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Social impact on families of children with complex congenital heart disease

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BACKGROUND AND OBJECTIVES: The care of children with complex congenital heart disease creates emotional and financial hardships for their families. We evaluated the social impact on families of patients with complex congenital heart disease (CHD) who underwent single ventricle repair.

DESIGN AND SETTING: Cross-sectional survey conducted at the pediatric cardiology outpatient department at Prince Sultan Cardiac Center-Qassim (PSCC-Q).

PATIENTS AND METHODS: All patients diagnosed and treated for complex CHD of single ventricle pathophysiology and seen in the pediatric cardiology at PSCC-Q were eligible for the study. Families of these patients completed a questionnaire conducted by one interviewer. The Impact on Family Scale (IFS) questionnaire of Stein and Riessman was instituted. Patients were divided into two groups according to the cardiac diagnosis and the requirement for medical or surgical management. The first group included patients with CHD who do not need any medical or surgical intervention, .e.g. tiny VSD or small ASD. The second group included patients with complex CHD with single ventricle pathophysiology who underwent Glenn and/or Fontan procedures. The mean impact on family scores was compared among the different groups by two sample t test analysis.

RESULTS: Families of 41 children with CHD were interrogated during the study period from September 2011 to February 2012. Patients were divided into two groups. Group one (20 patients, 49%) with simple CHD and group two (21 patients, 51%) with complex CHD who are managed in the univentricular tract. Families of children who underwent single ventricle repair had significantly higher IFS (mean and standard deviation of 62 [7]) than families with minor heart disease (mean of 51 [4]) (*P*=.005).

CONCLUSION: Families of patients who underwent single ventricle repair have significant social impact because of their child illness. A supporting public group should be initiated and encouraged.

The birth of a baby is a major life cycle event and is a source of great expectation and hope for parents. Congenital heart disease (CHD) is one of the most commonly found congenital anomalies. Congenital heart disease occurs in approximately 1% of live births. In Al-Qassim region, Saudi Arabia, approximately 110 children are diagnosed with severe CHD each year.[1]

When a child is born with CHD, families must adjust to the fact that the child's disease could be life-threatening, has the potential to cause permanent handicap and may affect familial daily routines. Improvements in the medical and surgical treatment of CHD have resulted in the majority of congenital cardiac malformations being amenable to some form of surgical intervention, with an ever-increasing duration of survival. Caring for a child with chronic illness such as complex CHD has been identified as one of the stressful experiences for any family and requires coping and adaptation.[2-4]

The impact on the family can be in the form of increased burden and responsibility of caring for the sick child or adolescent at home for which families have varying physical and emotional capabilities. Furthermore, as most medical treatments are delivered during working hours, there is a potential for increased loss of income for the caregivers in the family leading to financial strain. To determine the effects of chronic childhood illness on the family, Stein and Riessman (1980) developed the Impact-on-Family Scale (IFS). Although they considered positive effects, they focus

on negative effects. Negative influences of illness are conceptualized in terms of losses: financial burden, restrictions in social life, decreased interaction with significant others, less time for other family members, and increased subjective distress or strain. The IFS is a 24-item questionnaire measuring four dimensions of impact. Financial Burden refers to the economic consequences for the family. Familial/Social Impact concerns the disruption of social interaction. Personal Strain assesses the psychological burden experienced by the primary caretaker. Mastery refers to the coping strategies employed by the family.[5]

Since its publication in 1980, the IFS has been used in a considerable number of studies concerning a range of chronic childhood illnesses, mostly physical diseases. With respect to validity, the scale proved to discriminate between chronic illness (cancer and non-neoplastic illnesses (cardiopathy, hepatopathy, bronchopneumopathy, or rheumatic pathology) and acute illnesses (gastrointestinal, respiratory, genitourinary, or skin disorders). In addition, it has been found that the more severe and/or debilitating the illness, the greater the impact on the family.[6-8] This scale was validated in English as well as other languages including Arabic language and was tested across cultures.[8-11]

To date, there is limited information regarding the financial, social, and emotional burden on families of children diagnosed with complex CHD internationally as well as in Saudi Arabia. The aim of this study was to evaluate the financial, psychological, social, emotional impact associated with childhood CHD and the impact of the diagnosis on the children and their families in Saudi Arabia.

