

ORIGINAL ARTICLES

USE OF VIDEOTAPE TO PROMOTE PARENTING OF INFANTS WITH SERIOUS CONGENITAL HEART DEFECTS

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ABSTRACT

Parents of infants with serious congenital heart defects have misconceptions and negative feelings which may threaten their ability to provide optimal care for their infant. In an effort to increase knowledge and promote a more positive, less anxious attitude among these parents, a videotape entitled 'Your Baby with a Congenital Heart Defect' was developed and evaluated. Forty-three parents of thirty infants who required cardiac catheterization in the first 8 weeks of life were randomly assigned to experimental ($N = 23$) or control ($N = 20$) groups. In the videotape viewed by the experimental parents, three families of cardiac infants related common feelings, problems and infant care experiences. The control group viewed a videotape describing the cardiac anatomy and functional changes associated with defects. Post-videotape questionnaires demonstrated significantly greater knowledge of the infant's behavior and needs in the experimental parents compared to controls ($P < 0.0001$). In comparison to the control group, parents in the experimental group had fewer misconceptions related to the danger of cyanosis ($P < 0.001$), the risk of sudden death ($P < 0.01$) and vulnerability to infections ($P < 0.001$) after viewing the videotape. The experimental group parents also tended to report less negative feelings toward the infant ($P = 0.02$). We conclude that viewing the videotape on infant care improved parental attitude and their understanding of the behavior and needs of the neonate with congenital heart disease.

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INTRODUCTION

The diagnosis of significant congenital heart disease is often made soon after birth. It is a traumatic emotional experience for parents that can have lasting deleterious effects on the child and family. The initial reactions of the family to their child's defect have been described as acute fear and anxiety, immediate shock followed by mourning the loss of a healthy child, anger or resentment and guilt over causing the child's heart defect [1]. The infant with a heart defect is a complete distortion of the anticipated or planned-for child. The parents mourn the loss of the expected 'perfect' infant, a process that may take several months, before they can become fully attached to the living defective infant [2]. Because the exact cause of the child's defect is usually not known, parents tend to fantasize about the etiology [3]. Furthermore, they often do not appreciate the differences between congenital and acquired heart disease. Bergman and Stamm found that two-thirds of the parents interviewed believed the child had the same type of heart disease encountered in adults [4]. Related to this misconception, parents fear the child's sudden death from a 'heart attack' [5].

Parental reactions to the diagnosis may also interfere with their ability to cooperate with the therapeutic regimen [6] and even threaten their ability to provide satisfactory physical care to the infant. The loss of self-esteem that may accompany having produced an infant with a cardiac defect hinders the attainment of the mothering role [6,7]. Development of maternal role is influenced by the characteristics of the baby such as physical appearance and behavior. The infant with heart disease may be cyanotic, small for gestational age, tire easily or feed poorly. The infant's expected weight gain or motor development may not be achieved at a level sufficient to promote parental self-esteem [8]. Also, when the infant differs so greatly from expectations, parents may miscalculate what the baby needs. Misconceptions and anxieties may make it difficult for parents to make good judgements and to adequately care for the child.

In an effort to increase knowledge and promote a more positive, less anxious attitude among our parents of neonates with serious congenital heart disease, a videotape entitled 'Your Baby with a Congenital Heart Defect' was developed and utilized. In this videotape, three families of cardiac infants relate common feelings, problems, and infant care experiences from their home settings. The purpose of this study was to evaluate the effect of this videotape on parents' (a) knowledge (or misconceptions) related to the infant's behavior and needs, and (b) attitudes toward their infant with congenital heart disease.

METHODS

Subjects

During the period from July 1982 to August 1983, parents of infants who required cardiac catheterization in the first 8 weeks of life were selected for study. Parents of infants with multiple congenital anomalies or severe cardiac defects not amenable to surgical repair (e.g. hypoplastic left heart) were excluded. Forty-three parents of 30 infants participated in the study (Table I). There were 9 females and 21 male infants. More than three-fourths (83%) of the infants were less than 1 week of age when diagnostic cardiac catheterization was performed. The most common cardiac diagnoses were transposition of the great arteries, pulmonary atresia and complex coarctation of the aorta.

The parents of these infants were randomly assigned to a control ($N = 20$) or an experimental ($N = 23$) group. Fifteen mothers participated in each group. Thirteen fathers were available to participate, 8 from the experimental group and 5 from the control group. Four mothers were single parents. No available parent refused to participate in the study. Comparison of parental demographic variables between groups revealed no statistically significant differences at the $P < 0.05$ level as tested by analysis of variance (Table II). Mean age of parents in the control group was 24.2 years (range, 17–40) and in the experimental group 26.0 years (range, 18–36). Almost a third of the parents in both groups had never completed high school. There were no differences between the groups with regard to the number of other living children at home. Forty-three percent of the infants with congenital heart disease were firstborn to these parents.

