

THE YOUNG ADULT'S PERCEPTIONS OF THE EFFECT OF CONGENITAL HEART DISEASE ON HIS LIFE STYLE

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INTRODUCTION

Heart defects which were once completely untreatable and caused death in infancy are now being successfully corrected and many more individuals with these conditions are reaching adulthood. Some studies have investigated the effects of congenital heart disease on the child and his family. However, very little research has been done regarding the long-term psychological effects of congenital heart disease. By exploring how young adults perceive their condition and its effect on their lives, this investigator hoped to identify concerns and health problems encountered by these individuals both during childhood and as they adjust to the responsibilities of adult life.

THEORETICAL FRAMEWORK

This study was based upon three concepts regarding man, as described by Martha Rogers (1970). The overall concept is that "man is a unified whole". The impact of congenital heart disease on the individual would not be limited to the physiological alteration in the heart's functioning but would affect the whole individual. The second concept specific to this study is that man is constantly interchanging materials and energy with his environment. This constant interchange influences the individual's perception, his behavior and his total life style. Therefore the life style, perceptions, and responses of a young adult with congenital heart disease would be influenced by all events and interactions that occurred during his lifetime. The third concept, life process, describes development as a complex process evolving from man's interaction with the environment. If an individual's development during childhood was threatened by illness, hospitalization, surgery or abnormal relationships with his family and peers, his development as a young adult might be impaired.

THE LITERATURE

There is a paucity of research that has been done to investigate the long term psychosocial effects of congenital heart disease. The only available publication directly concerned with young adults investigated the quality of life of 102 adults with congenital heart disease and rheumatic fever (Ferencz, 1974). Though the main focus of this study was employment

and vocational choice in 23 to 27 year old men, several questions dealt with family and personal life. The results showed that familial conflict related to the heart disease occurred with 22 percent of the subjects. Thirty-two percent of the total sample were worried about their children having heart disease. This finding was related more to the individual's experience with traumatic procedures, such as surgery, rather than to the severity of his disease. Thirty-six percent of the subjects described themselves as heavy drinkers, while 45 percent were smokers. A history of heart disease made it difficult for patients to obtain insurance and employment, even if their hearts were normal or mildly diseased at the time. Job discrimination was experienced by 57 percent of the patients with moderate or severe heart disease. From the results of her study, Ferencz concluded that "the impact of the illness changed with successive developmental stages and often became quite negative as adult life was entered" (Ferencz: 73).

PURPOSE OF THE STUDY

The purpose of this study was to identify the young adult's reported perceptions of his past and present life styles, and the effect of congenital heart disease on his way of life.

RESEARCH METHOD

This investigation was an exploratory study because of the paucity of research done in the area of psychosocial adjustment of young adults with congenital heart disease. The method of data collection was a semi-structured interview, using an interview schedule developed by the investigator. The questions sought information regarding the respondent's perceptions of his past and present life style and experiences related to his heart disease. Open-ended questions were used in order to provide the individual with an opportunity to discuss freely his perceptions, feelings and thoughts. The interview was content-analyzed to identify the sample population's perceptions of personal experiences and of the effect of congenital disease on these experiences.

SETTING

Each subject was initially contacted at the congenital heart disease clinic of a large metropolitan general hospital at the time of his regularly scheduled visit. He was then interviewed in his home by the investigator as soon as possible after the initial contact at the clinic. When a spouse or a parent remained during the interview he/she was not asked to leave. Six interviews were conducted with the respondent's spouse in attendance and two other respondents each had one parent present during the interview.

SAMPLE

The final sample of 25 patients consisted of 14 males and 11 females. They ranged in age from 18 to 30 years. The average age was 24 years. Thirteen respondents were married; none were separated, widowed or divorced.

The respondents had a variety of congenital heart defects. Nine had diseases classified as being communications between the systemic and pulmonary circulation and sixteen had valvular and vascular lesions. Fifteen respondents had heart surgery. Two had heart surgery twice. Age at the time of surgery ranged from four days to 25 years. Eighteen respondents had cardiac catheterization; seven of these had two catheterizations, and one had three catheterizations.

