Effect of cardiac surgery in young children with congenital heart disease on parenting stress in central South Africa: Initial outcomes

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ABSTRACT

Introduction and aim: Parents of children with congenital heart disease (CHD) are at increased risk of ongoing stress and psychological morbidity. The aim of this study was to determine stress in parents of children with CHD who underwent cardiac surgery. The levels of stress experienced by parents of children with CHD in South Africa are unknown. Reported parenting stress outcomes in children with CHD in developed countries are conflicting.

Materials and methods: Forty-eight consecutive children, 30 months and younger, and their parents were recruited into this observational descriptive study. Parenting stress was assessed using the Parenting Stress Index Short Form. Parenting stress outcomes were compared over time, and variables associated with parenting stress determined at baseline, three-month and six-month post-cardiac surgery.

Sociodemographic information including maternal age, parental educational attainment and occupational status were collected using a self-developed questionnaire. Medical severity of the cardiac disease was rated according to the Cardiologists Perception of Medical Severity Scale. Socio-economic status was determined using Hollingshead's Index of Social Position and developmental status was assessed using the Bayley Scales of Infant and Toddler Development, Third Edition.

Results: Baseline data was collected for 40 parents. Sixty percent of parents (n=24) experienced clinically significant stress prior to cardiac surgery. Levels of parenting stress were significantly decreased at both three-month ($p<0.001$) and six-month post-cardiac surgery ($p<0.001$). However, just more than a third of parents experienced ongoing stress. There was a significant association between neurodevelopmental outcome ($p=0.03$), perceived health-related quality of life ($p=0.02$), age at first cardiac surgery ($p=0.03$) and maternal age ($p=0.04$) and levels of parenting stress.

Conclusion: The findings of this study showed that most parents experienced clinically significant levels of stress prior to cardiac surgery in their children. Parenting stress declined significantly post-cardiac surgery, but a considerable number of parents experienced ongoing stress. In conclusion, parents of children with CHD should be screened regularly for risk of psychosocial problems requiring referral for treatment.

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INTRODUCTION

Improved survival is seeing more parents than ever before raising children with congenital heart disease (CHD).[1-3] Parenting stress encompasses the psychological distress experienced in trying to meet the demands of parenting.[4] Raising a child with CHD has been described as "parenting under pressure",[5] and many parents find the experience to be a challenge.[6-9]

Research findings on parenting stress outcomes in children with CHD are conflicting, with some investigators reporting that parents experienced higher levels of stress,[1,6,7,10,11] whilst others have found stress levels to be similar to those experienced by parents of healthy children; in fact, in some instances parents of children with CHD have even reported lower stress levels than parents of healthy children. It has been suggested that these parents have likely developed a higher threshold for what they perceive to be stressful due to their experiences with their child with CHD.[8,9,11] Research findings suggest considerable variability in individual stress outcomes with disease severity, the changing health status of the child, specific stressors in play at the time and resiliency factors all, in part, explaining the variability.[2,12] In addition, the extent of the burden of care, social isolation and financial difficulties have also been shown

to heighten the risk of long-standing psychosocial problems.[13] Little is known about the experiences of parents of young children living with CHD.[2,11]

Parents of children with CHD face unique challenges that place them at increased risk of psychological distress. These challenges, or stressors, can relate to the child's illness and the child's specific characteristics, as well as to personal and socio-economic factors. For example, parents tend to find the diagnosis of their child with CHD,[15] as well as the hospitalisation,[14,15] cardiac surgery and intensive care unit stay[12,14-17] to be extremely stressful. Moreover, some children with CHD may also exhibit excessive irritability and behavioural difficulties that make them more difficult to parent.[10,19] In addition, approximately 30% of children with CHD may also have been born with a genetic disorder or syndrome, including Down syndrome (DS), which presents additional parenting challenges.[20-22]

Caring for a child with CHD increases the burden of care and role-related stress experienced, especially by mothers, who tend to fulfil the role of primary caregiver.[6,7,15,19,23] Parenting a child with CHD also comes at an emotional cost to siblings and the extended family resulting in strained personal relationships, which add to the psychological distress experienced by parents.[2,7,23,24] Caring for a child with CHD also places considerable financial strain on families.[2,14,15,18,24]

For many parents the chronic health problems faced by their child place them at a high risk of experiencing ongoing stress.[1,17,27] The effects of these ongoing stressors accumulate over time, and affect parents' ability to adapt, undermining their own health and wellbeing, as well as their family's functioning.[2,6] More than a third of parents of children with CHD have been found to exhibit poor adaptation.[27,28] Consequently, these parents may develop psychological problems, including anxiety and depression.[1,7,12,17,18,27]

