The quality of life, health needs and knowledge of children living with congenital heart disease in KwaZulu-Natal Province, South Africa

P Pillay, BSc (Physio), MSc (Physio); **N Pefile**, BSc, PGD (Public Health), MMedSc (Rehabilitation)
S Cobbing, BSc (Physio), MSc (Health Sciences), PhD; **T Gurayah**, B Occ Th, M OT

Inkosi Albert Luthuli Hospital, Mayville, Durban, KwaZulu-Natal, South Africa

Corresponding author: *P Pillay (pillaypre@yahoo.com)*

Background. An understanding of the lived experiences of children with congenital heart disease (CHD) will aid in improving the way that both parents and medical practitioners manage them holistically.
Objective. To explore the perceptions of children living with CHD in KwaZulu-Natal (KZN) province of South Africa (SA), on their quality of life (QoL), health needs and knowledge of their medical conditions.
Methods. A sequential explanatory mixed-methods design was employed. The study population comprised children aged between 8 and 12 years with CHD who attended cardiology clinics at the study hospital. Convenience sampling was used. Forty-three children participated in Phase 1 and 7 participants were interviewed in Phase 2. The study setting was a tertiary-level public hospital in eThekwini District, KZN, SA. The research procedure comprised a file audit of confirmed CHD in prospective participants. Caregivers completed a consent form while the children assented and completed the PedsQL 4.0 questionnaire. Interviews were conducted in Phase 2.
Results. Phase 1: Both genders had higher psychosocial functioning (PSF), compared with physical functioning (PF). Children with mixed cardiac defects had lower health-related quality of life (HRQoL), compared with cyanotic or acyanotic individuals. The effect of the number of cardiac procedures on the PF domain showed a significant effect (p=0.042). Phase 2: This group had poor knowledge of their medical condition and had specific health needs.
Conclusion. The findings highlight the need for improved knowledge/information on physical capabilities, medical information and support from family, caregivers and medical staff.

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Individuals with congenital heart disease (CHD) need lifelong healthcare.[1] CHD birth prevalence has reached a stable estimate of 9 per 1 000 live births.[2] An estimated 11 000 children are born annually with CHD in South Africa (SA) and it is the 9th most prevalent recorded cause of death in children >5 years.[3] Patients with CHD should receive continuous evaluation to determine their appropriate levels of physical activity, educational and emotional support and to improve their health-related quality of life (HRQoL).[4] A significant provision of the SA Children's Act No. 38 of 2005 (2010) is that the age of consent for medical and surgical treatment is set at 12 years, provided that children of this age have the maturity to understand the benefits, risks and other implications of treatment.[5] Failure of a healthcare worker to understand how to communicate knowledge about CHD to children may have a detrimental effect on their overall health and QoL.[6]

Despite progress in the development and utilisation of paediatric HRQoL measures,[7] there is limited research in SA on the HRQoL of children within this age group with CHD. The aim of the present study was to explore the perceptions of SA children living with CHD on their QoL, health needs and knowledge of their medical condition.

Methods

A sequential explanatory mixed-methods design was employed.[8] In Phase 1 of the study, descriptive data were collected on the domains of HRQoL, using the SA version of the PedsQL 4.0 Generic Core Scales Child report for children aged 8 - 12 years.[9] Semi-structured interviews were employed during the second phase of the study, which consisted of interviewing participants on their health needs and knowledge of CHD. This study was conducted at a tertiary-level public hospital in KwaZulu-Natal (KZN) Province, SA. Full ethical approval was obtained from the University of KwaZulu-Natal's Biomedical Research Ethics Committee (ref. no. BE090.16).

