OUTCOME AFTER PALLIATIVE CARDIAC SURGERY IN A DEVELOPING COUNTRY

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D E C L A R A T I O N

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ABSTRACT

The outcome of 121 children who underwent palliative cardiac surgery at the Red Cross War Memorial Children's Hospital over a 5 year period, 1980 - 1984, was retrospectively examined. 79 children had systemic artery to pulmonary artery shunt operations (SPS), 40 had pulmonary artery bands (PAB) and 2 had surgical septectomies. SPS was most often done for children with Tetralogy of Fallot (TOF, 26 cases) or complex univentricular hearts with right ventricular outflow tract obstruction (27 cases). PAB was done chiefly for ventricular septal defects, alone (VSD, 8 cases) or with coarctation of the aorta (9 cases). Children were referred from a wide area with 63 cases being referred from other major centres and foreign countries.

Overall, 36 children died (30 % mortality): 5 died at surgery, 6 within 48 hours of surgery, a further 5 within 31 days; and 20 died after 31 days. SPS and PAB had the same early mortality rates (13 %). SPS had higher late and overall mortality rates (20 and 33 %) than PAB (10 and 23 %). Age at operation was found to be the most significant determinant of the overall mortality rate: children less than six months had a mortality of 42 % and those over 6 months, 13 %. The children were grouped into those with lesions which were probably correctable and those that were

unlikely to be so, based on diagnosis and age at surgery: those with correctable lesions had a lower overall mortality (22 %) than those with uncorrectable lesions (43 %). Where the surgery was performed as an emergency, there was a higher overall and early mortality (55 and 35 % respectively), compared to those operations which were performed electively (25 and 9 %). The presence of other medical conditions, for example congenital abnormalities and infections, was also a determinant of death (44 % mortality if other medical condition present, 26 % if absent).

Sex, population group, home address and type of surgery performed did not significantly affect mortality when examined by multivariate analysis.

Using routine methods of follow up, it was initially thought that 17 % of all patients (22 % of survivors) were lost to follow up. An important determinant of this was the referral centre. 31 % of cases from other major centres and 20 % of foreign cases were lost, as compared to 8 % of cases from smaller towns near Cape Town and 2 % of children from Cape Town. Population group (35 % Blacks, 14 % Coloureds and 7 % Whites were lost), and palliative operation (23 % SPS, and 5 % PAB lost) were also significant determinants.

It was possible to trace 12 of the 20 children who were thought to be lost to follow. 8 had died, 3 were still

awaiting correction and 1 was traced and received corrective surgery.

The records of the children who underwent cardiac surgery in 1987 were also analysed. There was no difference in the demographic characteristics of either group, and the early mortality was the same.

This study shows that the outcome after palliative cardiac surgery is poor, with a high mortality rate and children often being lost to follow up. The decision to palliate rather than to correct a congenital heart defect must be made after balancing these risks with those of early correction for the particular surgical team. Should palliative surgery be undertaken, careful follow up is essential to ensure that complications of palliation do not set in and that corrective surgery is done at the optimal time.

CHAPTER 1

INTRODUCTION

The operative management of infants and young children with congenital heart disease has improved greatly over the past four decades[1 - 6]. Surgical correction of the underlying anatomical abnormality (definitive surgery) may be complex in the very young and is often associated with high mortality and morbidity. In these circumstances, definitive surgery may be deferred until later, when, once adequate growth has occurred, the risks of surgery are reduced. However, many of these children require early intervention and are therefore palliated either medically or surgically so that, with improved functional capacity, growth might occur and later correction might prove to be less hazardous.

The palliative operations include those that are designed to improve the blood flow to the lungs, to limit the pulmonary blood flow (with the aim of preventing pulmonary hypertension and the irreversible vascular changes which occurs with it), or to allow adequate mixing of saturated and desaturated blood[7].

In conditions with restricted pulmonary blood flow, systemic oxygen saturation can be improved by **increasing blood flow to the lungs.** This can be achieved by means of

a systemic-pulmonary artery shunt (SPS) or a right ventricular outflow tract patch. The end-to-side anastomosis of the subclavian to the pulmonary artery was described by Blalock and Taussig in 1945[8]. Since then other types of SPS have been described, for example central SPS (directly from the aorta to the pulmonary artery), but these have had problems with distortion of the pulmonary arteries, uneven growth, excessive blood flow and myocardial failure[7]. Synthetic materials were introduced in 1975 to create central SPS[9] and in Great Ormond Street Hospital these were later used to connect the subclavian artery to the pulmonary artery (the Modified Blalock-Taussig Shunt, MBTS)[10, 11]. The MBTS appears to be as good as, if not better[12 - 15] than the classic Blalock-Taussig Shunt (BTS) and is technically easier to do, especially where the subclavian artery is too short to reach the pulmonary artery. The operative mortality of SPS operations varies from 3% to 23%[12 - 18] but should now be less than 5% overall[7]. Most MBTS should remain patent for more than three years after operation but early SPS failure is dependent on size of SPS inserted and age of patient at the time of palliation[17, 18]. Good follow up is necessary not only to ensure that SPS occlusion (due to thrombosis, infective endocarditis or kinking of the graft) does not take place, but also to monitor and prevent distortion of the pulmonary arteries and stenosis at the suture line.

Children with excessive pulmonary blood flow, due to left to right shunts are at risk from cardiac failure, recurrent chest infections and the development of pulmonary artery hypertension. **Pulmonary artery bands** (PAB) were introduced by Muller and Dammann in 1952[19] as a method of reducing pulmonary hypertension and excessive pulmonary blood flow in children with large left-to-right shunts. A synthetic band (of Gore-Tex[20], Teflon[21], umbilical tape[4] or other material) is placed around the main pulmonary artery and tightened whilst measuring the distal pulmonary artery pressure. The PAB is then secured to the adventitia to prevent distal migration. Mortality varies from about 7% to 30%[4, 20, 21] and is mostly dependent on associated cardiac anomalies[4, 21]. With adequate palliation, irreversible pulmonary hypertension is prevented and improved growth should occur; corrective surgery can then be undertaken at an older age. At this stage the PAB can be removed.

In conditions with separate, unconnected systemic and pulmonary circulations, a septectomy may be necessary to allow adequate **mixing** to occur. Such a patient may have transposition of the great arteries (TGA) with intact ventricular septum where balloon septostomy has been inadequate. A SPS may also have to be made to improve mixing in cases where there is TGA with left ventricular outflow tract obstruction.

In the management of a child with congenital heart disease the goal should be total correction of the anatomical abnormality and restoration of functional capacity to within normal limits. In other words, the ultimate goal must be total correction. Conceptually, however, 'corrective' surgery for complex lesions may mean definitive palliation in that functional capacity is seldom restored to normal limits[22].

It should be realised that true corrective cardiac surgery in congenital heart disease is essentially limited to ligation of patent ductus arteriosus (PDA) and closure of atrial septal defects (ASD)[22]. Even repair of coarctation of the aorta is frequently associated with cardiovascular disease when reviewed after 25 years. The follow up period for surgery for congenital heart disease is relatively short (20 - 30 years): "corrective" surgery should therefore not be considered curative. With this in mind, however, it is still important to differentiate those operations which can be considered definitive from those which are merely palliative and a first stage procedure prior to eventual definitive surgery. In this dissertation, the terms "definitive" and "corrective" are used interchangeably: the definitions used are given in Appendix 1.

In the past, when the risks associated with early definitive repair were very high, there was little doubt

that palliation, with the lower risks, was justified. If palliation was successful, the child could then undergo corrective surgery at a later date.

With improved results after definitive surgery, the case has become less clear. The palliated child undergoes the combined risk of palliation, of the interim period between palliation and correction, and of corrective surgery itself, before he reaches his goal of total correction.

Palliative surgery itself carries significant risks, and there is a significant mortality in children awaiting definitive repair. SPS might thrombose, stenose or become infected and further palliation may be needed. PAB might become too restrictive, erode the pulmonary artery, slip thereby occluding the left or right pulmonary artery, or be too loose resulting in residual pulmonary hypertension[6].

In a developing country, the morbidity associated with palliative operations is further compounded by the problem of poor follow up[15] in the period between palliation and correction. Patients are referred from distant referral centres and may not return regularly. They may become acutely ill and may not be able to return to the surgical unit in time. The socio-economically disadvantaged do not have easy access to medical care. One would expect from this alone that the outcome after palliation would be worse than in a developed country.

In developed countries, with improved results of corrective surgery in the very young, the trend has been towards earlier definitive repair[1, 2, 3, 7, 23].

The equation whereby the combined risks of early palliation and later correction is weighed up against the risk of early correction needs constant re-evaluation in the light of improvements in the results after early correction[5, 6].

To determine this, the outcome of palliation needs to be known. This study examines this aspect of the equation. It does not address the question about the risks of correction - either early or late. The fact that the children were palliated precludes them from assessment of risks early correction. To determine the risks of late correction it would have been necessary for all the palliated children to have undergone correction. The study period is too short to expect this to have occurred here.

The group of children whose records were retrospectively examined underwent their first palliative operation during the period 1 January 1980 to 31 December 1984.

CHAPTER 2

AIMS AND OBJECTIVES

AIMS

To determine the outcome after palliative cardiac surgery in a developing country.

OBJECTIVES

1. To assess the effectiveness of palliative cardiac surgery in a developing country by:

    a. Determining the early and late mortality of children who underwent palliative cardiac surgery.

    b. Determining the risk factors associated with death after palliation.

    c. Determining the number of children in other outcome groups, namely inoperable, transferred, awaiting definitive repair and corrected.

2. To assess means of improving follow up after palliative cardiac surgery by:

   a. Determining the number of the survivors who were lost to follow up.

   b. Determining the risk factors associated with the children who were lost to follow up.

   c. Contacting the parents of children who were lost to follow up, determining the outcome, and re-establishing medical care.

CHAPTER 3

METHODS

PART I: Objectives 1, 2 (a), 2 (b)

The names and folder numbers of all children who underwent any palliative operation during the 5 year period 1 January 1980 and 31 December 1984 were obtained from the operation book which lists all cardiac operations performed at the Red Cross War Memorial Children's Hospital. The hospital folders and cardiology notes were then examined and details recorded on all children who underwent their first palliative operation during that period.

Definitions used are given in Appendix 1.

Data extracted are given in Appendix 2: this included demographic details, date of initial presentation, diagnosis, date of initial palliation, procedure performed and details of post-operative course and outcome. From the data, various calculations were performed and these are also given in Appendix 2.

The data were entered onto a computer data base and analysed by univariate and multivariate models to determine differences between various groups and to determine the

effect of various risk factors on actuarial survival. The assistance of Dr Robert Schaal of the Institute of Biostatistics (Medical Research Council, Tygerberg) was obtained.

The cardiology computer data base was accessed and the number of palliative operations and the early mortality rates for 1987 was determined. A comparison of the two time periods (1980 - 1984, and 1987) was then done.

PART II: Objective 2 (c)

Patients identified as having been lost to follow up were actively sought by the following means:

1.1 Letters and forms were sent to

a) parents
b) referring agency, where applicable
c) farm owners, where applicable.

These letters and forms were sent in the home language of parents (or in English if foreign). The details of the form which they were requested to complete are given in Appendix 3 and deal mainly with outcome.

1.2 For those who were not traced by the above method, the researcher attempted to exclude an outcome of death by approaching the Department of Home Affairs to determine if any of these deaths had been registered.

Contact with the parents was thereby established in those with whom contact had been lost.

CHAPTER 4

RESULTS

1. ALL PATIENTS:

22 children underwent initial palliative cardiac surgery during the five year period 1 January to 31 December 1984.

One child who underwent a Brock procedure was excluded from the study as he came from Rumania and was unlikely to return for corrective surgery in Cape Town. This left 121 patients for analysis.

Details of the data collected are given in Appendices 4 - 11.

The number of operations (palliative and total) performed each year is presented in Table 1. An increasing percentage of palliative operations, as a percentage of all cardiac operations, was performed over the study period (chi-square for trend = 14,23, 1 degree of freedom, p = 0,0002).

TABLE 1 : PATIENTS BY YEAR OF PALLIATIVE OPERATION

Year	Total Cardiac Operations	First Palliative Operation No. (%)
1980	174	5 (2,9)
1981	222	21 (9,4)
1982	235	31 (13,2)
1983	231	23 (10,0)
1984	244	41 (16,8)
Total	**1106**	**121 (10,9)**

Fifty seven percent of cases were male (See Table 2). The most common population group seen was Coloured, which accounted for 55% of the total. This group would also include any Asians and Mauritians, as they are classified as Coloured by the hospital. Twenty four percent were White Caucasian and only 21% were Black.

TABLE 2 : PATIENTS BY SEX AND POPULATION GROUP

Population group	Sex		
	Male	Female	Total
	No. (%)		
Coloured	40 (33)	26 (21)	**66 (55)**
White	14 (12)	15 (12)	**29 (24)**
Black	15 (12)	11 (9)	**26 (21)**
Total	**69 (57)**	**52 (43)**	**121 (100)**

The patient's home address and referring centre was recorded (Table 3). Thirty seven percent came from the immediate vicinity of Cape Town, and a further 40% from other major referral centres, chiefly

East London (17%). Those from elsewhere in South Africa (11%) were from smaller towns, all in the Cape Province. Twelve percent of the children came from foreign countries (one patient from Namibia/SWA was included in this group).

TABLE 3 : PATIENTS BY REFERRING CENTRE

Address		Patients (% of total)
Cape Town		**45 (37)**
Other major centres		**48 (40)**
East London	21 (17)	
Port Elizabeth	10 (8)	
George	7 (6)	
Kimberley	6 (5)	
Durban	4 (3)	
Elsewhere in South Africa		**13 (11)**
Foreign		**15 (12)**
Zimbabwe	4 (3)	
Mauritius	6 (5)	
Botswana	3 (2)	
Other	2 (2)	
Total		**121 (100)**

Diagnoses were made at catheterization in all cases, and are presented in Table 4. These were grouped into those with inadequate pulmonary blood flow (60%), excessive pulmonary blood flow (30%) and transposition of great arteries (10%) where the major problem is one of inadequate mixing of saturated and desaturated blood.

Common mixing disorders occurred with both restrictive and unrestricted pulmonary blood flow and accounted for 42% of cases. These were chiefly univentricular hearts (UVH, 26%), double outlet right ventricle (DORV, 8%) and atrioventricular septal defects (AVSD, 6%). Two of the eight children with AVSD were noted at cardiac catheterisation to have a partial defect, and both required PAB for pulmonary hypertension. A frequent cause of right ventricular outlet obstruction (RVOFTO) was Tetralogy of Fallot (TOF) which accounted for 21% of all palliated cases. Ventricular septal defects (VSD, 7%) and coarctation syndrome (usually with VSD, 7%) were relatively infrequent causes of palliative surgery.

TABLE 4 : PATIENTS BY DIAGNOSIS

Diagnosis	Patients No. (%)	
1. Inadequate pulmonary blood flow		**73 (60)**
i. Tetralogy of Fallot	26 (21)	
ii. Pulmonary atresia	14 (12)	
iii. Univentricular heart with RVOFTO	27 (22)	
iv. Atrioventricular septal defect with RVOFTO	2 (2)	
v. Double outlet right ventricle with RVOFTO	4 (3)	
2. Excessive pulmonary blood flow		**36 (30)**
i. Ventricular septal defect (VSD)	8 (7)	
ii. Coarctation syndrome	9 (7)	
iii. Tetralogy with LPA from the Aorta	1 (1)	
iv. Atrioventricular septal defect	6 (5)	
v. Double outlet right ventricle	6 (5)	
vi. Univentricular heart	5 (4)	
vii. Truncus arteriosus	1 (1)	
3. Transposition of great arteries		**12 (10)**
i. With VSD	9 (7)	
ii. Without VSD	3 (2)	
TOTAL		**121(100)**

The age at which the palliative operation was performed is given in Table 5, with a average of 11,9 months and a mode of 3 months (monthly intervals). The youngest child to be operated on was 3 days old and the oldest was 8,3 years.

TABLE 5 : AGE AT PALLIATIVE OPERATION

Age	Patients No. (%)
< 1 month	11 (9)
1 - < 6 months	61 (50)
6 - < 12 months	19 (16)
1 - < 2 years	14 (12)
2 - < 5 years	11 (9)
5 years and older	5 (4)
Total	**121 (100)**

The palliative operation performed is tabulated in Table 6. The majority were systemic to pulmonary artery shunt procedures (65%). Pulmonary artery bands made up 33% of all palliative procedures. Surgical septectomies were performed on 2 cases, where septostomies had failed to adequately palliate.

TABLE 6 : PATIENTS BY PALLIATIVE OPERATION

Palliative Operation	Number of Procedures No. (%)
SPS*	80 (65)
PAB	40 (33)
Septectomies+	3 (2)
Total	**123 (100)**

* One patient had PAB and SPS
\+ One patient had PAB and septectomy

2. SYSTEMIC TO PULMONARY ARTERY SHUNTS

There were 79 SPS operations. Of these the modified Blalock-Taussig Shunt (MBTS) was the most frequent (63%, see Table 7). 22 percent were 'classic' Blalock-Taussig Shunts (BTS). 11 patients (14% of SPS) were central aorto-pulmonary shunts. One patient received a shunt between the subclavian artery and a major aorto-pulmonary collateral artery (MAPCA) because the pulmonary arteries were too poorly developed.

TABLE 7 : SPS OPERATIONS

SPS	Patients No. (%)
MBTS*	50 (63)
BTS+	17 (22)
Aorto-pulmonary	11 (14)
Subclavian-MAPCA°	1 (1)
Total SPS	**79 (100)**

* Modified Blalock-Taussig Shunt
\+ 'Classic' Blalock-Taussig Shunt
° Major aorto-pulmonary collateral artery

The years in which these operations were done is shown in Table 8. Only three SPS operations were done in 1980.

TABLE 8 : SPS BY YEAR

Year	Patients (% of SPS)
1980	3 (4)
1981	16 (20)
1982	25 (32)
1983	11 (14)
1984	24 (30)
Total	**79 (100)**

The sex ratio is given in Table 9. Forty eight (61%) of the children receiving SPS were boys, a similar proportion to the overall group. The ratios of the population groups were also similar to the overall group. There were, however, slightly fewer whites in the SPS group (19% as compared to 24% in the overall cohort), but this did not reach statistical significance (chi-square = 0,89 on 1 degree of freedom, p = 0,34).

TABLE 9 : SPS BY SEX AND POPULATION GROUP

Population group	Sex		
	Male	Female	Total
	No. (% of all SPS)		
Coloured	28 (35)	17 (22)	**45 (57)**
White	9 (11)	6 (8)	**15 (19)**
Black	11 (14)	8 (10)	**19 (24)**
Total SPS	**48 (61)**	**31 (39)**	**79 (100)**

The referral centres of children requiring SPS are given in Table 10. Other major centres contributed more children who required SPS than other operations (chi-square = 7,50 on 3 degrees of freedom, p = 0,058).

TABLE 10 : SPS BY REFERRING CENTRE

Address		**SPS No. (%)**
Cape Town		**23 (29)**
Other major centres		**36 (46)**
East London	14 (18)	
Port Elizabeth	9 (11)	
George	5 (6)	
Kimberley	4 (5)	
Durban	4 (5)	
Elsewhere in South Africa		**8 (10)**
Foreign		**12 (15)**
Zimbabwe	2 (3)	
Mauritius	6 (8)	
Botswana	3 (4)	
Other	1 (1)	
Total SPS		**79 (100)**

The majority of SPS (92%) were performed for inadequate pulmonary blood flow (See Table 11), with a further 6 to improve mixing in transposition of great arteries. The type of operation is obviously dependant on the diagnosis (chi-square = 107,76, on 2 degrees of freedom, $p < 0,00001$.

