



Perceived barriers and facilitators to dental treatment among female caregivers of children with and without HIV and their health care providers

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Abstract

Purpose: This study sought to identify barriers and facilitators to dental care among families of predominately low socioeconomic status having children with and without HIV.

Methods: Twelve focus group sessions with African-American and Hispanic caregivers and 18 individual semistructured interviews with key informant health care providers were held at two sites: a hospital-based program (HBP) and a dental school-based program (DSBP), that provide pediatric dental services. SPSS Textsmart¹ software was used to analyze qualitative data within and across group types and sites.

Results: Focus group participants (n=72, averaging 6 women per group) included: HIV-seropositive biological mothers of HIV-seropositive children (4 groups); HIV-seronegative caregivers of HIV-seropositive children (4 groups); and Medicaid-eligible, HIV-seronegative caregivers of HIV-seronegative children (4 groups). The most commonly expressed barrier to dental care across groups was poor interpersonal communication between dental staff and caregiver/child. HIV-seronegative groups cited health care delivery system factors as barriers to receiving dental care more frequently than HIV-seropositive caregivers who cited shame/anger and family illness as being more important. Common facilitators were positive communication and transportation assistance. Unique facilitators for HIV-seropositive groups were coordination of the dental visits with medical appointments at the HBP. Key informants acknowledged high stress in families having children with HIV/AIDS, cited dental fear among caregivers as a barrier to dental treatment adherence and reported that dental care seemed to be a low priority among many of these families.

Conclusions: Facilitators and barriers to care included factors in the family, dental care and health care delivery systems as well as interpersonal communication between the dental providers and the families. (*Pediatr Dent.* 2002;24:301-308)

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As a result of recent advancements in medical treatment regimens, children and adolescents who are infected with the human immunodeficiency virus (HIV) are living longer. It is well established that having HIV/AIDS can increase one's risk of oral infection.² Although important for all children, oral health promotion in patients with HIV/AIDS is even more critical given their increased vulnerability and reported higher rates of primary

dentition caries status compared to the US pediatric population.³

The authors of this study and others have previously reported on oral health needs and utilization of dental services among children with HIV/AIDS.⁴⁻⁶ A significant proportion of children in a longitudinal study of oral health and HIV status had unmet dental needs and reported oral pain during clinical research examinations.⁶ A subsequent pilot study

examined reasons for referral for dental care and adherence with treatment recommendations among children who were participating in the HIV study.⁴ Of 88 children with dental disease serious enough to warrant referral for dental treatment (including dental caries, gingivitis, oral thrush and plaque), only 17 (32%) of the HIV-seropositive children and 3 (9%) of the HIV-seronegative siblings (children residing in the same household) adhered with treatment recommendations. The reasons why some children appeared for dental treatment while others did not, especially given that one-third of the sample reported oral pain, were unclear. Consequently, a dental care pilot program to increase dental attendance was developed for participants in the program with unmet needs.

In the pilot program, dental students were trained as case coordinators to arrange for dental appointments, child care, and transportation services for the seropositive children.⁵ Despite reimbursement for transportation, only one of 37 children completed treatment. Postprogram interview data with caregivers indicated that the care received at the school was perceived as being inefficient, and interpersonal communication between staff and caregivers was reported as being negative.

The purpose of this study was to utilize qualitative methods to identify perceived barriers and facilitators to dental care among low socioeconomic inner-city female caregivers of children with and without HIV. Qualitative techniques have been identified as useful tools for health research,⁷ and since the early 1980s a significant amount of literature has shown the many ways in which these techniques have been and can be used in health and policy.^{8,9} Such techniques are recommended: "To gain insight in exploratory or preliminary studies"; "when there is a communication or an understanding gap between groups or categories of people (eg, professionals and patients)"; and "to uncover issues related to complex behavior or motivation."¹⁰

Based on previous research conducted by this study's authors regarding barriers and facilitators of dental care as well as research in the area of health care utilization behaviors and adherence with pediatric care,¹¹⁻¹⁵ this study attempted to identify the perceived barriers and facilitators of dental treatment for HIV-positive and Medicaid-eligible children through focus groups with female caregivers and open-ended interviews with key informants at two clinical treatment locations. Open-ended questions serve to promote a range of responses by participants, which is not possible with survey-based research techniques.