The study population consisted of children aged between 8 and 12 years old with CHD who attended cardiology clinics at the study facility, during a 12-week data collection period. The population for Phase 1 consisted of 43 children who assented, after their parents had consented to participate in the study. The sample size was relatively small owing to the recruitment of participants of a specific age group within a specific timeframe. Seven children from Phase 1 agreed to attend in-depth semi-structured interviews for Phase 2 of the study. They were selected based on their willingness to participate and their ability to understand the interview questions (in either English or isiZulu). The selection of participants for the second phase of the study had to be altered from selecting patients based on diagnosis and HRQoL scores, owing to children in this age group being unwilling to be interviewed. In the end, however, the 7 children who participated were willing and able to give feedback that could be used. Data from Phase 1 were analysed using SPSS version 23 (IBM Corp., USA). As the data were not normally distributed, non-parametric tests were employed. The statistician reviewed the data and ran specific data analyses. Normality tests noted

the data to be non-normal distribution with the Shapiro-Wilks test; therefore, non-parametric tests were used to analyse data. The data for age and gender were analysed using descriptive frequency variables. Descriptive variables were used to analyse data on physical function (PF), social function (SF), emotional function (EF), school function (ScF), psychological function (PSF) and HRQoL of this sample group. Non-parametric tests on independent samples analysed included the Kruskal-Wallis test which was used to compare the domains of HRQoL with gender and the number of cardiac procedures on HRQoL. Interview data from Phase 2 were transcribed manually and thematic analysis employed to interpret the data.[10] This *t* method allowed the identifying, analysing and reporting of themes within data. This method emphasised organisation and description of collected data. An inductive approach allowed themes to be linked to the data.[10]

Results

Demographics

A total of 43 children participated in Phase 1; 23 (56.5%) were male and 20 (43.5%) female. The mean age was 10.07, median 10 and standard deviation 1.50. Seven children were interviewed in Phase 2: 4 male and 3 female, with tetralogy of Fallot (ToF) being their most common diagnosis (Tables 1 - 4).

The needs and knowledge of children living with CHD

The themes and quotes identified from interviews are shown in Table 5 to illustrate the qualitative results from Phase 2 of the study. Pseudonyms were used to maintain participant anonymity.

Our study found that both genders had higher PSF than PF. A significant effect (p=0.042) was noted when assessing the effect of the number of cardiac procedures on the PF domain. Phase 2 of the study found that these children demonstrated a relative lack of knowledge about their medical condition and had a need for information and support from family and healthcare professionals.

Discussion

Phase 1

The results of this study are similar to two African studies that identified VSD as the most common CHD.[11,12] and ToF as the most common cyanotic CHD in children.[12] ToF was the most common cyanotic heart defect presenting in early childhood, with surgical correction now routinely performed in the first year of life, giving patients an excellent long-term outlook with over 98% having a 20-year survival rate.[13] In our study, it emerged that boys had a higher overall HRQoL than girls, which contrasts with a study that showed that female gender was positively associated with higher life satisfaction and increased overall QoL.[14] Another study attributed poor PF to lack of knowledge, unrealistic expectations and misconceptions about the subjects' PF, which may be possible reasons for the low PF reported in our study.[15]

Children in the mixed cardiac defect group had lower HRQoL, although not statistically significant. An Iranian study[14] noted that QoL, health satisfaction, physical health and life satisfaction were independently associated with the presence of CHD, while the type of cardiac defect had no independent influence.

Cardiac surgery or hospitalisation, medication, severity of residual lesions and severity of physical limitations all had a negative impact on QoL.[14,16] A previous study noted that a greater number of cardiac interventions over the lifetime have been shown to have a significant negative impact on QoL,[17] which may explain the lower PF domain of HRQoL in children in our study.

Phase 2: Needs and knowledge of participants living with CHD

Participants' needs

Four out of 7 participants noted that they did not need help or assistance with any activities. A German study[18] of 10 - 30-year-olds

Table 1. Common participant characteristics (*N*=43)

Participant characteristics	*n* (%)
Type of CHD	
Tetralogy of Fallot	13 (30.2)
Atrial septal defect	14 (32.6)
Pulmonary stenosis	11 (25.6)
Ventricular septal defect	14 (32.6)
Procedures	
Cardiac catheterisation	24 (55.8)
Cardiac procedure	14 (32.6)

CHD = congenital heart disease.

