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Quality of care in American Indian child and adolescent behavioral health: A pilot study of patient and family perspectives

Matthew C. Podlogar and

University of Colorado Anschutz Medical Campus

Douglas K. Novins, M.D.

Centers for American Indian and Alaska Native Health, University of Colorado Anschutz Medical Campus

Abstract

Research regarding the quality of behavioral health care for American Indian (AI) children and adolescents is extremely limited, and no study has considered the qualitative perspectives of the AI children receiving such services or that of their families. This pilot study investigated AI patient and family perspectives of what quality of care means to them. Data were drawn from interviews of parents ($n = 15$), and the youth (if they were age 11 or older; $n = 11$) of 16 children and adolescents who received treatment at three behavioral health programs serving AI communities. Interview transcripts were coded and analyzed for key themes that related to treatment structure, process, and outcomes. According to these participants, the principal indicator of treatment quality was “being able to trust the clinician.” The most valued treatment outcomes for improvement were the youth’s “self-efficacy and self-worth,” “functioning in school,” and “relationship with the family.” Future research is needed on how to best integrate these domains into specific and objective indicators for standardized quality of care assessments of AI child and adolescent behavioral health services.

Keywords

American Indians; Families; CAHPS; Qualitative Interviews; Qualitative Analysis; Cultural Competency

American Indian (AI) children and adolescents are at a higher risk than other major U.S. ethnic groups for developing behavioral health problems, including post-traumatic stress disorder, alcohol use disorders, depression, anxiety, and suicidality (Indian Health Service, 2011; Gone & Trimble, 2012; Lau et al., 2012; McGuire & Miranda, 2008). For over a decade, The U.S. Department of Health and Human Services (2000), The Institute of

Correspondence should be addressed to Matthew C. Podlogar, Department of Psychology, Florida State University, 1107 W. Call St., Tallahassee, FL 32306. podlogar@psy.fsu.edu.

Matthew C. Podlogar, University of Colorado Anschutz Medical Campus; Douglas K. Novins, MD, Centers for American Indian and Alaska Native Health, University of Colorado Anschutz Medical Campus.

Matthew C. Podlogar is now at the Department of Psychology, Florida State University.

Medicine (National Research Council, 2001, 2003), and numerous independent researchers have argued for increased attention to improving patient-centered and cross-cultural quality of care in order to address racial and ethnic health disparities (Alegria et al., 2010; Betancourt et al., 2003; Bokhour et al., 2009; Harris, 2010; Sofaer & Firminger, 2005). Yet despite the behavioral health disparities observed among AI children and adolescents, only a handful of scholarly commentaries have addressed the need to examine the quality of behavioral health services for this group (Inouye, 1993; Novins et al., 2000b). We were also unable to identify any published research regarding quality of behavioral health care that included qualitative explorations regarding the perspectives of AI child and adolescent patients and their families.

As contemporary descendants of the indigenous peoples of North America, AI populations share a cultural history that extends from the time of diverse pre-colonial ethnicities (i.e., hundreds of tribes represented by unique languages and spiritual traditions) to the modern aftermath of reservation-based categorization and forced acculturation (see Gone & Trimble, 2012; Nagel, 1995). The disproportionately high rates of behavioral health problems among AI populations are generally agreed to be due to historical trauma, acculturation pressures from mainstream society, loss of traditional societal and familial social structures, lack of economic opportunities, and poverty (Duran & Duran, 1995; Evans-Campbell, 2008; Gone & Trimble, 2012); yet perniciously, many AI populations have had limited opportunities to participate in clinical and health research services—meaning that results such efforts may not be fully applicable to AI communities.

A number of studies have drawn attention to the disparity between the need for and utilization of AI child and adolescent behavioral health services (Manson, 2000; Nelson et al., 1992; Novins et al., 2000a; Stiffman et al., 2006). However the precise physical and cultural barriers to accessing such services are less clear. One line of evidence highlights the importance of trust, or conversely a lack of trust, in the service provider (Guadagnolo et al., 2009; Oetzel et al., 2006). Barriers of distrust have been hypothesized to be due to cultural dissimilarities between the patient and clinician, perceived discrimination by clinicians, or perceived ignorance of AI historical trauma among clinicians (Duran & Duran, 1995; Grandbois, 2005; Guadagnolo et al., 2009; Johnson & Cameron, 2001). In addition to distrust of service providers, other potential barriers to care include that AIs prefer to rely on their own resources (i.e., self, family and friends) rather than on outside behavioral health services, concerns about privacy and stigma among their families and communities, poor/unacceptable quality of available services, and an explicit preference for traditional healing over mainstream services (Chester et al., 1999; Guadagnolo et al., 2009; Johnson & Cameron, 2001; Novins et al., 2004; Oetzel et al., 2006).

Guidelines have been offered for how to best provide behavioral health services to AI children and families, including being aware of historical cultural trauma and mistrust, of what the patient expects his/her role to be in therapy (e.g., a passive recipient versus active agent), of the need for acceptance of the clinician by the patient, and of differences in interpersonal and social norms (Everett, Proctor, & Cartmell, 1983; Garwick & Auger, 2000). Though these guidelines should be taken into consideration, ultimately, it is most important for clinicians and health researchers to avoid the trap of stereotyping in AI culture

and to recognize diversity across AI populations, as well as across AI individuals (Trimble, 1990; Williamson & Harrison, 2010). Of the few assumptions that can be made regarding cultural competency in the research and delivery of health care for AI populations, one safe assumption is to *listen* to each patient before prescribing potential solutions (Whitbeck, 2006).

