

Primary Preventive Health Care in Children with Heart Disease

Karen Uzark, James Collins, Kimberly Meisenhelder, Macdonald Dick, and Amnon Rosenthal

Division of Cardiology, Department of Pediatrics, C.S. Mott Children's Hospital, University of Michigan, Ann Arbor, Michigan, USA

SUMMARY. In order to evaluate the preventive health care practices in children with heart disease, 499 families were surveyed in outpatient settings. Data were collected on 215 children with heart disease and 284 control children without known chronic illness. There was no significant difference between the groups in the type of primary physician utilized or frequency of visits to the primary care physician. Immunizations were incomplete in 32.7% of the children with heart disease compared to only 2.5% in the control group ($P < 0.0001$). Among the children over 3 years of age with heart disease, 29% had not received routine dental care within the past year compared with 23.4% in the controls ($P = NS$). The parents of children with heart disease were found to pay less money out-of-pocket for their child's health care than the parents of control children ($P < 0.0001$). The data suggest that important aspects of primary health care were neglected in a large group of children with heart disease and that cost was not a major cause for the inadequate preventive care delivery. An educational program directed at health care professionals and parents is proposed.

KEY WORDS: Children — Heart Disease — Preventive Health Care

Each year approximately 30,000 new patients with congenital heart disease enter the health care system in this country [14]. Health care providers are not only responsible for the evaluation and management of the child's cardiac problem, but must be responsible for the continuing primary health care needs of this population. While the provision of comprehensive health care is the goal for every child, the added burden of cardiac disease reinforces our concern for the primary and preventive health care needs of these children.

Approximately 7.5% of all children seen each year by primary physicians have one or more chronic disorders [11]. Serious gaps have been shown to exist in the primary care provided for children with chronic conditions [11]. These children are at risk for inadequate health care, particularly when responsibility is divided between the primary physician and a specialist [11]. In a study of

children attending specialty clinics such as diabetes, pulmonary, or rheumatology, lack of a source of primary care was observed for almost one-third of the children [10]. Similarly, responsibility for specific elements of well-child care (immunizations, assessment of growth and development, dietary advice) was neglected in 14% of the children with spina bifida [7]. Children with developmental disabilities were reported not to have equal access to immunizations [6].

Compliance with immunization schedules and receipt of dental care may be two important indicators of preventive health care maintenance. While active immunization is an effective tool in the prevention of infectious disease, it does not seem to be a universal practice as evidenced by current morbidity and mortality from such preventable infections as measles, rubella, and pertussis [2, 5]. A child with a hemodynamically significant heart defect may risk further serious compromise from potentially preventable infectious disease. Dental health, like immunizations, is a desirable component of child health maintenance. Even though dental disease has been shown to be almost univer-

Address reprint requests to: Karen Uzark, RN, MS, Section of Pediatric Cardiology, Box 66, Room F1123, C.S. Mott Children's Hospital, University of Michigan, Ann Arbor, MI 48109, USA.

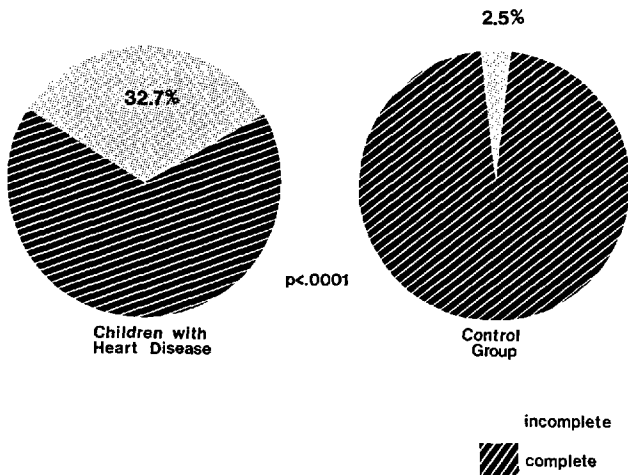


Fig. 1. Immunization status of children (all ages) with heart disease and the control group without heart disease.

