)	8 (24.2)
Other: mom, in-laws, spouse/partner, cousin	10 (30.3)
Informal-family under 18 years of age	19 (43.3)
Grandchildren	12 (63.2)
Son(s) and daughter(s)	9 (47.4)
Other: sister(s), cousin(s)	< 5
Formal caregiving assistance	
Aides, housekeepers, others paid to provide assistance	14 (31.8)

Percentages may not add up to 100% due to rounding errors

[a] More than one answer allowed

[b] One do not know, unsure or refused to answer

developmental delay. Most care recipients needed assistance for long and short term physical health conditions (79.5%), old age (77.3%) and emotional/mental/behavioral health issues (43.2%) (Table 2). The mean number of reasons recipients needed care was 2.2 ± 1.2 with a range of 1–6. Half of the care recipients utilized traditional healers (50.0%).

Caregiving Experience

Caregivers were asked about their reasons for becoming a caregiver (Table 3). The desire to take care of their relative was the most common reason for why they became a caregiver, with 68.2% choosing this option. Additional reasons included: cultural expectation of Hopi's taking care of their relatives (61.4%), and the elder not wanting to go to an assisted living facility (45.5%).

Assisting in Health Care

Caregivers reported those activities of daily living and other duties that they provided their relative (Table 3). Most caregivers provided transportation (93.2%) or arranged transportation (38.6%) for their relative. Caregivers also provided instrumental activities of daily living by assisting with incontinence or restroom related issues (18.2%), and bathing and showering (65.9%). Most caregivers performed housework (93.2%), prepared meals (88.6%) and helped feed their relatives meals (25.0%). Caregivers also assisted in getting in and out bed (65.9%), and getting dressed (47.7%). More than half of all caregivers (54.5%) provided help by talking on their relatives' behalf with healthcare providers and government agencies.

Table 2 Characteristics of Hopi care recipients

	N (%)
Age[b] (years)	
< 79	8 (18.6)
80–89	22 (51.2)
90+	13 (30.2)
Average age ± SD	83.6 years ± 12.1
Relationship to caregiver	
Parent	31 (70.5)
Grandparent	6 (13.6)
Other family: spouse, sibling, aunt, in-law, child	7 (15.9)
Health condition	
Dementia	12 (27.3)
Cancer	8 (18.2)
Cardiac related condition	8 (18.2)
Diabetes	6 (13.6)
Other disease, health condition, disability	10 (22.7)
Reasons needing caregiving[a]	
Physical health conditions	35 (79.5)
Old age	34 (77.3)
Emotional or mental health issues or behavioral health issues	19 (43.2)
Learning disability, mental disability or developmental delay	7 (15.9)
Go to a traditional healer	
Yes	22 (50.0)
No	22 (50.0)

Percentages may not add up to 100% due to rounding error

[a] More than one answer allowed

[b] Does not total 44, one or more participants do not know, unsure or refused to answer

Caregiver Difficulties

Table 3 lists difficulties in the caregiving process. Only 11.4% of the women reported they had no difficulties as a caregiver. Caregivers stated they had difficulties with not having enough time for family and or friends (88.6%), financial burdens (75.0%), and not having enough time for themselves (61.4%). When the caregivers ranked difficulties, the greatest difficulties were with stress (45.5%) and financial burden (13.6%). More than half of the caregivers reported not being employed (52.3%) and of those employed, 85.7% reported they had to go in late or leave early, 66.7% had taken a leave of absence or reduced work hours or taken a less demanding job. Although most caregivers reported experiencing difficulties, 77.3% reported they would not consider placing their relative in an assisted living facility.

Types of Caregiver Services Desired

Of 43 caregivers that responded, 23.3% reported that they currently receive services from HOAAS, and 76.7% reported not receiving services. Caregivers were asked what kinds of services they would find beneficial, with 97.7% reporting they would like additional caregiving services (Table 3). Training on patient care services, such as physical therapy, proper nutrition, and activities of daily living was the most requested service (75.0%), followed by a support group (50.0%), and counseling services (40.9%). In addition, caregivers felt they needed more help or information on managing their personal emotional/physical stress (75.0%), keeping their relative safe at home (63.6%), and finding time for themselves (56.8%). Most caregivers (63.6%) had received some form of caregiver training and almost all caregivers (72.7%) were willing to attend a workshop or support group related to caregiving.