Methods

Study participants

Focus group participants included both HIV-seropositive and HIV-seronegative female caregivers of seropositive and seronegative children from two sites in the greater New York metropolitan area where dental services are available. Inclusion

criteria were (1) caring for children under 14 years of age, (2) having children who were eligible for either Medicaid or Ryan White funds and (3) having children who were currently under active dental or medical care at either location.

Focus group participants were recruited and assigned to one of 12 homogenous groups based upon the following criteria: (1) HIV status of the caregiver (seropositive vs seronegative); (2) HIV status of the child (seropositive vs seronegative); (3) family ethnicity (African-American or Latino); and (4) site (HBP vs DSBP). Homogeneity in focus groups was preserved in an attempt to foster open and honest group discussion. For example, at both sites, HIV-positive biologic mothers comprised separate groups (n=4 groups) and were not mixed with other caregivers to ensure a non-threatening environment for discussing their experiences as women and mothers living with HIV/AIDS.

In addition, caregivers of HIV-seropositive children who were not seropositive (eg, grandmothers, aunts and foster mothers) comprised two groups at each site. All of these caregivers were themselves Medicaid-eligible. Lastly, 4 groups (two at each site) of HIV-seronegative women with seronegative children were interviewed. The rationale for the number is based on recommendations from focus group specialists.^{9,10} It is generally believed that "two groups with a particular audience segment provide a considerable amount of new information and additional groups are of limited value."¹⁰ The particular segments relevant to this study are HIV status and treatment site.

Key informants included persons associated with the dental and medical clinics at the two medical centers (9 at each site) and included a variety of specialists with experience in serving the targeted populations: pediatric dentists, pediatricians, receptionists, nurses, social workers and dental auxiliaries. Whenever possible, similar specialists were interviewed at both sites.

Description of sites

Each site is affiliated with a medical service center that serves approximately 150 to 175 children with HIV/AIDS. One site is a hospital-based program (HBP), while the other site is a dental school-based program (DSBP). The HBP provides the following services: treatment of mouth trauma, root canals and extractions, oral surgery, preventive and prophylactic care, restorative procedures, orthodontic analysis and fluoride treatments. In addition to providing treatment for children through the Ryan White grant, the HBP serves children with other special needs like mental retardation, blindness, hearing impairment and mental illness. The HBP staffs a dental chair "literally 10 feet away from the play area" in the Infectious Disease Clinic (IDC—serving patients with HIV/AIDS). The goal is to enable patients/families to see health providers from the Infectious Disease Clinic and the HBP on the same day—"one-stop shopping."

At the DSBP, two different clinics treat pediatric HIV/AIDS patients: the Oral Medicine Clinic (OMC) and the

Table 1. Focus Group Guide/Interview Topics

1.	What do you (caregivers) do to stay healthy?*
2.	What is dental/oral health? (What are bad teeth?, What are good teeth?) How important is it?*
3.	What do children need to be healthy? What is the relationship between teeth and general health?*
4.	Why do caregivers take their children to the dentist?
5.	What is your experience with taking your children to the dentist?*
6.	Why do some caregivers not take their children to the dentist? What are some reasons for not showing up for appointments? What things get in the way from taking your children to the dentist (obstacles or barriers)?
7.	What are ways to improve dental care for children with special needs like HIV/AIDS?
8.	What might help caregivers keep their appointments for their children?
9.	Ideally, what should happen at a dental visit?*
10.	Please describe your role in working with children with HIV/AIDS and the dental service at your facility.†

* Focus group items asked only of the caregivers

† Interview item asked only of the healthcare providers (key informants)

Pediatric Dental Clinic (PDC). These clinics are both situated in the dental school. Pediatric residents frequently treat the children referred for ongoing dental care at the PDC. Individuals above 16 years of age are most often referred to the OMC for ongoing care. The dental services provided in both programs are similar to those offered at the HBP and both programs have access to emergency and operating rooms at the adjacent hospital. A major difference between the DSBP and the HBP is the lack of programmatic relationship between the dental and medical services at the DSBP.

Focus group sessions

All participants were advised of the purpose of the study and the focus group procedure and agreed to participate in accordance with the IRB-approved protocol. As recommended, group size averaged 6 participants.¹⁰ All focus groups were audiotaped, and at the close of the session participants received \$40 for their time and participation. Following the sessions, tapes were transcribed and then erased.