TABLE 11 : SPS BY DIAGNOSIS

Diagnosis	Patients No. (%)
1. Inadequate pulmonary blood flow	**73 (92)**
i. Tetralogy of Fallot	26 (33)
ii. Pulmonary atresia	14 (18)
iii. Univentricular heart with RVOFTO	27 (34)
iv. Atrioventricular septal defect with RVOFTO	2 (3)
v. Double outlet right ventricular wit RVOFTO	4 (5)
2. Transposition of great arteries	**6 (8)**
i. With VSD	5 (6)
ii. Without VSD	1 (1)
Total SPS	**79 (100)**

The age at which the operation was performed is given in Table 12. The average age was 14,1 months with a mode of 3 months (monthly intervals) and a range of 3 days to 8,3 years.

TABLE 12: SPS BY AGE AT PALLIATIVE OPERATION

Age	Patients No. (%)
< 1 month	9 (11)
1 - < 6 months	33 (42)
6 - < 12 months	11 (14)
1 - < 2 years	12 (15)
2 - < 5 years	9 (11)
5 years and older	5 (6)
Total SPS	**79 (100)**

3. PULMONARY ARTERY BANDS:

40 pulmonary artery bands were done, accounting for 33% of all palliative procedures. The procedure done is given in Table 13. Eight of the procedures were performed in conjunction with coarctation repair and 3 with ductus arteriosus ligation. Included in the group is one patient who had the pulmonary artery plicated (and not 'banded') and another who received PAB and SPS for transposition of the great arteries with a VSD.

TABLE 13 : PULMONARY ARTERY BAND OPERATIONS

PAB	**Patients No. (% of PAB)**
PAB* alone	24 (60)
With coarctation repair	8 (20)
With PDA+ ligation	3 (8)
Left PAB only	1 (3)
With SPS°	1 (3)
With septectomy	1 (3)
With pacemaker	1 (3)
Plicate and coarctation repair°	1 (3)
Total PAB	**40 (100)**

* Pulmonary artery band
\+ Patent ductus arteriosus
° See text

The years in which the PAB was done are given in Table 14. Only 1 PAB was done in 1980 and then an increasing number were done in ensuing years.

TABLE 14 : PAB BY YEAR OF PALLIATIVE OPERATION

Year	PAB (% of total PAB)
1980	1 (3)
1981	5 (13)
1982	6 (15)
1983	12 (30)
1984	16 (40)
Total PAB	**40 (100)**

More girls (53%) than boys had PAB (see Table 15), the reverse of the situation in the SPS operations, but statistically not significant (chi-square = 1,67 on 1 degree of freedom, p = 0,20). The distribution amongst the population groups was similar to the overall group.

TABLE 15 : PAB BY SEX AND POPULATION GROUP

Population group	Sex		
	Male	Female	Total
	No. (% of all PAB)		
Coloured	11 (28)	9 (23)	**20 (50)**
White	4 (10)	9 (23)	**13 (33)**
Black	4 (10)	3 (8)	**7 (18)**
Total PAB	**19 (48)**	**21 (53)**	**40 (100)**

The majority of PAB operations, 53%, were done on patients from the immediate Cape Town area (Table 16). This association

did not reach the conventional levels of statistical significance (chi-square = 7,32 on 3 degrees of freedom, p = 0,062).

TABLE 16 : PAB BY REFERRING CENTRE

Address		Patients No. (%)
Cape Town		**21 (53)**
Other major centres		**11 (28)**
East London	7 (18)	
Port Elizabeth	1 (3)	
George	1 (3)	
Kimberley	2 (5)	
Durban	0 (0)	
Elsewhere in South Africa		**5 (13)**
Foreign		**3 (8)**
Zimbabwe	2 (5)	
Mauritius	0 (0)	
Botswana	0 (0)	
Other	1 (3)	
Total PAB		**40 (100)**

Diagnoses of children who received PAB are given in Table 17. Four children (10%) had transposition of great arteries and ventricular septal defect, the rest had excessive pulmonary blood flow due to left to right shunts or common mixing disorders.

TABLE 17 : PAB BY DIAGNOSIS

Diagnosis		Patients No. (%)
1 Excessive pulmonary blood flow (90)		**36**
i.	Ventricular septal defect	8 (20)
ii.	Coarctation syndrome	9 (23)
iii.	Tetralogy, LPA from Aorta	1 (3)
iv.	Atrioventricular septal defect	6 (15)
v.	Double outlet right ventricle	6 (15)
vi.	Univentricular heart	5 (13)
vii.	Truncus arteriosus	1 (3)
3. Transposition of great arteries (10)		**4**
i.	With VSD	4 (10)
Total PAB (100)		**40**

Table 18 gives the age of children at the time of PAB operation. The average age was 6,7 months, the mode was 4 months (monthly intervals) and the range was 19 days to 3,5 years. The majority of PAB operations (70%) were done before the age of 6 months (chi-square = 2,12 on 1 degree of freedom, p = 0,14, comparing PAB with other palliative operations).

TABLE 18 : PAB BY AGE AT PALLIATIVE OPERATION

Age	**Patients No. (%)**
< 1 month	2 (5)
1 - < 6 months	26 (65)
6 - < 12 months	8 (20)
1 - < 2 years	2 (5)
2 - < 5 years	2 (5)
5 years and older	0 (0)
Total PAB	**40 (100)**

4. OUTCOME

The children were categorised according to outcome. The initial outcome categories, determined from the records and cardiology notes available, are given in Table 19A. Once the attempts to trace the patients who were deemed to be lost from follow up were completed, the outcome categories were revised and are given in Table 19B.

TABLE 19A : OUTCOME CATEGORIES

	Patients : No (%)			
	SPS	**PAB**	**Septectomies**	**Total**
Palliative death	18 (23)	9 (23)	1 (50)	**28 (23)**
Inoperable	4 (5)	3 (8)	0 (0)	**7 (6)**
Awaiting correction	15 (19)	9 (23)	0 (0)	**24 (20)**
Lost to follow up	18 (23)	2 (5)	0 (0)	**20 (17)**
Corrected	21 (27)	16 (40)	1 (50)	**38 (31)**
Transferred	3 (4)	1 (3)	0 (0)	**4 (3)**
Total	**79 (100)**	**40 (100)**	**2 (100)**	**121 (100)**

TABLE 19B : REVISED OUTCOME CATEGORIES

	Patients : No (%)			
	SPS	**PAB**	**Septectomies**	**Total**
Palliative death	26 (33)	9 (23)	1 (50)	**36 (30)**
Inoperable	4 (5)	3 (8)	0 (0)	**7 (6)**
Awaiting correction	17 (22)	10 (23)	0 (0)	**27 (22)**
Lost to follow up	7 (9)	1 (3)	0 (0)	**8 (7)**
Corrected	22 (28)	16 (40)	1 (50)	**39 (32)**
Transferred	3 (4)	1 (3)	0 (0)	**4 (3)**
Total	**79 (100)**	**40 (100)**	**2 (100)**	**121 (100)**

Twenty patients (17% of the overall group, 22% of the survivors) were initially thought to be lost to follow up (Table 19A) in that there was no record of them having been seen or heard from for at least a two year period during which they should have returned. Factors important in determining the outcome lost to follow up will be examined later. Once efforts at tracing the patients were made, the number who remained lost to follow up was only 8 (7% of the overall group, and 9% of the survivors).

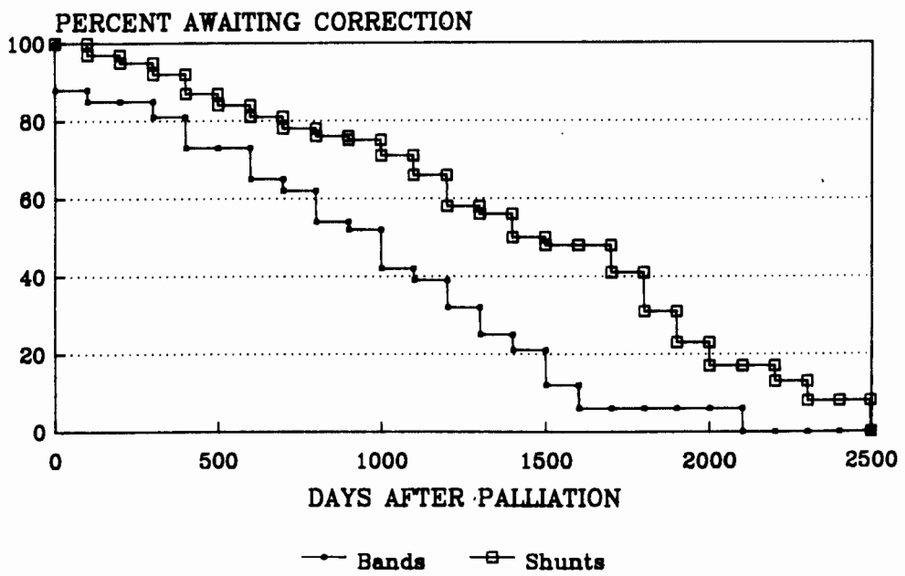
The revised outcome categories (Table 19B) were used in the analysis on mortality (palliative deaths). The original outcome categories (Table 19A) were used in determining which factors played a role in the outcome lost to follow up.

Overall, 32% of the original group (46% of the survivors) had definitive surgery. When considering only the two categories, corrected and awaiting correction, PAB (16/26 = 62%) was more likely to have been corrected than was SPS (22/39 = 56%) but this was not statistically significant (chi-square = 0,02 on 1 degree of freedom, p = 0,88).

The time between palliation and correction was shorter for PAB than for SPS. This is illustrated in Figure 1. Only patients who were corrected or who were awaiting correction were considered - children who were inoperable, or who died after palliation or who transferred to other units were excluded. Shown is the percentage awaiting correction against the interval between palliation and correction

for PAB and for SPS. The follow up period has been taken into account for those patients who are still awaiting correction. There are therefore fewer patients as the period after palliation increases. Not all patients have been corrected: those who are still awaiting correction have fallen out of the follow up period shown on the figure. The mean and standard deviation of time to palliation for those patients who underwent correction is 642 ± 462 days for PAB (n = 16), and 1175 ± 666 days for SPS (n = 22), p = 0,009 (Student's t-test).

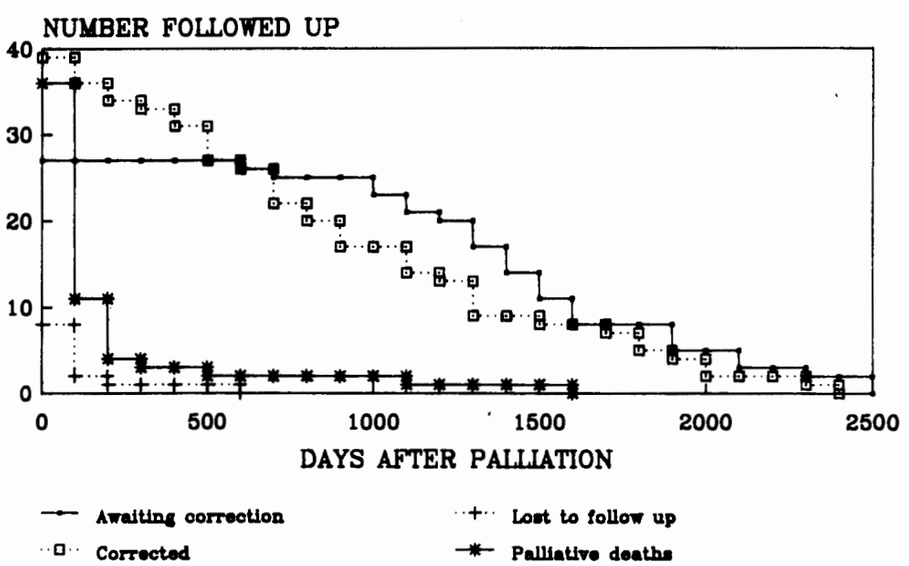
FIGURE 1: TIME TO CORRECTION: PAB AND SPS



4 patients transferred to other units, 7 were deemed inoperable (it was felt that they were not suitable for definitive repair) and 27 patients were awaiting correction. This last category amounted to 22% of the overall group and 32% of the survivors.

An indication of the follow up period is given in Figure 2. Shown is the number of patients still being followed up by the period following palliation for the outcome categories listed. Once a patient underwent corrective surgery, he was excluded from follow up for the purposes of this study: the period shown for those patients is therefore the interval between palliation and correction (average 941 days). Patients who were lost to follow up had short follow up periods (average 115 days). Palliative deaths usually occurred early in the follow up period (average of 135 days). Those awaiting correction were followed up for an average of 1487 days with a range of 542 - 2518 days.

FIGURE 2: FOLLOW UP PERIOD BY OUTCOME CATEGORY



The outcome categories "palliative deaths" and "lost to follow up" will now be examined in greater depth.

4.1 Palliative Deaths

Palliative deaths, including all children who died before any definitive surgery could be performed, accounted for 30% of all patients. These do not include children who may have died after corrective surgery.

The time of death is given in Table 20. The early mortality rate (deaths within 30 days of operation) was 13%, and a further 17% are known to have died after 30 days after operation (late mortality). Almost all of children who died in hospital (89%) died within 30 days.

TABLE 20 : DEATHS IN OR OUT OF HOSPITAL BY SURVIVAL TIME

Survival time	No of deaths (% of total) In hospital	Out of hospital	Total	Mortality Rate (n = 121) %
≤ 30 days	16 (44)	0 (0)	**16 (44)**	**13**
> 30 days	2 (6)	18 (50)	**20 (56)**	**17**
Total	**18 (50)**	**18 (50)**	**36 (100)**	**30**

The individual figures of SPS and PAB are given in Table 21 and Table 22 respectively. The early mortality for SPS and PAB was the same (13%). The late mortality was higher for patients who had SPS (20%) than for those that had PAB (10%), but this was not significant (chi-square = 0,90 on 1 degree of freedom, p = 0,34.)

TABLE 21 : SPS DEATHS IN OR OUT OF HOSPITAL BY SURVIVAL TIME

Survival time	No of SPS deaths (% of SPS deaths) In hospital	Out of hospital	Total	Mortality Rate (n = 79) %
≤ 30 days	10 (38)	0 (0)	10 (38)	13
> 30 days	0 (0)	16 (62)	16 (62)	20
Total	**10 (38)**	**16 (62)**	**26 (100)**	**33**

TABLE 22 : PAB DEATHS IN OR OUT OF HOSPITAL BY SURVIVAL TIME

Survival time	No of PAB deaths (% of PAB deaths) In hospital	Out of hospital	Total	Mortality Rate (n = 40) %
≤ 30 days	5 (56)	0 (0)	5 (56)	13
> 30 days	2 (22)	2 (22)	4 (44)	10
Total	**7 (78)**	**2 (22)**	**9 (100)**	**23**

The causes of death are given in Table 23. 31 percent of all deaths occurred within 48 hours of operation. Chest infections accounted for five deaths (18%), either in or out of hospital. These could also have been the result of sub-optimal palliation. SPS blockage possibly accounted for 6 deaths, one of whom died during repeat palliation. In a large group (9 patients) the cause of death was not established: most of these patients died in other centres.

TABLE 23 : CAUSE OF DEATH BY OPERATION

	Palliative Operation Deaths No. (%)			
	SPS	PAB	Septect	Total
Intraoperative	**3 (8)**	**2 (6)**	**0 (0)**	**5 (14)**
Post-Operative < 48 hours	**3 (8)**	**2 (6)**	**1 (3)**	**6 (17)**
Pre-Discharge	**4 (11)**	**3 (8)**	**0 (0)**	**7 (19)**
Operative complications	2 (6)	1 (3)	0 (0)	3 (8)
Cardiac failure	0 (0)	1 (3)	0 (0)	1 (3)
Feed aspiration or pneumonia	1 (3)	1 (3)	0 (0)	2 (6)
Unknown	1 (3)	0 (0)	0 (0)	1 (3)
After Discharge	**16 (44)**	**2 (6)**	**0 (0)**	**18 (50)**
Definite* SPS blockage	3 (8)	-	-	3 (8)
Probable+ SPS blockage	2 (6)	-	-	2 (6)
Chest infections	2 (6)	1 (3)	0 (0)	3 (8)
Death during repeat palliation	1 (3)	0 (0)	0 (0)	1 (3)
Unknown	8 (22)	1 (3)	0 (0)	9 (25)
Total	**26 (72)**	**9 (25)**	**1 (3)**	**36 (100)**

* Autopsy confirmed, or clinical record of no SPS murmur
\+ Sudden unexplained death

Risk factors were examined to determine their role in the outcome "death". Univariate analysis was done using the log-rank test, in which not only the outcome (death) is examined but the survival time after operation is taken into account. For this the date of death must be known. One child, from Zimbabwe, was known to have died, but the date of death was unknown. For the purposes of the log-rank test, she is included insofar as she is known to have survived for at least 48 days.

Year of Operation: The mortality rates for year of operation are given in Table 24. The mortality rate decreased with successive

years for PAB (Table 26, chi-square for trend = 3,72 on 1 degree of freedom, p = 0,054) but not for SPS (Table 25, chi-square for trend = 0,01, 1 degree of freedom, p = 0,91).

TABLE 24 : DEATHS BY YEAR OF OPERATION

Year	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------No. deaths (% mortality)-----		
1980	5	1 (20)	2 (40)	3 (60)
1981	21	3 (14)	2 (10)	5 (24)
1982	31	3 (10)	7 (23)	10 (32)
1983	23	5 (22)	4 (17)	9 (39)
1984	41	4 (10)	5 (12)	9 (22)
Total	**121**	**16 (13)**	**20 (17)**	**36 (30)**

TABLE 25 : SPS : DEATHS BY YEAR OF OPERATION

Year	Total SPS	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------No. deaths (% mortality)-----		
1980	3	0 (0)	2 (67)	2 (67)
1981	16	2 (13)	1 (6)	3 (19)
1982	25	3 (12)	5 (20)	8 (32)
1983	11	3 (27)	3 (27)	6 (55)
1984	24	2 (8)	5 (21)	7 (29)
Total	**79**	**10 (13)**	**16 (20)**	**26 (33)**

TABLE 26 : PAB : DEATHS BY YEAR OF OPERATION

Year	Total PAB	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------No. deaths (% mortality)-----		
1980	1	1(100)	0 (0)	**1(100)**
1981	5	1 (20)	1 (20)	**2 (40)**
1982	6	0 (0)	2 (33)	**2 (33)**
1983	12	2 (17)	1 (8)	**3 (25)**
1984	16	1 (6)	0 (0)	**1 (6)**
Total	**40**	**5 (13)**	**4 (10)**	**9 (23)**

Sex: The mortality rate was slightly worse for boys (33%) than it was for girls (25%). Using the log-rank test, chi-square = 0,82 on 1 degree of freedom, p = 0,36.