Table 1. Characteristics of population surveyed with heart disease and control group without known heart disease or chronic illness

| | With heart disease <i>n</i> = 215 | Without heart disease <i>n</i> = 284 |
|-----------|--------------------------------------|---|
| Sex | | |
| Females | 109 | 133 |
| Males | 106 | 151 |
| Age (yrs) | | |
| Range | 0.2–17.0 | 0.2–14.0 |
| Mean | 5.2 | 3.7 |

sal, surveys indicate that 30% of the population under 17 years of age in this country have never made a visit to the dentist [3, 4]. In children with heart disease, however, the increased susceptibility to infective endocarditis places the child's health in greater jeopardy when dental or periodontal disease is not controlled. The purpose of this study was to evaluate the current preventive health care of children with heart disease, as measured by immunization status and the utilization of dental services.

Materials and Methods

During a two-year period, parents of children with heart disease were selected at random to complete a questionnaire while attending the pediatric cardiology outpatient clinic at our institution. Parents of children in a control group completed the same questionnaire when seen at three different physicians' offices within the geographic area served by the cardiology clinic. Informed consent was obtained from all parents. A total of 499 children were included in the survey (Table 1). There were 215 children with heart disease (mean age 5.2 years, range 0.2–17.0 years) and 284 control children without known heart disease or

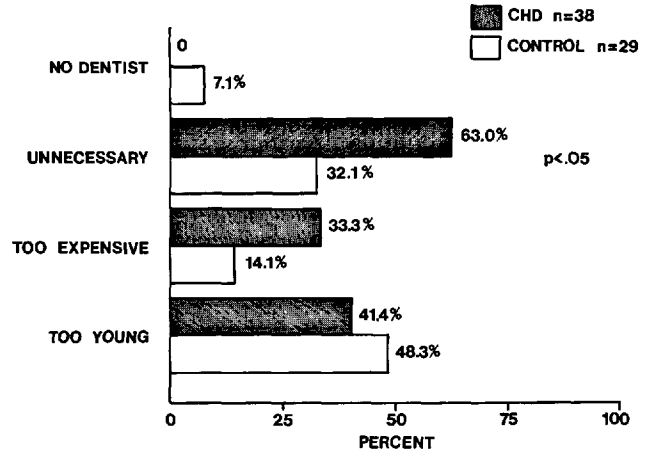


Fig. 2. This figure illustrates the reasons for failure to receive dental care cited by the parents of children who had not utilized dental services within the past year.

other chronic illness (mean age 3.7 years, range 0.2–14.0 years). Among the children with heart disease, cardiac diagnoses varied greatly, with ventricular septal defect being the most common (42 of 215, 18.5%). More than 30% of the patients in this group (65 of 215) had previously undergone corrective or palliative cardiac surgery. Hemodynamically severe cardiac disease, defined as the presence of cyanosis or congestive heart failure, was present in 12% of the patients at the time of the survey.

The questionnaire consisted of two parts. The first inquired about the child's overall health care including immunizations and dental care. The second part was age specific and elicited information on the child's diet, development, activities, etc. Information obtained regarding availability of private medical insurance [10], type of health care provider, and frequency of well-child care visits per year to the primary physician was used as proxy measure of socioeconomic status.

Data compiled in Michigan Terminal System computer facilities were analyzed utilizing chi-square or group *t*-tests.

Results

The administration of immunizations was significantly neglected in children with heart disease on comparison with a control population (Fig. 1). Complete immunization status was defined using the criteria and age-specific schedule established by the American Academy of Pediatrics Committee on Infectious Disease [1]. Approximately one-third (32.7%) of the children with congenital heart disease had incomplete immunizations compared with only 2.5% of the control group ($P < 0.0001$). Incomplete immunization status was directly related to the severity of the cardiac disease ($\chi^2 = 18.5$, $P < 0.0005$).

Dental visits in children over 3 years of age were not statistically different between the groups. There was, however, poor utilization of preventive dental care services by the children with congenital heart

Table 2. Comparison of primary health care utilization characteristics and patterns

| | With heart disease <i>n</i> = 215 | Without heart disease <i>n</i> = 284 | <i>P</i> value |
|---|--------------------------------------|---|----------------|
| Health care provider | | | |
| Pediatrician | 155 (72.1%) | 234 (82.4%) | NS |
| General practitioner | 60 (27.9%) | 50 (17.6%) | |
| Frequency of visits (no. per year) | 3.25 | 3.27 | NS |
| Method of payment | | | |
| Private insurance | 184 | 233 | 0.0001 |
| Medicaid | 28 | 16 | |
| Division of services to crippled children | 45 | 2 | 0.0001 |
| Total third-party resources | 257 | 251 | |
| Parent | 98 (45.6%) | 215 (76.3%) | 0.0001 |
| Satisfaction with health care | | | |
| Good or fair | 212 (98.6%) | 276 (97.2%) | NS |
| Poor care | 1 (0.5%) | 5 (1.8%) | |

