Endocarditis prophylaxis in children with congenital heart disease

A parent’s awareness

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ABSTRACT

Objectives: The aim of this study is to determine the parental knowledge of bacterial endocarditis prophylaxis (BEP).

Methods: Parents of 205 patients attending the Pediatric Cardiology Clinics at King Khalid University Hospital, Riyadh, King Fahad University Hospital, Al-Khobar and Prince Sultan Cardiac Center, Riyadh, Kingdom of Saudi Arabia from July 1999 to June 2000, were interviewed by a standard questionnaire pertaining to their knowledge of their child's cardiac disease, medications, and BEP. The patients' cardiac lesions and current medications were verified by a review of medical records. Each patient's need for BEP was determined according to American Heart Association recommendations.

Results: All parents answered the interview questions. The patients' mean age was 5 years and 8 months with a range of one month to 15 years. One hundred and two (50%) parents were high school graduates. Fifty-two (25%) parents correctly defined endocarditis. Two hundred and one (98%) parents knew the correct name of their child’s cardiac condition, and 46/50 (92%) of those on medication knew the names of their child's current medications. Only 113/176 (64%) parents with at risk children were aware of measures to prevent endocarditis.

Conclusions: While most parents know the name of their child's heart lesion and current medications, parental knowledge of endocarditis and BEP was limited. Intensified education and awareness programs are needed in order to prevent potential major morbidity and mortality for pediatric patients with congenital heart disease.


Bacterial endocarditis (BE) causes major morbidity and mortality for patients with congenital heart disease (CHD). A recent review demonstrated an annual BE incidence of one in 1280 to one in 4500 pediatric admissions at major North American medical centers.¹ The American Heart Association (AHA) established guidelines for bacterial endocarditis prophylaxis (BEP) in 1990, revised in 1997.² Families of children with heart disease must become aware of preventive measures and must communicate the need for BEP to dental and medical personnel who care for their children. Previous studies from the United States of America, determined that parents of children at risk for BE...
have poor knowledge of endocarditis and prophylaxis.\(^3,4\) The goal of our study was to assess current parental knowledge of BEP.

**Methods.** Parents of 205 patients attending the Pediatric Cardiology Clinics at King Khalid University Hospital, Riyadh, King Fahad University Hospital, Al-Khobar and Prince Sultan Cardiac Center, Riyadh, Kingdom of Saudi Arabia (KSA) were interviewed with an 8 question survey (Appendix 1) after they were translated to Arabic language by the interviewer, pertaining to their knowledge of their child's cardiac disease, current medications, endocarditis prevention, and prophylaxis. All parents visiting the Pediatric Cardiology Clinics were eligible for the study. Correct definitions of endocarditis mentioned phrases such as, "infection of the heart" or "infection of the heart valves." Parents were aware on BE preventive measures if their response mentioned dental or skin hygiene measures or regular dental follow up. The patients' cardiac lesions and current medications were verified by a review of medical records and echocardiographic reports. The need for BEP was determined by referring to AHA recommendations.\(^3\) Mean and median ages for study patients and chi-squared analysis were determined with the use of a standard biostatistics package (Gold-Stat® Software).

**Results.** Two hundreds and five parents were interviewed with the translated questionnaires. One hundred and sixteen girls and 89 boys with variety of CHD. The patient’s mean age was 5 years and 9 months, median age was 5-years, with a range of 4 weeks to 15 years. One hundred and two (50%) parents were high school graduates. Six (3%) children had a history of BE. Twenty-five (61%) parents knew the correct name of their child's heart disease. Fifty (24%) patients were currently taking medications and 17/50 (34%) parents knew the correct medication names. Thirty-three (16%) patients had either palliative or corrective cardiac surgery. Nineteen (9%) patients were born with cyanotic heart disease and 4/19 (21%) of their parents correctly defined endocarditis. Results of questions pertaining to endocarditis prevention and prophylaxis are presented (Table 1). Knowledge regarding the definition of endocarditis, need for prevention and use of antibiotics for prevention was not related to child's age (\(p>0.05\)) (Table 2). There is a statistically significant deference between the patients on medications and their knowledge regarding the need for antibiotics for BE prophylaxis (\(p=0.0017\)), those parents whom their child had previous operations and their ability to define BE (\(p=0.0334\)) and those parents whom their child had previous operations and there knowledge regarding the need for antibiotics for BE prophylaxis (\(p=0.0009\)) (Table 3).