TABLE 27 : MORTALITY BY SEX AND OPERATION

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------No. deaths (% mortality)-----		
SPS				
Male	48	5 (10)	12 (25)	17 (35)
Female	31	5 (16)	4 (13)	9 (29)
Total SPS	**79**	**10 (13)**	**16 (20)**	**26 (33)**
PAB				
Male	19	2 (11)	3 (16)	5 (26)
Female	21	3 (14)	1 (5)	4 (19)
Total PAB	**40**	**5 (13)**	**4 (10)**	**9 (23)**
ALL PATIENTS				
Male	69	8 (12)	15 (22)	23 (33)
Female	52	8 (15)	5 (10)	13 (25)
Total	**121**	**16 (13)**	**20 (17)**	**36 (30)**

Population Group: The mortality rates were 24%, 26% and 46% rates amongst the white, coloured and black population groups respectively. Although this was not statistically significant (chi-square = 4,46 on 2 degrees of freedom, p = 1,08), Blacks who had PAB had a higher overall mortality (chi-square = 6,52 on 2 degrees of freedom, p = 0,03). The late mortality was highest for Blacks, but again this was not statistically significant (p = 0,06, Fishers exact test, comparing Blacks and "non-Blacks", survivors and late deaths).

TABLE 28 : PATIENTS AND DEATHS BY POPULATION GROUP AND OPERATION

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------No. deaths (% mortality)-----		
SPS				
Coloured	45	5 (11)	7 (16)	12 (27)
White	15	2 (13)	4 (27)	6 (40)
Black	19	3 (16)	5 (26)	8 (42)
PAB				
Coloured	20	3 (15)	1 (5)	4 (20)
White	13	0 (0)	1 (8)	1 (8)
Black	7	2 (29)	2 (29)	4 (57)
ALL PATIENTS				
Coloured	66	9 (14)	8 (12)	17 (26)
White	29	2 (7)	5 (17)	7 (24)
Black	26	5 (19)	7 (27)	12 (46)

TABLE 29B: MORTALITY BY REFERRAL CENTRE

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	---No. deaths (% mortality)----		
Cape Town	45	10 (22)	4 (9)	14 (31)
Other major centres	48	3 (6)	9 (19)	12 (25)
Elsewhere in SA	13	2 (15)	2 (15)	4 (31)
Foreign	15	1 (7)	5 (33)	6 (40)
Overall	**121**	**16 (13)**	**20 (17)**	**36 (30)**

Diagnosis: The mortality rates for the different diagnoses are given in Table 30. The overall mortality rates were slightly higher for patients with inadequate blood flow (33%) than those with excessive blood flow (22%).

TABLE 30 : MORTALITY RATES BY DIAGNOSIS AND OPERATION

Diagnosis	Deaths/Patients (% mortality)			
	Total	SPS	PAB	Septectomies
1. Inadequate pulmonary blood flow	**24/73(33)**	**24/73(33)**	**0/0 (-)**	**0/0(-)**
i. TOF	7/26(27)	7/26(27)		
ii. PA	5/14(36)	5/14(36)		
iii. UVH/RVOFTO	12/27(44)	12/27(44)		
iv. AVSD/RVOFTO	0/2 (0)	0/2 (0)		
v. DORV/RVOFTO	0/4(0)	0/4 (0)		
2. Excessive pulmonary blood flow	**8/36(22)**	**0/0 (-)**	**8/36(22)**	**0/0(-)**
i. VSD	2/8 (25)		2/8 (25)	
ii. Coarct	2/9 (22)		2/9 (22)	
iii. TOF, LPA from Aorta	0/1 (0)		0/1 (0)	
iv. AVSD	0/6 (0)		0/6 (0)	
v. DORV	1/6 (17)		1/6 (17)	
vi. UVH	2/5 (40)		2/5 (40)	
vii. Truncus	1/1(100)		1/1(100)	
3. Transposition of great arteries	**4/12(33)**	**2/6 (33)**	**1/4 (25)**	**1/2(5**
i. With VSD	2/9 (22)	1/5 (20)	1/4 (25)	0/0
ii. Without VSD	2/3 (67)	1/1(100)	0/0 (-)	1/'
TOTAL	**36/121(30)**	**26/79(33)**	**9/40(50)**	**1**

Key to abbreviations used in Table 30

RVOFTO	Right ventricular outflow tract obstruction
TOF	Tetralogy of Fallot
PA	Pulmonary atresia
UVH	Univentricular heart
AVSD	Atrioventricular septal defect
DORV	Double outlet right ventricle
VSD	Ventricular septal defect
Coarct	Coarctation syndrome
Truncus	Truncus arteriosis
LPA	Left Pulmonary Artery

TABLE 30 : MORTALITY RATES BY DIAGNOSIS AND OPERATION

Diagnosis	Deaths/Patients (% mortality)			
	Total	SPS	PAB	Septectomies
1. Inadequate pulmonary blood flow	**24/73(33)**	**24/73(33)**	**0/0 (-)**	**0/0(-)**
i. TOF	7/26(27)	7/26(27)		
ii. PA	5/14(36)	5/14(36)		
iii. UVH/RVOFTO	12/27(44)	12/27(44)		
iv. AVSD/RVOFTO	0/2 (0)	0/2 (0)		
v. DORV/RVOFTO	0/4(0)	0/4 (0)		
2. Excessive pulmonary blood flow	**8/36(22)**	**0/0 (-)**	**8/36(22)**	**0/0(-)**
i. VSD	2/8 (25)		2/8 (25)	
ii. Coarct	2/9 (22)		2/9 (22)	
iii. TOF, LPA from Aorta	0/1 (0)		0/1 (0)	
iv. AVSD	0/6 (0)		0/6 (0)	
v. DORV	1/6 (17)		1/6 (17)	
vi. UVH	2/5 (40)		2/5 (40)	
vii. Truncus	1/1(100)		1/1(100)	
3. Transposition of great arteries	**4/12(33)**	**2/6 (33)**	**1/4 (25)**	**1/2(50)**
i. With VSD	2/9 (22)	1/5 (20)	1/4 (25)	0/0(-)
ii. Without VSD	2/3 (67)	1/1(100)	0/0 (-)	1/2(50)
TOTAL	**36/121(30)**	**26/79(33)**	**9/40(50)**	**1/2(50)**

Key to abbreviations used in Table 30

RVOFTO	Right ventricular outflow tract obstruction
TOF	Tetralogy of Fallot
PA	Pulmonary atresia
UVH	Univentricular heart
AVSD	Atrioventricular septal defect
DORV	Double outlet right ventricle
VSD	Ventricular septal defect
Coarct	Coarctation syndrome
Truncus	Truncus arteriosis
LPA	Left Pulmonary Artery

"Correctability": The diagnoses were categorised according to whether or not they could be corrected (Appendix 1) and the mortality rates in these two categories is shown in Table 31. The mortality of conditions which can be corrected at the patient's age was lower (22%) than those that can be considered "uncorrectable" (43%). This was found to be statistically significant (chi-square = 4,15 on 1 degree of freedom, p = 0,042).

TABLE 31 : MORTALITY RATE BY CORRECTABILITY AND OPERATION

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	------Deaths (% mortality)-----		
SPS				
Correctable	41	5 (12)	4 (10)	9 (22)
Uncorrectable	38	5 (18)	12 (32)	17 (45)
PAB				
Correctable	34	3 (9)	4 (12)	7 (21)
Uncorrectable	6	2 (33)	0 (0)	2 (33)
ALL PATIENTS				
Correctable	77	9 (12)	8 (10)	17 (22)
Uncorrectable	44	7 (16)	12 (27)	19 (43)

Age: The effect of age at operation on mortality rates is shown in Table 32. The majority of deaths (83%) occurred in children less than 6 months. The mortality rates were highest in children under 6 months (42% overall). This was evident in both early and late

mortality. The overall mortality rate in children 6 months and older was 13%.

TABLE 32: MORTALITY RATES BY AGE: I

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	-----No. deaths (% mortality)-----		
SPS				
< 1 month	9	3 (33)	0 (0)	3 (33)
1 - 6 months	33	5 (15)	12 (36)	17 (52)
6 - 12 months	11	0 (0)	2 (18)	2 (18)
1 - 2 years	12	1 (8)	0 (0)	1 (8)
2 - 5 years	9	1 (11)	2 (22)	3 (33)
5 years and older	5	0 (0)	0 (0)	0 (0)
Total	**79**	**10 (13)**	**16 (20)**	**26 (33)**
PAB				
< 1 month	2	1 (50)	0 (0)	1 (50)
1 - 6 months	26	4 (15)	4 (15)	8 (31)
6 - 12 months	8	0 (0)	0 (0)	0 (0)
1 - 2 years	2	0 (0)	0 (0)	0 (0)
2 - 5 years	2	0 (0)	0 (0)	0 (0)
5 years and older	0	0 (-)	0 (-)	0 (-)
Total	**40**	**5 (13)**	**4 (10)**	**9 (23)**
ALL PATIENTS				
< 1 month	11	4 (36)	0 (0)	4 (36)
1 - 6 months	61	10 (16)	16 (26)	26 (43)
6 - 12 months	19	0 (0)	2 (11)	2 (11)
1 - 2 years	14	1 (7)	0 (0)	1 (7)
2 - 5 years	11	1 (9)	2 (18)	3 (27)
5 years and older	5	0 (0)	0 (0)	0 (0)
Total	**121**	**16 (13)**	**20 (17)**	**36 (30)**

Statistical analysis of age as a predictor of death was done using different age categories in order that the age group below 6 months can be more closely examined. The grouping and mortality rates are given in Table 33. Using these age groups, age is a good predictor of death (chi-square = 23,91 on 4 degrees of freedom, p = 0,0001, overall mortality for all patients).

TABLE 33 : MORTALITY RATES BY AGE: II

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	----No. deaths (% mortality)----		
SPS:				
< 1 month	9	3 (33)	0 (0)	3 (33)
1 - 2 months	7	2 (29)	2 (29)	4 (57)
2 - 3 months	6	0 (0)	2 (33)	2 (33)
3 - 6 months	20	3 (15)	8 (40)	11 (55)
6 months and older	37	2 (5)	4 (11)	6 (16)
PAB:				
< 1 month	2	1 (50)	0 (0)	1 (50)
1 - 2 months	5	2 (40)	2 (40)	4 (80)
2 - 3 months	4	1 (25)	0 (0)	1 (25)
3 - 6 months	17	1 (6)	2 (12)	3 (18)
6 months and older	12	0 (0)	0 (0)	0 (0)
ALL PATIENTS:				
< 1 month	11	4 (36)	0 (0)	4 (36)
1 - 2 months	13	5 (38)	4 (31)	9 (69)
2 - 3 months	11	1 (9)	2 (18)	3 (27)
3 - 6 months	37	4 (11)	10 (27)	14 (38)
6 months and older	49	2 (4)	4 (8)	6 (12)

Other Medical Conditions: The presence of other medical conditions was examined. The medical conditions found are listed in Table 34 and the effects they have on mortality in Table 35A. Although the presence of a medical condition prior to surgery has a higher mortality rate (44%) than the absence of one (26%), this does not reach statistical significance (chi-square = 2,19 on 1 degree of freedom, p = 0,14). The presence of a medical condition affected the late mortality (Table 35B, p = 0,0091, Fishers exact test, comparing presence and absence of other medical conditions, survivors and late deaths). One might not expect some of these conditions to have any effect on mortality. Further breakdown and analysis is not possible because of the small numbers.

TABLE 34 : OTHER MEDICAL CONDITIONS

	Patients	Deaths
1. Congenital abnormalities	**14**	**5**
Down's Syndrome	2	0
Foetal Alcohol Syndrome	2	1
Noonan's Syndrome	1	1
Dysmorphic	3*	2*
Velocardiofacial Syndrome	1	0
Congenital rubella	1	0
Cleft lip/palate	2	0
Tracheooesophageal fistula	1	1
Laryngomalacia	1	0
2. Infections (pre-op)	**4**	**3**
Pneumonia	1	1
Bronchiolitis, gastroenteritis	1*	1*
Tuberculosis	2	1
3. Neurological	**7**	**4**
Hydrocephalus	1	1
Moribund/cardiac arrest preop	2	1
Subarachnoid haemorrhage	1	1
Convulsions	2	0
Motor retardation	1	1
4. Other (Obstructive jaundice)	**1**	**0**

* 1 dysmorphic patient also had bronchiolitis and gastro-enteritis

TABLE 35A : MORTALITY BY OTHER MEDICAL CONDITIONS AND OPERATION

	Total	SPS	PAB	Septect
	Deaths/patients (% mortality)			
Type of medical condition:				
Congenital abnormality	5/14(36)	3*/8*(38)	2/6 (33)	0/0(-)
Infection	3/14(75)	2*/3*(67)	1/1 (100)	0/0(-)
Neurological	4/7 (57)	4/5 (80)	0/2 (0)	0/0(-)
Other	0/1 (0)	0/1 (0)	0/0 (-)	0/0(-)
Medical condition present	**11/25(44)**	**8/16(50)**	**3/9 (33)**	**0/0(-)**
Medical condition absent	**25/96(26)**	**18/63(29)**	**6/31(19)**	**1/2(50)**
All patients	**36/121(30)**	**26/79(33)**	**9/40(23)**	**1/2(50)**

* 1 patient with 2 conditions

TABLE 35B : EARLY AND LATE MORTALITY BY OTHER MEDICAL CONDITIONS

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	----No. deaths (% mortality)----		
SPS:				
Medical cond. present	16	2 (13)	6 (38)	8 (50)
Medical cond. absent	63	8 (13)	10 (16)	18 (29)
PAB:				
Medical cond. present	9	0 (0)	3 (33)	3 (33)
Medical cond. absent	31	5 (16)	1 (3)	6 (19)
ALL PATIENTS				
Medical cond. present	25	2 (8)	9 (36)	11 (44)
Medical cond. absent	96	14 (15)	11 (11)	25 (26)

Weight: The weight within one month of operation was known in 81 cases. The effect this has on mortality is shown in Table 36. The overall mortality in children less than 4 kg (40%) was slightly higher, though not statistically significant, than the mortality in children of 4 kg or more (29%) (here chi-square = 2,44 on 1 degree of freedom, p = 0,12).

TABLE 36 : MORTALITY BY WEIGHT AND OPERATION

Weight	Total	SPS	PAB
	Deaths/patients (% mortality)		
<3 kg	4/10 (40)	3/8 (38)	1/2 (50)
3 - 4 kg	12/30 (40)	5/13 (38)	7/17 (41)
4 - 5 kg	4/12 (33)	4/8 (50)	0/4 (0)
5 kg and more	8/29 (28)	8/24 (33)	0/5 (0)
Total	**28/81 (34)**	**20/53 (38)**	**8/28 (29)**

Height: The heights within one month of operation were recorded in 76 children (Table 37). Shorter children had higher mortality rates.

TABLE 37 : MORTALITY BY HEIGHT AND OPERATION

Height	Total	SPS	PAB
	Deaths/patients (% mortality)		
< 50 cm	7/13(54)	5/10(50)	2/3 (67)
50 - 60 cm	14/40(35)	9/22(41)	5/18(28)
60 - 70 cm	2/12(17)	2/8 (25)	0/4 (0)
70 - 80 cm	0/3 (0)	0/2 (0)	0/1 (0)
80 - 90 cm	1/2 (50)	1/2 (50)	0/0 (-)
90 - 100 cm	1/5 (20)	1/4 (25)	0/1 (0)
100 cm and more	0/1 (0)	0/1 (0)	0/0 (-)
Total	**25/76(33)**	**18/49(37)**	**7/27(26)**

Palliative operation: There was a higher mortality rate for SPS (33%) as opposed to PAB operations (23%) - Table 38. This is not statistically significant (chi-square = 1,47 on 2 degrees of freedom, p = 0,48).

TABLE 38: MORTALITY BY PALLIATIVE OPERATION

Palliative Operation	Total Ops	Total Deaths	Mortality Rate %
SPS	79	26	33
PAB	40	9	23
Septectomy	2	1	50
Total	**121**	**36**	**30**

Elective/Emergency: The degree of urgency with which the operation was performed was determined by noting whether or not there was a written record of the operation being done as an emergency or if the operation was done out of usual working hours. The results of this

are given in Table 39. Eleven of these 20 patients who had emergency operations died (55%). This is significantly higher than for elective operations (chi-square = 7,13 on 1 degree of freedom, p = 0,0076). In particular, the early mortality was highest for patients who underwent emergency SPS (chi-square = 9,65 on 1 degree of freedom, p = 0,0019).

TABLE 39 : MORTALITY RATES BY OPERATIVE URGENCY

	Total Patients	Early Mortality	Late Mortality	Overall Mortality
	--No.--	----No. Deaths (% mortality)----		
SPS:				
Elective operation	64	4 (6)	13 (20)	17 (27)
Emergency operation	15	6 (40)	3 (20)	9 (60)
PAB:				
Elective operation	36	4 (11)	3 (8)	7 (19)
Emergency operation	4	1 (25)	1 (25)	2 (50)
ALL PATIENTS:				
Elective operation	101	9 (9)	16 (16)	25 (25)
Emergency operation	20	7 (35)	4 (20)	11 (55)

The summary of the univariate analysis using the log-rank test for determining risk factors for the outcome death is given in Table 40.

TABLE 40 : RISK FACTORS FOR DEATH AFTER PALLIATIVE SURGERY

Risk Factor	Chi-square	Degrees of freedom	P
Age	23,91	4	0,0001
Elective/Emergency	7,13	1	0,0076
Correctability	4,15	1	0,042
Population Group	4,46	2	0,11
Weight	2,44	1	0,12
Other Medical Cond	2,19	1	0,14
Sex	0,82	1	0,36
Palliative Operation	1,47	2	0,48
Referral centre	0,41	3	0,94

Multivariate analysis using Cox regression was then performed on the variables. As with the log rank test, patients lost to follow up are included up until the date they were last seen: thereafter they are treated as censored observations. The groups used for this analysis are given in Table 41.

TABLE 41 : GROUPING FOR MULTIVARIATE ANALYSIS

Risk Factor	Groups
Age at palliation	< 2 months
	2 - 6 months
	6 months and older
Weight at palliation	4 kgs and less
	> 4 kgs
Correctability	Correctable
	Uncorrectable
Palliative Operation	SPS
	PAB
Population Group	White
	Coloured and Black
Sex	Male
	Female
Home Address	Cape Town/elsewhere in Cape
	Other major centres/Foreign
Elective/Emergency	Elective
	Emergency
Other Medical conditions	Present
	Absent

Results of the multivariate analysis are shown in Table 42, and show that age at palliation, correctability, elective/emergency and the presence of other medical conditions to be the better set of variables associated with death. This is confirmed using fewer variables (Table 43).

TABLE 42 : MULTIVARIATE ANALYSIS

Variable	Chi-square	p	R
Age group 1	11,79	0,0006	0,176
Age group 2	6,60	0,0102	0,120
Elective/emergency	2,07	0,1498	0,015
Other Medical Cond	1,92	0,1653	0,000
Correctability	1,09	0,2967	0,000
Population group	0,50	0,4789	0,000
Address	0,10	0,7563	0,000
Palliative op	0,04	0,8444	0,000
Sex	0,06	0,8032	0,000

TABLE 43 : MULTIVARIATE ANALYSIS USING FEWER VARIABLES

Variable	Chi-square	p	R
Age group 1	14,17	0,0002	0,196
Age group 2	7,34	0,0068	0,130
Correctability	3,09	0,0788	0,059
Other Medical cond	2,60	0,1066	0,044

Survival curves were then drawn up and demonstrate the effect of age - here only 2 groups were used (less than 6 months, and over 6 months) (Figure 3), correctability (figure 4) and presence or absence of other medical conditions (figure 5) on survival whilst averaging out the other two variables in question.

