

## PW1-11

### **Home surveillance program clearly reduces interstage mortality after the Norwood operation for patients with Hypoplastic left heart syndrome**

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#### Objectives

Since 1996 the hospital mortality after the Norwood operation of children with hypoplastic left heart syndrome (HLHS) in our centre could be steadily decreased to recently less than 3%. However, the interstage mortality till the superior cavopulmonary anastomosis (SCPA) remained high and was a major concern. Therefore we established a home surveillance program with the aim to overcome this problem.

#### Patients and Methods

45 infants with HLHS surviving the Norwood Operation between 10/05 and 09/09 were enrolled into the program. For comparison, infants before the start of the program (historical controls;n=99) were used as well as 20 infants who were not discharged between the first and second stage operation. During the initial stay in the hospital parents were taught the handling of a monitor which recorded heart rate, respiration and arterial oxygen saturation. Additionally they were trained in cardiopulmonary resuscitation, recording daily saturation, heart rate, weight, fluid intake and instructed when to call the hospital (Saturation <75%, no weight gain of 20 to 30g in 3 days or an acute weight loss of more than 30g in a day). An experienced paediatric cardiologist called them at home once a week.

#### Results

Interstage mortality was reduced significantly ( $p=0.037$ ) from 14.1% ( $n=14/99$ ) to 2.2% ( $n=1/45$ ). There was no significant differences between the three groups in their anatomical subgroups, the weight at the time of the Norwood operation or the shunt index diameter. At the time of SCPA children in the home surveillance program had a significantly lower age (102(67-299) vs 152 (77-1372) days) and weight ( $5.09\pm 0.79$  vs  $5.75\pm 1.22$  kg) compared to those without it ( $p<0.001$ ). 14 infants did not meet the criteria all the time. 1 patient was late referred to the local hospital and died, 8 infants were operated earlier (SCPA  $n=6$ , shunt replacement  $n=2$ ), but 5 could be discharged after observation.

#### Conclusion

The implementation of the home surveillance program led to a drastic decrease of interstage mortality. The time, effort and costs involved in such program are justified by the improved survival of this patient group. Therefore this should be continued.