disease. Preventive dental service within the past year was not received by 29% (38 of 131) of the children over 3 years of age with heart disease. Among the children without known heart disease, 23.4% (26 of 124) also had not utilized preventive dental service. Unlike immunizations, however, neglect of dental care was *not* related to the severity of the cardiac disease ($\chi^2 = 0.554$, $0.1 < P < 0.5$). The reasons parents reported for the lack of dental care were of interest (Fig. 2). Among children over 3 years of age with heart disease who had not utilized dental services, 63% (24 of 38) of the parents indicated they did not feel a dental visit was necessary, compared with only 32.1% (9 of 28) of the control group ($P < 0.05$). Despite the age of this group of children, 41.4% of those with heart disease who had not had dental care felt that the child was too young to be seen by a dentist. Cost was another reason cited, though less frequently, by both groups who had not received dental care.

Comparison of the children with heart disease to the control group did not disclose any significant differences with respect to the frequency of visits to the primary physician for routine well-child care or the type of physician provider utilized (Table 2). The proportions of children with heart disease examined by pediatricians (72.1%) and by general practitioners (27.9%) were similar to controls (82.4% to 17.6%, respectively). The frequency of visits to these physicians for well-child care was virtually identical in children with heart disease (3.25 visits/year) and children without heart disease (3.27 visits/year), suggesting that children in both groups had equal opportunity to be immunized. The percentage of families with private insurance coverage was similar among the groups although a slight-

ly higher percentage with heart disease received Medicaid.

To explain the substantial preventive health care deficits in children with heart disease despite the similar frequency of physician visits, data regarding parental dissatisfaction with health care and method of payment for medical services were further examined. There were no substantial differences between the groups in the described satisfaction with the child's total health care. Less than 2% of the parents described poor health care for their child, 0.5% of the group with heart disease and 1.8% of the control group. When the relationship of financial resources to receipt of primary care was explored, results indicated that parents of children with heart disease were more likely to receive support from third-party sources with their eligibility for crippled-children services providing an additional resource. The child's medical expenses were paid for completely or partially by 45.6% of the parents of children with heart disease compared with 76.3% of the control group ($P < 0.0001$, Table 2).

Discussion

The greater incidence of incomplete immunizations and inadequate utilization of dental services in infants and children with congenital heart disease than that found in control children in our study suggests deficient primary health care in this population. While there are no specific contraindications and perhaps an increased need for immunizations in the presence of a heart defect, children with heart disease were less likely to have up-to-date immuni-

zations. The increased vulnerability to respiratory infections and poor nutritional status in some children with congenital heart disease require a more meticulous adherence to routine immunizations and some special inoculations when an epidemic is expected [12, 15]. In our study, the reasons for incomplete immunization were not readily apparent and were not directly solicited by the questionnaire. Failure to receive complete immunizations did not seem related to availability of medical care, the family's financial investment in medical expenses, or the parent's dissatisfaction with their child's health care. It has been postulated that the lack of immunizations in children who are not "normal" may be due to fear of producing a seizure or febrile reaction [6]. These reactions are infrequent, but could be perceived by the health practitioner and/or parent as a significant stress to a child already medically compromised. This "lack of involvement" by primary physicians also appeared to be acceptable to many parents surveyed by Kanthor et al. [7].

Despite the increased risk to the development of infective endocarditis and greater frequency of dental caries and periodontal disease [12, 13] in children with congenital heart disease, there was no increase in utilization of dental services in this population. Cost, fear, family problems, lack of knowledge, and distrust of the dentist have been cited in the literature as barriers to dental treatment [3]. However, a study by Okada and Wan [9] found generally low dental utilization levels among persons covered by Medicaid. Financial barriers were also not implicated by Lawson [8], who noted that, although less-educated families pay a lower percentage of the total charge for their children's dental visits because of government assistance programs, their children receive less preventive care than children from more educated households.