FIGURE 3 : SURVIVAL CURVE: EFFECT OF AGE AT PALLIATION

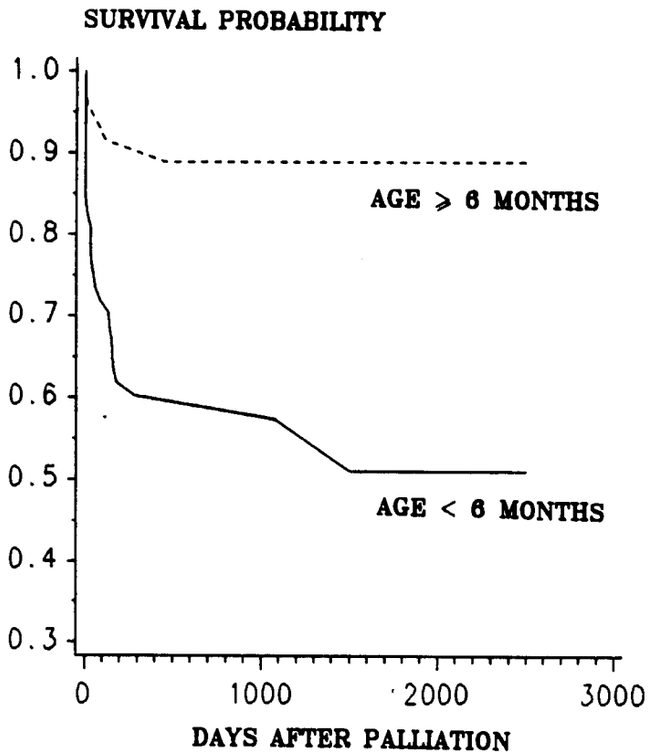


FIGURE 4 : SURVIVAL CURVE: EFFECT OF CORRECTABILITY

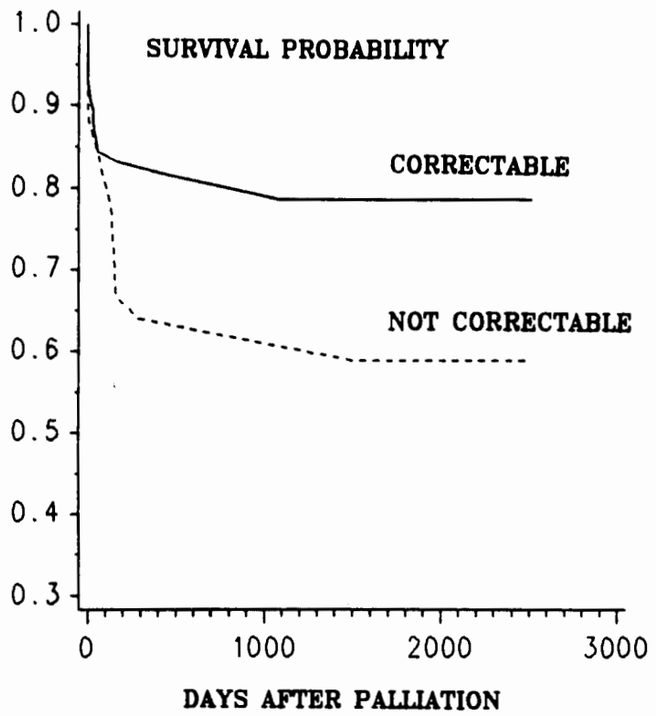
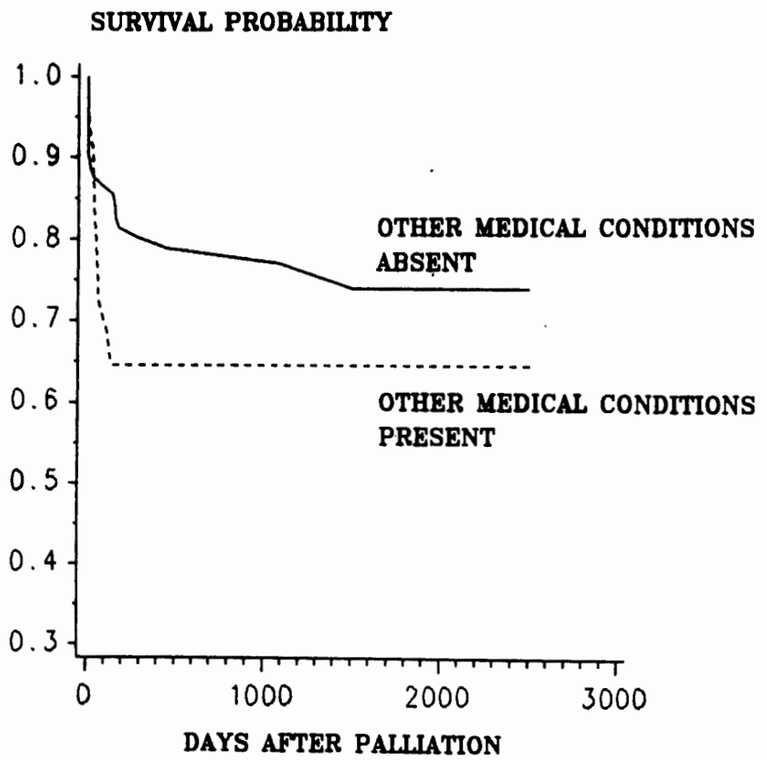


FIGURE 5 : SURVIVAL CURVE: EFFECT OF OTHER MEDICAL CONDITIONS



4.2 Lost to Follow Up:

The second part of the study was directed at determining how many patients were lost to follow up, what risk factors were associated with this outcome, and contacting those parents whose children were thought to be lost and reestablishing medical care.

Routine folder and cardiology notes review resulted in 20 children being placed in this category (see Table 19A, page 27). This amounted to 17% of the original group, and 22% of survivors.

Age: Children who were originally thought to be lost to follow up are categorised according to the age in Table 44. Analysis shows that age is not significant in determining whether there will be a breakdown in follow up (chi-square = 1,35 on 4 degrees of freedom, p = 0,85).

TABLE 44 : LOST TO FOLLOW UP BY AGE GROUP

Age Group	Number of Patients	Number lost to follow up	Percentage
0 -<1 month	11	1	9
1 -<2 months	13	2	15
2 -<3 months	11	2	18
3 -<6 months	37	8	22
6 months and more	49	7	14
Total	121	20	17

Sex: There was no difference in the follow up of boys and girls (chi-square = 0,0033 on 1 degree of freedom, p = 0,95, see Table 45).

TABLE 45 : LOST TO FOLLOW UP BY SEX

Sex	Number of Patients	Number lost to follow up	Percentage
Male	68	10	15
Female	53	10	19
Total	121	20	17

Population Group: The population group of the patient was significant in determining how good the follow up was (Table 46). Thirty five percent of Blacks were thought to be lost to follow up. Statistically, chi-square = 8,52 on 2 degrees of freedom, p = 0,014.

TABLE 46 : LOST TO FOLLOW UP BY POPULATION GROUP

Population Group	Number of Patients	Number lost to follow up	Percentage
White	29	2	7
Coloured	66	9	14
Black	26	9	35
Total	121	20	17

Referral centre: The grouping according to centre from which the children came, was highly significant in determining follow up (Table 47, chi-square = 15,68 on 3 degrees of freedom, p = 0,0018). Poorest follow up rate was from referrals from other major centres.

TABLE 47 : FOLLOW UP BY REFERRAL CENTRE

Referral centre	Number of Patients	Number lost to follow up	Percentage
Foreign	15	3	20
Other Major centres	48	15	31
Cape Town	45	1	2
Elsewhere in Cape	13	1	8
Total	121	20	17

Weight: A weight of greater than 4 kg was associated with poorer follow up of the child (see Table 48, chi-square = 3,23 on 1 degree of freedom, p = 0,073).

TABLE 48 : LOST TO FOLLOW UP BY WEIGHT PRIOR TO PALLIATION

Weight	Number of Patients	Number lost to follow up	Percentage
4 kgs and less	39	4	10
> 4 kgs	46	13	28
Total	85	17	20

Diagnosis: Diagnosis had no bearing on follow up (Table 49, chi-square = 7,64 on 4 degrees of freedom, p = 0,11).

TABLE 49 : LOST TO FOLLOW UP BY DIAGNOSIS

Diagnosis	Number of Patients	Number lost to follow up	Percentage
Excessive Pulm Blood Flow			
Left to right Shunts	18	0	0
Common mixing disorders	18	2	11
Inadequate Pulm Blood Flow			
Common mixing disorders with RVOFTO	33	9	27
RVOFT obstruction	40	8	20
Transposition	12	1	8
Total	**121**	**20**	**17**

Palliative Operation: The operation performed did determine the adequacy of follow up, with PAB operations receiving much better follow up than SPS (Table 50, chi-square = 6,49 on 2 degrees of freedom, p = 0,039).

TABLE 50 : LOST TO FOLLOW UP BY PALLIATIVE OPERATION

Palliative Operation	Number of Patients	Number lost to follow up	Percentage
SPS	79	18	23
PAB	40	2	5
Other	2	0	0
Total	**121**	**20**	**17**

Urgency of operation: The urgency with which the operation was performed did not make a difference with the follow up rates (Table 51, chi-square = 0,28 on 1 degree of freedom, p = 0,60).

TABLE 51 : LOST TO FOLLOW UP BY OPERATIVE URGENCY

Operative Urgency	Number of Patients	Number lost to follow up	Percentage
Elective	101	18	18
Emergency	20	2	10
Total	121	20	17

Other Medical Conditions: The presence or absence of other medical conditions did not affect follow up (Table 52, chi-square = 0,49 on 1 degree of freedom, p = 0,82).

TABLE 52 : LOST TO FOLLOW UP BY OTHER MEDICAL CONDITIONS

Other Medical Conditions	Number of Patients	Number lost to follow up	Percentage
Absent	96	15	16
Present	25	5	20
Total	121	20	17

Table 53 summarises the statistical analysis of the risk factors for patients lost to follow up.

TABLE 53 : FACTORS DETERMINING FOLLOW UP

Risk Factor	Chi-square	Degrees of Freedom	p
Referral centre	15,68	3	0,0018
Population Group	8,52	2	0,014
Palliative Operation	6,49	2	0,039
Weight	3,23	1	0,072
Diagnosis	7,64	4	0,11
Operative urgency	0,28	1	0,60
Other medical cond	0,05	1	0,82
Age	1,35	4	0,85
Sex	0,003	1	0,95

Tracing patients lost to follow up: Letters were then sent to the parents of the children, the referring doctors and, where applicable, the farm owners on whose farms the patients were last known to reside. The return rate is given in Table 54.

TABLE 54 : RETURN RATE FOR LETTERS

	Letters sent to:		
	Parents	Referring Doctor	Farm Owner
	Number (percent)		
Replies received	7 (39)	3 (33)	0 (0)
Letters returned unclaimed	3 (17)	0 (0)	1 (33)
No reply received	8 (44)	6 (67)	2 (67)
Total	**18 (100)**	**9 (100)**	**3 (100)**

The Department of Home Affairs was then approached to determine if they had any details of possible death certificates for the remaining South Africans. By this method it was possible to trace the death certificate for one patient and a change of address for another.

The outcome of 12 of the 20 patients originally thought to be lost to follow up was therefore determined (60%). The new categories into which they were placed is given in Table 55 and the final outcome categories for all the patients is in Table 19A on page 23.

TABLE 55 : LOST TO FOLLOW UP - OUTCOME OF 20 APPARENTLY LOST PATIENTS

Category	After Tracing
Lost to follow up	8
Palliative death	8
Awaiting correction	3
Corrected	1

Of those 12 patients who were traced, 8 had died, all of whom had SPS. Three have been followed up elsewhere and there were no records in the folder or cardiology notes in Cape Town. One other presented back in Cape Town in the interim, and needed further SPS surgery because of inadequate palliation. A further patient who was traced underwent corrective surgery.

Follow up was re-established in those patients who were awaiting correction.

5. COMPARISON OF DATA FROM 1980-1984 WITH DATA FROM 1987:

In order to determine how representative the data obtained from the study is of the present situation, data was extracted from the Cardiology computer data base for operations performed in 1987 for purposes of comparison.

The total number of cardiac operations and the number of palliative operations performed is given in Table 56.

TABLE 56 : OPERATIONS 1980-1984, 1987

	1980-1984	1987
All cardiac operations	1106	293
SPS	79 (7%)	27 (9%)
PAB	40 (4%)	18 (6%)
Septectomy	3 (0,3%)	2 (0,7%)
All palliative operations	122 (11%)	47 (16%)

Only early mortality (within 30 days) is compared: the period of follow up in the second study period is too short to make comparisons of the long term outcome in the two periods. Early mortality for PAB and SPS during the two periods is given in Table

57, showing little change in outcome for the various palliative procedures.

TABLE 57 : EARLY MORTALITY, 1980-1984, 1987

	Deaths/patients (%)	
	1980-1984	1987
SPS	10/79 (13)	2/27 (7)
PAB	5/40 (13)	2/18 (11)
Septectomies	1/ 3 (33)	2/ 2 (100)
All palliative ops	**16/122 (13)**	**6/47 (13)**

The early mortality was constant when comparing the sex and population groups during the two periods (Table 58). Although there were proportionately more Coloured in 1987, this was not statistically significant (chi-square = 3,19 on 2 degrees of freedom, p = 0,20). The higher early mortality in whites in 1987 was also not significant (p = 0,18, Fisher's exact test).

TABLE 58 : EARLY MORTALITY BY SEX AND POPULATION GROUP 1980-1984, 1987

	1980-1984	1987
	Deaths/patients (%)	
Sex:		
Male	8/69 (12)	5/32 (16)
Female	8/52 (15)	1/15 (7)
Population Group:		
Coloured	9/66 (14)	4/32 (13)
White	2/29 (7)	2/ 6 (33)
Black	5/26 (19)	0/ 9 (0)

The age distribution was similar, as was the early mortality for the age groups, in the two periods, 1980-1984 and 1987 (Table 59).

TABLE 59 : EARLY MORTALITY BY AGE AT PALLIATION, 1980-1984, 1987

	1980-1984	1987
	Deaths/patients (%)	
SPS:		
Less then 6 months	8/42 (19)	1/12 (8)
6 months and over	2/37 (5)	1/15 (7)
PAB:		
Less then 6 months	5/28 (18)	2/13 (15)
6 months and over	0/12 (0)	0/ 5 (0)
Septectomy:		
Less then 6 months	1/ 2 (50)	2/ 2 (100)
6 months and over	0/ 0 (-)	0/ 0 (-)
All palliated patients:		
Less then 6 months	14/72 (19)	5/27 (19)
6 months and over	2/49 (4)	1/20 (5)

The diagnoses are given in Table 60. The two periods are comparable, except for a higher number of children with VSD, and fewer children with univentricular hearts in 1987. Early mortality rates are comparable.

TABLE 60 : DIAGNOSIS AND EARLY MORTALITY, 1980-1984, 1987

	1980-1984		1987	
	Patients	Deaths	Patients	Deaths
	No. (%*)	No. (%+)	No. (%*)	No. (%+)
Tetralogy of Fallot	27 (22)	3 (11)	8 (17)	0 (0)
Pulmonary atresia	14 (11)	2 (14)	7 (15)	1 (14)
Univentricular heart	32 (26)	5 (16)	3 (6)	0 (0)
AVSD	8 (7)	0 (0)	6 (13)	0 (0)
DORV	10 (8)	0 (0)	6 (13)	1 (17)
Pulmonary stenosis	0 (0)	0 (-)	1 (2)	0 (0)
Tricuspid atresia	0 (0)	0 (-)	1 (2)	0 (0)
VSD	8 (7)	1 (13)	19 (40)	2 (11)
Coarctation of Aorta	9 (7)	1 (11)	3 (6)	0 (0)
Other L -> R shunts	1 (1)	0 (0)	0 (0)	0 (-)
Truncus arteriosus	1 (1)	0 (0)	0 (0)	0 (-)
TGA with VSD	9 (7)	2 (22)	2 (4)	2 (100)
TGA with intact septum	3 (2)	2 (67)	1 (2)	0 (0)
Total	**122 (100)**	**16 (13)**	**47 (100)**	**6 (13)**

* Percent of all diagnoses during that period
\+ Diagnosis-dependent early mortality rate

CHAPTER 5

DISCUSSION

1. Year of Operation:

Fewer children received palliative operations in 1980 than in subsequent years. Only 5 palliative operations were performed in 1980 - this accounted for only 2,9% of all cardiac operations during that year. This compares with an average of 29 palliative operations yearly amounting to 12% of cardiac operations for the years 1981 - 1984.

This suggests that there was either a difference in the pathology presenting to the hospital, or that there was a different approach whereby children who could have been palliated were either being corrected or declared inoperable.

In a previous series of children who underwent surgery for congenital heart disease in this unit during the period 1975 - 1981, it was stated that some conditions, for example complete AVSD, UVH and hypoplastic left heart syndromes were seldom seen[24]. However, an analysis of cardiac catheterisations performed in this unit between 1976 and 1980 revealed that 11 percent had complex univentricular

hearts[25]. Another series, from this unit, during the period January 1982 - May 1984[26] reported 37 cases of univentricular hearts (not all were palliated). In this study 32 patients had univentricular hearts, and 8 had AVSD, partial or complete.

It is therefore almost certain that these conditions existed in the early years of this series. In the subsequent years the patients with these conditions probably survived long enough to be offered palliative surgery. It is also possible that changing staff and changing unit policies could account for at least part of this increase in number of palliative operations after 1980.

Pre-operative management and assessment of children with complex abnormalities has improved over the past decade[5].

Prostaglandin was first used in this unit[27] in December 1981 for a neonate with pulmonary atresia. By maintaining or improving the patency of the ductus arteriosus, Prostaglandin has a dramatic effect in improving the general condition of neonates with critical pulmonary blood flow, thereby improving the operative risk. Prior to the use of prostaglandin, neonates were referred to surgery as an emergency whilst hypoxic and acidotic. With the use of prostaglandin it is now possible to resuscitate the baby,

improve the oxygen saturation, correct the acidosis and fluid balance, and perform surgery more electively. This study did not specifically examine the mortality of the neonates who underwent SPS operations in the pre-prostaglandin era and compare it with that from the post-prostaglandin era: only 3 of the 19 children who had SPS during 1980 or 1981 were less than 31 days old.

Echocardiography has also improved the outlook for children with congenital heart disease[5]. 2D-echocardiography was started in this unit in January 1982. Echocardiography improves the preoperative assessment of cases and the need for invasive cardiac catheterisation, with its inherent risks, is circumvented. It is not possible, though, to determine what effect this may have had on the mortality of the cases in the current series.

The mortality rates were not significantly different for each year, although there was an improvement in the survival rate for children who underwent PAB operations. This is similar to the experience from another centre[4] and can be expected to occur with a procedure which is being performed with greater frequency. It is uncertain why this does not occur with SPS operations.

The data from this study were compared with more recent data from 1987. Accepting that the method of data collection was

different, there was no difference in either the type of patient or the early mortality over the two periods. The experience gained from this study is probably still relevant today. If more aggressive palliative surgery is being performed with the passage of time (that is, children who may have previously been deemed inoperable were now being palliated), then mortality rates which are comparable may in fact mirror an improvement in outcome.