More than half (54.5%) of all caregivers reported seeking information related to providing care to their relative. For information on caregiving, the majority of caregivers reported they would turn to a healthcare provider (79.5%), friends and family (56.8%), and other caregivers (38.6%).

Discussion

In this study of the caregiver experience on the Hopi Reservation, female caregivers primarily provided care to a parent or grandparent with dementia, cardiovascular health

Table 3 Perceived responsibilities, difficulties, and health behaviors of Hopi caregivers (June–October 2017)

	N (%)
Reason for becoming a caregiver[a]	
I wanted to take care of the care recipient/relative	30 (68.2)
Everyone that is Hopi are expected to take care of their relatives	27 (61.4)
The care recipient/elder preferred to live in my home instead of an assisted living facility	20 (45.5)
As the female in my family, it was expected that I become the caregiver instead of other male family members	19 (43.2)
I am the only family member that lives on Hopi that can take care of the care recipient	15 (34.1)
I am not employed outside the home right now, so I am available to help	15 (34.1)
Caregiver responsibilities[a]	
Transportation-driving	41 (93.2)
Housework	41 (93.2)
Grocery shopping	40 (90.9)
Preparing meals	39 (88.6)
Giving medications, pills or injections	32 (72.7)
Bathing or showering	31 (70.5)
Getting in and out of bed	29 (65.9)
Managing finances (such as bills, or insurance paperwork)	22 (50.0)
Getting dressed	21 (47.7)
Transportation-arranging	17 (38.6)
Arranging or supervising unpaid services (such as family members or friends)	14 (31.8)
Feeding	11 (25.0)
Arranging or supervising paid services (such as nurses, aids, others)	8 (18.2)
Dealing with incontinence or diapers or restroom related issues	8 (18.2)
Caregiver difficulty experienced[a,b]	
Don't have enough time for your family or friends	39 (100.0)
A financial burden	33 (84.6)
Don't have enough time for yourself	27 (69.2)
Created or aggravated your own health problems	19 (48.7)
Affects family relationships	19 (48.7)
Interferes with being able to go to your own doctor or dental appointments	16 (41.0)
Stress	15 (38.5)
Interferes with your work	13 (33.3)
Don't have time to attend cultural, religious ceremonies	12 (30.8)
Affects friendships	10 (25.6)
No difficulty	5 (11.4)
Caregiving affecting work[a]	
Go in late, leave early, take time off	18 (40.9)
Take a leave of absence, reducing work hours, taking a less demanding job	14 (31.8)
Losing job benefits, giving up work entirely, choosing early retirement	5 (11.4)
Information seeking-where would you seek caregiving information[a]	
Healthcare provider (doctor, nurse, social worker, hospital, hospice)	35 (79.5)
Friends, family	25 (56.8)
Other caregivers	17 (38.6)
Internet	15 (34.1)
Books, magazines, library	15 (34.1)
Aging or disease specific organizations	14 (31.8)
Social or community services	11 (25.0)
Government programs	5 (11.4)
Caregiver services desired[a]	
Training on patient care such as physical therapy, proper nutrition, activities of daily living	33 (76.7)
Support group	22 (51.2)

Table 3 (continued)

	N (%)
Counseling services	18 (41.9)
Education on relative's illness/problem	17 (39.5)
Help in filling out paperwork (i.e. enrollment forms, applications, etc.)	14 (32.6)
Pamphlets/brochures on illness/problem	11 (25.6)
Transportation services	10 (23.3)
Don't need extra services	< 5
What do you need help or information on?	
Managing your emotional/physical stress	33 (75.0)
Keeping relative safe at home	28 (63.6)
Finding time for yourself	25 (56.8)
Balancing work and family responsibilities	20 (45.5)
Managing challenging behaviors of your relative that needs care	19 (43.2)
Moving, lifting your relative that needs care	18 (40.9)
Making end of life decisions	14 (31.8)
Choosing home care agency or assisted living facility	9 (20.5)
Managing diapers, restroom related issues	8 (18.2)
Finding non-English language materials on caregiving or on your relatives health condition	5 (11.4)