Recently, there have been concerted efforts to expand our assessment of quality of care from AI patients' perspectives. For example in 2005, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program of the U.S. Agency for Healthcare Research and Quality (AHRQ), in collaboration with Choctaw Nation Health Services (CNHS), developed a standardized and publicly available CAHPS American Indian survey (CAHPS-AI) for use by service providers to self-monitor and improve the quality of care they deliver to AI patients (Agency for Healthcare Research and Quality, 2012; Weidmer-Ocampo et al., 2009). The CAHPS-AI survey asks AI patients to rate the quality of services they received within 9 domains, including getting needed care, the courteousness of office staff, how well health professionals communicate, receiving guidance about personal health, if they experienced discrimination, and overall satisfaction (Weidmer-Ocampo et al., 2009). Although the CAHPS-AI survey supports the collection of self-report data on AI patient perceptions of established quality indicators, these data only set the stage for patient-centered quality of care improvement for AI communities. With the exception of two additional questions on whether the patient perceived discrimination, the content of the CAHPS-AI survey remained largely unchanged from the general CAHPS survey—most changes were simply of terminology (e.g., replaced *health professional* with *health provider*). As noted by the AHRQ, “it is critical to *understand* [emphasis added] the perspectives and concerns of the variety of people who will be involved in or affected by the improvements being made,” and that survey analysis “can benefit from good information on the views, experiences, needs, and motivations of the various stakeholders who are involved” (Agency for Healthcare Research and Quality, 2011, p. 55). Beyond AI levels of agreement on general indicators of quality of care, culturally competent quality of care research is in need of more descriptive AI-specific perspectives of what quality of care means in their own words, in order to enrich and expand potential areas of assessment.

Efforts to improve quality of care by mental health clinicians and programs serving AI children and adolescents could benefit from the identification and evaluation of AI patient-centered and community-specific quality of care indicators. The aim of this pilot study was, therefore, to better describe indicators of quality of care in AI child and adolescent behavioral health and to highlight potential directions for improvement by inviting AI patients and families to provide their perspectives of what quality of care means to them. This was achieved by qualitatively investigating how AI patient and family perceptions of quality of care related to established indicators, and by exploring what their perspectives could offer for subsequent quality of care research.

Method

Setting and Participants

Data for these analyses were drawn from the Centers for American Indian and Alaska Native Health's Building a Foundation for Quality of Care Research for American Indian Children and Adolescents research project. Three child and adolescent behavioral health programs serving AI communities participated in this exploratory project: two outpatient mental health programs and one residential substance abuse treatment program. One of these programs was located in a Northern Plains community and was operated by the Indian Health Service. Two of these programs were located in a Southeastern AI community and were operated by the same AI Tribe. One program was located in a small metropolitan area, one in a suburb of a large metropolitan area, and one in a micropolitan community. The educational level of behavioral health service providers in all of the centers included Masters level counselors and psychologists, and in two of the centers included Doctoral level psychologists. Two of the centers also had a psychiatrist on staff. None of the centers had a traditional healer on staff (i.e., practitioner of medicine according to tribal spiritual beliefs). The types of services rendered varied across centers, and included unstructured individualized counseling or play therapies, evidenced-based individual and family therapies, and psychopharmacological treatment.

Study participants were 16 AI youth who had received or were receiving treatment from one of the three programs and their legal guardians. Data were drawn from qualitative interviews of guardians (i.e., parents; $n=15$), and the youth themselves if they were age 11 or older ($n=11$). Five children were age 10 or younger. Six of the participating children and youth were male; 10 were female.

Procedure

All procedures were reviewed and approved by the Colorado Multiple Institutional Review Board, the participating Tribes' Health and/or Institutional Review Boards, and the corresponding Indian Health Service Institutional Review Boards. An Advisory Board with clinical, administrative, and AI patient (i.e., parent) representatives from all 3 facilities assisted in the design of data collection instruments and procedures. Participant recruitment was through a convenience sample, such that clinicians in each center were asked to approach their patients for participation in the study. There were no specific criteria to be included in the study besides being an AI child or adolescent and getting mental health treatment at the participating programs. Youth patients and families who agreed to participate completed an authorization for members of our research staff to contact them and complete the consent process. All interviews were conducted privately with only the research participant and interviewer present. These interviews were audio recorded and transcribed, after which the recordings were destroyed. Interviews took less than 60 minutes to complete. Parent and youth participants received \$20 for completing the qualitative interviews.

Measures

The Advisory Board developed interview guides designed to generate open-ended conversations about the patient and family experience with care, and what contributed to their perceptions of quality of care. The interviews were structured around three main categories: (1) characteristics of the patient, family, and community (i.e., PFC characteristics); (2) treatment process; and (3) treatment outcomes. The interview guides included a series of open-ended “stem” questions that were used to steer the conversation through the key topics of interest determined by the Advisory Board. These stem questions were often followed by one or more “probes” that allowed the interviewer to explore specific issues if these were not spontaneously identified by participants. Key stem questions and probes from the interview guides are summarized in Table 1.