Key informant interviews

One-hour interviews were conducted with each of the 18 key informants. A single experienced research interviewer who was unaffiliated with either medical center performed all of the interviews. Participants were phoned by the interviewer to arrange a convenient time and setting for the interview and were paid \$25 for their time and effort at the conclusion of the session. A semi-structured interview schedule with both open-ended and close-ended questions was utilized. All interviews were audiotaped, transcribed, and erased.

Interview schedules/focus group guides

The focus group guides and interview topics were developed based on the findings from the investigators' preliminary studies on adherence with dental treatment^{4,5} as well as published literature on health care utilization and adherence.¹¹⁻¹⁵ The guides ensured that consistent topics were addressed across groups and interviews and included cognitive, socio-cultural-psychosocial and sociomedical factors). The focus group guide and interview topics are shown in Table 1.

Data analysis

The SPSS/PC data entry program¹ was used to enter and verify demographic data (eg, age and ethnicity) from focus group participants. Focus groups and key informant interviews were audiotaped and the tapes were then transcribed. A codified transcription text from each of the focus groups was entered into a qualitative software program (SPSS Textsmart, Version 1.0)¹ and analyzed to identify patterns and themes that emerged across and within caregiver groups. Trigger words were used to identify themes. Key informant interviews were summarized, and, in addition to data from the audiotapes, notes from these interviews were examined to allow for triangulating sources of data. Categorical analysis permitted the identification of common concepts and comparisons across sites and across subject groups.

Results

Focus groups

Twelve focus groups comprising 72 caregivers were conducted over a period of 8 weeks during the spring months of 1998. Six groups were held at each site. Group characteristics by caregiver and child serostatus are shown in Table 2. Groups differed significantly ($P<.01$) regarding the mean age of the participants. Groups composed of biological mothers (both seropositive and seronegative) were younger than groups of seronegative caregivers of seropositive children; participants of these groups included primarily grandmothers, yet foster mothers, aunts and sisters were also represented.

Although the response rate for agreement to participate was high (over 85%), actual attendance at the focus group session ranged from a low of 42% (5 persons) to a high of 80% (7 persons). The attendance rates of participation in the HIV-caregiver/child groups were higher than those for the non-HIV groups, most likely a result of the prior contact that the recruiters had had with these caregivers.

Table 2. Characteristics of Focus Group Participants

Caregiver serostatus	Child serostatus	Participation rate	Mean age (mos) (SD)	Caregiver age (yrs)
Positive	Positive	25/41 (62%)	36 (7)	23-50
Negative	Positive	22/40 (55%)	49 (10)	23-67
Negative	Negative	25/48 (52%)	33 (7)	21-49

Table 3. Barriers and Facilitators Identified via Focus Group Analyses

Barriers	# groups	Facilitators	# groups
Family attitudes and beliefs		Family attitudes and beliefs	
Dental fear*	10	Dental values	5
Attitude towards health care providers	7	Dental knowledge	4
Fear of the spread of HIV†	5	Attitude towards health providers	7
Dental knowledge	10		
Family stress			
Busyness	7		
Dysfunction*	10		
Illness	10		
Social shame/anger‡	3		
Social support/child care	5		
Logistics		Logistics*	
Scheduling†§	7	Scheduling	7
Coordination with medical appointments	3	Coordination with medical appointments†	3
Waiting†	7	Reminder calls	8
Quality of care		Quality of care	
Lack of continuity of care§	4	Continuity of care	5
HIV issues—lack of confidentiality	3	Competent dentist/staff	9
Lack of expeditious care§	2	HIV issues	3
Cleanliness†	2	Provision of treatment	6
Physical environment		Physical environment	
Uncomfortable	3	Comfortable	3
Clinic too small	3	Child-friendly environment	3
Interpersonal communication*		Interpersonal communication*	
Dentist/staff behaviors	12	Dentist/staff behaviors	12
Prejudice towards poor/HIV	6	Education	7
Language barrier	1	Rewards	8
Access to care†		Access to care†	
Transportation	9	Transportation—availability, cost	6
Costs (child care, treatment, transportation)	8	Agency/social support	8
Regulations (health policy)	8	Regulations (health policy)‡	
		Cost/coverage for dental treatment	6

* Across groups

† Predominantly HIV-negative groups

‡ Predominantly HIV-seropositive groups

§ Predominantly DCBP

|| Predominantly HBP

Focus group responses

Focus group data revealed both common and unique group barriers and facilitators to dental care across groups and sites. The responses are summarized in Table 3. Major domains of responses included dental and health care delivery system characteristics, the family system and attitudes and beliefs regarding dental and general health.