PATIENTS AND METHODS

All pediatric patients with complex CHD and had cardiac surgey who were on follow up at the pediatric cardiology clinic at PSCC in Qassim were eligible to participate in the study. Their diagnosis had to have been made at least 6 months prior to enrolment into the study. Exclusion criteria included families of children with CHD diagnosed less than 6 months prior to enrolment. Patients with CHD who had a curative single-stage intervention were also excluded. Ethical approval by the institutional review board was obtained prior to the commencement of the study. Eligible participants were approached at their regularly scheduled outpatient follow-up. Upon agreeing to participate and after informed consent was obtained, they were interrogated by one investigator with the IFS questionnaire. The impact in family questionnaire of Stein and Riesman was instituted.[5]

This questionnaire has been used to assess the impact of chronic illness on parents and families. It is based on four subscales assessing perceived 1. Financial Burden; 2. Familial/Social Impact; 3. Personal Strain; and 4. Mastery. The first subscale contains four statements, for example "My child with CHD is causing financial problems for the family". The second subscale contains nine statements assessing social effects of CHD, for example "People in the neighbourhood treat us differently because of my child's CHD". The third subscale has six statements relating to the personal stress imposed by CHD on the parent, for example "Nobody understands the burden I carry". The final subscale contains positively phrased statements to assess the positive effects of the child's CHD on the parents feeling of control in his or her life, for example "Learning to manage my child's CHD has made me feel better about myself". The parents response is given as a number from 1 to 4, where 1 represents strong agreement, 2 predominant agreement, 3 weak partial agreement, and 4 strong disagreement. The fourth subscale is reverse coded, so that it is compatible with the other subscales to calculate a final score where a low score corresponds to a high impact. This score is then inverted so that a high score is equivalent to high impact. The questionnaire was administered by one researcher. The original 24-item IOF has since been expanded into a 33-item self-administered questionnaire to further include 6 items relating to financial impact and sibling impact.[12]

In our study, we used the shorter original version, the 24-item IOF scale. A total score for the IFS was obtained by the summation of all 24 scores as a general measure of impact, where a higher score indicates a greater impact. We calculated the mean and standard deviation for each category as well as for the total scores.

A control population was formed from 20 families with children with minor CHD defined as lesions that have no significant clinical or hemodynamic consequences and not requiring any medical or surgical intervention like small ASDs and small VSDs. The mean impact on family scores was compared by the two-sample t test analysis. Analyses were performed using Statistical Package for Social Science 16.0 Window version (SPSS v16.0).

RESULTS

From September 2011 to February 2012 a total of 70 patients seen at pediatric cardiology clinic were interrogated. Among them, 29 patients were excluded due to the following reasons: ineligible criteria as outlined by the eligibility checklist (normal cardiac exam and echocardiography during the time of interrogation, patients

Table 1. Diagnosis of the patients whom families were interrogated.

Diagnosis	Frequency (%)
ASD	1 (2.44)
MV thickened	1 (2.44)
Post-cardiac cath	1 (2.44)
PM-VSD	2 (4.9)
Single ventricle and waiting for Glenn	3 (7.3)
PS	4 (10)
Single ventricle completed Fontan	7 (17)
Single ventricle and had Glenn	11 (26.8)
VSD	11 (27)
Total	**41 (100)**

Abbreviations: ASD=Atrial septal defect, MV= Mitral valve, PM =perimembranous PS =pulmonary stenosis VSD=ventricular septal defect,

Table 2. Comparison between the response of Families with Mild CHD and those with single ventricle.