**Discussion.** Bacterial endocarditis is rare in children.\(^5,6\) An increased incidence is seen in patients with structural heart disease.\(^7,8\) Incidence varies between 60-90% in children with CHD.\(^5,6,9\) *Streptococcus viridans* was by far the most common isolated organism (22%), followed by *Coagulase-negative staphylococcus* (17%) in a local series similar to internationally reported series.\(^10\)

In 1985, the AHA Council on Cardiovascular Diseases in the Young Committee on Rheumatic Fever and Bacterial Endocarditis published BEP recommendations.\(^11\) These recommendations were subsequently revised twice, in 1990 then in 1997.\(^2,3\)

### Table 1 - Parental knowledge of endocarditis prophylaxis (n=205).

<table>
<thead>
<tr>
<th>Item</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent correctly defined endocarditis</td>
<td>52 (25)</td>
</tr>
<tr>
<td>Parent knew any measures to prevent endocarditis</td>
<td>63 (31)</td>
</tr>
<tr>
<td>Parent knew antibiotics were needed for dental procedures</td>
<td>119 (58)</td>
</tr>
<tr>
<td>Patients needing endocarditis prophylaxis</td>
<td>176 (86)</td>
</tr>
<tr>
<td>Whose parent correctly defined endocarditis</td>
<td>46 (22)</td>
</tr>
<tr>
<td>Whose parent knew any measures to prevent endocarditis</td>
<td>57 (28)</td>
</tr>
<tr>
<td>Whose parent knew antibiotics were needed for dental procedures</td>
<td>109 (53)</td>
</tr>
</tbody>
</table>

### Table 2 - Potential variables affecting parental knowledge of bacterial endocarditis prophylaxis.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Defined endocarditis n (%)</th>
<th>Knew prevention n (%)</th>
<th>Knew need for antibiotics n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking regular medications (n=50)</td>
<td>11 (22)</td>
<td>15 (30)</td>
<td>19 (38)</td>
</tr>
<tr>
<td>Not taking medications (n=155)</td>
<td>41 (26)</td>
<td>48 (31)</td>
<td>100 (65)</td>
</tr>
<tr>
<td>Postoperative (n=33)</td>
<td>3 (9)</td>
<td>6 (18)</td>
<td>10 (30)</td>
</tr>
<tr>
<td>Un-operated (n=172)</td>
<td>49 (28)</td>
<td>57 (33)</td>
<td>109 (63)</td>
</tr>
</tbody>
</table>

In our Pediatric Cardiology Clinics at 3 main cardiac centers serving pediatric population at the Central and Eastern provinces of the Kingdom of Saudi Arabia (KSA), AHA printed guidelines or BEP cards are routinely distributed to each new patient. Furthermore, pediatric cardiology team members discuss BEP with families at each clinic visit. In 1971, Caldwell et al\(^1\) reported that 58% of families with children attending the Indiana University Pediatric Cardiology Clinic had no knowledge of BEP. Furthermore, only 57% of the families that were aware of the necessity for BEP understood why antibiotics were indicated. In 1984, Sholler and Çelermajer\(^1^3\) reported that 46% of Australian parents with at-risk children had insufficient knowledge of BEP. Lastly in 1993, Cetta et al\(^1^4\) reported that 44% of families who had children at risk of BE, attending the Loyola University Pediatric Cardiology Clinic had no knowledge of BEP. Compared to the previous studies from different areas of the world, our study shows significantly low percentage of parents with at risk children, knew the exact name of their child's heart disease. Twenty-five percent of parents in our study define exactly endocarditis, and have knowledge on their children’s medications. However, only 56% of parents with at risk children were aware of measures to prevent BE such as 44% had no knowledge of BEP, similar to the Cetta et al study.\(^1^4\) Sixty-three percent of parents in our study knew antibiotics were needed for dental procedures. This is a significant percentage as compared to data obtained by Caldwell et al\(^1^2\): We also observed a higher incidence (5%) of BE among our study patients than reported from other centers.\(^4\) We speculate, that there is more than one reason for these results, first; our cards are printed mainly in English language which need to be translated into Arabic language or supported by explanatory pamphlets to be understandable by caregivers. The caregivers should know exactly, to whom these cards should be presented and it should be always with them when they visit health care services. Second; some physicians are only English speaking, which limit their ability to deliver the exact message to the child’s family, as most of pediatric cardiology clinics do not provide oral health education and oral screening, but it would be beneficial.\(^1^5\) The need to find an easy accessible resources, to improve the parental knowledge in their health problems such as pamphlets, TV Interviews and internet. In addition, we need further research to examine the causes for parental ignorance of BEP guidelines and how to improve it. Adolescents and adults with CHD should be surveyed to discover their knowledge of BEP as previous studies shows that they have important gaps in their knowledge regarding their condition.\(^1^6\) Lastly, recommendations on the prevention of bacterial endocarditis are not well known to all dentists and oral surgeons who perform procedures for which it is indicated.\(^1^7\)

In conclusion, parental knowledge of BE and BEP is limited. Current BEP education programs for parents with at risk children need to be reevaluated. Children with CHD could be encouraged to wear med alert bracelets alerting health professionals to their need for BEP. Physicians and dentists dealing with at risk children should intensify their efforts to educate parents for BEP. Parents should be encouraged to educate their school age children regarding the need for BEP.

### References

Appendix 1

Congenital heart disease patient questionnaire.

1. How old is your child?

2. Did you graduate from high school?

3. What is the name of your child’s heart condition

4. What medications does your child take

5. Has your child ever had endocarditis?  Yes ☐  No ☐

6. What is endocarditis?

7. What can your child do to prevent endocarditis?

8. If your child has dental work performed does he/she need to take additional medicine?

   Yes ☐  No ☐

If yes what was the name of the medicine?