The reason most often cited for the absence of dental care by the parents of children with heart disease was lack of recognition of their child's need for dental services. This suggests inadequate parent education regarding the preventive health care needs of children with congenital heart disease. While parents may be provided with comprehensive information regarding their child's cardiac disease and its consequences, appropriate information about their child's health may be omitted. Parents are frequently counseled regarding their child's need for antibiotic prophylaxis for the prevention of infective endocarditis during dental procedures, but information concerning the importance of dental disease prevention may be omitted. The child's cardiac disease is such an overwhelming priority for the parent, the pediatric cardiologist, and the pri-

mary health care provider, that other equally important health care needs may be neglected or ignored. The reported gaps in health care may be related to the assumption by specialists that the primary physician will take responsibility for certain aspects of care and a similar but reverse assumption by the primary physician [7]. As suggested by Kanthor et al. [7], to provide complete and effective health care to children with complex, chronic disabilities, physicians and parents must clearly understand as early as possible who is to be responsible for each aspect of the child's care.

To improve preventive health care in children with cardiac disease, we recommend:

- 1) Written communication by pediatric cardiologist to primary physician clearly supporting the need for immunizations and good dental care.
- 2) Routine screening by the clinic or office nurse regarding immunization status and receipt of dental care.
- 3) Availability of immunizations in the pediatric cardiology clinic or office for children without a primary physician.
- 4) Availability and distribution of health education literature to parents promoting the child's need for preventive health care.
- 5) Increasing participation of nursing personnel in the education of families regarding health needs.
- 6) If feasible, screening by a dental hygienist of all children over 3 years of age attending the pediatric cardiology clinic. Children with evidence of dental disease should be promptly referred to a dental clinic if a family dentist is not available.

We conclude that some aspects of primary health care, such as the administration of immunizations and adequate dental care may be neglected in children with heart disease, and that insufficient education and emphasis on preventive health care may be the primary reason for these deficiencies. Increased educational efforts directed at parents and their children with heart disease, as well as for health professionals, regarding primary preventive health care needs of children with heart disease may remedy the insufficient care. Further studies are needed to identify any other primary health care deficits, their possible adverse effects on prognosis, and their appropriate management in this population.

Acknowledgment. We are indebted to Drs. Allen Dumont, Steven Manikas, and James W. Collins for their support in allowing us to survey their patients.

References

1. American Academy of Pediatrics Committee on Infectious Disease (1982) 1982 redbook. American Academy of Pediatrics, Evanston, IL, p 7

2. Backes CR (1981) Immunization practices and controversies 1981: Part 1—the “big seven” vaccines. *Am Osteopath Assoc* 80:595–603
3. Douglass CW, Coll DO (1979) Utilization of dental services in the United States. *J Dent Ed* 43:223–235
4. . . . Health United States 1979—Washington DC: Government Printing Office (DHEW publication no. 80-1232)
5. Isbister JL (1978) MD's must use initiative to assure all children are immunized. *Mich Med* 77:622–623
6. Juntti MJ (1977) Accessibility of immunizations for children with developmental disabilities in public clinics. *Ment Retard* 15:42
7. Kanthor H, Pless B, Satterwhite B, Myers G (1974) Areas of responsibility in the health care of multiply handicapped children. *Pediatrics* 54:779
8. Lawson WR (1980) Children and dental care: charge and probability of a visit by individual characteristics. *J Am Dent Assoc* 101:32–37
9. Okada LM, Wan TT (1979) Factors associated with increased dental care utilization in five urban, low income areas. *AM J Public Health* 69:1001–1007
10. Palfrey JS, Levy JC, Gilbert KL (1980) Use of primary care facilities by patients attending specialty clinics. *Pediatrics* 65:567
11. Pless B, Satterwhite B, Van Vechten D (1976) Chronic illness in childhood. *Pediatrics* 58:37
12. Rosenthal A, Fyler DC (1976) General principles in the treatment of congenital heart disease. In: Gellis SS, Kagan B (eds) *Current Pediatric Therapy* 7. Saunders, Philadelphia, p 136
13. Rosenthal A, Nadas AS (1977) Infective endocarditis in infancy and childhood. In: Rahimtoola SH (ed) *Infective Endocarditis*. Grune and Stratton, New York, pp 149–178
14. Rowland TW (1979) The pediatrician and congenital heart disease. *Pediatrics* 64:180–185
15. US Public Health Service (1978) Influenza vaccine recommendations. Centers for Disease Control *Morbidity and Mortality Weekly Report* 27:285 and 351