2. Sex and Population Group

The 57:43 percent male:female ratio is similar to the general ratio found in most hospital based studies, while the 55:24:21 coloured:white:black ratio has a greater proportion of white children than are usually seen at the Red Cross War Memorial Children's Hospital. This can be explained by the fact that while the hospital serves mostly indigent people, the Cardiac Unit sees many children referred by private practitioners because there is limited expertise and fewer facilities for complex cardiac surgery for young children in private hospitals.

Blacks had a higher mortality than whites and coloureds for all palliative operations, but this was only significant for PAB. This can be

expected in view of the differing socio-economic circumstances of the various population groups in South Africa. White children have better access to health care than do children from less advantaged groups. Chest infections are frequent problems encountered in disadvantaged populations, and are also recurrent problems amongst patients with excessive pulmonary blood flow. Children from poor socio-economic groups are frequently malnourished and on this basis alone may be at higher risk from surgery.

Population group was significant when one analysed the number of patients who were originally thought to be lost to follow up: 35% of blacks were in this category. Apart from the reasons given above, there are also problems with communication with patients of different population groups. The parents may be under the impression that the corrective operation has been performed, and when there is marked improvement, for example in cyanosis, feel that it unnecessary to continue with follow up.

3. <u>Referring Centre</u>:

A large proportion of the patients came from places outside of the Cape Peninsula: 52 percent were from other major centres and other countries. Only 37 percent were from Cape Town. 11 percent were from other towns in the Cape Province requiring regular follow up in Cape Town.

Children requiring PAB operations were more likely to come from Cape Town. An explanation of this could be that conditions requiring PAB, for example large VSD, AVSD etc may not be grossly cyanosed: their clinical presentation may not be evidently cardiac in origin. Therefore, where health services are not as developed as they are in Cape Town, these children may not be diagnosed as having a cardiac defect and referred. Alternatively, the policy within the unit may be more towards total correction rather than doing palliation for children requiring PAB when the children come from afar (the possibilities for good follow up may not seem as good as those from Cape Town).

The referral centre did not affect mortality in either the univariate or the multivariate analysis. It did, however, play a part in follow up. Understandably, those who were followed up in Cape Town (those from Cape Town and the smaller towns in the Cape) were seldom lost (2 and 8% respectively), whereas those from other major centres in South Africa (31%), and those from other countries (20%) were often lost. Distance must play the major role in this.

Another factor is that once the child has undergone corrective surgery, for the purposes of this study, follow up is no longer necessary. Children who are being regularly followed up in Cape Town are possibly more likely to receive

corrective surgery at an earlier age than those who are only seen intermittently.

4. Diagnosis and Palliative Operation:

Children who received SPS had a slightly higher overall mortality (33%) than those who had PAB (23%), reflecting a higher late mortality.

Of the more frequently occurring diagnoses, the 32 children with **univentricular hearts** had the poorest outlook: those requiring SPS had a 44% mortality, and those requiring PAB, a 40% mortality. This is similar to the 39%[28] and 31%[29] mortality reported in palliated cases of UVH in other series. In a previous report from this unit[26] 37 cases of UVH were reviewed - 14 (38%) of these were known to have died (presumably prior to any surgery).

Tetralogy of Fallot was the next most frequent cause for palliation, with 26 cases undergoing SPS operations. Seven children died (27% mortality) - three within 30 days, and 4 dying later, before correction. The current operative (corrective) mortality in patients with favourable anatomy should be less than 5%[30]. The fact that palliation rather than correction was offered to these children indicates that other factors were probably present: they were probably too

young or their anatomy was unfavourable. An early report from Liverpool[31] indicated that prior to 1977 there was an operative mortality of 26% in children under the age of 2 years undergoing primary repair. However after 1977[32] they had no deaths in 17 infants under the age of 2 years who had undergone repair. Secondary repair had a higher mortality (15%) than primary repair. Casteneda et al[33] showed a hospital mortality of 7% in children under the age of 1 year undergoing total correction. They felt that palliation and secondary repair carried a greater operative mortality than primary repair. Sanchez et al[24], from this unit, reported a surgical mortality rate from correction in infants less than a year of age of 8% (2/25) and from SPS of 13% (1/8). They specify what they consider to be contraindications to correction in infants: inadequate size of the pulmonary arteries, abnormal origin of a main coronary artery in the very small infant, single pulmonary artery, and age less than 6 months if a patch across the pulmonary valve annulus was needed. This was presumably the policy of the unit in about 1982/83 as the paper was published in 1984. However, reviewing the catheter diagnoses of the children in this study (Appendix 6), only one child had abnormal origin of the coronary artery, while another had dysplastic pulmonary arteries. It is therefore uncertain why these children were palliated and not corrected.

Seven children with **pulmonary atresia with intact septum**: 2 of these died. All of these children were too young to be considered for correction: only children over the age of 4 years[30] could be considered suitable for corrective surgery.

Three of the seven children with **pulmonary atresia with VSD** died. All the children with this condition were younger than 2 years, the age at which they could be suitable for correction.

Atrioventricular septal defects were present in 8 cases, and all children survived palliation. Two of these required SPS - both of these children were over 5 years of age, well over the 2 years which we would now consider to be suitable for Fontan operation. The other 6 cases had excessive pulmonary blood flow and had a PAB. Recent studies[34 - 36] indicate that repair is the operative procedure of choice, even for young infants, as reported mortality from PAB in children with complete AVSDs is between 11 and 47%[36]. The results of palliation in patients in this series is good, but one must bear in mind that there were few patients with this condition.

There were 10 children with **double outlet right ventricle** (DORV): 4 required SPS and 6 required PAB. One child (10%) died 57 days after PAB.

Most units have abandoned palliative operations for **ventricular septal defects** in favour of primary correction[24, 30, 37]. Associated coarctation in young infants, or uncontrolled pulmonary infection may be indications for PAB. Muscular VSD cannot be repaired in infancy: PAB is done and definitive repair at about 4 years of age. 17 children with VSD (with or without coarctation of the aorta) received PAB, and 4 died prior to correction (overall mortality = 24%). Only one of the children had multiple muscular VSDs: the others may well have been correctable. Mortality from correction in infants less than 12 months old should be less than 10%[37]. PAB may not make any difference to the outcome of neonates with coarctation and VSD[38].

Twelve children with **transposition of the great arteries** were palliated, 6 with SPS, 4 with PAB and 2 by means of surgical septectomies. Four children (33%) died before correction. Children with TGA and intact septum had a higher mortality (2/3: 67%) than those with a VSD (2/9: 22%). Many procedures are possible in these children[30], but the Senning and the arterial 'switch' operations are favoured if correction is to be performed. These operations may have a mortality as low as 5 and 20% respectively in some units[30].

The decision whether to offer correction to children with congenital heart disease (rather than palliation and later correction) depends on whether, by current criteria, it is possible to correct the underlying defect with reasonable safety. It is for this reason that patients were divided into those that can be considered correctable and those who are not correctable. These categories are based on past experience, experience of other units, catheter diagnosis, age at operation, and what we would consider to be reasonable corrective surgical risks in our unit today (see Appendix 1). Because other determinants, for example, condition of the child, are not taken into account, these categories may not be strictly valid for individual cases. The "correctability" of the condition was found to be a statistically significant determinant of mortality in the multivariate analysis, with its effect on survival shown on figure 4. Correctable lesions have a lower mortality (22%) than uncorrectable lesions (43%), an important factor when considering whether to palliate or to correct ab initio. This would tend to argue against doing corrective surgery early if there is substantial gain from early palliation and late correction in the correctable cases. However, the mortality of 22% from palliation is particularly high when one considers that these children would then have to undergo the risks of secondary correction.

5. **Age at Operation:**

PAB was done mostly on young children (70% of PAB were on children less than 6 months), whereas SPS was done throughout childhood. PAB needs to be done at least before the age of 9 months to prevent irreversible pulmonary hypertension. If surgery is done at this stage, PAB is frequently used because it may have a lower mortality, whereas later on in life, primary correction is more likely to be performed.

Age was the best predictor of death in the multivariate analysis. Mortality in those children less than 6 months was 38%, as compared to 12% in those children aged 6 months and older. The worst affected group were those less than 2 months of age, where 13 of the 24 cases died (54%).

Children who require palliation at a very young age are likely to have conditions which are particularly severe. Some may not be correctable at this early age. However, multivariate analysis showed that young age, independent of "correctability", was a predictor for death.

The argument that young children should not undergo corrective surgery because of the high mortality associated with it, should therefore be balanced by the knowledge that there is a high mortality associated with palliation.

6. **Other Medical conditions**:

Congenital heart disease is often associated with other anomalies and problems. These may influence not only the decision as to whether to perform any surgery at all, but also what surgery to perform. The incidence of other conditions (21%) may well be an underestimation of the true incidence, as this was a retrospective folder review. It is interesting to note that the presence of other conditions, although having some effect on mortality rates (44% vs 26%) did not significantly affect outcome. This is probably due to the fact that the conditions are a heterogeneous group, some of which one would expect not to have any effect on mortality (for example, dysmorphic syndromes, foetal alcohol syndrome etc), and others which may e.g. pneumonia. The presence of other medical conditions did affect the late mortality.

7. **Weight and Height**:

One can postulate that children who are not thriving may have a poorer outcome than those who are, and for this reason, weight and height were examined as possible predictors. With a retrospective survey, one cannot be certain of the accuracy of these measurements. The smaller children did have a higher mortality, but, as far as weight

is concerned, this did not add much significance in the multivariate analysis: age was by far a better predictor.

Measurement of weight is, in any event, a poor indicator of how a child is thriving: it would have been necessary to examine it with reference to the expected weight for age (or height). This was not done, in view of the uncertain quality of the data.

8. Operative urgency:

Sixteen percent of the operations are known to have been performed as an emergency: the majority of these were SPS (75%). Children are less likely to require PAB as an emergency. The mortality after emergency operations was higher (55%) than after elective operations (25%). This affected mainly the early mortality, particularly in SPS operations. Children who have SPS as an emergency are likely to be severely cyanosed and perhaps acidotic at the time of surgery. Once again, the limitations of a retrospective folder review are important. One can only determine whether an operation was performed as an emergency by what is written in the notes. It can be assumed that the fact that an operation was performed as an emergency is more likely to be recorded in the notes of a patient who dies intraoperatively than in one who survives surgery.

9. Follow-up study:

A high percentage of patients were originally thought to be lost to follow up (17% of all patients, 22% of survivors). The system for follow up in this unit involves an appointment for follow up at an outpatient clinic. Patients who fail to attend are sent letters, with repeat bookings. The system appears to work well for those patients who are followed up in Cape Town, where only 2 (of 58) patients were lost.

Problems arise with those who are followed up at other major centres (31% lost to follow up). These children may not be truly 'lost' - they may, in fact, be receiving medical care at these centres. Alternatively, they may have died in the interim, and notification of their deaths may not have been recorded in our files.

Of the 20 patients who were originally thought to be lost, 12 were traced: 8 had died and a further 4 are still alive. It was beyond the scope of this study to determine the reasons for failure of follow up.

Patients with SPS were more likely to be lost than those with PAB: This could be due to the increased symptomatology of children who receive PAB, as well as the shorter time interval between palliation and correction in this group.

Blacks had the poorest follow up amongst the population groups. The poorer socio-economic circumstances under which they live is likely to play a role in this. They are more likely to be living in remote areas, with poor access to health facilities. Lack of transport could well play a major role. The exact nature of the condition and plans for future follow up are more difficult to explain to parents through an interpreter.

Most children were traced by means of writing to the parents at their last known address - 39% of parents replied. It is distressing to note that only 3 of the 9 referring doctors replied to the request for information about the children that were sent by them or their hospitals.

CHAPTER 6

CONCLUSIONS

This study has examined the outcome of children who underwent palliative cardiac surgery in Cape Town. A large number of palliative operations are performed annually. An audit of their effectiveness is essential in order to assess whether palliation is really a safer option than early definitive repair.

This study has shown that there is a poor outlook for these patients: at least 30 percent die before corrective surgery is undertaken. A further 7 percent are lost to follow up, even after extensive efforts at tracing them. It is particularly significant that 50 percent of deaths after palliative surgery occur after discharge from hospital. This study has the advantage of examining the long term outcome of palliated cases, and not just the early mortality, and therefore a true assessment of the results of palliation can be made.

Should such highly sophisticated surgery be undertaken in a developing country where the health problems are mainly infective diseases, which can be treated more cost effectively? This question could be extensively debated:

some might say that the expense associated with paediatric cardiac surgery can never be justified in a country such as South Africa. Others might argue that one needs to develop all fields of medical care: not only the preventative, curative and rehabilitative services, but also research and technology as well.

In a developing country with limited financial resources, the facilities which are offered must be carefully planned, in order to make them as cost-efficient as possible. In paediatric cardiac surgery, for example, there should be a limited number of centres which offer these services. These centres should have good facilities and sufficient trained staff. The reduction in the number of centres performing this type of highly sophisticated surgery would not only reduce the cost of maintaining the service, but also ensure that the personnel providing the service are developing adequate expertise. This can not happen if there are many centres operating on small numbers of patients.

Of particular importance, too, in a developing country, is ensuring adequate follow up for the patients who have undergone palliative surgery. It is senseless to embark on palliation if they do not ultimately undergo corrective surgery. This study has noted that using routine methods of follow up, 17 percent of the patients were lost to follow up

(this was reduced to 7 percent after further attempts at tracing the patients were done).

This study has identified some factors important in identifying those who are likely to be lost. Patients with SPS were more likely to be lost than those with PAB - they have a longer follow up period, and signs of SPS failure may be subtle. There was also a higher late mortality for patients with SPS. Likewise, Blacks had a higher late mortality and were more likely to be lost to follow up. Children who were referred from other major centres were also more likely to be lost.

Follow up in these other major centres must be improved - preferably by doctors trained in paediatric cardiology. Regular contact must be maintained between these doctors and the patients on the one hand, and between them and the Cardiac Unit on the other. Cardiologists should visit these major centres regularly. Where disadvantaged patients live in remote areas, funding should be made available to ensure that regular follow up can take place at these centres.

The onus is on both the paediatric cardiologist and the cardiac surgeon to ensure that the parents of the children who receive palliation are aware that the surgery is only temporary - that follow up is essential and that further surgery is needed.

In this study palliative surgery carried a high mortality, with 30 percent of children dying before correction. The associated morbidity was not examined. It is essential to compare the risks of early correction with the combined risks of palliation and late correction. This study examined only the risks of palliation: it has not evaluated the risks of later correction, not has it determined the risks of early correction. Palliation carried high risks, particularly for children less than 6 months, those who were operated on as an emergency, and for those lesions which were not correctable. Even those conditions which were possibly correctable had a high mortality of 22 percent. Ventricular septal defects and TOF carried a high mortality rate from palliation (24 and 27 percent respectively): the survivors still face the risks of later correction. On the other hand, children with atrioventricular septal defects had low mortality, but one must bear in mind the low numbers of children with this condition in this study.

There was a higher mortality for children under 6 months of age. This may well balance the higher mortality from early correction, but until the risks of early correction at this particular unit in this age group are available, this will not be known with certainty.

What is clear is that there are many problems associated with palliative cardiac surgery. The decision to palliate rather than to correct these defects must be made after balancing the risks of palliation and subsequent correction with those of early correction. Should palliative surgery be embarked upon, careful follow up by experienced doctors is essential, to ensure that corrective surgery is done timeously.

CHAPTER 7

LIMITATIONS

Any retrospective study has limitations with regards the quality of the data captured. Details may be missing, sometimes complete records may not be available. Interpretation of the notes may be flawed. Notes about patients who are being followed up in other centres may not be filed correctly. When children die at home or at another centre, these details will seldom be available.

Some of the data collected must be interpreted with caution. Weights and heights are seldom very accurately measured, and may not have been recorded shortly before operation. For this reason, only weights which were noted as having been done within one month of operation were considered. It is also not routine to record whether an operation is done electively or as an emergency: those that are noted as having been done as an emergency may well have had a poor outcome, influencing the results.

The grouping of patients into those who could be considered correctable and those who could not be corrected is theoretical, based retrospectively on the diagnosis and the age. This is never the case in clinical practice: many

other factors are taken into consideration. It was, however, important in this study to somehow differentiate those conditions in which a choice between correction and palliation was available from those in whom palliation is all that can be offered.

CHAPTER 8

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APPENDIX 1

DEFINITIONS

1.1 Palliative surgery: surgery performed with the goal of improving functional capacity, lengthening life expectancy, or both, in order to perform definitive surgery later. It usually does not involve open heart surgery or cardiopulmonary bypass.

1.2 Definitive/corrective surgery: surgery performed to correct anatomical defects or to normalize the haemodynamics and direction of blood flow. Usually involves open heart surgery or cardiopulmonary bypass. Includes operations such as Fontan procedure which some might consider to be "definitive palliation" - in these cases functional capacity cannot be restored to normal, but an attempt is made at normalizing haemodynamics.

1.3 Corrected: patients who have undergone definitive surgery.

1.4 Palliative death: death after palliative surgery, without any definitive surgery having been undertaken.

1.5 Corrective death: death after definitive surgery.

1.6 Operative mortality:

a) Early hospital mortality: death in hospital within 30 days of surgery (palliative or corrective).

b) Late hospital mortality: death in hospital after 30 postoperative days (palliative or corrective).

c) Early home mortality: death after initial discharge from hospital following surgery (palliative or definitive) but within 30 days of surgery.

d) Late home mortality: death as in 1.6 c) but after 30 postoperative days.

1.7 Lost to follow up:

a) No record of the child having been seen at this hospital for more than 2 years; and

b) No letters received from parents and or referral agency; and

c) Return date must be within time of study.

1.8 Diagnoses: classified as follows:

a) Excessive pulmonary blood flow

b) Insufficient pulmonary blood flow

c) Transposition of great artery

1.9 "Correctability": diagnoses were further classified according to whether they were considered correctable

or not. This is determined by standards applicable to most cardiac units for 1988, and is a theoretical determinant: the cases were analysed retrospectively according to age and diagnosis. The individual determinants, for example the condition of the child, are not considered. "Correctability" is given in the table below.

CORRECTABILITY

	Probably Correctable	Probably Uncorrectable
Perimembraneous VSD, Tetralogy of Fallot, Transposition, Truncus arteriosus, DORV, Coarctation Syndrome, AVSD with unrestricted pulmonary blood flow.	any age	-
PA with VSD, AVSD/PS	≥ 2 years	< 2 years
Muscular VSD, Univentricular hearts, PA with intact septum, Tricuspid atresia.	≥ 4 yrs	< 4 years

1.10 Palliative operations: classified as follows:

a) Systemic pulmonary artery shunts (SPS)

b) Pulmonary artery bands (PAB)

c) Other

1.11 Outcome groups: the patients were then placed in the following outcome groups:

a) Palliative deaths (see 1.4 above)

b) Inoperable: survived palliation but unsuitable for definitive surgery

c) Lost to follow up (see 1.7 above)

d) Awaiting correction: survived palliation, not lost to follow up and awaiting definitive surgery.

e) Transferred: transferred to other units.

f) Corrected: (see 1.3 above).

Patients can only fit into one category. If patient was lost to follow up or transferred after definitive surgery, they were placed in category f) above.