The stress experienced by parents of young children with CHD in South Africa is unknown. South Africa is classified as a developing country based on its degree of economic development, level of industrialisation, infrastructure and general standard of living.[29] Although South Africa has relatively good infrastructure, it faces considerable socio-economic challenges. Poverty and social disadvantage pose a considerable risk to parenting in South Africa.[30-33] A lack of financial resources does not only affect the ability of parents to provide nutrition, healthcare and education to their child, but inherently makes parenting more difficult.[30] More than half of the children in South Africa grow up in single-parent, mainly female-headed households, where the absent parent is largely uninvolved in the day-to-day parenting.[25,26,30] These families are at greater risk of poverty amplifying poor adaptation and coping.[25] In addition to this, low levels of parent education contribute to financial insecurity, and therefore parenting stress.[25,26] Parents living in poverty are also less likely to have the necessary social support to assist them in their parenting role,[30,33] and as a result are also more likely to suffer from stress, anxiety and depression.[30-32] A lack of financial means impedes access to healthcare due to the costs and a lack of access to transport.[25] Poor adaptation skills, and high levels of parenting stress, may be rooted in the lack of financial means to facilitate coping with the demands of care.[25] Accessing and complying with cardiac care is challenged in employed parents who may stand to lose income due to the frequent and sometimes extended periods of time needed off work in order to meet their child's care needs.[25,41,46-48]

A family's ability to come to terms with their child's cardiac diagnosis, and to then make the necessary lifestyle adjustments it demands, plays an important role in the outcome of the child with CHD,[1,7,15,38,39] currently driving interest into the impact of a child's CHD on parents' psychological health and parenting experiences.[2,5,12,26] The aim of this study was to determine stress in parents of children with CHD who had undergone cardiac surgery in central South Africa.

MATERIALS AND METHODS

Forty-eight consecutive children, 30 months old and younger, and their parents were recruited into this observational descriptive study at the Universitas Academic Hospital Paediatric Cardiology Unit in Bloemfontein over a 17-month period. Neonates, children who were critically ill and those who had undergone previous or emergency cardiac surgery were excluded. Ethical clearance was obtained from the Ethics Committee of the Faculty of Health Sciences, University of the Free State (ECUFS 177/2013) and the Committee for Research on Human Subjects, University of Witwatersrand (M131056) prior to the enrolment of the children and parents in the study.

The Parenting Stress Index Short Form (PSI-SF) was used to assess the levels of parenting stress prior to cardiac surgery, and at three-month and six-month post-cardiac surgery. Permission to use the PSI-SF was granted by Psychological Assessment Resources Incorporated (PAR-Inc.). The PSI-SF, developed by Abdin,[40] is a self-report measure containing 36 items across three subscales. Parents make use of a five-point Likert scale to indicate the extent to which they agree or disagree with each statement, where "strongly agree" is scored a 5, and "strongly disagree" a 1.[2] A total score is calculated for the

"parental stress", "parent-child dysfunction", and the "difficult child" subscales. In addition, a total stress score is also calculated. Scores are then converted into percentiles, with normal scores lying between the 15th and 80th percentile. Scores are considered to be high if they are above the 85th percentile, and clinically significant if above the 90th percentile. Clinically significant stress levels would identify parents that would likely benefit from psychological and educational interventions.[5,18,26,40] These interventions may include counselling, parent education, active listening and the provision of anticipatory guidance, teaching of coping skills and developing strategies for accessing social support within parents' families and communities, and parent support groups have all been found to mediate stress and anxiety.[7,15,17,38,39]

The PSI-SF has been used in several studies to determine parenting stress in children with CHD, and has been found to be a valid and reliable measure.[19,20,21,23,34,41] The PSI-SF has also been shown to have good test-retest reliability with Pearson correlations of .84 for total stress scores, and .68 - .85 for the subscale scores.[40]

Sociodemographic information including maternal age, parental educational attainment and occupational status was collected using a self-developed questionnaire. Medical severity of the child's cardiac disease was rated using the Cardiologists Perception of Medical Severity Scale.[7,19] Socio-economic status was determined using the Hollingshead Index of Social Position and development assessed using the Bayley Scales of Infant and Toddler Development, Third Edition. All standardised, objective measures have previously been used in the South African population, as well as in children and families with CHD, and were all shown to be valid and reliable measures. All participant material was available in Sesotho, English and Afrikaans in accordance with the language demographics of central South Africa.