Many respondents experienced multiple hospitalizations for a variety of reasons other than their heart condition, including infections, appendectomy, as well as many others. Only three respondents were never hospitalized and two others were never hospitalized for reasons associated with their cardiac condition.

DISCUSSION OF THE FINDINGS

Past Lifestyle

Perceptions of Condition and Hospitalization

The respondents' ages when they first became aware they had a heart condition ranged from four to sixteen years. Awareness of the cardiac condition seemed to be related to the time when surgery or catheterization occurred. Sixty-four percent of the respondents had surgery and/or cardiac catheterization within one year of the age when they first became aware of the cardiac condition. These traumatic experiences could have made such an impression that these individuals recall that time as being their first realization of the condition.

Seventy-two percent of the respondents lacked understanding of their condition during childhood. If explanations were offered to these individuals they were not understood or were misinterpreted. This finding is consistent with some of the research done regarding the child's perception of his body. Gellert (1962) interviewed 96 children, four to sixteen years of age, to identify how much knowledge they had about their body parts and their functions. Though most of the children had a fairly accurate conception of the heart's location and size, they had limited understanding of its function. Chapman (1977) interviewed 16 children, seven to twelve years of age, with congenital heart disease. She found that they had limited knowledge about their cardio-vascular system and particularly their cardiac defects.

Forty-four percent of the respondents stated they had negative feelings about their condition during childhood. They felt they were different from other children or feared surgery and a "decreased life span". All of the eleven respondents who expressed negative feelings about having a heart condition had had cardiac catheterization and nine had had surgery.

Sixty-four percent of the respondents remembered negative physical or psychosocial experiences related to their condition such as physical discomfort from injections, suture removal, sore arms after surgery or catheterization, and activity limitations. One man stated, "I had trouble relating to my peer group because of that. Not being able to participate in sports and things like that."

Three of the 15 respondents who had surgery could not remember anything about being in hospital for surgery. Eleven (92%) of the 12 respondents who remembered having surgery related a variety of unpleasant memories surrounding that event. No one aspect stood out as being most unpleasant. All eleven related memories of pain and physical discomfort such as suctioning, intravenous, removal of sutures and pacing wires and five of these recalled their fears of surgery and hospitalization. All but one respondent who remembered surgery thought that it was crucial for their well-being.

Cardiac catheterization was one of the most traumatic experiences associated with having congenital heart disease. Of the 18 respondents who had catheterization, 13 (93%) recalled unpleasant memories. (See Table I). Generally, descriptions of catheterization and the discomfort experienced were more vivid than those of surgery. Some comments made by the respondents follow:

I will never go through that again — ever... I think the part that bothered me the most is that I wasn't prepared mentally. They didn't explain anything... I was just scared. I was really scared... it was terrible. It made my heart flutter... I thought I was going to die...

Ferencz (1974) in her study of young adult cardiac patients, found that 37 percent of those who had cardiac catheterization chose it as the worst experience associated with their condition.

Though most respondents realized the significance of having catheterization, it was not viewed as essential to survival as surgery. Consequently, the perception of surgery might be less negative owing to its potentially positive effects on the individual as a whole.

TABLE I
TYPE AND FREQUENCY OF DISCOMFORTS
EXPERIENCED DURING CARDIAC CATHETERIZATION

Discomfort Experienced	Number of Respondents
Heat from angiogram	5
Sore arm or leg	5
Tube insertion	4
Fear of the procedure	2
Fear of death during catheterization	2
Nausea afterwards	2
Heart Fluttering	1
No discomfort	1
TOTAL	22

N = 14 Some respondents recalled more than one discomfort.

