

Caregiver Reported Oral Health-Related Quality of Life in Young American Indian Children

Patricia A. Braun · Kimberly E. Lind · Terry Batliner ·
Angela G. Brega · William G. Henderson · Kristen Nadeau ·
Anne Wilson · Judith Albino

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Abstract American Indian/Alaska Native (AI/AN) children experience high rates of dental decay, yet their pediatric oral health-related quality of life (POQL) has not been described. We measured POQL in AI children and compared it in children with reported excellent/very good/good versus fair/poor oral health status (OHS) and assessed association of OHS, child's age, dental service utilization, and dental insurance on POQL scores. Caregivers of 143 AI (100 %), young (mean age 25.1 months) children reported their POQL score as 4.2 (scale 0–100, lower score indicates better POQL); OHS as excellent (35 %), very good (27 %), good (21 %), fair (14 %), and poor (3 %); and utilization of urgent dental services (12 %). Worse

POQL was associated with worse OHS ($p = 0.01$). After adjustment, worse POQL was associated with increased reported use of urgent dental services ($p = 0.004$). POQL of young AI children was generally favorable but worsened with increased utilization of urgent dental services.

Keywords Quality of life · Oral health status · Early childhood caries · Dental caries · Children · American Indian/Alaska Native · Minority health · Dental services utilization

Abbreviations

ACASI	Audio computer-assisted self-interviewing
AI/AN	American Indian/Alaska Native
ECC	Early childhood caries
dmfs	Decayed, missing, filled surfaces
OHS	Oral health status
POQL	Pediatric oral health-related quality of life

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P. A. Braun (✉) · W. G. Henderson
Colorado Health Outcomes Programs, Children's Outcomes
Research, University of Colorado Anschutz Medical Campus,
13199 E. Montview Blvd., Suite 300 F443, Aurora, CO 80045,
USA
e-mail: patricia.braun@ucdenver.edu

K. E. Lind · T. Batliner · A. G. Brega · J. Albino
Colorado School of Public Health, Center of Native American
Oral Health Research, Aurora, CO, USA

K. Nadeau
Children Hospital Colorado, University of Colorado Anschutz
Medical Campus, Aurora, CO, USA

A. Wilson
Children's Hospital Colorado, University of Colorado School of
Dental Medicine, Aurora, CO, USA

Introduction

Early childhood caries (ECC) is defined as the presence of one or more decayed (noncavitated or cavitated lesions), missing (due to caries), and filled tooth surfaces (dmfs) in any primary tooth in a child <6 years of age [1, 2]. The prevalence of ECC is highest among low-income children with racial/ethnic disparities [3–5]. Oral health disparities are a public health concern, and Healthy People 2020 targets increasing the proportion of low-income children and adolescents receiving preventive dental care as one of the nation's ten most important health goals [6]. The ECC disease levels seen in American Indian/Alaska Native (AI/AN) children reflect the most extreme disparities in oral

health [7–9]. Indian Health Service (IHS) data collected in 2009 from a national sample of AI/AN children found that 62 % of AI/AN preschool children had caries compared to 42 % of Mexican–American and 25 % of non-Hispanic white children. Additionally, 44 % of AI/AN children had untreated dental caries [10]. In a recent longitudinal study of young AI children in the Northern Plains, 32 % of children experienced caries by 18 months of age [2].

The impact of oral health disease on oral health-related quality of life has been described in populations of various ages across the globe yet has not been described in young AI children. Dental caries has been shown to worsen the oral health-related quality of life in children, adolescents, and adults [11–14]. Validated instruments used to measure quality of life in children exist (9–11); however, few have been validated to measure quality of life in young children, especially children of low-income minority families. The pediatric oral health-related quality of life (POQL) instrument developed by Huntington et al. [13] specifically emphasizes the experiences and views of children from preschool through adolescents from low-income and minority populations. In the validation of this instrument, children at high risk for dental caries whose caregivers reported them to have favorable oral health status had a mean POQL score of 3.2 (scale 0–100 where a lower score indicates better oral health) compared to children whose oral health status was reported as unfavorable (mean score = 11.0).