Sample characteristics and clinical variables are presented as means with standard deviations and medians with ranges for continuous data and frequencies with percentages for categorical data. In addition to being treated as a numerical score, parenting stress levels were classified according to the measure-specific classification system. Classification data is reported using frequencies with percentages. Within-group changes in PSI-SF over time, from baseline (before cardiac surgery) to both three-month and six-month cardiac surgery, were calculated using 95% confidence intervals on the difference between z-score means. The association between identified variables and the PSI-SF total scores at baseline, and three-month and six-month post-cardiac surgery, were determined using ANOVAs.

RESULTS

Baseline data was collected for 40 parents. Two children and their parents were excluded following baseline as the children failed to undergo cardiac surgery. In addition, loss to follow-up resulted in data only being collected for 25 parents at three-month and 22 parents at six-month post-cardiac surgery.

The median age of the children at baseline was 7.4 months (with a range of 1.4 - 20.9 months). The majority of children (n=26) underwent open-heart surgery in infancy with cardiopulmonary bypass. Most children (n=30) had moderate disease severity, with 20% (n=8) having cyanotic lesions. A quarter of the children (n=10) were also diagnosed with Down syndrome (DS) (see Table I).

TABLE I: Information on cardiac diagnosis and cardiac surgery.

Variable	Sample size (n)
Primary cardiac diagnosis	**(n=40)**
Acyanotic defects	(n=32)
ASD	15 (37.5%)
AVSD	9 (22.5%)
PDA	4 (10%)
Coarctation of the aorta	3 (7.5%)
Aortic stenosis	1 (2.5%)
Cyanotic defects	(n=8)
DORV	3 (7.5%)
TGA	1 (2.5%)
TAPVD	1 (2.5%)
HLHS	1 (2.5%)
Tetralogy of Fallot	1 (2.5%)
Tricuspid atresia	1 (2.5%)
Presence of Down syndrome	**(n=40)**
No	30 (75%)
Yes	10 (25%)
Severity of the cardiac disease	**(n=40)**
Mild	1 (2.5%)
Moderate	30 (75%)
Moderate to severe	8 (20%)
Severe	1 (2.5%)
Age at first cardiac surgery (months)	**(n=38)**
Median (range)	7.5 [1.4 - 10.9]
Aim of the surgery	**(n=38)**
Definitive correction	28 (73.6%)
Staged correction	5 (13.2%)
Palliation	5 (13.2%)
Cardiac surgery with CPB	**(n=38)**
Yes	26 (68.4%)
No	12 (31.6%)

TABLE II: Parenting stress scores of the primary caregivers.

PSI-SF Scales	Baseline (n=40)	Three-month post surgery (n=25)	Six-month post surgery (n=22)
Parenting distress			
Median (range)	90 [10 - 99]	75 [1 - 95]	65 [1 - 95]
Mean and SD	83.3 (±19.9)	63.8 (±31.9)	57.8 (±31.9)
Parent-child dysfunction			
Median (range)	90 [40 - 99]	80 (±19.8)	85 [5 - 99]
Mean and SD	72.8 (±27.2)	80 [5 - 99]	63.5 (±34.2)
Difficult child			
Median (range)	77.5 [1 - 99]	67.1 (±26.3)	55 [1 - 95]
Mean and SD	52.6 (±27.6)	47.5 [1 - 95]	47.6 (±35.5)
Total stress			
Median (range)	90 [5 - 99]	83.8 (±19.2)	80 [1 - 99]
Mean and SD	69 (±28.5)	67.5 [1 - 99]	57.8 (±34.8)

TABLE III: Classification of the levels of parenting stress.

Subscales of the PSI-SF	Baseline (n=40)	Three-month post surgery (n=25)	Six-month post surgery (n=22)
Parenting distress			
Clinically significant*	24 (60%)	7 (28%)	5 (22.7%)
High	31 (77.5%)	11 (44%)	7 (31%)
Normal	8 (20%)	11 (44%)	12 (54.4%)
Low	1 (2.5%)	3 (12%)	3 (13.7%)
Parent-child dysfunction			
Clinically significant*	22 (55%)	11 (44%)	9 (40.9%)
High	22 (55%)	13 (52%)	9 (40.9%)
Normal	18 (45%)	11 (44%)	10 (45.5%)
Low	0 (0%)	1 (4%)	3 (13.6%)
Difficult child			
Clinically significant*	7 (17.5%)	3 (12%)	3 (13.6%)
High	14 (35%)	4 (16%)	5 (22.7%)
Normal	24 (60%)	19 (76%)	11 (50%)
Low	2 (5%)	2 (8%)	6 (27.3%)
Total stress			
Clinically significant*	24 (60%)	6 (24%)	7 (31.8%)
High	27 (67.5%)	9 (36%)	7 (31.8%)
Normal	12 (30%)	14 (56%)	11 (50%)
Low	1 (2.5%)	2 (8%)	4 (18.2%)