Commonly expressed barriers across groups included dental fear (10 of 12 groups) and attitudes of distrust toward dental/health providers (7 of 12 groups). Many

caregivers recounted both their own and their children's painful dental encounters (eg, "feel terrified to go," "do not like to see my child hurt") and objected to the use of the papoose board. Exclusive to the HIV-negative groups were statements underscoring their fear of the spread of HIV infection in the clinics. One Hispanic parent reported: because of "careless dentists, I don't take my children. I'm afraid of [dentists]." Another caregiver who reported having worked as a dental assistant for a dentist explained that "he did not clean his instruments."

Family stress was also widely experienced across groups at both sites. Family dysfunction including drug/alcohol use, alleged child abuse, homelessness, loss of significant others and mental illness was discussed. One caregiver exclaimed: “Well my children know I’m HIV, but to them I don’t look like I’m sick. But my insides get tired fast these days. I have to tell them, you know I’m sick and my body is not strong like it used to be. It just stresses you.”

Family illness was pervasive: “My daughter died last year and my sister died the year before, so I don’t have much stress now. Just the little baby drives me crazy—you know, running around.” Lack of social support, specifically lack of child care, was also reported across groups. “I have nowhere to put my kids”; “I cannot find help to look after the children.” Several women reported that they “did not want to take [their] child out of school” for dental treatment. In fact, caregivers of the children without Ryan White support resented not having financial support to help them obtain dental care for their children.

Most mothers had some idea about what caused dental disease and understood that there was a direct relationship between behavior (eg, diet and hygiene) and dental health. Many participants were aware of an increased risk of tooth decay associated with providing the children juice and formula at will in bottles: “The problem I have with my babies is that they like to drink something at night with their bottles.” A caregiver of a child without HIV reported: “You know the sugar in the juice usually eats up their teeth, and my baby’s teeth hurt.” Another mother stated: “They told me (milk formula) would eat up his teeth but he needed it for nourishment. The bottle messed up his teeth, and he had 12 cavities.”

Interpersonal communication was the most common barrier to adherence with dental treatment. Specific incidents of poor treatment experience, negative attitudes among specific staff members, and behaviors such as rudeness, moodiness and unfriendliness of the staff were frequently cited. In discussing the importance of a caring, empathic dentist, one caregiver reported: “I want my doctor to explain to me what a checkup is.” Another added: “If you’re going to learn to be a dentist or doctor you should know how to talk to people—if you’re going to have a nasty attitude all the time, then you might as well not be a dentist.”

Perceived “meanness” (eg, use of the papoose board) and inadequate education were also cited as objectionable. Several caregivers felt that their expectations were unmet by the dentist and staff in that it became clear that radiographs and examinations were not perceived as “treatment.”

Dental care delivery system barriers included logistical problems, questions regarding the quality of care received by the children and objections to the physical environment of the dental office. Complaints about the physical environment being “too small” were cited by the HBP caregivers across groups. However, continuity of care and the lack of expeditious treatment were pervasive among the DSBP caregivers. There was a general agreement that children with

HIV should not be treated in a separate clinic. Comments included: “That is not fair,” and “that is discrimination.” Some caregivers perceived that the infected children need “more frequent visits” while others emphasized that “we are all in the same boat—teeth don’t know that they are rich or poor or have HIV or nothing—they are all teeth.”

Caregivers whose children qualified under the Ryan White program had positive sentiments about the program’s resources facilitating their children’s access to care. Many of the caregivers reported assistance from caseworkers and that Ryan White covered the children’s dental costs as well as transportation. Women whose children were not covered by Ryan White frequently stated that “approval for care” was necessary to pay for dental treatment and that transportation was an ongoing, critical barrier to care. Furthermore, they felt that the health care system discriminated if they (the mothers) had Medicaid, a history of drug use or prior contact with social services.

Perceptions of the importance of dental health and dental knowledge differed between sites. In general, caregivers of HIV-seropositive children from the HBP site perceived that oral health was extremely important, while the caregivers from the DSBP uniformly felt that dental health was not a priority compared to general health. Furthermore, caregivers from the DSBP asserted that “medical care is easier to get than dental care,” explaining that a child is taken to the dentist only when there is a specific problem, although a child is taken to the physician for “medical check-ups.” Dental knowledge differed across groups regarding whether HIV infection had an effect on teeth, although many caregivers mentioned thrush.