Perception of Relationships with Family and Peers

Fourteen respondents (58%) felt their parents treated them differently from their siblings. (One respondent did not have siblings). Eight indicated that their parents were overprotective (i.e. they restricted the child's physical activities or play). Six respondents felt they were pampered (i.e. given special attention). Similar findings have been previously documented by several investigators. Glaser *et al* (1964) found parents were reluctant to discipline the child with a cardiac condition. Linde *et al* (1966) found that children with cardiac conditions were more pampered and protected by their mothers than were a group of normal children. Overprotectiveness often occurs regardless of the severity of the cardiac condition. Bergman and Stamm (1967) studied a group of 75 children who had been labelled as having heart disease but had no evidence of it at the time of the study. Forty percent of the children had been restricted in some way.

Parental pampering and overprotectiveness could have affected the respondent's feelings about his condition. Of the 11 respondents who stated they had negative feelings about their condition during childhood, nine reported they were treated differently from their siblings. These individuals' feelings about their condition could be an indication that they were generally unhappy or discontent. Linde *et al* (1966) found that pampered children with heart disease tended to be frustrated and unhappy while normal children adjusted better to some pampering.

Nine respondents (36%) felt their condition affected their relationships with friends. They could not do things their friends did or were "treated differently" by them.

Most respondents stated they were reluctant to discuss their condition during childhood. Thirteen respondents (52%) did not openly discuss their condition with anyone. Only three indicated they discussed it outside of their families. One individual did not tell people because "I felt somehow weak and wouldn't tell anybody". Another woman commented "I guess it wasn't a topic you'd discuss. It was just there."

Perception of Activity during Childhood

Each respondent's level of activity during childhood was assessed. Information reported regarding participation in activities and sports, and the individual's limitations and restrictions were considered in determining levels of activity. Several references were used as guidelines for establishing criteria (American Heart Association, 1971; Larson, 1974; Larson and Michelman, 1973).

According to the system used for classifying activity, generally the respondents in this sample do not appear to have been overly restricted. Seventy-six percent reported they were at least moderately active during most of their childhood.

Generally, those with higher levels of activity appeared to be more satisfied with their activity. Five of the six who had low or sedentary activity levels wanted to be more active. And some who reported moderate or high levels of activity wanted to take part in more strenuous or competitive sports.

One-half of the respondents who had siblings reported their level of activity was lower than their siblings because of restrictions or limitations resulting from their condition. Thirty-six percent indicated that their level of activity was lower than both siblings and friends. Of these, fifty-five percent were in the sedentary or low activity group.

All respondents who reported high levels of activity or whose activity was lower than siblings or peers indicated that limitations or restrictions created problems, or they wanted to be more active but could not.

The impact of activity restriction must be viewed in relation to the individual's interests and his perception of the importance of activity. As one might expect, some respondents lacked interest in sports which accounted for them not being as active as they might have been. It is possible that their lack of interest could be related to the cardiac condition, but determining such a relationship was beyond the scope of this study. Within the general population, there are many children with no physical ailments who do not participate regularly in vigorous activity. A study

comparing activity of a control group with a group of children with congenital heart disease would be valuable in determining if children with cardiac defects tend to be less interested in sports and vigorous activity.

Perception of Education and Related Experiences

Table 2 shows the highest level of education achieved by the respondents. Seventeen respondents (68%) had not completed grade 12. The educational attainment of the sample was compared to that of the Ontario population. Of the Ontario population, aged 20-34 years, 61.76 percent had completed at least grades 11 to 13, including those who completed university degrees (Census of Canada 1971). Forty-eight percent of the sample in this study had completed at least grades 11 to 13.

The overall low level of education of the respondents could reflect the socioeconomic group attending the clinic used for data collection. The clinic might tend to cater to individuals who belong to low and average socioeconomic groups. Individuals who are more highly educated and possibly of a higher socioeconomic group might tend to make private visits to the cardiologist, rather than attend the clinic.

Having congenital heart disease directly affected the education or career plans of only three respondents. However, it did have a negative effect on school progress of almost one-half of the sample. Difficulties, such as missing grades and poor marks, could have indirectly influenced the individual's perception of the value of staying in school and of continuing his education. Lack of achievement could lead to feelings of inferiority and inadequacy, and ultimately contribute to dislike school and to leaving school early.