The categories utilized in the interview guides were largely consistent with the often-used “structure-process-outcomes” (SPO) framework for assessing quality of care (Donabedian, 1980). Two primary differences between the SPO framework and the interview guides were that the guides’ focus on PFC characteristics is not an explicit component of the SPO framework, and that the interview guides had very few questions related to the structural characteristics of treatment. Thus, while the interview guides allowed participants to explore many aspects of quality in great detail as well as the PFC characteristics for these services, they were not designed to facilitate the exploration of the resources available to the patient and family (e.g., clinic operating hours) or the physical setting in which they are provided (e.g., staff friendliness).

Data Analyses

Data were analyzed utilizing qualitative analysis principles drawn from Grounded Theory techniques; more specifically, by using illustrative examples in the interview transcripts to develop a data driven theory (Strauss & Corbin, 1990, Willms et al., 1992). NVivo software (QSR International, 2012) was used to code the interview transcripts for key themes. This software permits detailed searches of coded textual data to support or call into question emerging interpretations and models. An initial review of the transcripts generated a tentative list of themes, while subsequent reviews expanded and modified the coding framework. Theme and subtheme prevalence were also noted in two ways. First, according to the number of supporting spontaneous statements only (i.e., statements not elicited by a probe), and second, according to all participant statements regardless of whether they were spontaneous or elicited by a probe. MP performed the initial coding, which was reviewed by DN and discussed to establish consensus. After confirming major themes and subthemes, the authors identified exemplary quotes that captured these ideas.

Results

Key themes and subthemes identified from the patient/family interviews were aligned with the three main categories developed by the Advisory Board (i.e., PFC characteristics, treatment process, and treatment outcomes). Prevalence counts of the subthemes maintained a consistent hierarchy whether we used spontaneous responses only, or all interview responses. To maximize the use of qualitative information, we therefore included all

interview responses in the reported results. See Table 1 for a summary. More detailed descriptions are provided below.

PFC characteristics

Themes regarding PFC characteristics largely followed the structure of the interview probes, and included: (1) the problems that brought the youth to treatment (i.e., reason for treatment, where problems occurred, and sources of stress), (2) parents' behavioral health and ability to access treatment for their youth, and (3) AI identity and culture.

Regarding the problems that led to treatment, most youth received treatment for a Substance Use Disorder (e.g., cannabis, alcohol, methamphetamine), a Mood Disorder, or Attention-Deficit/Hyperactivity Disorder (ADHD). Difficulties for most youth manifested in school. This included academic problems (e.g., trouble paying attention in class, difficulty managing homework) and social problems (e.g., giving in to negative peer influences, social isolation, being teased, aggression towards others), both of which were associated with poor grades. Another area of difficulty was legal problems, including shoplifting, running away, or possession of drugs. Many youth also identified significant psychosocial stressors within the family as a major precipitant for their behavioral health problems. Most youth cited the death or illness of a loved one—often their grandmother—as a source of stress. Other stresses included loss of father figure (e.g., divorce, abandonment, suicide), or intra-family conflict (e.g., arguing/fighting with family, violence/alcoholism among relatives). One youth reflected on these stresses in this quote:

I started coming last year cause well for a long time I was just down, depressed and my grandmother had died. And so I just really wanted to just be up there with her so I wouldn't have to suffer any more misery and um, then my dad had walked out on us and so, then I just really just really wish I wasn't even here, I wish I was just gone, so then my mom decided that maybe I needed someone else to talk to... Yeah, my grades just started dropping, I was just a wreck, I was, everything just started just falling through and I just stopped turning in work, I couldn't even concentrate on school and, so, I just couldn't concentrate at all. (Youth-2-30)

Regarding parents' behavioral health and access to care for their children, a number of parents had a history of problems related to substance misuse, but nearly all stopped using substances when they had children. Nonetheless, many parents and youth reported that they were still surrounded by substance abuse and its consequences among their relatives and in their communities. Additionally, a number of mothers reported being treated for depression and described a history of depression in their relatives. Community barriers to getting needed care included lack of specialty services (especially child and adolescent psychiatry), over-extended clinical staff (e.g., clinicians seeming to be 'spread thin' between too many patients, resulting among other things in long waiting lists), long travel distances to clinical services, difficulty coordinating behavioral health services with schools, and difficulty getting to appointments given parental work schedules.

Regarding AI identity, it should first be acknowledged that such is a complex and multilevel concept (See Markstrom, 2011). Within the scope of this study, the use of the term AI identity included such sources of influence as one's identification (e.g., tribal and ethnic

heritage), connection (e.g., reservation ties), and involvement in traditional cultural practices and spirituality. In this study, parent and youth perspectives on the importance of his/her AI identity varied greatly. Some families regularly participated in tribal ceremonies and/or spoke their Tribe's language, while other families described themselves as largely acculturated into mainstream society. In terms of religious practices, most parents and youth associated with a branch of Christianity; involvement ranged from believing in God but not participating in organized religious practices, to being regular church attendees. A number of parents were not interested in using a traditional healer to help with their child's problems, or thought it would not be helpful. However, some parents noted that they would definitely utilize traditional healing if their clinician recommended it. Youth were generally more open to utilizing traditional healing to help with their problems than their parents, and a few gained interest in their Tribe's traditions and practices throughout treatment, as noted by this parent:

[My child] was familiar with sweat lodge before we, before he came down here, So I was like really into that, I was like "Oh man, that is cool", because you don't find a lot of facilities that will introduce them to that or keep them you know um, keep them into going, so I thought that was a really neat thing. (Parent 1-35)

For some participants, the issue of Tribal and non-Tribal identities interacted in complex ways indicative of equally complex family histories and structure, and of the disorienting effects of acculturation, as illustrated by this parent:

I'm not Native – my husband is – that's why we all go for care here is through my husband. Um, we don't practice it, I've learned just through my own um, I work here too as a nurse, so I, you know just I've taken some classes on [the Tribe's language], um, been to some sweats and I think my kids are kind of... it's always been a joke in our family "what is our culture?" You know because we don't practice it per se and like they all go for care here, the schools identify them as being Native, but they're basically in a white community. So we don't really practice Native – my husband does a little bit, understands it more because he was raised that way, but I wasn't, so... Um, I think more the sense of how it affects my family is more the... the Christianity is not just, it's opened my eyes to that, you know where there's other gods out there, or understand other religions and other beliefs. Um and I think letting the kids explore that, um, versus I was raised, you know, that stern Lutheran "do it this way, do it that way". And the kids are more open to it I guess, you know. Um, the big joke at school is where the kids, teachers call me, "So what is your culture?" Where the kids, you know, and it's, it's always been a joke, our family is like, "Well I'll be Indian today, I'll be white tomorrow". So we don't really, we're kind of a lost... that biracial type marriage. (Parent 3-31)

Treatment process

Themes regarding treatment process emerged above and beyond the structure of the interview probes, and included: (1) the centrality of establishing trust with the clinician and (2) descriptions of how this feeling of trust was built. Regarding the centrality of establishing trust with the clinician, 73% of parents and 54% of youth described the quality of treatment process primarily in terms of their trust of the clinician. Cases where treatment

process was described in terms other than trust were limited to those where the parent already knew and trusted the clinician (e.g., from the community) or where the parent or child described process in terms of time or familiarity—though these may be indirectly related to the establishment of trust. Descriptions of how trust was able to be built involved: (a) good communication, (b) delivery of helpful and enjoyable care, (c) sensitivity and respect, (d) patience in prescribing medication, and (e) coordination of care with the youth's school or parole officer.

Regarding good communication, parents and youth described it as having the following key components: (a) involving parents in developing the treatment plan and assessing progress by inviting parents to ask questions and to provide input throughout treatment; (b) checking with parents regarding their understanding of the diagnosis and of the treatment plan; (c) having educational discussions with parents and making sure the treatment provider explains treatment options, but does not direct treatment; and (d) building rapport with the youth by approaching the youth as an equal, acting like a friend as opposed to a counselor, and making the youth comfortable enough to be honest. Communication was also generally expected to be with the immediate family only. Although youth were often close to their grandmother, and the grandparents for many families were interested and supportive during treatment, grandparents were rarely directly involved with treatment. Parents and youth described that not feeling involved (i.e., poor communication) was the main reason for a perceived lack of trust and diminished perceptions in the quality of clinical services. An example of good communication is reflected in the following statement by a parent:

I guess I was kind of like not understanding, you know it was all new experience, you know I think there's a sense of shame, you know when your kid first gets diagnosed...there's a sense of shame with parenting skills, you look at all the chaos that's going in your home when the kids were little...but at that time we saw [the clinician],...he was very good, I mean he just was um, very understanding, very open, you know, kind of took the shame out of it, you know, and explained you know, the genetics – that probably nothing we did as parents, you know, that type of thing, so that was very good. (Parent-3-31)

Another example, as stated by a youth:

She talks to me on, on an equal level, like she, I don't want to say she lowers herself to my level, but she can bring it down and explain stuff on my level where, to I, where I get it and she doesn't try to speak all professional and you know, sophisticated and stuff like that, and she's just real honest and head to head with me. She lets me choose what we're going to be doing and how I want to handle things or suggests ways to handle and if I tell her I don't want to do it that way then she don't do it that way. (Youth-1-37)

Regarding descriptions of what constituted helpful and enjoyable care, parents expressed their perspectives not necessarily in terms of technical effectiveness, but more often as whether their child enjoyed and wanted to return to therapy, as this parent expressed:

He made [my child] feel confident about coming back to see him, and that was my biggest point of view, I mean I really felt good – he didn't feel like he was being

routed in here like cattle, and shoved out like a stuck pig, I don't know how to explain it but he, he really likes coming here. (Parent-3-37)

Parents also appreciated being taught techniques to use at home, especially if the techniques proved helpful. Youth reported that particularly helpful clinical practices included journaling, group therapy, 12-step groups, and sweat lodges (i.e., a type of purification ceremony through the use of a steam bath and prayer; see Smith, 2005).