Most caregivers of HIV-seropositive children felt that children with HIV and those without HIV infection could be treated by the same dentist. Several mothers of HIV-seronegative children disagreed and expressed fear regarding the spread of HIV in the office.

Facilitators identified by the caregivers often related to family attitudes, dental knowledge and interpersonal communication. Good doctors and continuity of care were emphasized as foundations for dental treatment and a positive treatment experience. Suggestions from the caregivers included: reminder calls about appointments, coordinating dentist visits with other doctor appointments for their children, open clinic hours, no waiting time, afternoon appointments, and a comfortable waiting area. Other facilitators that involved the health care system included improved, reliable transportation and support services from social workers to home health aides. Suggestions for the physical environment included: coloring books for the children, a kid-friendly waiting area (eg, toys and colorful walls), free toothbrushes, prizes for the kids and healthy snacks.

Key informant responses

A total of 18 semistructured individual interviews (9 per site) were conducted with key informants. Key informants included nurse practitioners, receptionists, patient care

Table 4. Barriers and Facilitators Identified via Key Informant Interviews

Barriers	# informants	Facilitators	# informants
Family attitudes and beliefs			
Dental fear*†	4		
Attitude toward health/dental care	6		
Low dental knowledge*†	4		
Family values‡	12		
Family stress			
Illness‡	8		
Lack of social support/child care	5		
Dysfunction/daily hassles‡	11		
Logistics		Logistics	
Scheduling‡	10	Scheduling/flexibility	2
Waiting†§	5	Coordination with medical services‡	9
Inflexible appointment times*§	7	Reminder phone calls†	2
Incoordination with medical appointments	6	Dental chair in medical clinic for screenings†	3
Hours limited*§	5	Support staff (eg, social workers)	3
Quality of care		Quality of care	
Lack of continuity of care	2	Continuity of care	3
Lack of confidentiality§	3	Skilled and experienced staff/professionals	3
Insensitivity to HIV issues§	4	Expeditious care	1
		Anticipatory guidance	3
		Team care/emphasis on dental care†	6
		Immediate access to medical records	1
		Rewards	1
Interpersonal communication		Interpersonal communication	
Prejudice toward HIV	2	Bilingual staff	2
Dental/staff behaviors‡	8	Supportive staff*†	6
Poor relationship between medical and dental service§	3	Anticipatory guidance	2
Language barrier	2	Dentist/staff behaviors‡	10
Physical environment			
Clinic too small†	2		
Distance between medical and dental facility	1		
Access to care		Access to care	
Lack of transportation‡	10	Transportation	1
Restrictive regulations (health policy)*, †	6	Agency/social support	2
Cost/lack of coverage for dental care*, †	6	Regulations (health policy—Ryan White)	
Poor agency/social support	1	Cost/coverage for dental care	

* Primarily dental personnel at DSBP

† HBP personnel

‡ Across sites

§ Primarily medical personnel from the DSBP location

coordinators, dentists, pediatricians, dental residents, hygienists, dental assistants and social workers. The interviews averaged about 45 minutes in length. The barriers and facilitators to care expressed by the key informants are summarized in Table 4.

Key informants perceived family values as a major barrier to care. Dental care was perceived as a low priority for

the parents of children with HIV as well as those on Medicaid. When speaking of the seropositive children, a dental auxiliary at the HBP site remarked that change in utilization of dental care is developed “as a partnership and trust evolves between the doctor and the patient/family.” Many respondents’ lack of an adequate support system and difficulty arranging transportation in these family systems were

noted. "The van will only take the parent and patient, not other seronegative siblings, so what do they do with the other kids?"

For the seropositive children, the issue of coordinating medical and dental appointments was emphasized across sites with acknowledgment of the "daily hassles" in the families (eg, children often get sick in the winter; caregivers are often sick; and grandparents (caregivers) can be too frail to take the children for multiple appointments).

Dental fear and low oral health knowledge were also discussed across sites. "They do not think that baby teeth are important and look at dental care as a reparative service—they are crisis oriented," stated the DSBP dental director. Health care system barriers included no health insurance and financial stress. Logistical issues were also perceived as potential barriers. For example, extended waiting time for follow-up, the physical layout of the clinic (eg, too crowded), and restricted appointment times (eg, during school hours) were reported. The waiting time for follow-up visits also varied across sites, with as much as a 3- to 4-month wait for revisits for patients in the HBP. Several informants from both sites lamented that the managed care system often limits the amount and type of dental care allowed and that some of the plans mandate prior approval for care. Additionally, inefficient exchange of medical information between the medical and dental site furthered the extended time needed to complete care at the DSBP.