Table 2. HRQoL in children living with CHD: PedsQL 4.0 scores (*N*=43)

Gender	Data values	PF	EF	SF	ScF	PSF	Total score
Female (*n*=20)	Median	63	80	90	80	79	73
	Minimum	44	30	50	30	43	47
	Maximum	100	100	100	100	97	98
Male (*n*=23)	Median	66	70	95	80	77	74
	Minimum	28	40	20	20	40	46
	Maximum	94	100	100	100	98	97

HRQoL = health-related quality of life; CHD = congenital heart disease; PF = physical function; EF = emotional function; SF = social function; ScF = school function; PSF = psychosocial function.
p-value = 0.585.

Table 3. Influence of the type of cardiac defect on HRQoL

Types of CHD	PF	EF	SF	ScF	PSF	Total score
Cyanotic CHD (*n*=8)	66	90	75	62.5	81	75
Acyanotic CHD (*n*=30)	66	77.5	92.5	80	78	74
Mixed cardiac defect (*n*=5)	63	70	80	75	80	70

CHD = congenital heart disease; HRQoL = health-related quality of life; PF = physical function; EF = emotional function; SF = social function; ScF = school function; PSF = psychosocial function.

Table 4. Effect of the number of cardiac procedures on individual HRQoL domains

Domain of HRQoL	*p*-value
PF	0.042*
EF	0.517
SF	0.089
ScF	0.979
PSF	0.652
Total HRQoL score	0.348

HRQoL = health-related quality of life; PF = physical function; EF = emotional function; SF = social function; ScF = school function; PSF = psychosocial function.
*The effect of the number of cardiac procedures was statistically significant on PF.

Table 5. Needs and knowledge of children living with CHD – themes and quotes arising from interviews

Subthemes (*n*=7)	Quotes arising from Phase 2
Information needs and transition to adult care	'I can describe when I do something, what happens to it [my heart].' (Bongiwe, female, age 9) 'What did they do to my heart?' (Samkelo, male, age 9) 'I don't know [why I see the doctor].' (Zandile, female, age 11) 'Will my heart get better soon or am I going to have another operation when I'm older?'(Bongiwe)
Family and multidisciplinary support	'Sometimes my parents remind me because I forget.' [About medication] (Ben, male, age 12) 'Yes [I need help], at school … at home, homework… [my mum] or my sister [help].' (Bongiwe) '[Healthy food] is the one with the most vitamins but [I don't follow a diet because] I like food.' (Ben)
Knowledge of diagnosis, medical procedures and sources of knowledge	'I don't know [why I see the doctor].' (Zandile) 'To check my heart.' (Zayn, male, age 12) 'When I was small, I had a heart operation, now every July, they give me a date and I must come back, and I have a check-up every year.' (Bongiwe) 'I don't know [what operations I had].' (Zandile) 'Catheterisation, five times. They make a hole in my thigh and put a camera up to my chest to see my heart.' (Ben)
The emotional and physical impact of chronic illness	'I know everything I need, I google it… that a lot of people have the same heart condition but the person that had the biggest heart hole was the size of a 50 cents and they did an operation and got it.' (Ben) 'Sometimes I'm a little bit worried… maybe I could stay at the hospital.' (Bongiwe) 'At school, the children only come and irritate me, and I get angry. Not often, sometimes. They come, and they talk and talk and talk and I don't know what they are saying.' (Ben) 'Sometimes I do have fear but not always.' (Bongiwe) 'Sometimes somethings go wrong and be sad-ish and when my friends tease on me.' (Bongiwe) 'Most of the time I do soccer, I play tennis, ball, I play scores and stuff like that.' (Zayn) "It wasn't sport [that's bad], I must not run… because I get tired.' (Zandile, female, age 11) 'I don't get tired.' (Zayn) 'Because my lungs [and] the pressure thing… I strain myself too much [and] I can't breathe.' (Ben)
The influences of self-management, assistance from caregivers and parental overprotection	'I can't breathe, I take [my] pump because I can breathe a lot. Sometimes I feel dizzy, so I lie down.' (Ben) 'Panado, Demazine or Corenza when I cough and my heart is sore, it beats a lot, you see when I cough [then] my heart is sore.' (Bongiwe) 'Sometimes I feel dizzy so I lie down.' (Ben) 'Eating healthy, fruits and veg, almost like every day, jogging, doing sports regularly and going to the gym.' (Luyanda, female, age 10) 'Sometimes I can't breathe so the teacher makes me sit aside…but it makes it hard for me.' (Ben) 'Sometimes my parents remind me because I forget.' [About medication] (Ben) 'My mum is scared that my heart will beat [fast] and something will happen [if I run] ... I don't know. My mother didn't tell me anything.' (Bongiwe)
Denial and acceptance of living with CHD	'One lady came [from the] hospital to our school once and tested me and my friend, because he has liver disease. His liver is failing. He's going to die soon but they going to do a transplant in a few years and me they tested and said everything is fine, only my breathing … No, I'm fine.' (Ben) 'Others they know and others they don't know [about my heart condition].' (Ayabonga, male. age 12) 'Only my teacher, no [friends] because my mum told me to.' (Bongiwe) 'People that have pressure in their heart, they [doctors] can't do it, when doctors are cutting, the blood will squirt out … No [I don't worry about having a heart condition].' (Ben) 'When we were changing in the change rooms, they saw the scar, line… I told them that I had a heart operation.' (Luyanda)
Interaction with doctors	'They [doctors] normally say "Hi", they don't talk to me, and they speak to my mother.' (Bongiwe) 'The doctor says how I am feeling and how I'm keeping in school.' (Zandile) 'First, they talk to my mother, then if there is a bed then I lie there and they check on my heart.' (Luyanda)