Poorer oral health-related quality of life also has been reported to be associated with increased utilization of dental services, particularly urgent dental services. As children begin to experience dental pain, they may encounter difficulty eating and performing daily functions such as going to school or work, and seek out urgent dental care in dental offices as well as in emergency departments [15, 16]. While it is preferable to receive restorative dental services, or better yet, preventive dental services, before negative oral health sequelae of dental disease occur, limited access to dental services presents a barrier to these alternatives [16–18]. Although AI/AN communities carry a disparately high burden of disease, they are underserved by dental health care providers and consequently have limited access to preventive or restorative dental services. This is particularly true for large rural reservations, such as the Pine Ridge Indian Reservation, where this study was conducted. Nationwide, there is only one dentist for every 2,800 AI/AN tribal members, compared with one dentist for every 1,250 people in the general US population [19]. Given the dearth of available dental services to AI children at high risk for caries, a better understanding of their utilization of urgent dental services and the association of this utilization and oral health-related quality of life is needed.

Our objective was to examine pediatric oral health-related quality of life (POQL) and oral health status in a sample of young American Indian (AI) children and examine the relationship of utilization of dental services and POQL. We summarized caregiver-reported measures of POQL, oral health status (OHS), utilization of dental services, and dental insurance and examined the relationship of these variables on POQL. We hypothesized that worse POQL in AI children would be associated with worse OHS, increased utilization of urgent dental services, and lack of dental insurance besides IHS, recognizing that this could be a barrier to accessing dental services.

Methods

Overview

The study was conducted on the Pine Ridge Indian Reservation, the second largest reservation in the US. Its estimated population is 28,797 and is spread over 3,159 square miles.

Caregiver-reported POQL was examined using cross-sectional survey data collected across the reservation as part of a pilot test conducted in preparation for a large clinical trial addressing early childhood caries (ECC) in AI children. A community-based participatory approach was taken in the development of this project. To establish acceptability and cultural appropriateness of the study, a careful process was undertaken that included conducting focus groups with key community partners and community members. An Oglala Sioux Community Advisory Committee provided insight and guidance to the study team on all aspects of this project and reviewed all study materials. In addition, full approval was obtained from the Tribal Research Review Board, with ongoing review for all phases of the study.

Study Subjects

Caregivers of young AI children were recruited to complete an oral health survey. To participate, respondents were required to be 15 years of age or older, AI, and the parent or primary caregiver of an AI child 0–7 years of age, living on or near the Pine Ridge Reservation. One hundred and fifty individuals consented to participate. One participant subsequently declined to complete the survey, two others were determined not to be AI, and four did not report their child's oral health status and were subsequently excluded from the analysis. Participants represented a sample of parents and caregivers interested in completing the parental oral health survey. Recruitment was

accomplished through informational posters placed in various locations across the reservation, including tribal colleges, gas stations and Community Action Program offices; in addition, some participants learned about the study by word-of-mouth. Interested individuals contacted the research field office to make an appointment to complete the survey or simply came to an advertised data collection event without a scheduled appointment. Participants received compensation of \$40 for their time.

Institutional Review

This research project was approved by the Colorado Multiple Institutional Review Board at the University of Colorado Anschutz Medical Campus, the Oglala Sioux Tribe Research Review Board, and the Aberdeen Area Indian Health Service Institutional Review Board. All participants provided written informed consent and Health Insurance Portability and Accountability Act authorization prior to participation.

Procedures

Data Collection

Data were collected in May and June, 2010. Data collection events were held primarily at tribal colleges in four towns on or near the reservation. Some surveys also were collected in community centers and at the research field office.

Participants completed a computerized survey containing questions regarding their sociodemographic characteristics and those of their child, as well as their child's POQL, OHS, and utilization of dental services. Participants with more than one child were instructed to answer the survey questions thinking about one particular child between the ages of 0 and 7 years for whom he/she was the primary caregiver.