Percentages may not add up to 100% due to rounding error for all variables

[a] More than one response allowed

[b] Percentages based on the number that reported a difficulty (n = 39)

issues or other chronic disease conditions. These Hopi caregivers were similar to national caregivers in that the majority provided care to a parent, yet few provided care to a partner/spouse or an in-law which was more common in national data, 12 and 7% respectively for national data [1]. Hopi female caregivers were older, 57 years compared to the national average of 49 years, and provided care for someone older (83.6 years compared to the national average of 69.4 years). Furthermore, Hopi caregivers and their recipients lived together more frequently (63.6%) than the national trend (34%) [1].

On average, Hopi caregivers had been caregiving for longer (5.5 years) than the national average (4 years). Almost half of the Hopi caregivers (45.4%) were providing more than 40 h of caregiving/week, compared to almost a quarter (23.0%) nationally [1]. Hopi caregivers also assisted in activities of daily living at higher frequencies than national for all categories except for managing care recipient finances (50.0% vs. 54%) [1]. Hopi caregivers provided substantially more personal care, e.g. 70.5% of Hopi caregivers reported helping with bathing and showering, in comparison to 26.0% for national data [1]. For instrumental activities of daily living in comparison to national reporting, Hopi caregivers prepared more meals (88.6% vs. 61.0%) gave more medications including, injections (72.7% vs. 46.0%) than reflected in the national data [1]. More Hopi caregivers received unpaid assistance in the form of family members, 75.0% compared to 53.0% of caregivers surveyed nationally [1].

Both the Hopi and national survey asked about caregiver difficulties, perceived stress and financial burden. National caregivers (38.0%) reported somewhat higher frequency of stress than Hopi (34.1%), and much lower amounts of financial burden (18.0% national vs. 75.0% Hopi) [1]. Stress also was found to be a difficulty in prior Hopi caregiver research. Reports from the 2012 survey of cancer and chronic diseases and also reported stress as caregivers' greatest difficulty [3]. The caregivers in this 2017 survey also were more likely to request additional services than the caregivers responding to the 2012 survey [3].

Most Hopi female caregivers reported attending cultural ceremonies (84.1%) and using traditional healers (54.6%) at higher percentages than in a cross-sectional survey of AI caregivers in the Northern Plains and Southwest [4]. The study by Goins et al. [4] used a sample of male and female AIs with 519 from the Northern Plains and 286 from the Southwest AIs [4]. In the Southwest AI sample, 30% reported attending ceremonies and 53% reported attending and participating at ceremonial events; and 44% reported using a traditional healer [4]. These percentages were similar for the Northern Plains sample.

The experiences described in this study are specific to female caregivers on the Hopi reservation. Efforts were made to include not only those with access to caregiving services through HOAAS but also others who do not currently receive services to more fully capture caregiving on Hopi by female caregivers, with 74.7% reporting they currently do not receive services.

Conclusions

This study describes the multiple and complex components of the caregiving experience provided by AI women on a rural reservation. This information provides detailed information on the AI caregiver experience including who the caregivers and care recipients are, amount of time caregiving, caregiving duties and services caregivers would like to receive. The results can be used by health and family agencies to provide additional training and assistance to caregivers living on reservations. With the differences between these caregivers and national caregivers, Hopi females may need additional services to help them in their caregiving as they provide more hours/week, caregiving for longer periods of time (years), provide more services to the care recipient and desire more time for self. With the stress and long amount of time caregiving, respite care services may be needed as well as the self-identified requests in this survey for training on providing care to the care recipient such as providing physical therapy and proper nutrition to the care recipient. The findings that stress was identified as the greatest caregiver difficulty in this survey suggest local services should also focus on this, increasing services and respite care may be a way of doing so. Future studies on stress and the role that resilience plays are planned by the research team.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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