	Category	N	Mean (SD)	Sig. (2-tailed)
Financial score	Mild	20	9.10 (1.12)	
	Single Ventricle	21	10.19 (2.32)	0.063
Family score	Mild	20	19.25 (2.07)	
	Single Ventricle	21	23.29 (3.62)	0.000
Mastry score	Mild	20	14.50 (2.21)	
	Single Ventricle	21	18.00 (2.21)	0.000
Personal strain score	Mild	20	9.15 (1.81)	
	Single Ventricle	21	9.81 (1.75)	0,244
Total score	Mild	20	52.00 (4.14)	
	Single Ventricle	21	61.29 (6.90)	0.000

with single ventricle physiology less than 6 months of age, as well as the presence of CHD which require one stage and curative intervention). Of the remaining 41patients included in the analysis, 21patients were having complex CHD of single ventricle pathophysiology and had one or more staged univentricular repair. The control group include 20 patients with simple CHD which will not require any cardiac intervention.

The study cohort comprised 15 males (37%) and 26 females (63%). Patients with complex CHD were diagnosed in the first 3 month s of life. The diagnosis of patients with complex CHD as well as the control group is represented in **Table 1**. The majority of children with complex CHD were still undergoing treatment at the time of enrolment into the study.

Of the 4 domains of the IFS, among patient's families with complex CHD the highest score was in the family score, hence the highest impact was in the perceived Familial/Social Burden. This was followed by Mastery scale, Financial Burden and then Personal Strain. The total score for all 4 domains of impact was 61.3 (7) for families of patients with complex CHD compared with a 52 (4) in the control group (**Table 2**). Comparing the scores with the control group revealed significant differences between the two groups. There was a less degree of significance regarding the financial score.

DISCUSSION

Chronic illnesses were defined as any health condition that lasts more than 12 months, or at the time of diagnosis is likely to have a duration of at least 12 months.[13] Children with complex CHD especially those who will require a single ventricle pathway of repair full fill this definition.[14,15]

Many studies showed that families of children with congenital cardiac malformations experience significant social impact.[2] A diagnosis of complex CHD impacted the family life at many levels.[16] To our knowledge, our study is the first one trying to measure the Social Impact of Complex CHD on the families.

To make the study more reliable we have used a standard and validated scale and we compared the results with a control group with minor heart disease. We found that families of patients with complex CHD had a higher impact scores than those with simple CHD.

There exists an assumption in our societies that people often place a higher value on the opinions of other family members and neighbors, which may contribute towards a perceived higher Familial and Social burden. Additionally, Islamic cultural beliefs may influence the parents' responses socially. However, further studies are needed.

We also found that because medical services are freely delivered to Saudi patients by the government there was a lower Financial Burden impact with less significant differences between those with complex CHD and the control group. In other areas of the world there are significant financial burden on the families of patients with chronic illnesses.[17]

Caring the sick child may affect the care of other

siblings. In a study conducted in United Kingdom on 20 parents of children with cancer, the caregivers of children with cancer reported new responsibilities and role expectations, and they felt that the 'proximity', i.e. being able to provide 'comfort', or 'keep-watch' to the sick child was of importance. This in turn compromised their ability to function in other roles, i.e. the role as parent of other children who are healthy.[18]

In Saudi Arabia many supporting groups for children with chronic diseases like diabetes, renal failure, and autism were established but non for children with complex CHD. There is a need for more studies on this aspect for more public awareness. Hopefully this will result in establishing a supporting group.

Limitations of the study

We acknowledge that there are limitations of our study. This is a small sample size, Single centre hospital-based study.The cross-sectional nature of the study further limits our findings and the benefits of longitudinal research needs to be taken into account especially when one is studying the impact and coping mechanisms in these families.

CONCLUSION

Despite the high governmental support and the freely delivered medical services, the overall burden of childhood complex CHD in SA is high. We saw a higher impact in Social/Familial domain. Locally, there has been little research efforts to understand the psychosocial consequences of Complex CHD and their treatment to the child or the impact it has on the child's family. Based on our initial findings, we aim to strive further to identify the gaps in the provision of a holistic medical and psychosocial care, prevent or ameliorate of the impact of childhood Complex CHD, and strengthen the coping capacity for children and their families once a child is diagnosed with Complex CHD. Families of patients who underwent single ventricle repair have significant social impact because of their child illness. A supporting public group should be initiated and encouraged.

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