TABLE I
CHARACTERISTICS OF INFANTS

	$N = 30$
Age at catheterization (days)	
(Range)	0.5–59
(Mean)	6.4
Sex	
Females	9 (30.0%)
Males	21 (70.0%)
Primary diagnoses	
Transposition of the great arteries	13
Complex coarctation	5
Pulmonary atresia	3
Critical pulmonic stenosis	3
Tricuspid atresia	3
Total anomalous pulmonary venous return	2
Severe aortic stenosis	1

TABLE II

PARENTAL DEMOGRAPHIC VARIABLES

	Control	Experimental
Relationship		
Mother	15 (75.0%)	15 (65.2%)
Father	5 (25.0%)	8 (34.8%)
Parental age (years):		
Mean	24.2 ± 6.5	26.0 ± 4.9
Range	17–40	18–36
Parental education		
<High School	6 (30.0%)	7 (30.4%)
≥High School	14 (70.0%)	16 (69.6%)
Number of other children at home		
Mean	0.65	1.0
Range	0–3	0–3

Procedures

Prior to the infant's discharge from the hospital, parents in the experimental group viewed the videotape 'Your Baby With a Congenital Heart Defect' [9]. Much of the content selected for this videotape was based on parental misconceptions and feelings which are commonly observed among families in our experience and which are identified in the literature. Topics discussed included parental feelings of fear and guilt and their responses to the infant's crying, cyanosis, feeding problems, developmental needs and health care. Parents in the control group viewed 'Congenital Heart Defects', [10] a videotape describing the cardiac anatomy and functional changes associated with defects. When both parents were available, they viewed the same tape together to avoid the possible confounding influences of their communication with each other about a specific videotape's content. Both groups received the usual verbal information provided to the family by the medical and nursing staff. Information provided was variable and largely related to the child's specific defect, therapeutic plan and prognosis. Staff were blinded with regard to parents' study group assignment.

After viewing a videotape, both groups completed a questionnaire consisting of 10 true or false knowledge items. A total knowledge score was determined and individual knowledge items were subjected to chi-square analysis. An additional seven items elicited information regarding the parent's feeling or attitude toward the infant with heart disease, such as 'my baby is very abnormal', 'my baby is a great worry' or 'my baby requires constant attention'. These items were scaled from 1 through 5, with 1 being the most positive response and 5 being the most negative response. An overall 'attitude' score was obtained for each parent by averaging across the

seven items, and comparisons were made between groups by analysis of variance. After completing the questionnaire (Appendix), parents were given the opportunity to discuss their feelings and ask questions.

RESULTS

Post videotape questionnaires revealed significantly greater knowledge of the infant's behavior and needs in the experimental parents ($M = 9.74$) compared to controls ($M = 7.25$, $P = 0.0001$). (Fig. 1). Moreover, an item by item analysis confirmed several common misconceptions (Table III). Eighty percent of the control group parents believed that cyanosis was very harmful to their infant. No parent in the experimental group reported this belief. More control (40%) than experimental (4.3%) parents felt that a problem related to the heart defect would occur suddenly and that their infant therefore needed constant watching and checking. Among the control parents, 70% also viewed their infant as unable to tolerate a common cold or virus versus 13% in the experimental group. These differences between the experimental and control groups were found (by chi-square analysis) to be statistically significant (Table III).

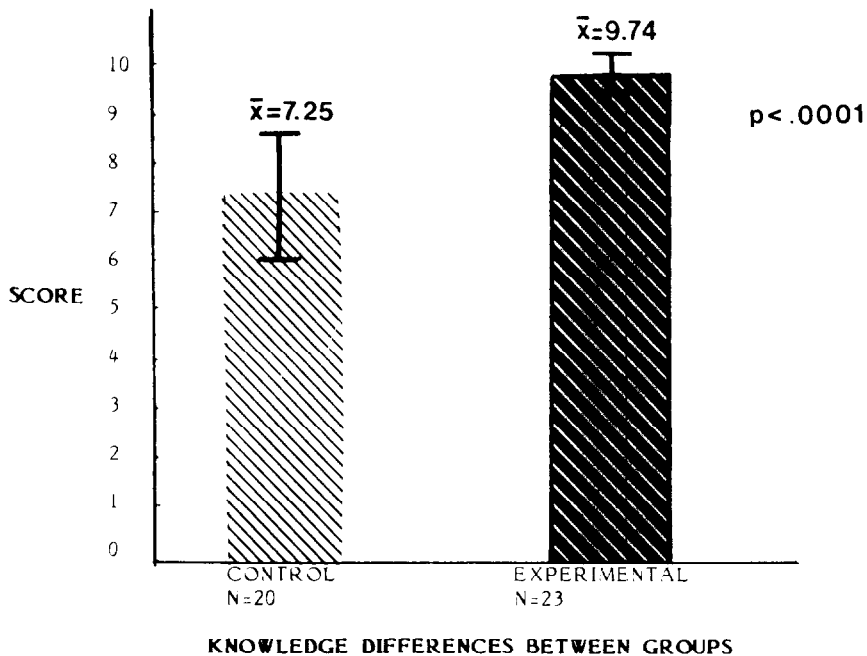


Fig. 1. This figure illustrates the increased knowledge of parents in the experimental group.