**Clinically significant PSI-SF scores indicate the number of individuals who should be referred to psychological support services based on their stress scores being above the 90th percentile.*

The median age of the mothers at baseline was 30 years (with a range of 16 - 43 years) and the average level of education for both mothers and fathers was grade 9 - 11. Most mothers (n=33) did not work outside the home, and the majority of families (n=35) had a low socio-economic status. In most (97.5%) instances mothers fulfilled the role of primary caregiver.

Sixty percent of parents (n=24) experienced clinically significant levels of stress in their parenting role at baseline, shortly before their child underwent cardiac surgery (see Tables II and III). More than half (n=22) of the primary caregivers felt that their child did not meet their expectations (refer to scores on the parent-child dysfunction subscale in Table III). Most parents (n=26), however, felt that their children were not difficult to parent (refer to the scores on the difficult child subscale in Table III).

Levels of parenting stress declined significantly from baseline to both three-month ($p<0.001$) and six-month post-cardiac surgery ($p<0.001$) (see Figure 1). Even though total stress scores decreased over time, 36% and 31.8% of parents continued to experience high levels of stress at respectively three-month and six-month post-cardiac surgery.

Neurodevelopmental outcome in children, in particular delayed language development, was significantly associated with levels of parenting stress prior to cardiac surgery ($p=0.04$) and at three-month post-cardiac surgery ($p=0.03$). Parents' perception of their child's health-related quality of life (HRQOL) prior to cardiac surgery was also found to be significantly associated with levels of parenting stress ($p=0.02$). In addition, younger age of the child at the time of the first cardiac surgery ($p=0.03$) and more advanced maternal age ($p=0.04$) were also found to be significantly associated with levels of parenting stress at three-month post-cardiac surgery (see Table IV).

Sub-groups were too small and insufficiently powered to allow for meaningful conclusions to be drawn from formal statistical analysis, but still allowed for the identification of trends. Parents of children with CHD and DS tended to experience similar levels of stress to parents of children with CHD without DS prior to cardiac surgery (median total stress score of 90 compared to 92), but tended to experience higher levels of stress at both three-month (median total stress score of 90 compared to 77.5) and six-month post-cardiac surgery (median total stress score of 80 compared to 50). Levels of parenting stress tended to be similar in parents of children with cyanotic and cyanotic heart defects.

Failure to undergo cardiac surgery (n=2), post-operative mortality (n=6), non-compliance with follow-up (n=9) and

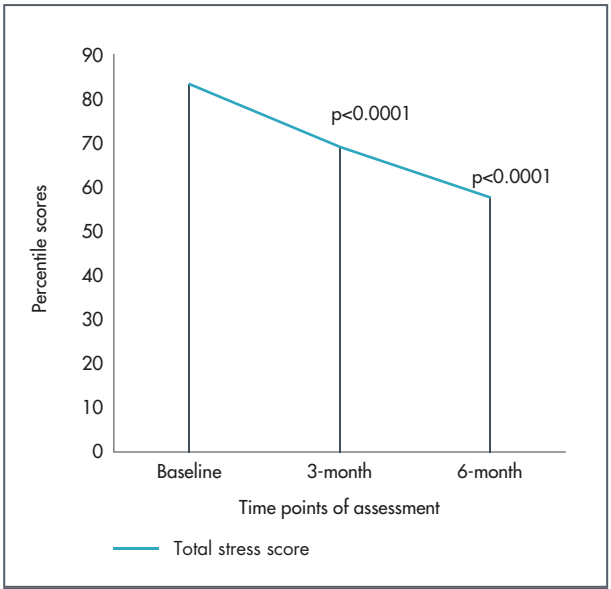

FIGURE 1: Mean PSI-SF total stress scores across the time-span study.

TABLE IV: Variables associated with levels of parenting stress.