Survey Development

The parental oral health survey was the product of the collaborative efforts of three oral health disparities centers funded by the National Institute of Dental and Craniofacial Research (NIDCR): the University of Colorado Anschutz Medical Campus, Boston University, and the University of California San Francisco. Previously validated items or instruments were used whenever possible.

Measures

Pediatric Oral Health-Related Quality of Life Scale (POQL)

We used the twelve-item preschool version of the POQL measure developed and validated by Huntington et al. [13]

to assess a caregiver's perception of the extent to which his/her child's functioning was negatively affected by oral health experiences. The measure addresses the impact of oral health problems on three types of functioning: Role Functioning (missing school/day care), Physical Functioning (experiencing pain or having trouble eating), and Emotional Functioning (being angry/upset, worrying, or crying). Each item characterizes the impact of oral health experiences on these three types of functioning by asking the frequency of the experience ("how often") and "how bothered" the child was by the experience. We report both item frequencies and overall POQL scores. As specified by Huntington et al., we calculated overall scores by multiplying the "how often" response (0–3) by the "how bothered" response (0–4). These "impact" scores were then summed and converted to a percent of the maximum possible score, resulting in an overall POQL score ranging from 0 to 100, with higher scores indicating worse POQL. If fewer than two-thirds of the questions were answered, a POQL score was not calculated and the observation was dropped from analyses. A standardized Cronbach alpha coefficient was calculated for the impact scores to assess internal consistency.

Sociodemographic Characteristics

Sociodemographic variables reported include: gender and age of the caregiver and child, the caregiver's highest grade of formal schooling completed, employment status, the number of children in the household, household income, and child's dental insurance status. Children were categorized as having dental insurance other than IHS if the caregiver reported them to have Medicaid, SCHIP, or private insurance. We believe most participants to have been IHS eligible, given their residence on/near the Reservation and identification of AI status and considered insurance besides IHS an indicator of greater access to dental care.

Child Oral Health Status (OHS)

The child's OHS was measured using an item adapted from the 2007 National Survey of Children's Health [20]. Caregivers were asked to "describe the health of your child's teeth and mouth," using the following categories: excellent, very good, good, fair, or poor. For the regression analysis, OHS was rated on a scale of 1 (excellent) to 5 (poor).

Utilization of Dental Services

Utilization of non-urgent dental services was measured by caregiver report of the child having gone to the dentist for a routine checkup or cleaning. The utilization of urgent

dental services was measured by caregiver report of having sought care for their child for a cavity or toothache; whether the child received care in a dental clinic, an emergency room or a hospital operating room for a cavity or toothache; and whether the child had a tooth pulled due to a cavity or toothache in the past year. A positive report of the child ever having any one of these urgent dental experiences was categorized as having utilized urgent dental services. Participants responded “Yes,” “No,” or “Don’t know” to these questions or were able to skip them.

Data Analysis

Summary statistics regarding caregiver and child sociodemographic characteristics, POQL, OHS and utilization of dental services were computed. Mean overall POQL scores were compared across OHS categories. To account for the right skewed distribution of the POQL scores, a Mann–Whitney test was used to compare the ranked POQL scores between the group reporting excellent/very good/good oral health and those reporting poor/fair oral health. Multi-variable linear regression was used to test the associations between POQL score and variables hypothesized to be associated with POQL including: child OHS, child age, utilization of non-urgent (preventive) dental services in the past year, utilization of urgent dental services in the past year, if the child was covered by any form of dental health insurance other than IHS, and the number of children in the household. All analyses were conducted in SAS version 9.3 (SAS Institute, Cary, NC).

Results

A total of 143 AI caregivers completed the survey (Table 1). Caregivers were primarily female (86 %) and mothers (73 %). Their children were all AI and had a mean age 25 months (range 0–87).