TABLE 2
HIGHEST EDUCATIONAL ATTAINMENT

Highest Educational Attainment	Number of Respondents
Less than grade 7	1
Completed grade 7 or 8	5
Attended high school	10
Presently in grade 12	1
Completed grade 12	4
Completed college	2
Attending university	1
Completed university	1
Total	25

N = 25

PRESENT LIFE STYLE

Perception of Condition

Seventeen respondents (68%) were experiencing symptoms related to their condition. Of these, ten had surgery. Table 3 shows the type and frequency of symptoms experienced.

When asked if their attitude toward their condition had changed since childhood, 14 respondents (56%) said it had. Three stated the only change was that they had greater understanding of their condition. Five respondents became more anxious and cautious because they felt their condition was a threat to present and future health and might possibly decrease their life span.

I'm more aware of it now... in those days I wouldn't think twice about what I was doing. I'd participate in most sports. Whereas today I just don't. I restrict myself. I think because I'm older now and I understand it more maybe. I understand the danger of it...

I have more respect for it now. The fear of dying is constantly there.

Six respondents became more positive and seemed to have learned to accept their condition. They realized that activity restriction was not necessary and that they could lead a normal life.

When you are a child it's hard to understand... You always say "why me"... right now there's nothing wrong with me. That's the way I take it.

I'm getting used to it. When I was a kid I thought I would die next year... But now that I've lived longer I think I'm going to live longer.

TABLE 3
SYMPTOMS EXPERIENCED

Symptoms	Number of Respondents
Short of breath, tired	9
Short of breath, palpitations	2
Short of breath, chest pain	1
Chest pain	2
Pain in incision	1
Palpitations, head throbbing	1
Hypertension, edema	1
Total	17

N = 17

Perception of Employment or Career

Twenty respondents (80%) were employed at the time of the interview. Of those who were not employed, none attributed their unemployment to having a heart condition. Most respondents were employed in occupations requiring some skill or where they were learning a trade or skill. However, none were employed in professional or administrative occupations. This finding reflects the generally low level of education of the respondents as reported in perceptions of past life style.

Only three respondents were refused jobs because of their heart condition. An additional nine respondents (36%) indicated that having a heart condition influenced employment in other ways. Of these, seven sought jobs that do not require a great deal of physical exertion, which could limit job opportunities for the unskilled worker.

Fifty-seven percent of those who had ever been permanently employed reported that they would have preferred another occupation. Of these, twenty-five percent did not pursue their preference because they were restricted by their heart condition. In a future study, the job satisfaction of a group of young adults with congenital heart diseases could be compared with that of a control group.

Reluctance to leave a job and get a more satisfying position might be due to fear that no one else will hire an individual with a cardiac condition. One-half of the respondents who had worked on a permanent basis did not tell their employers about their condition when they were hired.

Perception of Social and Physical Activity

The current level of activity was assessed for all respondents. The assessment was based upon occupational demands as well as participation in sports or other activities during leisure time. Several references were again used as guidelines for establishing criteria for classification (American Heart Association, 1971; Larson, 1974; Larson and Michelman, 1973). Sixty percent of the respondents were less than moderately active.

Each respondent's current level of activity was compared to his activity during childhood. The overall activity of the respondents was definitely lower than activity during childhood. For some individuals levels of activity would have been lower if work activity had not been considered. Those who had low activity levels during childhood tended to stay low and those with higher levels tended to become less active. Only five respondents who were moderate or highly active maintained those levels, and two respondents had higher levels as young adults than during childhood. This finding might not be peculiar to the population of individuals with congenital heart disease. It is perhaps a reflection of our society in general, where often activity decreases between twenty and thirty years of age.

Five respondents indicated that their condition influenced their choice of recreational activities. Four of the five were experiencing some cardiac symptoms at the time of the interview.