When asked for recommendations likely to increase the adherence of children to dental care, a range of suggestions was presented by the key informants. Categories were similar to those identified in the focus groups: the dental care delivery system, communication, and regulations associated with the health care and allied health service system all contained components that could improve care delivery and adherence.

Coordination of services between the dental and medical facilities was emphasized as a facilitator; the endorsement and positive support of the medical services for dental care was reiterated as important across sites and care providers. The establishment of the "one stop shopping" at the HBP facility reportedly reduced the number of appointment days, and the use of the staffed dental chair at the infectious disease clinic twice weekly helps to "accomplish cleanings, scalings and prophylaxis treatment while the children are waiting to get their medical care." The dental and infectious disease personnel meet on a monthly basis and review the patients' health status, treatment plans, etc., thereby ensuring that children do not "slip through the cracks." Competent, dedicated staff "taking interest in the children and their families" was a noted facilitator and intrinsic to team philosophy. Continuity of care as a facilitator was emphasized at the HBP site: "We have established a relationship over time"; and the "staff has been here for over 15 years."

At the HBP, the availability of translators and bilingual receptionists was noted as a facilitator. At the same site,

support personnel include a social worker and child life specialist who can "work with caseworkers to assist the children/families with special needs to their respective appointments" (eg, transportation arrangements). "If you deliver good service and treat people well, they'll come no matter what their socioeconomic status might be.

Discussion

Similar factors were identified by both the caregiver in the focus groups as well as the health providers in their interviews. For example, communication was seen as either a facilitator or barrier—and was largely dependent on their perceptions of the interactions. Perhaps dialogue between health and dental school administrators and those who experience the interaction and other stakeholders like medical personnel and community health advocates might be fostered to identify possible ways to intervene to achieve appropriate, efficient and acceptable dental services for children and their caregivers. Such dialogue might be ongoing and create unique opportunities to enhance communication and establish new methods to find "common ground" to improve the oral health of children. Health promotion programs have identified that such dialogue is critical in reaching out to reduce oral/health disparities in poor communities.^{16,17}

An important distinction between the two sites is the context and mission of these dental delivery systems. This factor has been emphasized in Andersen's model regarding access to medical care.¹⁴ The primary mission of DSBP is largely associated with training dentists, while the HBP is focused on health care delivery to medically compromised patients. Therefore a dental school-based program may not be the ideal setting to carry out expeditious treatment which appears congruent with the multiple needs of children with chronic conditions like HIV/AIDS and their families. Furthermore, it may be beyond the scope of a dental school, with its current structure and resources, to adequately address the multitude of such needs intrinsic in families having children with HIV/AIDS, despite the desire to serve all children.

Transportation and support services were emphasized as facilitators. Use of allied health personnel (eg, social worker or child life specialist) at the HBP to deal with ongoing needs (eg, family stress) and services (eg, child care and transportation) is part of the provision of care at the community/hospital-based facility which is subsidized by Ryan White funding. Structured, regularly scheduled team meetings are advocated as a mechanism to improve staff communication in an already busy health care environment as well as a "kind of a safety net for our patients" that facilitates continuity of care.

Although use of qualitative techniques is an excellent mechanism to better understand barriers to care and facilitators to increasing adherence to dental regimens, the results from this investigation can not be generalized to other settings. The study has limitations such as its small, select

sample with no control group. Development of a survey or questionnaire to quantify the presence of specific barriers and family attitudes regarding facilitating access to care must be quantified and replicated before definitive conclusions can be made. Such quantification and ongoing evaluation may be useful as the dental health community strives to meet pediatric oral health needs. Further, it should be emphasized that the family attitudes, needs and values may be critical in providing ongoing care for children with chronic conditions like HIV/AIDS. Therefore, inclusion of evaluations by families and patients may be important when assessing the effectiveness of health care systems.

Conclusions

1. Interpersonal communication was perceived as the most significant barrier and facilitator to care across caregiver groups.
2. Access-to-care barriers can be reduced by coordinating dental and medical appointments.
3. Both caregivers and key informants reported that negative attitudes about dental care and dental fear were barriers to care.
4. Support from the Ryan White Program facilitated access to dental care for children with HIV/AIDS. Such coverage is not available to Medicaid-eligible children who are not HIV positive.

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