Compliance is poor among HIV-infected children with unmet dental needs

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AIDS is the eighth leading cause of death among U.S. children. AIDS has been diagnosed in 4906 children and an additional 14,000 are HIV-positive; the majority from poor, minority, urban settings. Minority and low-income groups have worse oral health status, lower rates of dental service utilization, and greater unmet dental treatment needs compared with whites or those of higher socioeconomic status. HIV-positive children have high rates of untreated caries, periodontal pockets, and oral pain. No reports exist regarding the utilization of dental services by HIV-positive children; further, few studies have addressed the barriers to access care that minorities experience or to compliance with recommended treatment regimens. The purpose of this study was to examine compliance rates with research protocol and with referral appointments for dental treatment among HIV-positive patients and HIV-negative children who are part of a longitudinal research project on oral health needs.

Methods and materials

One hundred five HIV-positive children and 67 HIV-negative household members participating in a study of oral manifestations of HIV at a large, urban, university-based health center underwent oral evaluations every 6 months. Subjects received $25 to defray travel and related expenses. Children with unmet dental needs were referred to the university’s pediatric dental clinic (PDC); unmet dental needs were primarily dental caries, oral pain, and gingivitis. Between October 1993 and November 1994, dental records documenting referral rates to the PDC, reasons for referrals, and compliance with treatment were obtained. Attendance records of self-referred PDC patients (not in the HIV study) were examined to compare compliance rates. Compliance with treatment was categorized as “completed treatment”, “no show”, or “not following through with treatment”. No show was defined as not showing up for appointments; not following through with treatment was defined as appearing for at least one appointment, but not attending later appointments.

Subjects were categorized into three groups. Group 1 (N = 53) included children with perinatal transmission of HIV. The mean CD4 count for these children was 466. Group 2 (N = 35) “siblings”, presumably HIV-negative, included household members who might be biological siblings, cousins, etc. of the children in group 1. Group 3 (N = 416) comprised local children who were self-referred to the PDC for dental treatment. Subjects in groups 1 and 2 were between 2 and 14 years of age (mean = 6.8 years); subjects in group 3 had a mean age of 6.1 years. Approximately 80% of the HIV-positive children and their siblings were black, 13% Hispanic, 5% white, and 2% other. In group 3, 50% were black, 21% Hispanic, 22% white, and 6% other.

Descriptive statistics were used to describe the proportion of subjects adhering to protocol. Chi-square statistics were used to compare group differences regarding compliance with dental appointments.

Results

Eighty-five percent of the children in the longitudinal study on oral manifestations of HIV followed the dental research exam protocol. Siblings had a higher

<table>
<thead>
<tr>
<th>Subject Group</th>
<th>N</th>
<th>% Completed Treatment</th>
<th>% No Show</th>
<th>% Did Not Follow Through with Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV positive*</td>
<td>53</td>
<td>32 (n = 17)</td>
<td>49 (n = 26)</td>
<td>68 (n = 36)</td>
</tr>
<tr>
<td>HIV siblings*</td>
<td>35</td>
<td>9 (n = 3)</td>
<td>91 (n = 32)</td>
<td>91 (n = 32)</td>
</tr>
<tr>
<td>PDC subjects*</td>
<td>416</td>
<td>91 (n = 379)</td>
<td>16 (n = 67)</td>
<td>9 (n = 37)</td>
</tr>
</tbody>
</table>

*HIV+ children enrolled in NMOHRC; *Siblings of HIV+ children enrolled in NMOHRC; *Children from Newark Pediatric Dental Clinic.
failure rate (N = 13; 19%) than HIV-positive children (N = 13; 12%), although differences were not significant.

Fifty-three of the 105 (50%) HIV-positive children and 35 of the 67 siblings (52%) were referred for immediate treatment at the PDC. The table shows rates of noncompliance with recommended dental appointments for these children and for regular PDC patients. Children in group 2 (siblings) had the lowest compliance, which was significantly lower than group 3, the regular PDC patients (chi-square = 6.6; P < 0.01). Children who were HIV positive had better compliance rates compared with their siblings, but had significantly lower rates of compliance than regular PDC patients (chi square = 36.8; P < 0.001). Overall, noncompliance among children in families with a child who was HIV positive was relatively high and was two to three times higher than noncompliance rates among regular patients.

Discussion

The results show that the children with HIV and their siblings have significantly lower compliance than the regular patients from the PDC. In short, children with HIV have high rates of participation in research protocols, yet do not comply with needed dental treatment. The high rate of noncompliance with dental referrals among these children and their siblings underscores the importance of improving our understanding about dental services, utilization practices, and barriers to care among HIV-infected and minority populations. Further, the added burden of HIV in families to comply with dental treatment needs and ways of assisting families to obtain care requires investigation.

Information provided by this preliminary study on compliance with referrals raises concerns about how children could be brought into the dental care system and have their dental treatment needs met. Ethical questions regarding use of appropriate incentives for subjects participating in research as well as receiving needed dental treatment may require increased attention for investigators and service providers. Considerations for future research include:

1. Developing a sensitive instrument to predict compliance with dental regimens
2. Increasing our understanding of attitudes about oral health and dental treatment
3. Using educational and behavioral techniques to improve oral health status
4. Creating a culturally sensitive dental environment to increase patient compliance.

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