

## EDITORIAL

### Congenital heart diseases – a future burden for Papua New Guinea

Previous studies on congenital heart diseases (CHDs) in Papua New Guinea (PNG) were mainly on clinical assessment of CHD (1,2) and not about the significance of the problem. Studies in other developing countries, however, have estimated the incidence of CHD to be between 6 and 8 per 1000 livebirths (3-5), similar to that reported from developed countries (6).

With PNG's crude birth rate of 36 per 1000 (7), total population of 5 million and using CHD incidence of 6-8 per 1000 livebirths, the number of cases of CHD is estimated to be between 1100 and 1400 per annum.

Taking PNG's current high growth rate of 2.3%, not only its current population of 5 million is expected to double in 30 years time, but the current number of 1100-1400 children with CHD per year is also expected to double. Thus, although CHDs are not a current national health priority they will certainly be a burden in the future that needs to be considered.

Only a small fraction (1 in 25) of CHD children in PNG (8) are detected by current screening methods. Of the estimated 1100-1400 (mean 1250) cases of CHD per year, a third (417) will require hospitalization in the first year of life because of symptoms (9,10); one-third (417) will require attention later in life and one-third (417) will experience little functional consequence. Of those hospitalized in the first year, one-half (208) will require cardiac surgery before their first birthday to prevent death. Thus, 625 of the 1250 CHD children (50%) will require surgery if they survive infancy. This estimate is remarkably similar to one reported by Dickinson (11), who calculated that 53% of CHD children require surgery.

Taking the mean of 1250 (1100-1400 livebirths with CHD) as the number of children born with CHD in PNG every year and assuming that 53% of all patients with CHD will require surgery (11), we can calculate that 663 PNG children will require surgery every

year. However, because 208 of these children will die during the first year due to the lack of operative facilities in PNG and an infant mortality rate of 82 per thousand will apply to the remaining 455 CHD children ( $82 \times 455/1000=37$ ), one would expect a total of 418 children to survive infancy and require CHD surgery per year.

In the last 3 decades two approaches to cardiac surgery have been tried: 1, funding travel to Australia, surgery and hospital costs in Australian cardiac institutions, particularly the Royal Alexandra Hospital in Sydney; 2, cardiac teams visiting PNG hospitals (Operation Open Heart, run by the Seventh Day Adventist Hospital in Sydney). The Royal Alexandra Hospital for Children (RAHC) program (Sydney, 1978-1992) operated on 133 children over 14 years, averaging 10 per year, or 2.4% of the expected CHD caseload (12). The 'Operation Open Heart' (OOH) program has operated on 221 children over 9 years, averaging 25 CHD per year or 6.0% of the expected number per year. This represents a 150% increase in the number of CHD operated on each year under the present in-country program compared to the RAHC experience that preceded it. The OOH Program currently has an early case fatality rate of 2% (12), and if 418 children with CHD were to receive surgery, 410 (98%) of them would have a good short-term outcome. For the RAHC program with a 6% case fatality rate, of 418 PNG children receiving surgery 393 (94%) would have a good short-term outcome. This mortality difference most probably results from a selection bias. Because of the limited intensive care facilities, patients operated on in PNG are strictly limited to 40, and will include those expected to have a low incidence of postoperative complications.

It is difficult to estimate the overall annual cost of the 'Operation Open Heart' program team visit because a lot of the costs are hidden. The team consists of members recruited from hospitals throughout Australia on a voluntary basis. Accounting for food, accommodation

and incidental expenses, the estimated cost per year is about 100,000 kina (63,000 dollars Australian in 1999) for a moderately sized team (20 people) although a larger team consisting of about 30 people is normally required for open-heart surgery. There were 102 children operated on over 6 years with an average cost of \$3706 per child. These costs were borne in PNG by the Health Department and by private and corporate donors. The cost does not include airfares or consumables – all of which are met by the team itself. Because these costs are not known we cannot calculate the total cost per child under the OOH program. The estimated total cost to repair an uncomplicated congenital heart defect at RAHC was about 26,000 dollars Australian per child. Assuming these calculations reflect costs at the mid-point of the RAHC period these would be equivalent to 1985 Australian dollars.

Overall the current 'Operation Open Heart' program would be the best option for PNG in terms of the future surgical management of CHD. It has already doubled the rate of surgery, is less disruptive and traumatic for parents and is almost certainly much cheaper. Additionally, it enhances training opportunities for local staff.

However, both programs have operated on less than 10% of the expected number of children requiring cardiac surgery. The RAHC in particular had a high proportion of children with complications including pulmonary hypertension and congestive heart failure. These complications led to some mortality and morbidity. To avoid these complications, CHD children must be detected earlier, which implies the necessity for substantial improvements in the current screening programs in terms of primary detection. Existing health programs into which CHD screening could be incorporated include mobile immunization clinics, maternal and child health clinics and schools. Earlier detection would also result in a better outcome for the small but significant proportion of PNG children labelled as 'unresponsive severe or recurrent pneumonia' but who may well have underlying congenital or acquired cardiac abnormalities. The general population too must be made aware of CHD signs and symptoms. Doctors

and paediatricians should be instructed in the use of modern medical therapy to control those children with CHD who present with cardiac failure. The short-term increased cost of drugs will be easily defrayed if the children can proceed to surgical cure. The burden of CHD is estimable and the significance of the problem can be calculated quantitatively and qualitatively. Despite inability to prevent CHD, it can be detected and treated with satisfactory results. Consequently, a program of early detection and management is both essential and viable.

While the need to act is pressing, with a constantly expanding number of cases and increasing surgical costs, better diagnosis, safer surgical procedures and the capacity to attract philanthropic support offer hope in the future for children with CHD.

The following recommendations are made to the PNG Health Department:

1. It should recognize that (a) CHD is not uncommon and is a substantial cause of preventable mortality and morbidity, (b) children surviving CHD without surgery have a low quality of life and require ongoing expensive health services (12), and (c) children receiving surgery have excellent long-term outcomes for potentially normal lives.
2. Findings from completed research work should be incorporated in the National Health Plan in order to guide policy and plans for managing children with CHD.
3. A recurrent and realistic annual budget for detection and management of children with CHD should be established and attempts to obtain funds from philanthropic organizations interested in CHD be endorsed.
4. The Health Department should collaborate with national and provincial paediatricians, other health staff, and Education Department personnel to develop and test suitable community and school CHD screening strategies for national application.
5. Health workers engaged in primary and secondary care should be taught to better

recognize children with possible cardiac defects.

6. A National Congenital Heart Register should be developed and maintained in Port Moresby.
7. The Health Department should establish a referral centre for all PNG children with CHD. This centre will perform mostly noninvasive investigations and coordinate closed heart operations and open-heart surgery, with input from overseas collaborators.
8. A long-term agreement at governmental or departmental level should be made with an Australian cardiac institution, preferably one of those already involved in the current management of CHD in PNG.
9. The Health Department should organize further training in cardiology and cardiac surgery for PNG doctors and nurses locally, or overseas.
10. The Health Department should encourage the current SDA 'Operation Open Heart' team to continue its annual visits indefinitely since it is recognized that full-time, in-country facilities for open cardiac surgery are unlikely to be available in the near future. In the meantime, national surgeons, medical staff, anaesthetists, nurses and paediatricians should be encouraged to develop their skills locally and should establish a program for children with lesions correctable by closed surgery which they can already safely perform. Likewise, visiting paediatric cardiologists should be encouraged to continue supporting national paediatricians involved in the program and contribute to the final selection decisions for open-heart surgery in conjunction with the visiting cardiac surgical team.

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