Variables for PSI-SF total score	P-values		
	Baseline	Three-month post cardiac surgery	Six-month post cardiac surgery
Disease type and severity			
Disease severity	0.39	0.67	0.56
Type CHD	0.57	0.68	0.61
Peri-operative risk factors			
Age at surgery	0.11	0.03*	0.43
Patient factors			
Genetic comorbidity (Down syndrome)	0.11	0.41	0.67
Growth (weight-for-age)			
Feeding problems	0.79	0.69	0.33
Socio-demographic factors			
Age of mother	0.55	0.04*	0.10
Level of maternal education	0.07	0.39	0.30
Socio-economic status	0.50	0.11	0.12
Neurodevelopmental outcome			
Cognitive development	0.29	0.94	0.44
Language development	0.04*	0.03*	0.77
Motor Development	0.50	0.21	0.19
Perceived HRQOL			
PedsQL® total score	0.02*	0.08	0.97

*Indication of statistical significance: *p<0.05, **p<0.01, ***p<0.001.*

family relocation (n=1) contributed to the high attrition rate of 47.5% over the time-span of this study. Non-compliance with follow-up was attributable to the distance to be travelled to the cardiac centre for follow-up, unreliable inter-hospital transport services, limited methods of distance communication available, financial constraints and a possible lack of a clear understanding on the part of parents regarding the importance of cardiac follow-up, even if their child appeared to be "doing well".

DISCUSSION

The majority of primary caregivers in the current study experienced clinically significant levels of parenting stress just prior to their child undergoing cardiac surgery. This is consistent with reports that parent stress levels are particularly high just before their child undergoes cardiac surgery.[12,14-17] Levels of stress in this study were found to be comparable to those of mothers of children with HIV,[42] but higher than those of mothers of children with cerebral palsy in South Africa.[43] Similarly, it has been found in developed countries that parents of children with CHD experience higher levels of stress than parents of children suffering from other chronic health conditions, and parents of healthy children.[6,44,45]

Even though total stress scores decreased over the time-span of the current study, just more than a third of the parents continued to experience high levels of stress after their child's cardiac surgery. This is similar to reports by several authors who found that parents of children with CHD continued to experience high levels of stress over the continuum of their child's cardiac care.[2,4,12,14,23,26] Although most parents show resilience in the face of the challenges caused by their child's CHD; it has been suggested that as many as 40% of parents are considered to be at risk of experiencing ongoing stress and psychological problems.[26]

Parenting stress levels decreased significantly from baseline to both three-month and six-month post-cardiac surgery. The significant decrease in the levels of parenting stress after cardiac surgery is likely to be attributed to the resolution of – or improvement in – cardiac symptoms, and the improved health and wellbeing of the children following cardiac surgery. Consistent with previous findings, parental emotions in this study are likely to have changed over time in accordance with their child's health condition.[2,12] In addition, a large number of children in the current study underwent definitive corrective surgery (73.6%), leaving minimal lasting deficits.[23]

Neurodevelopmental outcome, in particular language development, was found to be significantly associated with parenting stress prior to cardiac surgery (p=0.04), as well as at three-

month post-cardiac surgery (p=0.03). One may speculate that a lack of communication and social interaction on the part of the child with a parent is likely to increase parental anxiety and negatively affect the parent-child relationship. Similarly, several investigators in developed countries have indicated that parenting stress negatively impacts on the quality and responsiveness of caregiving, ultimately having a detrimental effect on the child's social-emotional, motor, cognitive and language development.[10,16,38,46-48] Findings in developing countries are comparable.[38]

Parents' perception of their child's HRQOL was significantly (p=0.02) associated with levels of parenting stress before cardiac surgery. Parental perception of their child's HRQOL may be closely linked to their perception of their child's level of functioning and their view of the parent-child relationship, which in turn is influenced by the child's unique characteristics, including their temperament, behaviour, health status and developmental skills. If parents perceive their child as having a poor ability to function in everyday situations, their stress levels are likely to increase.[9]

The age of the child at first cardiac surgery (p=0.03) and the age of the mother (p=0.04) were found to be significantly associated with parenting stress at three months post-cardiac surgery. A possible reason for this finding in this study could be the young age of the children and that the cardiac surgery was recent, both factors which likely contributed to the care burden and therefore the levels of parenting stress experienced. This is consistent with findings that the age of the child was significantly associated with parenting stress and that parenting infants, toddlers and pre-schoolers resulted in higher levels of stress by virtue of the higher burden of caregiving in children of these ages.[10,34]