Caregivers reported a range of OHSs of their children, with the majority reporting favorable OHS (82.6 % excellent, very good, or good). Most caregivers (65.9 %) reported that their children had not utilized any dental services within the past year: 33 % reported that their child had received a dental check-up or cleaning; 12 % reported utilization of urgent dental services that included care in the hospital or emergency department (0.7 %), operating room (5.6 %), a visit to a dental clinic for a cavity or toothache (11.9 %), or had a tooth pulled due to a cavity or toothache (4.9 %).

The impact scores of the POQL scale had good internal consistency, with a standardized Cronbach alpha coefficient of 0.78. The majority of caregivers reported favorable POQL for their children (Table 2). The mean POQL score

was 4.2 (on a scale from 0 to 100, where a higher score indicates worse POQL). Only a minority of caregivers reported their children had experienced pain, anger, crying, worrying, difficulty with eating, or missed school/daycare related to their teeth or mouth. Results of the Mann–Whitney test suggested that the ranked mean POQL scores were significantly higher (worse) in the fair/poor oral health group compared to the excellent/very good/good oral health group ($p = 0.01$).

In the multi-variable linear regression analysis, higher POQL score (indicating worse POQL) was associated with increased utilization of urgent dental services in the past year ($p = 0.001$) (Table 3). The POQL score of children who were reported to have utilized urgent dental services was 8.2 points higher than those children who had not utilized these services. OHS, child age, utilization of non-urgent dental services, and number of children in the household were not significantly associated with POQL ($p > 0.05$ for all).

Discussion

We describe POQL in a sample of young, AI children and its relationship to the OHS, child’s age, utilization of dental services, dental insurance, and number of children in the household, as reported by their caregivers. In this sample of young children, most caregivers reported their children to have favorable POQL and OHS, and most reported that they had not utilized any dental services, either preventive or urgent, in the past year. Poorer POQL was associated with worse OHS in unadjusted analyses but after adjustment for child age, utilization of dental services, dental insurance, and household size, POQL and OHS were no longer significantly associated ($p = 0.08$). After adjustment with these aforementioned variables, poorer POQL was highly associated with having utilized urgent dental services in the past year ($p = 0.001$).

This is the first report of the oral health quality of life in young AI children who were on average 2 years of age (25 months). Although we do not have clinical dental assessment data for this study population, 12 % of caregivers reported that their child had experienced caries. In a recent longitudinal study by Warren et al. [2] that followed 232 young AI children in the same Northern Plains Tribal community, 32 % of the children had experienced caries by age 18 months with a mean dmfs of 1.57 (range 0–44). A mean of 1.57 tooth surfaces does not indicate severe disease [21] and may not be noticed by the caregiver which may be why the caregivers in our cohort reported their children’s OHS and POQL as generally favorable. Another possible explanation for this favorable reporting of oral health status may stem from the high prevalence of caries in AI communities; caregivers may not perceive their

Table 1 Sociodemographic characteristics of Oglala Sioux AI caregivers of AI children and the reported oral health status and utilization of dental services of their children

Caregiver characteristics N = 143	
Mean age (SD)	28.6 (8.2)
Range (years)	15–54
Gender [n (%)]	
Female	123 (86.0)
Race/ethnicity [n (%)]	
American Indian	143 (100)
Relationship to child [n (%)]	
Mother	104 (72.7)
Father	18 (12.6)
Grandparent	13 (9.1)
Other	8 (5.6)
Caregiver education [n (%)]	
High school or more	88 (61.5)
Employment [n (%)]	
Unemployed	63 (46.0)
Employed	47 (34.3)
Student	10 (7.3)
Homemaker	11 (8.0)
Disabled/medical leave	6 (4.4)
Household income below FPL adjusted for number of people in household [n (%)] ^a	
Below FPL	
Yes	47 (52.2)
Children In household [n (%)]	
0	3 (2.2)
1	13 (9.4)
2	38 (27.5)
3	34 (24.6)
4	25 (1.87.5)
5 or more	25 (1.8)
Child characteristics N = 143	
Mean age in months (SD)	25.2 (±16.5)
Gender [n (%)]	
Female	73 (51.1)
Dental insurance ^{b,c} [n (%)]	
IHS	31 (21.7)
Medicaid	73 (53.3)
SCHIP	12 (8.8)
Private/other	3 (2.2)
None	49 (35.7)
Tribal membership	
Yes	66 (46.2)
No	14 (9.8)
Pending	62 (43.4)
Child oral health status [n (%)]	
Oral health status	
Excellent	50 (35.0)
Very good	38 (26.6)