CHD = congenital heart disease.

with CHD noted that children express fewer information needs than adolescents and adults. A Belgium study[19] noted a desire for better quality of information about their medical condition and the process of transfer of care. Our study identified similar information to that in a study of 8 - 19-year-olds with CHD, who were unsure about their condition, and suggested reasons for this as either that they felt they had enough information, or they did not want to receive available information.[20] Likewise, the most important need of patients with CHD was to receive information about their illness, regarding the symptoms and course of the illness and to clarify any doubts they may have.[21]

A shift in roles between parents and themselves was acknowledged in children with CHD.[19] The client and family caregiver should be provided with both an explanation about the condition, progression, prevention, and management of symptoms, as well as the importance of regular follow-up, so as to encourage the client to learn health-related self-management behaviours.[21] In contrast to the present study, school-age children between 8 and 13 years old were noted to be increasingly knowledgeable about their chronic conditions and exhibited adequate skills to manage their activities. It is recommended that children develop self-care before adolescence, when there is a decline in self-management.[22]

Parental involvement in their child's care is fundamental, and at the same time the parents, as caregivers, might need support for facilitating their adolescents becoming independent and autonomous.[1] School performance of children with CHD is often impaired, and they usually fall behind in their school performance compared with their healthier schoolmates, owing to treatment processes involving hospital admissions and absence from school,[23] which may be the norm for our participants. Survivors of paediatric cardiac surgery required support services that included physical, occupational and speech therapy throughout their lives, which reinforced the need for a multidisciplinary team approach in managing patients with CHD.[24] Children experienced uncertainty about physical activity, and found it difficult to manage the physical aspects of their daily lives, if they were not given individualised information about how much physical activity they could participate in, without an adverse effect on their heart.[25] An SA study, involving under-2-year-olds with CHD and their parents, recommended developmental and psychosocial support services as a way to improve outcomes in children with CHD and their families.[11]

Knowledge of medical condition

Children are not always knowledgeable about their heart defect, with some having little understanding of their medical condition,[19] which was also the case with the participants in our study. A Canadian study[26] noted possible reasons for this as some patients not liking to think or talk about their heart, not understanding information from their doctors or information was difficult to understand because it was delivered rapidly.[1] Another possible reason for the poor knowledge of participants in our study was that patients' information needs were not met by the doctors. A possible reason for this is that doctors chose to address the parents, rather than the children themselves.[18] Poor knowledge and understanding of their heart condition in adolescents appeared to influence their HRQoL.[27] Ben was the only participant in our study who used the internet; however, it is difficult to validate the source and reliability of information from the internet because education thus obtained is considered as being of uncertain value.[25]