The activity of some individuals might have been indirectly influenced by their condition but they might not recognize or acknowledge that influence. Those who were more active as a child might have decreased activity as they got older because they felt it was detrimental to health. When younger they would be more likely to disregard any concern about activity because of peer influence.

Perception of Marriage and Relationships with Peers

Thirteen respondents, 7 females and 6 males, were married. Seven of the married respondents had children and five planned to have children. Two unmarried females (18% of the females in the sample) had children. This figure is considerably higher than Ontario statistics for the number of unmarried women with children. During the 1971 Census (Vol. 2, part 2) 0.2 percent of the female population in Ontario were the heads of their families and never married. None of the respondents' children had any known health problems.

All respondents were asked if they had ever had concerns about having children. Concerns about pregnancy and the health of their children were expressed by a total of 15 respondents. Females were mainly concerned about the effect of pregnancy on their heart condition. A total of six females feared they would have a difficult pregnancy or labor or that pregnancy would be too stressful for their heart. Nine respondents expressed concern that their children would have a heart defect.

Four unmarried respondents indicated that having a heart disease might have affected their ability to relate with the opposite sex. Four married respondents indicated that they felt their condition had some effect on relationships with their spouses.

The relatively small number of problems or concerns reported regarding peer and marital relationships would seem to indicate that this group had adjusted fairly well to marriage and peer relationships as young adults. Possibly respondents feel uncomfortable in admitting problems in this area, which could account for the small number of problems expressed. Of the thirteen who were married, six had their spouse with them during the interview. These individuals might be particularly reluctant to discuss marital problems with the spouse present. Spouses of the four individuals who related marital problems were not present during the interview.

Detrimental Health Behavior

The respondents were asked about behaviors that might be a risk to their health. Included in this aspect of the interview were questions about smoking, alcohol and drug consumption, and diet.

Fifty-two percent of the respondents smoked cigarettes at the time of the interview. Of the 12 who did not, 4 had smoked and stopped. The ages when they began smoking ranged from 9-20 years. Sixty-nine percent of those who smoked, smoked at least one half of a package per day.

Forty-six percent of those who smoked did so because they wanted to be accepted by their peers. All but one of these individuals started smoking between 9-16 years of age. Only one did not experience activity restrictions during childhood. This group could have turned to smoking to achieve acceptance from peers and to compensate for the loss they felt because they were not as physically active.

The detrimental effects of smoking are greater when combined with other risk factors such as obesity, decreased physical activity, and high cholesterol consumption. Though only three individuals who smoked considered themselves overweight, none of the smokers indicated that they tried to decrease their intake of high cholesterol foods.

When questioned about their diet, only two respondents indicated that they had tried to avoid foods high in cholesterol because it might be detrimental to health. Seven respondents considered themselves overweight and were aware of the need to keep their weight down, but only three had tried to decrease their weight. Six of these individuals had low activity levels and one was moderately active.

Both alcohol and drugs, especially if used in excess, are potentially harmful to various aspects of health. "Alcohol has been directly associated with hypertension, arteriosclerosis... and atrial fibrillation..." In addition "heavy drinkers may acquire cardio-myopathy" and be more likely to have heart attacks than moderate drinkers (Health and Welfare Canada, 1976). The respondents seemed to be aware of the hazards of using alcohol and drugs. Many of those who did not use drugs feared they would be harmful to their health.

Alcohol use of the respondents in this sample was compared with the latest Ontario statistics. Eighty-eight percent of the sample used alcohol. A 1976 survey of alcohol use in Ontario showed that 90.6 percent of those between 18 and 29 years of age used alcohol (Alcoholism and Drug Addiction Research Foundation 1976-1977). The overall percentage of users was 80.5. Therefore, the percentage of users in this sample is fairly consistent with Ontario statistics.

Similar statistics were not available for patterns of drug use in Ontario or Canada. Three individuals (12 percent of the sample) were drug users when interviewed.

Perception of Present Concerns

The respondents were asked to identify their main concerns about their present life. Most of the respondents' concerns about their present life

were typical for their stage of development. They were concerned about becoming established in an occupation and marriage and wanted an enjoyable life. Seven respondents mentioned health as an area of concern.