Table 1 continued

Good	30 (21.0)
Fair	20 (14.0)
Poor	5 (3.4)
Utilization of dental services [n (%)]	
Child ever been to a dentist or dental clinic	
Yes	63 (44.1)
Dental visit in past year for cavity or toothache	
Yes	17 (11.9)
Hospital emergency room visit in past year for cavity or toothache	
Yes	1 (0.7)
Hospital operating room visit in past year for cavity or toothache	
Yes	8 (5.6)
Tooth pulled in past year for cavity or toothache	
Yes	7 (4.9)
Child been to a dentist for a routine checkup or cleaning in past year	
Yes	48 (33.6)

^a 37 % of cohort reported “don’t know” or skipped this item and were excluded from the analysis of this variable

^b Figures exceed 100 % due to participants having multiple sources of dental insurance (if we include IHS)

^c 12.6 % of cohort reported “Don’t know” or skipped this item and were excluded from the analysis of this variable

child’s oral health status to be poor *relative* to the other children in their community. Additionally, in other minority groups, caregivers have demonstrated a tendency to report their child’s oral health status positively, even in the presence of caries [13]. Associations between poor POQL and poor OHS have been reported in older children, adolescents, and adults [11, 12, 22] and further emphasize the importance of optimal oral health and the prevention of dental decay in all populations, including the youngest children before their oral health quality of life is affected.

Most caregivers evaluated here did not report that their child had utilized urgent dental services in the past year. This may be attributable to their lack of severe disease warranting the use of emergency rooms, operation rooms for a cavity or toothache, or the need to have a tooth pulled. An alternative explanation is that access to dental services is challenging for this population. Lack of access to dental and medical services in AI communities has been well documented [23–25]. The dental workforce shortage on AI/AN reservations presents a challenge to caregivers to access any dental services for their children [19, 26]. Our findings of the association between POQL and utilization of urgent dental services may imply that *when* the decay is severe enough to cause a visible cavity or toothache, it both impacts the children’s POQL, as well as results in an urgent visit for dental services to the emergency room, operating room, or the tooth be pulled. These findings emphasize the need for innovative interventions to promote optimal oral

Table 2 Pediatric oral health quality of life scale and association with oral health status in young Oglala Sioux AI children

	Overall	Oral health status (excellent/very good/good)	Oral health status (fair/poor)	<i>p</i> value
N (%)		118 (80.3)	25 (17.0)	
POQL score (mean, SD) ^a	4.1 (±7.7)	3.6 (±7.4)	6.7 (±8.9)	0.01
POQL measure: “in the past 3 months, did your child experience—event—because of his/her teeth or mouth?” [n/N (%)]				
Quality of life events experienced by the child				
Pain N (%) ^b	33/134 (24.6)	25/112 (22.3)	8/22 (36.4)	0.18
Bothered ^c	32/133 (24.1)	24/111 (21.6)	8/22 (36.4)	0.17
Anger/upset ^b	22/134 (16.4)	16/112 (14.3)	6/22 (27.3)	0.20
Bothered ^c	21/133 (15.8)	15/111 (13.5)	6/22 (27.3)	0.12
Cry ^b	36/138 (26.1)	28/115 (24.4)	8/23 (34.8)	0.31
Bothered ^c	33/135 (24.4)	25/112 (22.3)	8/23 (34.8)	0.29
Worried ^b	22/128 (17.2)	16/109 (14.7)	6/19 (31.6)	0.10
Bothered ^c	16/122 (13.1)	13/106 (12.3)	3/16 (18.8)	0.44
Trouble eating ^b	19/136 (14.0)	9/111 (8.1)	10/25 (40.0)	<0.01
Bothered ^c	18/135 (13.3)	9/111 (8.1)	9/ (37.5)	<0.01
Missed school/daycare ^b	1/136 (0.7)	0/112	1/24 (4.2)	0.18
Bothered ^c	0/135	0	0	n/a