Participants expressed a variety of emotions during their interviews that included fear, sadness, worry and anger. A large proportion of patients with CHD experienced psychological symptoms such as depression, anxiety, loneliness, behavioural problems and concentration difficulties.[28] Anxiety and depression could be attributed to recurrent hospitalisations, daily chronic medication and limitations on activities as a result of their illness.[23] Participants interviewed reported enjoying social sport activities with friends and siblings, which may be due to children having an innate need to be physically active. It has been suggested that children should be advised to participate in a large variety of activities to develop proper exercise habits, motor coordination, aerobic capacity, muscle strength, mental development and QoL.[29] Two participants, Bongiwe and Zandile, who noted that running was 'bad', were misinformed or incorrect, and this could be as a result of poor comprehension or parental overprotection or, as a UK study[30] suggested, children did not know the safe level of activity for their condition. Parents underestimating their child's physical ability could impose unnecessary restrictions on their child, thus depriving the child of the health and psychological benefits of exercise.[31] However, some children like Ben, who was diagnosed with Eisenmenger and pulmonary hypertension, need restrictions in activities and physical education at school. Playing inappropriate contact sports by choice may put children with chronic illness at significant risk of death, but some children were unaware of the danger.[30] Some participants in the present study understood their limitations as well as the repercussions on their health if they 'strained' themselves. While some participants in our study attempted to complete tasks independently, it is vital that patients are aware of their specific symptoms associated with the complications to which they are susceptible and know what actions to take if these symptoms present.[26] A good level of disease-specific knowledge has also been found to enhance treatment compliance.[18] Living with physical limitations may be frustrating, and sometimes the environment can result in restrictions such as those posed by overprotective parents and teachers.[1] In our study, participants who had the same diagnosis and similar management viewed parents' involvement in their life situations differently, e.g. some participants noted their parents' involvement in their healthcare decisions, which they felt were required. Parents nurturing their children, and a higher level of psychosocial maturity and autonomy, have been associated with better-perceived mental health status and QoL.[32]

In some cases, lack of knowledge can make it difficult for children with CHD to explain their cardiac condition to others,[20] which is why participants in our study may have chosen not to inform others, and hence the denial aspect with chronic illness. Providing teachers or employers with accurate information about the disease, including instructions on medication, exercise and work should be communicated timeously.[21] Interactions with peers revealed peer interest in their condition and, once peers had some information, they tended not to treat children with CHD any differently,[20] which was true for Luyanda, who informed her friends about her sternotomy scar, thus showing acceptance of her condition. Ben's understanding of his condition showed a level of maturity, describing how a friend's poor medical outlook would not affect him, despite the severity of his own condition. While maintaining a sense of personal privacy, the perspectives of patients and their parents regarding disease disclosure should be respected,[21] while it was also important that patients be provided with realistic evidence-based advice on their prognosis.

None of the participants in this study communicated directly or interacted with the doctor about their medical condition or treatment. Similarly, a German study[18] found that doctors communicated primarily with the parents and not directly with the child with CHD. Cardiologists interviewed in a previous study, stressed the importance of good communication when meeting families, but their strategies for facilitating such communication varied in terms of structure, relationship and degree of formality, and consisted of providing factual information to evaluate the emotional factors.[29] It has been proposed that education on CHD, QoL and self-care must begin during the school-age period if the child is to have the best opportunity to succeed in assuming responsibility for their own care as adults.[33]

Study limitations

The study was conducted in a specific age group in one hospital, which may have contributed to the relatively small sample size; this limits the generalisability of our findings and further resulted in limited statistical significance in the overall HRQoL measures of children with CHD. The results are still noteworthy, given the lack of evidence related to the HRQoL of SA children within this age group living with CHD.

Conclusion

The present study found that both genders had higher PSF and that the number of cardiac procedures had a significant influence (p=0.042) on the PF domain of HRQoL. These children demonstrated a relative lack of knowledge about their medical condition and its management. Participants demonstrated limited autonomy, but they had an overwhelming trust in their parents to take charge of medical

decisions, which was necessary for the children. Participants' needs were focused on receiving appropriate information about their condition and good support structures. Recommending the use of HRQoL measures may be beneficial in the clinical management of children with CHD, as well as the ability of health professionals and parents to meet these individuals' needs more holistically.

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