Regarding sensitivity and respect, parents and youth described it as being “down to earth,” listening without making assumptions, and asking comprehensive questions about the family, home, and school life—questions beyond those just focused on presenting symptoms. Questions about the family, for example, were emphasized by this parent:

He asks everything with the family, ah, how [my child's] done in the last two months, since he's seen him, he's really inquisitive when it comes to the family. (Parent-3-39)

Regarding medication management (for families that were provided it), many parents and youth reported that they were impressed with the improvement they saw in symptoms after using medications. However, a number of parents described being initially resistant to their child using medications. Parents greatly appreciated the clinician spending a long time talking with them and their child before prescribing medication in order to better understand their needs and expectations, and to fully discuss the risks and benefits of medication, as described by this parent:

He didn't just put [my child] on a medicine right away, I mean he, you know asked for um paperwork from the school, he had me and his dad fill out paperwork, um he met with him [my child] a couple of times before he ever made any kind of decision about what kind of medicine to put him on. You know so he uh, he took his time, um he incorporates what [my child] has to say, you know... (Parent-3-33)

Such deliberate approaches to medication management helped maintain parents' positive perceptions of quality in the treatment process, even in cases when the prescribed medication was not ultimately efficacious.

Regarding coordination of care, a few parents and youth mentioned that helping the school understand about the youth's diagnosis was particularly beneficial. Examples of coordination ranged from calling the school for reports of behavior, to participating in the youth's Individualized Education Program (IEP) meetings. One youth who had legal problems also described how communicating with his/her parole officer was particularly helpful and further aided in developing trust.

Treatment outcomes

Themes regarding treatment outcomes closely followed the structure of interview probes, and included: (1) satisfaction with treatment and (2) valued observations of improvement. Values of improvement were explored again following the structure of the interview probes, in the youth's: (a) self-efficacy and self-worth, (b) functioning in school, (c) relationship with family, (d) relationship with peers, and (e) relationship with community.

Regarding satisfaction, every parent and youth interviewed said they were satisfied with the services they received. Notably, the degree of satisfaction was largely dependent on their perceptions of the quality of the services they received, and not on their perceptions of clinical improvement. The importance of a supportive clinical relationship for one's degree of satisfaction was demonstrated by this parent's statement:

Yeah, I hope we don't ever have to lose [my clinician]...our family really struggles, every day it's a struggle...it's hard – you know I'll be honest, it's hard having a family with all these issues...Somebody actually believes me, I mean or, they don't – [my clinician] doesn't blame me for the way the boys are, he just helps me. (Parent 3-33)

Despite being satisfied, a number of parents and youth described only partial improvement in symptoms/functioning, that improvement occurred in only one area of functioning with no changes in other problem areas, or that their child's problems returned after a brief period of improvement. Still, all parents and youth who were generally satisfied saw at least some improvement in their child's symptoms or functioning. Low levels of satisfaction were explained by almost all parents and youth, including this parent, again not in terms of symptom improvement, but in relation to communication during the treatment process:

Well I would say yes [I am satisfied], because [my child] has, is drug free and alcohol free from being in this facility,...[but] um, because [our involvement in developing my child's treatment plan] that I thought was going to come never happened I would say, on a scale from 1 to 5, 3 – average. (Parent 1-41)

Some parents and youth also mentioned that poor access to appropriate care or poor coordination with the school contributed to their low satisfaction.

Regarding valued observations of improvement, the area most frequently noted by parents and youth was improvement in the youth's self-efficacy and self-worth, including the youth caring more about their appearance, being proud of their accomplishments, gaining insight into their difficulties, or learning new coping mechanisms, as noted by this youth:

I feel better about myself and I just feel, I feel better about myself and I learned to just move them aside, like just, if someone says something bad to me I just move them aside. (Youth 2-24)

Also frequently valued by parents and youth was the youth's improvement at school (i.e., grades) and at home with his/her family. Parents and youth listed perceived reasons for improved grades as the youth being prescribed medication, the school providing educational accommodations, the youth being motivated to graduate on time, or the youth getting involved in extracurricular activities. Involvement in sports was frequently noted, for example by this parent:

He's doing real good in school, he's really picked up the pace...Became a starter for the basketball team...And they were the, they got runner up in state, so see he's, he knows, he knows what's out there, you just have to go and get it and you can't get it by doing drugs. (Parent-1-36)

Improvement in the youth-family interaction was evident to parents and youth through reduced arguing/fighting, more listening/respect, and more supportive family relationships, as described by this parent:

Like I said, we have our moments still, right?...but I think we had a disagreement last week as a matter of fact...and we had a discussion...and it's the first time that [my child] ever said "I care about how you feel about me, Mom." (Parent-2-28)

The youth's relationship with his/her peers or community were less often cited indicators of change. In the youth's relationship with peers, some parents noted their child showed more leadership or made new, healthier friends. Likewise, some youth described how they learned to be aware of and avoid negative peer pressure. Many parents and youth, however, still had concerns about the youth's relationship with peers, particularly regarding peers who were unsupportive of the youth making positive changes in their lives and continued negative peer influences. This uncertainty was expressed by both this parent and youth:

He was like "well yeah I know I'm on probation but they're my best friend" and you know I'm not going to tell them they can't [come] over and things like that... and I've run 'em off and told them not to come back, but here lately maybe that's my problem, I give in and his friends have started coming back around. (Parent 1-35)

My old friends, I don't know. They tell me that I would be better off just dropping my old friends cause they're nothing but drug addicts. (Youth 1-33)

Community-related outcomes were almost exclusively described for youth who had legal problems. Parents often said that their child still had the same poor judgment despite the insight they had gained through treatment, and that they continued to get in trouble at school or with the police. However, both parents and youth seemed to perceive the youth's improvement in his/her insight rather than improvement in judgment and behavior as the more important sign of progress, as this parent expressed:

He's really smart and he really remembers a lot of what happened down here, so hopefully some of those decision making skills will stick with him, even though he don't, you know, he chooses not to use them right now, um, maybe in the future... like I said he's a lot more respectful now, so you know, that's, that's helpful... You know he knows better, he knows more than he did before you know he came here, but he's still choosing to drink and do alcohol, I don't know, I don't think as much, ...so I don't know, there was some improvement, but not the improvement you would like to see...it's good sometimes but still he's getting in trouble with the law, so, I don't know. (Parent 1-35)

Discussion

The aim of this pilot study was to better describe indicators of quality of care for AI child and adolescent behavioral health and to highlight potential directions for improvement by inviting AI patients and families to provide their perspectives of what quality of care means to them. Previous research suggests a common set of themes encompass patient perspectives of quality; including access to care, communication and information, courtesy and emotional

support, technical quality, efficiency of care/organization, structure and facilities, etc. (Donabedian, 1980; Sofaer & Firminger, 2005). The interview responses of these AI youth and their parents deepen the descriptions of these common themes and highlight other indicators that may be unique to AI patients and families.

First, it is important to note that AI patient and family descriptions of their cultural identification, beliefs, and practices varied greatly in this sample. Although our sample was too small in this study to detect any patterns across participants relating to mental health outcomes, we did find that AIs with various levels of traditionalism and acculturation all were willing to seek help from non-AI service providers. Further, parents described barriers to care in the sense that access to specialty services (especially child and adolescent psychiatry) was limited; either because services were too far away, came at too high of a cost, or had long waiting lists. Research regarding AI access to care often focuses on cultural barriers to primary-level prevention and intervention. Our findings however, highlighted the additional need to consider barriers to higher levels of care for those who desire it, but are unable to access it. On the other hand, because our study sample was limited to service users, it likely did not represent the full spectrum of perceived barriers to care in ways that would have been evident if we had interviewed a community sample.

Descriptions of AI identity also highlighted the cultural ambiguity that existed for some participants. The finding that youth tended to express more interest than their parents about traditional healing suggests there may be a window of opportunity among AI youth for therapies that incorporate traditional practices and encourage cultural reclamation (Gone, 2011). Parents expressed less interest in utilizing traditional healing, but also claimed to fully endorse whichever treatment the clinician would recommend. All parents and youth were satisfied with the treatment they received, whether the clinician practiced mainstream evidence-based therapies (EBTs) or experiential- or animal-based therapies. Our sample was too small to explore differences in outcomes by types of services provided, but one should be aware that effective treatments for AI communities may not necessarily be limited to EBTs (Gone & Alcántara, 2007). Regardless, parent perspectives were much more concerned with the process of delivery than the specific treatment method chosen.

The above findings provide support concerning the dangers of stereotyping within a culture, and highlight the potential fallacy of “ethnic glosses”; or the over-generalizing observations that are applied to a diverse group of people (Trimble, 1990; Williamson & Harrison, 2010). The wide variety of patient and family descriptions suggests that a safe practice of cross-cultural care means being aware of and sensitive to the variance in individual needs, and not simply relying on highly abstracted cultural norms.

Despite this notable diversity, the strongest consensus that emerged from our exploration of PFC characteristics was the considerable emphasis participants placed on the role of family in the development and remedial support of behavioral health problems. Consistent with previous findings (Chester et al., 1999), our results suggest that family stress and support, including from the immediate and extended family, are centrally important for AI children and adolescents receiving behavioral health services. Descriptions of the stressors also often related to family loss or grief. Given these findings, clinical assessment should prioritize

thorough investigation of the immediate and extended family, the expected role of each member of the immediate and extended family in treatment, and awareness of the immediate and extended family's impact on treatment. Also, family-oriented models of care, including family therapy, multi-family groups, family case management, and emerging models of helping with immediate and multigenerational family grief, may be important services in AI communities.

Regarding process indicators of care, participant responses particularly highlighted the central importance of establishing trust with the clinician in order for the patient and family to have positive perceptions of treatment, in line with previous research (Guadagnolo et al., 2009; Oetzel et al., 2006). Although in some cases trust was described as something that only came with either personal familiarity or the passage of time, in most cases trust was described as a malleable construct that was highly dependent on the quality of interpersonal communication.

Furthermore, our results suggest that the clinician's social and interpersonal skills in areas distinct from communication *per se* factored strongly into patient and family perspectives of trust and quality of services, again in line with previous research (Garrouette et al., 2004). For example, patients and families described evidence of appropriate care in terms of their child enjoying and wanting to continue treatment—an outcome which is more dependent on clinicians' interpersonal skills than their technical expertise. Also, patients and families described sensitivity and respect not in terms of the clinician demonstrating specific cultural knowledge, but in terms of asking comprehensive and caring questions beyond the immediate problem, including questions about the patient's family and community. Patients and families valued clinician competence in medication management, but many were uncomfortable with using medication, and they also valued the clinician addressing their concerns before going into the technical details of the medication. Finally, many patients and families referred to coordination of care as consisting of communication with the school or parole officer, thus emphasizing the need for clinicians to be able to work with others who are not necessarily health care providers.