p values are based on Mann–Whitney test for differences of group means and Fisher’s Exact test for differences in reporting of events by oral health category

^a Mean = sum (symptom (Likert 1–4) x bothered (Likert 1–4))

^b Responses of “yes” to question: “In the last 3 months, has your child ever experience—event—because of his/her teeth or mouth?”

^c Responses of “very bothered”, “somewhat bothered” or “bothered a little bit” to the question: “How bothered was your child by this event?”

Table 3 Regression analysis—associations between pediatric oral health-related quality of life score and select variables

Characteristic	Parameter estimate	95 % confidence interval	<i>p</i> value
Intercept	6.52	2.26, 10.78	0.003
Oral health status ^a	1.16	−0.14, 2.46	0.08
Child age	−0.10	−0.20, 0.005	0.06
Utilization of urgent dental services ^b	8.20	3.30, 13.09	0.001
Utilization of non-urgent dental services	0.55	−2.99, 4.09	0.76
Dental insurance ^c	−1.24	−4.06, 1.57	0.38
Number of children in household	−0.50	−1.42, 0.41	0.28

Higher POQL scores indicate worse oral health-related QoL

A total of 104 participants responded to all items of interest in the regression analysis

^a Oral health status scale: excellent (1), very good (2), good (3), fair (4), poor (5)

^b Reported on at least one occasion of: seeking care for a cavity or toothache, having a tooth extracted

^c Reported having Medicaid, SCHIP, private insurance, or other insurance that was not IHS

health and primary prevention of ECC at an early age, before POQL is impacted. Improved access to preventive dental services through community approaches, such as federally supported WIC (Women, Infant and Children) programs or by providing preventive dental services to children and their caregivers starting at birth through home visitation programs or during visits with a medical provider are among such potential innovations. Other service delivery innovations may include the mid-level dental provider option, which has attracted interest in some tribal

communities since its implementation in Alaska several years ago [27, 28].

This study has limitations that must be considered in the interpretation of our findings. We recommend care in interpreting our results, as the Huntington et al. survey POQL instrument was developed for use in low-income, minority families, but validation of its use in an AI/AN population is needed. Second, the availability of a standardized measure of caries (e.g., dental examinations) would improve our confidence in use of the POQL measure

in this population; however, quality of life scores and reported OHS have been previously compared (including in the validation of the Huntington instrument) and found to be associated [13, 29, 30]. Additionally, our findings may be limited by potential selection bias resulting from the utilization of a convenience sample. Although the study team recruited participants from across the reservation, we cannot be certain that these participants were representative of all caregivers of young children on this particular reservation. Also, our findings may not be generalizable to other populations given the notably high prevalence of caries in this population [31], the unique challenges imposed when attempting to access dental care in this rural setting, and potential cultural differences that may influence perceptions of oral health and quality of life.

Summary

Caregivers of young AI children reported their children to have generally favorable POQL and OHS. The relationship between POQL and OHS is complicated and likely influenced by a number of factors. Caregivers who reported that their children had worse POQL were more likely to have reported them having utilized urgent dental services. These findings may reflect that only the children experiencing severe decay at this young age will have levels of disease likely to impact POQL and warrant use of urgent dental services. Primary prevention of ECC in young AI children who are at the highest risk for developing the disease is necessary before their oral health-related quality of life is impacted and strategies to improve access to early preventive dental services are needed.

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Conflicts of interest None.

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