1.12 Referring centre: the patients were classified, according to their home address, into the following groups:

a) Foreigner: from outside the borders of the Republic of South Africa, black national and recently "independent" states. Includes patients from South West Africa/Namibia.

b) Cape Town: from the greater Cape Town area.

c) Other major centres: Durban, East London, Port Elizabeth, George, Kimberley.

d) Elsewhere: not within the immediate vicinity of a major centre.

APPENDIX 2

DATA

1. Data extracted

The following details were recorded:

1.1 Folder number.

1.2 Name.

1.3 Race.

1.4 Sex.

1.5 Date of birth.

1.6 Address.

1.7 Date of initial presentation.

1.8 Diagnosis: made at cardiac catheterization where done.

1.9 Weight prior to operation (usually at cardiac catherisation).

1.10 Height prior to operation (usually at cardiac catherisation).

1.11 Date when weight and height recorded.

1.12 Associated medical conditions.

1.13 Initial palliative surgery performed.

1.14 Whether 1.13 was noted to have been done as an emergency procedure. If not, it was assumed that the operation was performed electively.

1.15 Date of 1.13.

1.16 Whether definitive surgery is envisaged at a later date or not.

1.17 Outcome of palliative surgery.

1.18 Date of discharge from hospital, or death, after 1.13.

1.19 How good follow up was after 1.13.

1.20 Further palliative procedures: type and number of procedures.

1.21 Definitive surgery performed.

1.22 Whether 1.21 was done as elective or emergency procedure.

1.23 Date of definitive operation.

1.24 Outcome after definitive surgery.

1.25 Date of discharge from hospital, or death, after 1.21.

1.26 Success/failure after palliation.

1.27 Success/failure after definitive surgery.

1.28 Date last seen/received letter.

1.29 Condition at 1.28.

1.30 Cause of death (autopsy where available).

APPENDIX 3

FOLLOW UP STUDY

Parents, referring doctors or farm-owners who were contacted with regards patients who were initially lost to follow up, were requested to complete a form with the following information:

1.1 Name and address of person completing form.

1.2 Relationship of 1.1 to the child.

1.3 If the child is alive or dead.

1.4 Where the child was taken to be seen if he/she was ill.

1.5 When the child was last seen by a doctor.

1.6 If the child died: when and where the child died and if parent found out why.

1.7 Whether they would like the child to be seen by a cardiologist again.

APPENDIX 4:

DEMOGRAPHIC DATA

NO	FOLDER	SEX	RACE	DATE OF BIRTH	POSTAL CODE	AREA
1	64394125	Male	Coloured	27 Dec 1983	7945	Cape Town
2	65226680	Male	Coloured	15 Jun 1984	7785	Cape Town
3	61275822	Female	White	03 Dec 1981		Kenya
4	62405188	Female	Coloured	07 Oct 1982	7490	Cape Town
5	60337284	Female	Coloured	09 Sep 1981	7785	Cape Town
6	60074804	Male	Black	15 Jun 1981	5200	Major centre
7	63489694	Male	Coloured	13 Mar 1983		Mauritius
8	52526555	Male	Coloured	30 Apr 1977	7490	Cape Town
9	62649876	Male	White	10 Jan 1983	7700	Cape Town
10	65696577	Female	Coloured	24 Sep 1983	6016	Major centre
11	63185672	Male	White	30 Mar 1983	7460	Cape Town
12	60309423	Female	White	24 Mar 1981	5247	Major centre
13	62466842	Male	Coloured	27 Nov 1982	6531	Major centre
14	61568937	Female	Coloured	13 Feb 1982		Mauritius
15	60722188	Female	Coloured	05 Jan 1982	7783	Cape Town
16	60977592	Female	White	14 Feb 1982	7945	Cape Town
17	62657960	Female	White	06 Jan 1983	6001	Major centre
18	65445678	Female	White	12 Jun 1984	7995	Cape Town
19	64463862	Male	Coloured	14 Jan 1984	7925	Cape Town
20	62983366	Male	Coloured	24 Apr 1982	7405	Cape Town
21	64557838	Male	Coloured	20 Dec 1983	6760	Minor centre
22	57311839	Female	Coloured	28 Nov 1979	6740	Minor centre
23	64188386	Male	Coloured	05 Oct 1983	8220	Major centre
24	62251772	Male	Coloured	15 Aug 1982	7764	Cape Town
25	56568546	Male	Coloured	23 Sep 1979	7764	Cape Town
26	65013906	Female	White	17 Feb 1984	8001	Cape Town
27	59698944	Male	Black	27 May 1980		Botswana
28	61454351	Female	Black	10 Feb 1982	7750	Cape Town
29	64024524	Female	Coloured	31 Jul 1983	7945	Cape Town
30	64938293	Male	Coloured	10 Apr 1984	7764	Cape Town
31	65679078	Female	Coloured	09 Jun 1984	6802	Minor centre
32	63610927	Male	Coloured	12 May 1983	7785	Cape Town
33	57703969	Female	Coloured	03 May 1980	7500	Cape Town
34	64641251	Male	Coloured	14 Mar 1983	6530	Major centre
35	64001282	Female	Coloured	29 Jun 1983	5201	Major centre
36	60175361	Male	Coloured	08 Aug 1980	6500	Major centre
37	62355045	Male	Coloured	26 Oct 1982	6001	Major centre
38	63099733	Female	Black	01 Jan 1980	5760	Major centre
39	64958127	Female	Coloured	01 Apr 1984	8822	Major centre
40	53406591	Male	Coloured	27 Dec 1977	6850	Minor centre

NO	FOLDER	SEX	RACE	DATE OF BIRTH	POSTAL CODE	AREA
41	64182041	Male	Coloured	15 Sep 1983	7785	Cape Town
42	64200157	Female	Coloured	02 Aug 1983	6016	Major centre
43	65290181	Male	White	03 Mar 1983	3600	Major centre
44	64186687	Female	White	22 Nov 1982		Zimbabwe
45	58835141	Male	Black	06 Aug 1979	5219	Major centre
46	60803160	Male	White	10 Nov 1980	3290	Major centre
47	62738802	Female	White	13 Jan 1983	6335	Major centre
48	60218369	Male	Coloured	07 Oct 1978	4091	Major centre
49	65137622	Male	Black	07 May 1983		Botswana
50	65238883	Male	Black	15 Sep 1983	6530	Major centre
51	63930440	Male	Black	03 Mar 1983		Zimbabwe
52	63475248	Male	Coloured	18 Jun 1983	7560	Cape Town
53	60419926	Male	White	12 Aug 1981	6220	Major centre
54	65506966	Female	Coloured	18 Oct 1983	5201	Major centre
55	61017380	Male	Black	01 Dec 1981	5219	Major centre
56	61892972	Female	Black	04 Jul 1982	7745	Cape Town
57	63645592	Male	Black	26 Apr 1983	5445	Major centre
58	57222184	Male	Black	01 Nov 1979	5219	Major centre
59	61426144	Female	Black	27 Dec 1981	5310	Major centre
60	60457884	Male	Coloured	24 Aug 1981	6850	Minor centre
61	62122437	Female	Black	27 Sep 1982	7750	Cape Town
62	62323068	Female	White	27 Oct 1982	7700	Cape Town
63	60732450	Male	Coloured	23 Sep 1981	7800	Cape Town
64	63210108	Male	Coloured	22 Nov 1982		Mauritius
65	60754165	Female	Coloured	06 Jun 1981	7785	Cape Town
66	54805932	Male	White	20 May 1978		Zimbabwe
67	59028860	Male	White	03 Jan 1981	5200	Major centre
68	62028121	Female	Black	31 Aug 1982	5209	Major centre
69	52003654	Female	White	21 Mar 1976	4930	Major centre
70	61754859	Male	Coloured	27 Jul 1982	7345	Minor centre
71	59143271	Male	Coloured	26 Nov 1978	6850	Minor centre
72	64130289	Male	Coloured	03 Nov 1983	7764	Cape Town
73	63844815	Female	White	24 Jul 1983	7700	Cape Town
74	60569993	Female	Coloured	16 Nov 1981	7764	Cape Town
75	64240237	Male	Black	22 Mar 1981		Botswana
76	62281548	Male	Coloured	06 Jan 1982	6835	Minor centre
77	64263049	Male	White	10 Nov 1983	5201	Major centre
78	63314223	Female	Coloured	20 May 1983	7800	Cape Town
79	64425721	Male	Coloured	20 Dec 1983	6850	Minor centre
80	63516314	Female	White	22 Apr 1983	6730	Minor centre

NO	FOLDER	SEX	RACE	DATE OF BIRTH	POSTAL CODE	AREA
81	63230429	Female	Coloured	14 Apr 1983	7346	Minor centre
82	65129918	Male	White	29 May 1984	6001	Major centre
83	63506315	Male	White	23 Mar 1983	6620	Major centre
84	61142592	Male	Coloured	10 Mar 1982	7800	Cape Town
85	58917840	Female	White	15 Oct 1980		Namibia
86	61679296	Male	Coloured	05 Jul 1982	7800	Cape Town
87	56877616	Male	White	25 Nov 1979	6620	Major centre
88	58697384	Female	White	31 Oct 1980	8001	Cape Town
89	60023629	Female	Coloured	13 Mar 1981	8301	Major centre
90	61697462	Female	Coloured	26 Apr 1982	8460	Major centre
91	62275243	Female	White	14 Apr 1982	4930	Major centre
92	65380198	Male	Black	15 Apr 1984	5510	Major centre
93	65685893	Female	Black	02 Nov 1983	5209	Major centre
94	65633638	Female	Black	13 Aug 1983	7455	Cape Town
95	61494944	Female	Black	30 Apr 1982	5219	Major centre
96	65289803	Female	Black	20 Feb 1984	5219	Major centre
97	61310785	Male	Black	10 Jan 1982	5460	Major centre
98	65400632	Male	Coloured	25 Jul 1984	5201	Major centre
99	64730807	Male	White	10 Jan 1984	8445	Major centre
100	64958101	Male	White	19 Apr 1984	6001	Major centre
101	65551202	Male	White	03 Jul 1984	6001	Major centre
102	65119919	Female	Coloured	01 Feb 1984	7680	Cape Town
103	57687857	Male	Black	19 Jun 1980	7800	Cape Town
104	66002882	Male	Coloured	19 Jul 1984	4093	Major centre
105	64390743	Male	Coloured	17 Dec 1983	7764	Cape Town
106	64489107	Female	Black	11 Jun 1983		Zimbabwe
107	54015185	Male	Coloured	17 Nov 1977	7130	Minor centre
108	58448713	Female	Coloured	09 Apr 1973	7800	Cape Town
109	65359754	Male	Coloured	02 Aug 1984	7490	Cape Town
110	61282653	Male	Coloured	07 Sep 1981		Mauritius
111	60081569	Male	Black	15 Aug 1981	5219	Major centre
112	59238907	Female	Coloured	05 Dec 1980	7700	Cape Town
113	56373830	Male	Coloured	15 Aug 1979	6620	Major centre
114	60723608	Male	Black	22 Sep 1981	8584	Major centre
115	58926627	Female	Coloured	17 Jul 1980	6720	Minor centre
116	59503722	Female	Coloured	03 Feb 1981		Mauritius
117	60812898	Male	Coloured	21 Jan 1982	7785	Cape Town
118	59185272	Male	Coloured	08 Mar 1981	7925	Cape Town
119	62411509	Female	Coloured	06 Dec 1982	7764	Cape Town
120	60645819	Male	Coloured	09 Dec 1981	7764	Cape Town
121	61215844	Female	Coloured	10 Nov 1977		Mauritius

APPENDIX 5

WEIGHTS, HEIGHTS AND OTHER MEDICAL CONDITIONS

NO	FOLDER	SEX	AGE WHEN WEIGHED (days)	WEIGHT (kg)	HEIGHT (cm)	OTHER MEDICAL CONDITIONS
1	64394125	Male	-	-	-	
2	65226680	Male	20	3.900	55.0	
3	61275822	Female	134	4.200	60.0	
4	62405188	Female	627	8.600	78.0	
5	60337284	Female	35	3.200	53.0	
6	60074804	Male	72	3.900	52.0	
7	63489694	Male	102	6.100	58.0	
8	52526555	Male	-	-	-	
9	62649876	Male	-	-	-	
10	65696577	Female	375	6.260	67.0	
11	63185672	Male	-	-	-	Down's Syndrome
12	60309423	Female	-	-	-	
13	62466842	Male	9	2.600	48.0	
14	61568937	Female	118	6.600	59.0	
15	60722188	Female	87	3.900	58.4	
16	60977592	Female	-	-	-	
17	62657960	Female	-	-	-	Hydrocephalus
18	65445678	Female	111	3.100	58.0	
19	64463862	Male	-	-	-	
20	62983366	Male	980	13.600	96.0	
21	64557838	Male	204	6.000	63.0	
22	57311839	Female	-	-	-	
23	64188386	Male	71	3.000	52.0	
24	62251772	Male	-	-	-	
25	56568546	Male	-	-	-	
26	65013906	Female	90	4.300	58.0	
27	59698944	Male	1511	14.000	100.0	
28	61454351	Female	131	4.180	58.0	Bronchiolitis, diarrhoea, renal failure, dysmorphic
29	64024524	Female	398	3.600	53.0	
30	64938293	Male	192	5.930	64.5	
31	65679078	Female	142	2.900	52.0	
32	63610927	Male	-	-	-	
33	57703969	Female	-	-	-	Convulsions
34	64641251	Male	394	5.100	60.0	
35	64001282	Female	105	3.100	50.0	Dysmorphic
36	60175361	Male	-	-	-	
37	62355045	Male	17	2.700	48.0	
38	63099733	Female	1196	14.800	94.0	
39	64958127	Female	24	3.600	51.0	
40	53406591	Male	-	-	-	

NO	FOLDER	SEX	AGE WHEN WEIGHED (days)	WEIGHT (kg)	HEIGHT (cm)	OTHER MEDICAL CONDITIONS
41	64182041	Male	-	-	-	
42	64200157	Female	108	6.080	-	Subarachnoid haem-orrhage, convulsions
43	65290181	Male	546	10.300	78.0	Obstructive jaundice
44	64186687	Female	359	6.100	70.0	
45	58835141	Male	519	14.000	98.0	
46	60803160	Male	429	9.200	80.0	
47	62738802	Female	-	-	-	
48	60218369	Male	1082	12.400	90.0	Congenital rubella
49	65137622	Male	396	7.060	62.5	
50	65238883	Male	294	5.600	-	
51	63930440	Male	203	6.700	69.0	
52	63475248	Male	2	3.480	44.0	
53	60419926	Male	83	4.160	53.8	
54	65506966	Female	-	-	-	
55	61017380	Male	-	-	-	
56	61892972	Female	136	5.200	57.0	Tuberculosis
57	63645592	Male	90	3.800	56.0	
58	57222184	Male	106	3.700	58.0	
59	61426144	Female	141	5.800	66.0	
60	60457884	Male	-	-	-	Dysmorphic
61	62122437	Female	39	2.380	48.0	Tracheo-oesophageal fistula
62	62323068	Female	-	-	-	
63	60732450	Male	104	4.400	55.0	Tuberculosis
64	63210108	Male	161	6.400	60.0	General motor retardation
65	60754165	Female	-	-	-	
66	54805932	Male	-	-	-	Noonan's syndrome
67	59028860	Male	-	-	-	
68	62028121	Female	9	3.100	48.5	
69	52003654	Female	-	-	-	Convulsions
70	61754859	Male	-	-	-	
71	59143271	Male	1016	12.000	83.0	
72	64130289	Male	-	-	-	
73	63844815	Female	123	4.000	56.0	
74	60569993	Female	14	2.940	49.0	
75	64240237	Male	-	-	-	
76	62281548	Male	315	4.900	58.0	
77	64263049	Male	25	3.120	-	
78	63314223	Female	40	3.100	48.5	
79	64425721	Male	22	2.740	54.0	Laryngomalacia
80	63516314	Female	68	3.200	52.0	

NO	FOLDER	SEX	AGE WHEN WEIGHED (days)	WEIGHT (kg)	HEIGHT (cm)	OTHER MEDICAL CONDITIONS
81	63230429	Female	19	3.200	49.0	
82	65129918	Male	16	2.980	48.0	
83	63506315	Male	94	3.300	54.0	Pneumonia
84	61142592	Male	99	3.820	50.0	
85	58917840	Female	-	-	-	Velo-cardio-facial syndrome
86	61679296	Male	140	3.200	-	Foetal alcohol syndrome
87	56877616	Male	-	-	-	
88	58697384	Female	-	-	-	
89	60023629	Female	157	3.300	49.0	
90	61697462	Female	73	3.040	55.0	
91	62275243	Female	197	6.700	66.0	
92	65380198	Male	106	5.100	56.0	
93	65685893	Female	336	8.300	68.0	
94	65633638	Female	-	-	-	
95	61494944	Female	-	-	-	
96	65289803	Female	149	4.800	53.0	
97	61310785	Male	101	5.200	58.0	
98	65400632	Male	8	3.200	50.5	Cleft lip/palate
99	64730807	Male	-	-	-	Cardiac arrest pre-op
100	64958101	Male	-	-	-	
101	65551202	Male	62	2.700	49.0	
102	65119919	Female	138	3.000	51.0	
103	57687857	Male	41	3.400	-	
104	66002882	Male	145	3.900	59.0	
105	64390743	Male	122	3.600	57.0	
106	64489107	Female	261	4.700	57.0	Moribund pre-op
107	54015185	Male	-	-	-	
108	58448713	Female	-	-	-	Down's syndrome
109	65359754	Male	111	3.200	53.0	Foetal alcohol syndrome
110	61282653	Male	221	6.200	63.0	
111	60081569	Male	19	3.340	51.0	
112	59238907	Female	-	-	-	
113	56373830	Male	-	-	-	
114	60723608	Male	99	4.300	58.0	
115	58926627	Female	-	-	-	
116	59503722	Female	94	4.300	57.0	
117	60812898	Male	15	3.200	51.0	
118	59185272	Male	-	4.000	52.5	
119	62411509	Female	11	2.800	34.0	
120	60645819	Male	-	2.900	47.0	
121	61215844	Female	-	11.400	98.69	