Although the terms these patients and families used to articulate their perspectives are somewhat expected given their scope of interest, they are nevertheless reminiscent of the perspectives presented by the 1999 American Psychological Association, Division 29 Task Force on Empirically Supported Therapy Relationships. The products of this Task Force emphasized the extent to which clinical outcomes depend on therapy relationships—"the feelings and attitudes that therapist and client have toward one another, and the manner in which these are expressed" (Norcross, 2001, p. 348). In a summary of the Task Force's findings, Lambert and Barley (2001) pointed out that specific therapeutic techniques accounted for no more than 15% of the variance in therapy outcomes. Whereas the therapy relationship and other empathic factors common to different therapies accounted for 30% of the variance in therapy outcomes. Our findings suggest that attention to relationship quality may be especially pronounced among those who are of AI ethnicity.

With regard to outcomes, patient and family quality of care surveys (e.g., CAHPS-AI) have largely focused on satisfaction ratings despite the fact that these ratings present numerous

problems, including capping (i.e., how satisfaction may imply only adequate or acceptable quality), relativity (i.e., what may satisfy one may dissatisfy another), and expectation-experience confounding (i.e., how pre-conceived expectations may create unrealistically high or low standards) (Sofaer & Firminger, 2005). Our findings provide evidence of these problems existing in our sample; for example, every participant said that they were satisfied with the care they received, even though many also had complaints or at least suggestions for improvement.

Additionally, our findings support the argument put forward by other researchers that patient and family satisfaction levels do not necessarily correlate with perceptions of improvement in symptoms and functioning (Covinsky et al., 1998; Kane et al., 1997). In fact, our results suggest that far from relying on satisfaction as the primary indicator for quality of treatment outcomes, patients and families were able to directly provide highly-detailed and comprehensive accounts of changes in symptoms and functioning that did not require technical knowledge of clinical practice—perspectives that could be a vital tool in assessing the quality of treatment outcome and overall quality of care (Donabedian, 1992; Sofaer & Firminger, 2005). Accordingly, a number of patient-reported outcome measures for mental health services have recently been developed for use by youth and their families (Burlingame et al., 2001; Forrest et al., 2012; Riemer et al., 2012), and youth whose clinicians received routine feedback of outcome assessments during treatment were found to improve more rapidly than youth whose clinicians did not (Bickman et al., 2011). No patient-reported outcome assessment has yet been developed specifically for AI youth and families, nor has one been tested for effectiveness within the AI population; however, we found that our participants valued improvement in the youth's self-efficacy and self-worth and his/her functioning at school more frequently than they did improvement in other areas. Therefore, we suggest that standardized outcome evaluation in AI child and adolescent behavioral health care pay particularly close attention to domains which capture these valued areas.

This pilot study has several limitations. First, the sample size was small and participants were self-selected. It is possible that the study participants may have had more positive attitudes towards the services they received than others who did not choose to participate. It is likely that a larger, more representative sample would have added richness to our exploration of quality of care for AI children and adolescents, and perhaps would have identified issues that were not raised by study participants. Still, these participants raised many important concerns throughout the descriptions of the services they received. Second, many of the patients and families we interviewed chose to use Western behavioral health treatment and their perspectives of cultural characteristics (e.g., the importance of AI identity or spiritual association) as well as their perspectives of treatment process (e.g., attitudes towards traditional healing, cultural competency, medication management, etc.) must be understood in this context. It is likely that AI children and families who do not use biomedical services would have different perspectives on the importance of these issues (Novins et al., 2004). Third, the interview guides reflected priorities of the project's Advisory Board and were not explicitly designed to conduct a comprehensive assessment of established indicators of quality. Therefore, queries into the structure of services (i.e., perceptions about non-clinical staff and facilities) were not included in our interviews.

Fourth, while the interviewers allowed for patients and families to first speak freely in their responses to open-ended stem questions, interviewers also used follow-up question probes to explore areas that were of particular interest to the research team, and likely inflated the frequencies of certain themes. The use of question probes was most noticeable within treatment outcomes questions in particular, and often garnered more indications of perceived improvement. For example, not all participants spontaneously said that they looked for improvement in the youth's self-efficacy and self-worth, but after being prompted, all participants did agree that they valued change in the youth's self-efficacy and self-worth as an indicator of improvement. Still, it is important to note that the increase in endorsement was uniform across all the key themes and subthemes, suggesting that while the probes did increase the frequency of endorsement, it did not change the relative importance of each of these areas. Given these limitations, the results of this study should be viewed as preliminary and will require further investigation.

Although we have made important progress towards a patient-centered and ethnically equal health care system, we must continue to investigate how diverse patient populations think about quality of care if we are to effectively eliminate the aspects of health disparities that are most resistant to change. The qualitative analyses presented in this pilot study highlight patient and family perspectives that are particularly important for clinicians and programs serving AI children and adolescents to consider as they strive to provide the highest quality of clinical care, while being mindful of the exploratory nature of this work. Still, future research should focus on how to best incorporate more measures of interpersonal aspects of the treatment process and more specific and objective indicators in treatment outcomes into standardized AI quality of care assessments. With these considerations, more research is needed to better track the quality of care of AI child and adolescent behavioral health care services across larger participant samples and across more AI communities, and to prioritize areas for further improvement.