DISCUSSION

Parents of infants with serious congenital heart defects have many misconceptions regarding their infant's behavior and needs which may hinder attainment of their parenting role. Various negative reactions, feelings of guilt, fear and the mourning process, may interfere with the parent's ability to absorb or comprehend information offered by the physician or nurse. Parents are able to assimilate only the information about their child for which they are emotionally prepared and they are often apt to exaggerate and misinterpret the physician's explanations [5]. Furthermore, the actual cardiac pathology may assume such overwhelming importance for physician, nurse and parent that information regarding 'normal' infant behavior and needs is neglected.

Our study findings indicate that viewing the videotape 'Your Baby with a Congenital Heart Defect' increases parental knowledge of their infant's behavior and needs. The videotape successfully transmitted information about infant behavior which may not be included in the usual course of discussions with health professionals. This information may not be recognized as needed, especially if the parents have other children. The videotape also affirms the infant's normal attributes and behaviors and stresses the importance of facilitating the infant's development to potential by discouraging the parents' tendencies toward restricting activity.

Parental misconceptions about the danger of cyanosis or risk of sudden death and the perceived need to restrict their infant's exertion (crying or activity) are understandable. Confusion develops as a result of the parent's perpetual exposure to the dangers of heart disease in adults in contrast to the relatively rare experience with congenital heart disease. Since many parents are unable to verbalize this fear, the health care providers must often initiate discussion of activity and point out the harmful effects of unnecessary restrictions and overindulgence.

Perhaps the greatest effect of the videotape on parental knowledge and attitude is derived vicariously through the emotional support which comes from viewing other parents who have shared this traumatic emotional experience. Another parent can often provide unequalled support to a new parent of an infant with a similar problem, and such empathetic information seems to be readily received and valued [11,12]. However, such 'live modeling' can be time consuming and problematic as well. It has been suggested that videotape can be used to reduce anxiety via a role modeling effect [13,14]. A systematic comparison of different techniques for instructing parents in child rearing practices found videotape modeling to be superior to written or verbal presentation [15,16]. In our videotape, parents describe common feelings, acknowledging the emotional stress experienced due to the diagnosis of a congenital heart defect. This may help new parents express their feelings and manage their stress. Parents may be able to assimilate information previously communicated by health professionals through videotape exposure to other parents.

Greater attention to the emotional needs of these parents seems to be

critical at the time when the diagnosis is made, a decisive time in the ensuing chain of reactions [3,5]. For this reason, this study intervention was limited to parents of neonates. However these parents may be mourning and/or may not yet recognize many future needs particularly if they have not assumed the responsibility for most parenting duties while the infant was hospitalized. Optimal timing of this videotape presentation is a relevant issue to assess in the future.

The anxious responses of these parents, especially overprotection and viewing the child in a negative way, can be a significant source of psychological problems in the child with congenital heart disease. Previous studies have suggested that behavioral disorders and poor adjustment of the child are more highly related to maternal attitudes, (anxiety, protectiveness and overindulgence) than to the severity of the heart disease [5,7]. In a study of young adults who had been asymptomatic for almost 7 years from congenital heart disease, Garson et al. also found that psychopathology derives not so much from the direct effects of the disease or the severity of the physical symptomatology, as from life experiences associated with the diagnostic label of congenital heart disease [18]. Degree of psychopathology appeared to be related to the disparity between how the child perceives his illness and how others view his disease. Parents of infants with congenital heart disease may frequently have negative feelings about their baby. While our study did not evaluate the potentially harmful, long-term psychological impact of negative parental attitudes toward the child with congenital heart disease, it is hoped that the videotape will help to prevent or reduce these untoward consequences to the child. Further study of the long-term effect of this educational intervention may be warranted.

In summary, this study confirms that parents have negative feelings about their infant with congenital heart disease as well as various misconceptions especially with regard to cyanosis, sudden death and vulnerability to infection. We conclude that the videotape 'Your Baby with a Congenital Heart Defect' increases relevant knowledge and promotes a positive attitude among these parents which, in turn, should help them to direct their energies toward caring optimally and realistically for their child. The videotape is available through the University of Michigan Medical Media Library* and can be used to supplement oral and written communication currently used by health professionals.

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