APPENDIX 6

DIAGNOSIS

NO	FOLDER	DATE OF CATHETERISATION	*	DIAGNOSIS AT CATHETERISATION
1	64394125	30 Dec 1983	C	**TGA**, VSD, septostomy done
2	65226680	05 Jul 1984	C	**Tetralogy**, ASD, PDA, stenosed origin LPA
3	61275822	16 Apr 1982	C	**Coarctation**, VSD, PDA, PFO, PHT
4	62405188	25 Jun 1984	C	**Tetralogy**, ASD
5	60337284	14 Oct 1981	N	**UVH**, TA, PHT
6	60074804	26 Aug 1981	C	**Tetralogy**
7	63489694	23 Jun 1983	N	**UVH**, TA
8	52526555	08 Jan 1980	C	**AVSD**, PS, PDA
9	62649876	13 Jan 1983	C	**TGA**, VSD, PDA, septostomy done
10	65696577	03 Oct 1984	C	**Tetralogy**, PFO, dysplastic PV
11	63185672	18 Aug 1983	C	**AVSD**, PHT
12	60309423	14 Oct 1981	C	**Coarctation**, VSD, ASD, PDA, PHT
13	62466842	06 Dec 1982	C	**Tetralogy**, PDA
14	61568937	11 Jun 1982	N	**PA**, intact septum, PDA, ASD, hypoplastic RV
15	60722188	02 Apr 1982	C	**Tetralogy**, ASD, right sided Aorta
16	60977592	16 Feb 1982	C	**TGA**, intact septum, PDA, septostomy done
17	62657960	13 Jan 1983	N	**PA**, VSD, PDA, PFO
18	65445678	01 Oct 1984	C	**DORV**, VSD, PHT
19	64463862	14 Jan 1984	C	**TGA**, intact septum, PDA, septostomy done
20	62983366	29 Dec 1984	C	**Tetralogy**, PFO
21	64557838	11 Jul 1984	C	**DORV**, RVOFT obstruction, PHT
22	57311839	11 Mar 1981	N	**UVH**, PS, PAPVD
23	64188386	15 Dec 1983	C	**VSD**, ASD, PHT
24	62251772	14 Mar 1983	N	**UVH**, TGA, PS, ASD
25	56568546	01 Oct 1979	N	**PA**, intact septum, PDA, ASD, hypoplastic RV
26	65013906	17 May 1984	C	**AVSD**, PHT
27	59698944	16 Jul 1984	C	**PA**, VSD, hypoplastic RVOFT, right sided Aorta
28	61454351	21 Jun 1982	C	**Tetralogy**, PFO
29	64024524	01 Sep 1984	C	**Coarctation**, VSD, PDA, PHT
30	64938293	19 Oct 1984	N	**UVH**, TGA, PDA, coarctation, PHT
31	65679078	29 Oct 1984	C	**AVSD**, PHT
32	63610927	17 Aug 1983	C	**DORV**, ASD, PHT
33	57703969	02 Jul 1980	C	**TGA**, VSD, MS, PHT
34	64641251	11 Apr 1984	C	**Tetralogy**, right sided Aorta
35	64001282	12 Oct 1983	C	**VSD**, PHT
36	60175361	11 Sep 1981	N	**UVH**, single atrium, infundib PS, situs inversus
37	62355045	12 Nov 1982	N	**PA**, VSD, PDA
38	63099733	11 Apr 1983	C	**AVSD**, PHT
39	64958127	25 Apr 1984	N	**PA**, intact septum, PDA, hypoplastic RV
40	53406591	11 Jan 1979	C	**TGA**, VSD, ASD, PS

* CORRECTABILITIY: C = correctable, N = Not correctable

NO	FOLDER	DATE OF CATHETERISATION	*	DIAGNOSIS AT CATHETERISATION
41	64182041	28 Mar 1984	C	**Tetralogy**, ASD, right sided Aorta
42	64200157	18 Nov 1983	N	**UVH**, TA, septostomy done
43	65290181	30 Aug 1984	N	**PA**, VSD, overriding Aorta
44	64186687	16 Nov 1983	C	**AVSD**, hypoplastic LV, PHT
45	58835141	06 Jan 1981	C	**DORV**, PS, right sided Aorta
46	60803160	13 Jan 1982	C	**DORV**, PS, AVSD, interupted SVC, situs ambiguous
47	62738802	31 Jan 1983	C	**Tetralogy**, PDA, PFO, right sided Aorta
48	60218369	23 Sep 1981	C	**Tetralogy**, Abnormal origin coronary LAD
49	65137622	06 Jun 1984	C	**Tetralogy**, right sided Aorta, aberrant left Subclavian artery
50	65238883	05 Jul 1984	C	**Tetralogy**, Aortic incompetance
51	63930440	22 Sep 1983	C	**Coarctation**, VSD, ASD, PDA, PHT
52	63475248	20 Jun 1983	N	**PA**, intact septum, PDA, PFO
53	60419926	03 Nov 1981	C	**Tetralogy**, ASD, PDA, right sided Aorta
54	65506966	27 Aug 1984	C	**Tetralogy**, LPA ex Ao, RPA from MPA
55	61017380	04 Mar 1982	C	**Tetralogy**, ASD
56	61892972	17 Nov 1982	N	**UVH**, TA, rudimentary RV
57	63645592	25 Jul 1983	N	**UVH**, ASD, rudimentary RV, PHT
58	57222184	15 Feb 1980	N	**UVH**, PA, ASD, PDA
59	61426144	17 May 1982	C	**Tetralogy**
60	60457884	17 Dec 1981	C	**VSD**, common coronary ostium, PHT
61	62122437	05 Nov 1982	C	**DORV**, VSD, PHT
62	62323068	10 Nov 1982	C	**VSD**, repaired coarctation
63	60732450	05 Jan 1982	N	**PA**, ASD, VSD, PDA, anomalous origin left carotid artery
64	63210108	02 May 1983	N	**UVH**, PA, PDA, single coronary ostium
65	60754165	19 May 1982	N	**UVH**, single atrium, hypoplastic TV & MPA,interrupted IVC, situs ambiguous
66	54805932	25 Sep 1978	N	**UVH**, common AV valve, PA
67	59028860	27 Aug 1981	N	**UVH**, common AV valve, situs inversus, interrupted IVC, PHT
68	62028121	09 Sep 1982	N	**PA**, intact septum, PDA, ASD, septostomy done
69	52003654	22 Sep 1983	C	**TGA**, VSD, ASD, PS, supracardiac TAPVD, right sided Aorta
70	61754859	16 Sep 1982	C	**Tetralogy**, PDA, right sided Aorta
71	59143271	07 Sep 1981	C	**Tetralogy**, Situs inversus
72	64130289	03 Nov 1983	C	**TGA**, VSD, septostomy done
73	63844815	24 Nov 1983	C	**VSD**, PDA
74	60569993	30 Nov 1981	N	**UVH**, TA, PA, PDA
75	64240237	30 Nov 1983	C	**TGA**, VSD, PS, situs inversus
76	62281548	17 Nov 1982	C	**DORV**, UVH, PS
77	64263049	05 Dec 1983	C	**Tetralogy**
78	63314223	29 Jun 1983	C	**DORV**, subpulmonary VSD
79	64425721	11 Jan 1984	C	**Tetralogy**, PFO
80	63516314	29 Jun 1983	C	**Coarctation**, VSD, PDA, PHT

* CORRECTABILITIY: C = correctable, N = Not correctable

APPENDIX 7

PALLIATIVE OPERATIONS

NO	DATE OF PALLIATION	AGE AT OP (days)	PALLIATION DONE	
1	18 Dec 1984	357	PAB & Septectomy	Elective
2	17 Jul 1984	32	MBTS	Elective
3	27 Apr 1982	145	PAB & Coarct Repair	Elective
4	04 Jul 1984	636	MBTS	Elective
5	15 Oct 1981	36	PAB	Elective
6	01 Sep 1981	78	MBTS	Elective
7	28 Jun 1983	107	MBTS	Elective
8	26 Jul 1983	2278	MBTS	Elective
9	09 Mar 1983	58	MBTS	Emergency
10	03 Oct 1984	375	MBTS	Emergency
11	01 Nov 1983	216	PAB	Elective
12	08 Dec 1981	259	PAB & ligate PDA	Elective
13	21 Dec 1982	24	MBTS	Elective
14	17 Jun 1982	124	MBTS	Elective
15	07 Apr 1982	92	BTS	Elective
16	05 Jun 1982	111	Ao-PA Shunt	Elective
17	17 Aug 1983	223	MBTS	Elective
18	16 Oct 1984	126	PAB	Elective
19	15 Feb 1984	32	Septectomy & ligate PDA and left SVC	Elective
20	29 Dec 1984	980	MBTS	Elective
21	17 Jul 1984	210	PAB	Elective
22	09 Mar 1982	832	BTS	Elective
23	10 Jan 1984	97	PAB	Elective
24	04 Dec 1984	842	MBTS	Elective
25	09 Jun 1981	625	MBTS	Elective
26	29 May 1984	102	PAB	Elective
27	24 Jul 1984	1519	MBTS	Elective
28	23 Jun 1982	133	BTS	Elective
29	11 Jan 1984	164	PAB & Coarct Repair	Elective
30	06 Nov 1984	210	PAB & ligate PDA	Elective
31	06 Nov 1984	150	PAB	Elective
32	31 Jul 1984	446	PAB	Elective
33	02 Nov 1983	1278	PAB	Elective
34	11 Apr 1984	394	MBTS	Emergency
35	18 Oct 1983	111	PAB	Elective
36	28 Oct 1981	446	BTS	Elective
37	07 Dec 1982	42	MBTS	Elective
38	19 Apr 1983	1204	PAB	Elective
39	08 May 1984	37	MBTS	Elective
40	08 Feb 1983	1869	MBTS	Elective

NO	DATE OF PALLIATION	AGE AT OP (days)	PALLIATION DONE	
41	15 May 1984	243	MBTS	Elective
42	18 Nov 1983	108	MBTS	Emergency
43	18 Sep 1984	565	SA-Collat Shunt	Elective
44	22 Nov 1983	365	PAB	Elective
45	13 Jan 1981	526	BTS	Elective
46	19 Jan 1982	435	BTS	Elective
47	25 May 1983	132	MBTS	Elective
48	29 Sep 1981	1088	Ao-RPA Shunt	Elective
49	08 Jun 1984	398	Asc Ao-RPA Shunt	Elective
50	10 Jul 1984	299	MBTS	Elective
51	29 Sep 1983	210	Plicate PA, Coarct Repair,PDA ligation	Elective
52	21 Jun 1983	3	MBTS	Emergency
53	04 Nov 1981	84	BTS	Elective
54	02 Oct 1984	350	PAB to LPA only	Elective
55	15 Jun 1982	196	MBTS	Elective
56	01 Dec 1982	150	Asc Ao-MPA Shunt	Emergency
57	26 Jul 1983	91	PAB	Elective
58	26 Feb 1980	117	Desc Ao-LPA Shunt	Elective
59	19 May 1982	143	MBTS	Elective
60	19 Jan 1982	148	PAB	Elective
61	23 Nov 1982	57	PAB	Elective
62	28 Dec 1982	62	PAB	Elective
63	06 Jan 1982	105	Ao-PA Shunt	Elective
64	10 May 1983	169	MBTS	Elective
65	12 Oct 1982	493	BTS	Elective
66	09 Sep 1980	843	MBTS	Elective
67	06 Oct 1981	276	PAB & pacemaker	Elective
68	09 Sep 1982	9	MBTS & valvotomy	Emergency
69	03 Jul 1984	3026	MBTS	Elective
70	20 Oct 1982	85	Desc Ao-RPA Shunt	Elective
71	29 Sep 1981	1038	Asc Ao-LPA Shunt	Elective
72	24 Apr 1984	173	PAB & Shunt	Elective
73	30 Nov 1983	129	PAB & ligate PDA	Elective
74	01 Dec 1981	15	MBTS	Emergency
75	10 Jan 1984	1024	BTS	Elective
76	01 Dec 1982	329	MBTS	Elective
77	13 Dec 1983	33	BTS	Elective
78	12 Jul 1983	53	PAB	Elective
79	31 Jan 1984	42	MBTS	Elective
80	05 Jul 1983	74	PAB & Coarct Repair	Elective

NO	DATE OF PALLIATION	AGE AT OP (days)	PALLIATION DONE	
81	03 May 1983	19	PAB & Coarct Repair	Emergency
82	15 Jun 1984	17	MBTS	Emergency
83	25 Jun 1983	94	PAB	Emergency
84	22 Jun 1982	104	PAB & Coarct Repair	Elective
85	03 Feb 1981	111	MBTS	Elective
86	08 Dec 1982	156	MBTS	Elective
87	05 Feb 1980	72	Septectomy	Emergency
88	27 Jan 1981	88	PAB	Elective
89	19 Aug 1981	159	MBTS	Elective
90	20 Jul 1982	85	BTS	Elective
91	28 Oct 1982	197	MBTS	Emergency
92	30 Jul 1984	106	MBTS	Emergency
93	09 Oct 1984	342	MBTS	Elective
94	06 Nov 1984	451	BTS	Elective
95	13 Jul 1982	74	MBTS	Elective
96	01 Aug 1984	163	PAB	Elective
97	23 Apr 1982	103	BTS	Elective
98	14 Aug 1984	20	MBTS	Elective
99	29 May 1984	140	PAB	Elective
100	05 Jun 1984	47	MBTS	Elective
101	03 Sep 1984	62	MBTS	Emergency
102	19 Jun 1984	139	PAB	Elective
103	12 Aug 1980	54	PAB & Coarct Repair	Elective
104	11 Dec 1984	145	BTS	Emergency
105	20 Apr 1984	125	PAB	Emergency
106	19 Jan 1984	222	Asc Ao-MPA Shunt	Emergency
107	16 Nov 1983	2190	MBTS	Elective
108	05 Nov 1980	2767	MBTS	Elective
109	29 Nov 1984	119	PAB	Emergency
110	21 Apr 1982	226	MBTS	Elective
111	22 Sep 1981	38	PAB & Coarct Repair	Elective
112	07 Jul 1981	214	MBTS	Elective
113	17 Feb 1981	552	Asc Ao-LPA Shunt	Elective
114	05 Jan 1982	105	MBTS	Elective
115	28 Apr 1981	285	BTS	Elective
116	12 May 1981	98	MBTS	Elective
117	09 Feb 1982	19	PAB & Coarct Repair	Elective
118	13 Mar 1981	5	Asc Ao-RPA Shunt	Emergency
119	21 Dec 1982	15	MBTS	Elective
120	15 Dec 1981	6	BTS	Elective
121	13 Apr 1982	1615	BTS	Elective

MBTS: Modified Blalock Taussig Shunt
BTS : Classical Blalock Taussig Shunt
Ao-PA: Aorto-Pulmonary Artery
PAB: Pulmonary Artery Band
Coarct Repair: Coarctation Repair
PDA: Patent Ductus Arteriosus

Asc Ao: Ascending Aorta
Desc Ao: Descending Aorta
LPA: Left Pulmonary Artery
RPA: Right Pulmonary Artery
MPA: Main Pulmonary Artery

APPENDIX 8

OUTCOME AFTER PALLIATION

NO	PALLIATIVE OP	POST-OP STAY IN HOSP (days)	INITIAL HOSPITAL OUTCOME
1	PAB & Septectomy	9	Chest infections
2	MBTS	14	Poor shunt, repeat op, feed aspiration, pneumonia, died
3	PAB & Coarct Rep	10	Good
4	MBTS	9	Good
5	PAB	2	PAB too tight, re-op, died after 6 hrs
6	MBTS	35	Good
7	MBTS	39	Revision of shunt first post-op day, wound sepsis
8	MBTS	16	Wound debridement and resuturing
9	MBTS	1	Poor pulmonary arteries, shunt not functioning, died
10	MBTS	10	Good
11	PAB	17	Chest infections
12	PAB & ligate PDA	10	Good
13	MBTS	17	Good
14	MBTS	15	Good
15	BTS	10	Good
16	Ao-PA Shunt	0	Hypotensive, repeat op, died
17	MBTS	20	Good
18	PAB	45	Feeding problems
19	Septectomy & ligate PDA and Left SVC	1	Hypotensive, repeat op, died in theatre
20	MBTS	9	Good
21	PAB	26	Kinked PA, repeat op
22	BTS	11	Good
23	PAB	17	Good
24	MBTS	7	Good
25	MBTS	10	Reoperation to perfect shunt
26	PAB	17	Good
27	MBTS	37	Shunt failure, repeat shunt done
28	BTS	36	Shunt kinked, repeat operation
29	PAB & Coarct Rep	21	Intraop cardiac arrest, CNS damage
30	PAB & ligate PDA	15	Pulmonary effusion
31	PAB	21	Poor result, correction attempted, operative death
32	PAB	11	Satisfactory
33	PAB	12	Chest infections
34	MBTS	11	RUL lung collapse
35	PAB	16	Ineffective PAB, correction done, died 2 days post correction
36	BTS	9	Good
37	MBTS	9	Good
38	PAB	10	Good
39	MBTS	11	Good
40	MBTS	13	Chest infection

NO	PALLIATIVE OP	POST-OP STAY IN HOSP (days)	INITIAL HOSPITAL OUTCOME
41	MBTS	10	Good
42	MBTS	5	Caecal perforation, laparotomy, died
43	SA-Collat Shunt	13	Good
44	PAB	10	Good
45	BTS	13	Good
46	BTS	9	Good
47	MBTS	56	Stridor, tracheostomy
48	Ao-PA Shunt	16	Good
49	Ao-PA Shunt	0	Died postoperativelly
50	MBTS	11	Good
51	Plicate PA, Coarct Rep PDA ligate	13	Chest infection
52	MBTS	0	Intraoperative bradycardias, died postop
53	BTS	16	Pulmonary oedema
54	PAB to LPA only	11	Good
55	MBTS	10	Pulmonary oedema
56	Ao-PA Shunt	3	Died in hospital
57	PAB	0	Hypotensive, died intraoperativelly
58	Ao-PA Shunt	22	Blocked shunt, repeat shunt done, pneumonia
59	MBTS	23	Paralysis left hemi-diaphragm
60	PAB	31	Cardiac failure, died in hospital
61	PAB	45	Post op cardiac arrest, CNS damage
62	PAB	12	Good
63	Ao-PA Shunt	20	Chest infection, wound sepsis
64	MBTS	39	Chest infection
65	BTS	10	Good
66	MBTS	?	Chylothorax, further surgery
67	PAB & pacemaker	10	Good
68	MBTS & valvotomy	2	Died postoperativelly
69	MBTS	11	Chest infection
70	Ao-PA Shunt	6	Good
71	Ao-PA Shunt	11	Died postoperativelly
72	PAB & Shunt	24	Septostomy required 3 days postop
73	PAB & ligate PDA	27	Chest infection, IPPV for 3 weeks
74	MBTS	0	Died postop
75	BTS	17	Good
76	MBTS	20	Good
77	BTS	11	Good
78	PAB	?	?
79	MBTS	356	Chest infection
80	PAB & Coarct Rep	12	Good

NO	PALLIATIVE OP	POST-OP STAY IN HOSP (days)	INITIAL HOSPITAL OUTCOME
81	PAB & Coarct Rep	0	Intraoperative cardiac arrest, died
82	MBTS	31	Intraoperative cardiac arrest, myocardial infarction, CNS damage
83	PAB	36	Paralysed diaphragm, pneumonia, died
84	PAB & Coarct Rep	10	Good
85	MBTS	14	Good
86	MBTS	26	Good
87	Septectomy	17	Good
88	PAB	21	Satisfactory
89	MBTS	14	Good
90	BTS	25	Chest infection
91	MBTS	12	Good
92	MBTS	26	Chest infection, feeding problem
93	MBTS	11	Good
94	BTS	13	Good
95	MBTS	10	Supraventricular tachycardia
96	PAB	24	Bradycardia, prolonged IPPV
97	BTS	14	Good
98	MBTS	29	Shunt failure, repeat shunt 14 days postop
99	PAB	17	Chest infection
100	MBTS	11	Good
101	MBTS	11	Good
102	PAB	0	Hypotensive postop, died
103	PAB & Coarct Rep	14	Died in hospital, ? cause
104	BTS	11	Good
105	PAB	?	?
106	Ao-PA Shunt	48	Wound dehiscence, reoperation 12 days postop
107	MBTS	10	Good
108	MBTS	?	?
109	PAB	55	Prolonged stay in hospital
110	MBTS	14	Good
111	PAB & Coarct Rep	33	Chest infection, died in hospital
112	MBTS	?	?
113	Ao-PA Shunt	16	Chest infection
114	MBTS	24	Good
115	BTS	10	Good
116	MBTS	13	Good
117	PAB & Coarct Rep	10	Good
118	Ao-PA Shunt	31	Wound infection
119	MBTS	46	RUL lung collapse, wound sepsis, cardiac arrest
120	BTS	29	Failure to thrive
121	BTS	28	Good