The respondents were then asked specifically if they had concerns about their health at present. A total of 16 individuals (including those mentioned in the preceding paragraph) voiced some concern about their health. Of these, eight were concerned only about maintaining health or keeping their bodies in good condition (i.e. exercising, not smoking or gaining weight). Eight (32%) related concerns specific to their heart condition such as fear that future surgery would be needed or that their heart condition would deteriorate. For four of these individuals, their heart was the main concern in their life at the time of the interview.

When asked about their concerns regarding their future health, an additional 5 respondents expressed concern that their condition would deteriorate or that they would have a shorter life expectancy.

Implications for Care

Because of the tendency of parents to overprotect and pamper the child with congenital heart disease, the development of a good-parent child relationship with open communication would seem to be essential. Such a relationship can be facilitated by providing the parents with clear explanations of the child's condition, his prognosis, treatment, and limitations. Parents could be encouraged to treat the child with congenital heart disease normally. It would seem that it would be important for them to be realistic about their child's activity and, when possible, allow him the same responsibilities as his siblings. Parents could be encouraged to discuss the child's condition, symptoms and limitations with him at a level appropriate to his age. Such openness will hopefully encourage the child to discuss his feelings, concerns and problems with his family.

A clinical nurse specialist or public health nurse could be responsible for providing continuity of care. Follow-up visits to the patient's home could reinforce and clarify information given during hospitalization or the clinic visit. In addition, seeing the patient and family in the home environment would enable the nurse to assess their adjustment, especially after initial diagnosis, and to identify actual or potential problems the family might have.

Many respondents remembered surgery and cardiac catheterization as being traumatic and fearful events. This finding reinforces the need for thorough preparation for hospitalization and intrusive procedures. Some preparation might be done more effectively by a nurse in the home before the individual is hospitalized. After surgery or cardiac catheterization, the patient can be encouraged to express negative feelings. Follow-up home visits would be helpful to determine whether the patient and family have adjusted after hospitalization and to identify potential problems.

As the individual with congenital heart disease reaches adolescence and young adulthood, explanations about his condition must be revised in accordance with his increased level of understanding. Health education is essential, particularly as it relates to risk factors that could contribute to further cardiovascular disease. The chances of having a child with congenital heart disease should be discussed with all individuals with congenital heart diseases. The risks of pregnancy should be explained to young females. In addition, information about family planning should be available. In order to be most effective, it would seem that these interventions should begin to be implemented during pre-adolescence.

Some individuals might not be aware of behaviors or aspects of their lifestyle that could be potentially harmful. They might need help in identifying aspects of their lifestyle that could be a threat to their well-being. The young adult's feelings and thoughts about his condition and its effect on his life should be explored. Step must be taken to alleviate unrealistic fears and concerns and to help him with any real limitations or problems his condition might be creating.

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RÉSUMÉ

Effets d'une cardiopathie congénitale sur le mode de vie: perceptions du jeune adulte

Le chercheur a interviewé 25 jeunes adultes âgés de 18 à 30 ans chez qui on avait posé un diagnostic de cardiopathie congénitale au cours de l'enfance. On a analysé la teneur de l'entrevue afin d'identifier chez les sujets les perceptions d'expériences personnelles et l'effet d'une cardiopathie congénitale sur ces expériences.

Les données recueillies révèlent que les sujets qui ont répondu au questionnaire ont connu différents problèmes et préoccupations au cours de leur vie. Dix-neuf d'entre eux ont fait état de préoccupations ou de problèmes au cours de l'enfance qui étaient liés à leur atteinte cardiaque. Les limites au niveau des activités et les relations interpersonnelles étaient à l'origine de leurs plus grands soucis. Vingt sujets ont connu à l'âge adulte certains problèmes et certaines inquiétudes à cause de leur cardiopathie. Les soucis mentionnés le plus fréquemment avaient trait à l'emploi, aux relations interpersonnelles et à la santé.