Disease type and severity were not found to be significantly associated with levels of parenting stress. Parenting stress tended to be similar for parents of children with cyanotic and acyanotic heart defects in the current study. This is likely due to the fact that patient characteristics were similar for both groups, and the disease severity was only marginally worse in the cyanotic group. This is consistent with the reported findings in multiple studies.[3,9,27] Disease severity has, however, failed to explain parents' psychological morbidity over time.[2] Rather, parents' perception of the impact of their child's CHD on the child and family has proven to be a far more powerful predictor of long-term psychological morbidity.[50]

Although parents of children with CHD and DS tended to experience higher levels of stress over the time-span of the study, no significant association was found between the presence of DS and levels of parenting stress. The lack of association may be a reflection of the fact that parents viewed their children as either having a medical problem, or not, irrespective of the number of problems.

The majority of parents found seeing their child in the cardiac intensive care unit after cardiac surgery attached to machines and with drainage tubes to be the most stressful experience. This is consistent with reported findings throughout the literature.[12,14-17]

Parent stressors in the current study included the burden of caring for a child with CHD. Mothers fulfilled the role of primary caregiver in all but one instance, and as a result shouldered most of the burden of care. This is consistent with the findings in the literature.[1,2,6,7,39,51] Characteristics of the child also served as a stressor, in that more than half of the parents felt that their child failed to meet their expectations. Dysfunction in parent-child interaction improved over time, but remained the stressor that continually contributed most to parenting stress over time. Similar indications that parental perception of their child and acceptance of the child affects levels of parenting stress have been noted.[4] The majority of parents in the current study did not find their children demanding or difficult to parent.

Many of the parents in the current study highlighted the considerable impact their socio-economic circumstances had on their psychological wellbeing. It can be speculated that unemployment, social disadvantage and a lack of social support exacerbated the stress parents' were already experiencing in their parenting role. This is in agreement with reports that noted financial strain increased levels of parenting stress in developing countries.[25,33,52] The findings have been similar in developed countries in that social disadvantage has been found to contribute to levels of stress in parents of children with CHD.[1,2,4,10,14,24] Socio-economic status (SES) and maternal educational attainment were not shown to be strongly associated with levels of parenting stress in the current study, this can be possibly be explained by the fact that the SES and level of maternal education were similar across the sample.

Parenting stress outcomes and stressors identified in the current study would likely be similar to those experienced by parents of children with CHD living in other developing countries.

LIMITATIONS

The results of this study need to be interpreted in the light of several limitations. The outcomes reported are for a single cardiac-centre, making the findings specific to this population, and therefore not necessarily generalisable to the CHD

population at large. The study was limited, to some extent, by a small sample size and a relatively short follow-up period post-cardiac surgery. There was a high attrition rate in this study, and the limited number of participants available for evaluation at both three-month and six-month post-cardiac surgery may have influenced the analysis of variance findings used to determine associations between variables and parenting stress outcomes. Despite this limitation, participants remaining in the study throughout were found to be representative of the entire sample at baseline.

Studying parenting stress outcomes is complex as there are multiple factors that may influence individual stress outcomes. Factors that need to be taken into consideration include a genetic predisposition to anxiety and depression, personality and temperament, life stressors in play at the time and resiliency factors. Identifying specific factors that impact on individual parenting stress outcomes will require testing in a larger sample.

A shortcoming of the PSI-SF is that it only measures stressors directly related to the parenting role, yet several factors outside the parenting role itself may contribute to the stress experienced by parents. This is likely to have contributed to the lack of a strong association being shown between variables, such as SES and level of maternal educational attainment, and levels of parenting stress in this current study. It would be recommended that when investigating parenting stress both self-administered questionnaires and semi-structured interviews be included to adequately explore the factors influencing parenting stress.

CONCLUSIONS

Most parents experience clinically significant levels of stress in the period immediately before their child undergoes cardiac surgery. Even though parenting stress declines significantly post-cardiac surgery, and over time, a considerable number of parents continue to experience high levels of stress. Parents should be screened regularly for risk of psychological problems to assist clinicians in identifying parents who should be referred to, and who would likely benefit from, psychological and educational interventions.

Further research is indicated to explore the specific stressors that contribute to psychological stress and morbidity in parents of children with CHD in SA. Research is also required to determine the effect of psychological and educational interventions in reducing parenting stress in children with CHD in South Africa.

Moving past the goalpost of survival, and attending to the promotion of optimal outcomes in at-risk babies and infants with CHD and their families, it is of critical importance that larger studies with long term follow-up be conducted to identify ways in which to best assist these children and their families.

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