APPENDIX 9

CORRECTIVE OPERATIONS

NO	DATE OF OPERATION	AGE AT OP. (days)	DAYS BETWEEN PALL. & CORRECT	OPERATION	ELECTIVE OR EMERGENCY	POST OP STAY (days)	OUT-COME
3	19 Sep 1984	1021	876	Deband	Elective	9	Good
6	27 Jan 1987	2052	1974	Repair TOF, ligate PDA	Elective	9	Good
10	10 Dec 1985	808	433	Repair TOF, ligate PDA	Elective	2	Died
12	01 Mar 1983	707	448	Deband, close VSD, ASD, patch RVOFT	Elective	17	Satis
13	14 Jan 1984	413	389	Repair TOF, ligate PDA	Emergency	0	Died
15	29 Nov 1983	693	601	Repair TOF, with patch	Elective	10	Good
18	16 Jan 1985	218	92	Correct DORV, internal conduit	Elective	9	Good
23	04 Nov 1986	1126	1029	Deband, close VSD	Elective	10	Good
26	13 Aug 1986	908	806	Deband, repair AVSD	Elective	13	Satis
27	04 Aug 1987	2625	1106	RVOFT homograph, close VSD, divide shunts, PDA	Elective	10	Satis
31	27 Nov 1984	171	21	Deband, repair AVSD	Emergency	0	Died
34	29 Apr 1986	1142	748	Repair TOF, ligate PDA	Elective	45	Further surgery needed
35	03 Nov 1983	127	16	Deband, close VSD	Emergency	2	Died
40	17 Feb 1987	3339	1470	Rastelli	Elective	10	Died
41	06 Aug 1985	691	448	Repair TOF, ligate PDA	Elective	10	Satis
45	26 Jun 1984	1786	1260	Correct DORV, deband	Elective	1	Died
47	28 Feb 1984	411	279	Repair TOF, with patch	Elective	17	Good
53	10 Apr 1984	972	888	Repair TOF, ligate PDA	Elective	11	Good
54	15 Oct 1985	728	378	Rastelli	Elective	11	Good
55	24 Jan 1984	784	588	Repair TOF, with patch	Elective	10	Good
62	12 Feb 1985	839	777	Deband	Elective	6	Good
67	25 Mar 1986	1907	1631	Modified Fontan, deband	Elective	3	Died

NO	DATE OF OPERATION	AGE AT OP. (days)	DAYS BETWEEN PALL. & CORRECT	OPERATION	ELECTIVE OR EMERGENCY	POST OP STAY (days)	OUT-COME
73	22 Oct 1985	821	692	Deband, close VSD, infundib RV resection	Elective	10	Good
75	28 Jul 1987	2319	1295	Rastelli	Elective	52	Good
77	27 Jun 1984	230	197	Repair TOF, with patch	Elective	0	Died
78	18 Nov 1986	1278	1225	Arterial Switch, deband, close VSD	Elective	0	Died
84	02 Aug 1983	510	406	Deband, close VSD	Elective	10	Good
85	31 Jan 1984	1203	1092	Repair TOF, with patch	Elective	10	Good
87	13 Oct 1981	688	616	Sennings	Elective	11	Good
99	28 Apr 1987	1204	1064	Correct DORV, deband	Elective	10	Good
105	21 Jan 1986	766	641	Deband, close ASD, VSD	Elective	10	Good
107	17 Mar 1987	3407	1217	Fontans	Elective	2	Died
110	11 Mar 1987	2011	1785	Repair TOF, homograph PV	Elective	16	Satis
113	08 Jul 1987	552	2332	Correct DORV	?	0	Died
115	04 Feb 1986	2028	1743	Fontans	Elective	20	Satis
117	03 Aug 1982	194	175	Deband, close VSD	Elective	328	Died
118	14 Apr 1987	2228	2223	Rastelli	Elective	10	Good
120	05 May 1987	1973	1967	Fontan	Elective	2	Died
121	24 MAr 1987	3421	1806	Fontan	Elective	@$	Good

APPENDIX 10

FOLLOW UP

NO	DATE LAST SEEN	FOLLOW UP PERIOD (days)	INTERVAL BETWEEN LAST SEEN & 01 Mar 88	FINAL OUTCOME CATEGORY
1	04 Feb 1988	1143	26	Awaiting correction
2	31 Jul 1984	14	-	Died after palliation
3	28 Sep 1984	885	1250	Corrected, alive
4	12 Jan 1988	1287	49	Awaiting correction
5	17 Oct 1981	2	-	Died after palliation
6	05 Feb 1987	1983	390	Corrected, alive
7	15 Aug 1987	1509	-	Died after palliation
8	17 Jul 1987	1452	228	Awaiting correction
9	10 Mar 1983	1	-	Died after palliation
10	12 Dec 1985	435	810	Corrected, died
11	15 Sep 1987	1414	168	Inoperable
12	29 Apr 1986	1603	672	Corrected, alive
13	14 Jan 1984	389	1508	Corrected, died
14	12 Jun 1987	1821	263	Awaiting correction
15	07 Aug 1986	1583	572	Corrected, alive
16	05 Jun 1982	0	-	Died after palliation
17	07 Dec 1983	112	-	Died after palliation
18	16 Mar 1987	881	351	Corrected, alive
19	16 Feb 1984	1	-	Died after palliation
20	28 Mar 1986	454	-	Died after palliation
21	19 Nov 1987	1220	103	Awaiting correction
22	26 Feb 1988	2180	4	Inoperable
23	14 Nov 1986	1039	473	Corrected, alive
24	19 Jun 1987	927	256	Awaiting correction
25	15 Dec 1986	2015	442	Awaiting correction
26	12 Feb 1987	989	383	Corrected, alive
27	14 Aug 1987	1116	200	Corrected, alive
28	10 Aug 1982	48	-	Died after palliation
29	25 Jan 1988	1475	36	Awaiting correction
30	12 Mar 1987	856	355	Inoperable
31	27 Nov 1984	21	1190	Corrected, died
32	23 Mar 1987	965	344	Awaiting correction
33	18 Oct 1986	1081	500	Inoperable
34	03 Mar 1987	1056	364	Corrected, alive
35	05 Nov 1983	18	1578	Corrected, died
36	27 Apr 1987	2007	309	Awaiting correction
37	06 May 1983	150	-	Died after palliation
38	31 Jan 1985	653	1125	Lost to follow up
39	05 Nov 1987	1276	117	Awaiting correction
40	27 Feb 1987	1480	368	Corrected, died

NO	DATE LAST SEEN	FOLLOW UP PERIOD (days)	INTERVAL BETWEEN LAST SEEN & 01 Mar 88	FINAL OUTCOME CATEGORY
41	09 Oct 1986	877	509	Corrected, alive
42	23 Nov 1983	5	-	Died after palliation
43	27 Sep 1985	374	886	Inoperable
44	13 Jan 1988	1513	48	Awaiting correction
45	27 Jun 1984	1261	1343	Corrected, died
46	18 Sep 1985	1338	895	Transferred
47	20 Jan 1986	971	771	Corrected, alive
48	05 Jan 1983	463	1882	Transferred
49	08 Jun 1984	0	-	Died after palliation
50	21 Jul 1984	11	1319	Lost to follow up
51	13 Jan 1988	1567	48	Awaiting correction
52	21 Jun 1983	0	-	Died after palliation
53	06 May 1986	1644	665	Corrected, alive
54	09 Oct 1986	737	509	Corrected, alive
55	05 Jan 1986	1300	786	Corrected, alive
56	04 Dec 1982	3	-	Died after palliation
57	26 Jul 1983	0	-	Died after palliation
58	17 May 1980	81	-	Died after palliation
59	11 Jun 1982	23	2090	Lost to follow up
60	19 Feb 1982	31	-	Died after palliation
61	19 Jan 1983	57	-	Died after palliation
62	25 Aug 1986	1336	554	Corrected, alive
63	23 May 1982	137	2109	Lost to follow up
64	23 Sep 1983	136	-	Died after palliation
65	13 Nov 1987	1858	109	Awaiting correction
66	13 Nov 1980	65	-	Died after palliation
67	28 Mar 1986	1634	704	Corrected, died
68	11 Sep 1982	2	-	Died after palliation
69	29 Apr 1986	665	672	Awaiting correction
70	11 Oct 1985	1087	-	Died after palliation
71	10 Oct 1981	11	-	Died after palliation
72	08 Dec 1987	1323	84	Awaiting correction
73	01 Nov 1985	702	851	Corrected, alive
74	01 Dec 1981	0	-	Died after palliation
75	18 Sep 1987	1347	165	Corrected, alive
76	21 Dec 1982	20	1897	Lost to follow up
77	27 Jun 1984	197	1343	Corrected, died
78	18 Nov 1986	1225	469	Corrected, died
79	16 Mar 1987	1140	351	Inoperable

NO	DATE LAST SEEN	FOLLOW UP PERIOD (days)	INTERVAL BETWEEN LAST SEEN & 01 Mar 88	FINAL OUTCOME CATEGORY
80	25 Jul 1985	751	950	Transferred
81	03 May 1983	0	-	Died after palliation
82	10 Jun 1987	1090	265	Awaiting correction
83	31 Jul 1983	36	-	Died after palliation
84	14 Nov 1986	1606	473	Corrected, alive
85	03 Sep 1984	1308	1275	Corrected, alive
86	10 Jan 1983	33	-	Died after palliation
87	10 Apr 1986	2256	691	Corrected, alive
88	13 May 1987	2297	293	Awaiting correction
89	24 Jun 1988	2501	-115	Awaiting correction
90	08 Oct 1988	2266	-183	Awaiting correction
91	05 Mar 1987	1589	362	Awaiting correction
92	22 Jan 1985	176	-	Died after palliation
93	19 Nov 1984	41	1198	Lost to follow up
94	02 May 1986	542	669	Awaiting correction
95	23 Jul 1982	10	2048	Lost to follow up
96	20 Apr 1988	1358	-50	Awaiting correction
97	02 May 1986	1470	669	Awaiting correction
98	18 Apr 1988	1343	-48	Awaiting correction
99	08 May 1987	1074	298	Corrected, alive
100	22 Oct 1984	139	-	Died after palliation
101	23 Jun 1985	293	-	Died after palliation
102	19 Jun 1984	0	-	Died after palliation
103	26 Aug 1980	0	-	Died after palliation
104	22 Dec 1984	11	1165	Transferred
105	04 Sep 1986	867	544	Corrected, alive
106	07 Mar 1984	48	-	Died after palliation
107	19 Mar 1987	1219	348	Corrected, died
108	28 Sep 1987	2518	155	Awaiting correction
109	16 Oct 1987	1051	137	Awaiting correction
110	03 Apr 1987	1808	333	Corrected, alive
111	25 Oct 1981	33	-	Died after palliation
112	13 Jan 1987	2016	413	Inoperable
113	08 Sep 1981	2332	237	Corrected, died
114	15 Jun 1982	161	-	Died after palliation
115	06 Mar 1987	2138	361	Corrected, alive
116	15 Oct 1981	156	-	Died after palliation
117	27 Jun 1983	503	1709	Corrected, died
118	24 Apr 1987	2233	312	Corrected, alive
119	11 Feb 1988	1878	19	Awaiting correction
120	07 May 1987	1969	299	Corrected, died
121	17 Apr 1987	1830	319	Corrected, alive

APPENDIX 11

OUTCOME

	INITIAL HOSP OUTCOME	FOLLOW UP	FURTHER PALL	CORR-ECTED	OUTCOME AFTER CORR	FINAL OUTCOME CATEGORY
1	Satisf	Satisf	No	No	-	Awaiting Corr
2	Died	-	No	No	-	Palliative death
3	Good	Satisf	No	Yes	Good	Corrected, alive
4	Good	Satisf	No	No	-	Awaiting Corr
5	Died	-	No	No	-	Palliative death
6	Good	Satisf	No	Yes	Good	Corrected, alive
7	More Sx	Lost	Shunt x1	No	-	Palliative death
8	Satisf	Satisf	No	No	-	Awaiting Corr
9	Died	-	No	No	-	Palliative death
10	Good	Satisf	No	Yes	Died	Corrected, died
11	Satisf	Satisf	No	No	-	Inoperable
12	Good	Satisf	No	Yes	Satisf	Corrected, alive
13	Good	Satisf	No	Yes	Died	Corrected, died
14	Good	Satisf	Shunt x1	No	-	Awaiting Corr
15	Good	Satisf	No	Yes	Good	Corrected, alive
16	Died	-	No	No	-	Palliative death
17	Good	Lost	No	No	-	Palliative death
18	Satisf	Satisf	No	Yes	Good	Corrected, alive
19	Died	-	No	No	-	Palliative death
20	Good	Satisf	Brock	No	-	Palliative death
21	More Sx	Satisf	No	No	-	Awaiting Corr
22	Good	Satisf	Shunt x1	No	-	Inoperable
23	Good	Satisf	No	Yes	Good	Corrected, alive
24	Good	Satisf	No	No	-	Awaiting Corr
25	More Sx	Satisf	Shunt x1	No	-	Awaiting Corr
26	Good	Satisf	No	Yes	Satisf	Corrected, alive
27	More Sx	Satisf	Shunt x1	Yes	Satisf	Corrected, alive
28	More Sx	Satisf	No	No	-	Palliative death
29	CNS damage	Sporadic	No	No	-	Awaiting Corr
30	Satisf	Satisf	No	No	-	Inoperable
31	More Sx	-	No	Yes	Died	Corrected, died
32	Satisf	Sporadic	No	No	-	Awaiting Corr
33	Satisf	Satisf	No	No	-	Inoperable
34	Satisf	Satisf	Shunt x1	Yes	More Sx	Corrected, alive
35	More Sx	-	No	Yes	Died	Corrected, died
36	Good	Satisf	Shunt x1	No	-	Awaiting Corr
37	Good	Lost	No	No	-	Palliative death
38	Good	Lost	No	No	-	Lost
39	Good	Satisf	Septect	No	-	Awaiting Corr
40	Satisf	Satisf	No	Yes	Died	Corrected, died

	INITIAL HOSP OUTCOME	FOLLOW UP	FURTHER PALL	CORR-ECTED	OUTCOME AFTER CORR	FINAL OUTCOME CATEGORY
41	Good	Satisf	No	Yes	Satisf	Corrected, alive
42	Died	-	No	No	-	Palliative death
43	Good	Satisf	No	No	-	Inoperable
44	Good	Satisf	No	No	-	Awaiting Corr
45	Good	Satisf	No	Yes	Died	Corrected, died
46	Good	Satisf	Shunt x1	No	-	Transferred
47	Satisf	Satisf	No	Yes	Good	Corrected, alive
48	Good	Satisf	No	No	-	Transferred
49	Died	-	No	No	-	Palliative death
50	Good	Lost	No	No	-	Lost
51	Satisf	Satisf	No	No	-	Awaiting Corr
52	Died	-	No	No	-	Palliative death
53	Satisf	Satisf	No	Yes	Good	Corrected, alive
54	Good	Satisf	No	Yes	Good	Corrected, alive
55	Satisf	Satisf	No	Yes	Good	Corrected, alive
56	Died	-	No	No	-	Palliative death
57	Died	-	No	No	-	Palliative death
58	More Sx	Satisf	Shunt x1	No	-	Palliative death
59	Satisf	Lost	No	No	-	Lost
60	Died	-	No	No	-	Palliative death
61	CNS damage	Satisf	No	No	-	Palliative death
62	Good	Satisf	No	Yes	Good	Corrected, alive
63	Satisf	Lost	No	No	-	Lost
64	Satisf	Lost	No	No	-	Palliative death
65	Good	Satisf	Shunt x1	No	-	Awaiting Corr
66	More Sx	Satisf	No	No	-	Palliative death
67	Good	Satisf	No	Yes	Died	Corrected, died
68	Died	-	No	No	-	Palliative death
69	Satisf	Satisf	No	No	-	Awaiting Corr
70	Good	Lost	Shunt x1	No	-	Palliative death
71	Died	-	No	No	-	Palliative death
72	More Sx	Satisf	Septect	No	-	Awaiting Corr
73	Satisf	Satisf	No	Yes	Good	Corrected, alive
74	Died	-	No	No	-	Palliative death
75	Good	Satisf	No	Yes	Good	Corrected, alive
76	Good	Lost	No	No	-	Lost
77	Good	Satisf	No	Yes	Died	Corrected, died
78	?	Satisf	No	Yes	Died	Corrected, died
79	Satisf	Satisf	Brock	No	-	Inoperable
80	Good	Satisf	No	No	-	Transferred

	INITIAL HOSP OUTCOME	FOLLOW UP	FURTHER PALL	CORR-ECTED	OUTCOME AFTER CORR	FINAL OUTCOME CATEGORY
81	Died	-	No	No	-	Palliative death
82	CNS damage	Satisf	No	No	-	Awaiting Corr
83	Died	-	No	No	-	Palliative death
84	Good	Satisf	No	Yes	Good	Corrected, alive
85	Good	Satisf	No	Yes	Good	Corrected, alive
86	Good	Satisf	No	No	-	Palliative death
87	Good	Satisf	No	Yes	Good	Corrected, alive
88	Satisf	Satisf	No	No	-	Awaiting Corr
89	Good	Satisf	Shunt x1	No	-	Awaiting Corr
90	Satisf	Lost	Shunt x1	No	-	Awaiting Corr
91	Good	Satisf	Brock	No	-	Awaiting Corr
92	Satisf	Lost	No	No	-	Palliative death
93	Good	Lost	No	No	-	Lost
94	Good	Satisf	No	No	-	Awaiting Corr
95	Satisf	Lost	No	No	-	Lost
96	Satisf	Lost	No	No	-	Awaiting Corr
97	Good	Satisf	No	No	-	Awaiting Corr
98	More Sx	Satisf	Shunt x1	No	-	Awaiting Corr
99	Satisf	Satisf	No	Yes	Good	Corrected, alive
100	Good	Lost	No	No	-	Palliative death
101	Good	Satisf	Shunt x1	No	-	Palliative death
102	Died	-	No	No	-	Palliative death
103	Died	-	No	No	-	Palliative death
104	Good	Satisf	No	No	-	Transferred
105	?	Satisf	No	Yes	Good	Corrected, alive
106	Satisf	Lost	No	No	-	Palliative death
107	Good	Satisf	Shunt x1	Yes	Died	Corrected, died
108	?	Satisf	No	No	-	Awaiting Corr
109	Satisf	Sporadic	No	No	-	Awaiting Corr
110	Good	Satisf	No	Yes	Satisf	Corrected, alive
111	Died	-	No	No	-	Palliative death
112	?	Satisf	Shunt x1	No	-	Inoperable
113	Satisf	Lost	Shunt x1	No	-	Lost
114	Good	Lost	No	No	-	Palliative death
115	Good	Satisf	No	Yes	Satisf	Corrected, alive
116	Good	Lost	No	No	-	Palliative death
117	Good	Satisf	No	Yes	Died	Corrected, died
118	Satisf	Satisf	No	Yes	Good	Corrected, alive
119	Satisf	Satisf	Shunt x2	No	-	Awaiting Corr
120	Satisf	Satisf	Shunt x1	Yes	Died	Corrected, died
121	Good	Satisf	No	Yes	Good	Corrected, alive