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Table 1

Youth and Parent Interview Guide Developed by the Advisory Board

Stem Questions and Probes
<p><i>Patient-Family-Community Characteristics</i></p> <p>Tell me a little bit about you, your family and how you/your child ended up in treatment?</p> <ul style="list-style-type: none"> • What are the problems that brought you here? • Do you/your parents have/have had an alcohol, drug or mental health problem? • Has anyone else in your family ever received treatment? What kind and how helpful was it? • Have you/your child had problems or difficulties in your family such as painful experiences, losses of loved ones, or dangerous/threatening situations? • Were the appointments with you and your child as often as you wanted them to be? <p>Tell me about the role spirituality or religion plays in your life?</p> <ul style="list-style-type: none"> • How important is your Indian identity to you and your family? What are the kinds of things you do to follow the Indian way? • What kind of religious/spiritual traditions do you and your family participate in?
<p><i>Treatment Process</i></p> <p>What were your first few meetings here like?</p> <ul style="list-style-type: none"> • How was the treatment process explained to you at intake? • How did the clinician/counselor/etc learn about your family's cultural background? • How did the clinician/counselor/etc learn about your family's current situation? <p>What type of information did the clinician discuss with you regarding your (child's) treatment?</p> <ul style="list-style-type: none"> • How did the clinician educate you about the problems you and your family were experiencing? • Was medication discussed as part of your (child's) treatment? • How did the clinician check in to make sure you understood what he/she was recommending? <p>How was your experience with the treatment you received here?</p> <ul style="list-style-type: none"> • Do you feel your family participated in assessment? In treatment? • Do you feel your child's services were provided when you wanted them? • Are other programs involved in the treatment? How do they work together? • How does your clinician/counselor/etc. treat you? How does he/she involve you in the treatment process? How do you get along with him/her? Do you trust him/her?
<p><i>Treatment Outcomes</i></p> <p>Now that [your child is in treatment/treatment is finished], how is your (child's) life?</p> <ul style="list-style-type: none"> • After receiving services, how are you/is your child: <ul style="list-style-type: none"> Feeling about him/herself? Interacting with peers? Doing at home? Performing in school? Behaving in the general community? • Are you seeing an improvement in the problems that brought you/your child into these services? • Are you satisfied with the services you/your child received here?

Note. Stem questions (in **bold** text) were asked in every interview. Probes (in plain text) were asked if an interviewee did not raise the issue spontaneously.

Table 2

Dominant Response Themes and Mentioning Frequencies by Parents and Youth

	Parents (n = 15)		Youth (n = 11)	
	n	(%)	n	(%)
PATIENT-FAMILY-COMMUNITY CHARACTERISTICS				
Reason for treatment				
Youth seeking/receiving treatment for substance abuse	5	(33%)	5	(45%)
Youth seeking/receiving treatment for a mood disorder	3	(20%)	2	(18%)
Youth seeking/receiving treatment for ADHD	7	(47%)	3	(27%)
Where problems occurred				
Youth having difficulties with school	10	(67%)	8	(73%)
Youth having difficulties with legal involvement/arrests	6	(40%)	5	(45%)
Sources of stress				
Death or illness of a loved one as a stress to youth	9	(60%)	5	(45%)
Loss of father figure as a stress to youth	6	(40%)	3	(27%)
Intra-family conflict as a stress to youth	5	(33%)	2	(18%)
Parental behavioral health				
Parent(s) having a history of substance abuse	6	(40%)	1	(9%)
Parent(s) currently using substances	2	(13%)	0	(0%)
Barriers to treatment				
Community barriers to getting needed behavioral health care	5	(33%)	1	(9%)
Indian Identity				
Important and active part of daily life	5	(33%)	3	(27%)
Valued, but not an active part of daily life	5	(33%)	6	(55%)
Unimportant or not applicable	5	(33%)	2	(18%)
Traditional Healing				
Desires Access to Traditional Healing	2	(13%)	2	(18%)
Openness to Traditional Healing	3	(20%)	7	(64%)
Not interested in Traditional Healing	5	(33%)	1	(9%)
Spiritual association				
Christianity	11	(73%)	7	(64%)
Traditional Tribal beliefs	3	(20%)	0	(0%)
No spiritual association	2	(13%)	4	(36%)
TREATMENT PROCESS				
Trust				
Trusted clinician because of treatment process	9	(60%)	6	(55%)
Did not trust clinician because of treatment process	2	(13%)	1	(9%)
Trusted clinician for reasons other than treatment process	2	(13%)	0	(0%)
Did not trust clinician for reasons other than treatment process	1	(7%)	0	(0%)
Valued aspects of treatment				
Good communication	10	(67%)	6	(55%)
Delivery of helpful and enjoyable care	10	(67%)	5	(45%)

	Parents (n = 15)		Youth (n = 11)	
	n	(%)	n	(%)
Sensitivity and respect	9	(60%)	3	(27%)
Patience in prescribing medication	7	(47%)	1	(9%)
Coordination of care with school/parole officer	4	(27%)	1	(9%)
TREATMENT OUTCOMES				
Satisfaction				
Very satisfied	10	(67%)	9	(82%)
Somewhat satisfied	5	(33%)	2	(18%)
Unsatisfied	0	(0%)	0	(0%)
Valued areas regarding youth's improvement in treatment				
Self-efficacy and self-worth	15	(100%)	11	(100%)
Functioning in school	11	(73%)	9	(82%)
Relationship with his/her family	11	(73%)	9	(82%)
Relationship with his/her peers	9	(60%)	5	(45%)
Relationship with his/her community	7	(47%)	5	(45%)