Pediatric Heart Surgery Waiting Time in Thailand and Its Effect on Mortality: A Cooperative Study from Chulalongkorn, Children and Chiang Mai University Hospitals

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Background: *Thai children who need cardiac surgery are often put on a waiting list. The waiting time and mortality during waiting have not been previously systematically studied.*
Material and Method: *A cooperative study was conducted at King Chulalongkorn Memorial hospital (Chula), Children hospital (CH), and Chiang Mai University hospital (CMU). The status of children who were referred for cardiac surgery at these hospitals in the year 1999-2000 (Chula and CMU) and the year 2000 (CH) were analyzed by Kaplan-Meier survival curve. The patients who lost to follow up and could not be contacted were censored at the time of last clinic visit. Log-Rank test was used to compare the survival curve and waiting time between three hospitals.*
Results: *The averaged annual referrals for cardiac surgery at the three hospitals were 846 cases (205 for Chula, 462 for CH and 179 for CMU). Mean age was 4.3±4.2 years and 51% were male. Follow up data were complete in 96.3%. Surgical procedures were correction of simple shunt lesions (ASD, VSD, AV canal) in 33.9%, close heart surgery (PDA ligation, coarctation repair, BT shunt) in 29.9%, total repair TOF in 19.6%, complex surgery in neonate and infants (arterial switch, TAPVR repair, Norwood procedure, truncus and interrupted aortic arch repair) in 4.2% and others in 12.3%. Median waiting time was 195 days and was significantly different between the three hospitals ($p < 0.01$). Mortality while waiting were approximately 5% at 2 years at Chula and CH, which was significantly higher than CMU (0%, $p = 0.02$). Further analysis revealed difference in age (lower Chula than CH than CMU) and types of surgery (more complex at Chula and CH) which may be the causes for difference in the mortality observed.*
Conclusion: *Waiting time for cardiac surgery for children in Thailand is long and should be viewed as a problem in public health policy. Optimal waiting time at each hospital may not have to be the same, depending on the type and severity of the disease seen at each particular center. Attempt should be made to solve this problem at the national level.*

Keywords: *Heart surgery, Congenital heart disease, Children, Mortality, Waiting time, Health service*

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The most important treatment for children with symptomatic heart disease is cardiac surgery. While this modality is highly effective for most symptomatic congenital heart diseases, its availability is limited in most developing countries, including Thailand[1-3]. This results in a long waiting list for most elective surgeries. The studies of this waiting period and the mortality incurred by waiting are important in the planning for health care delivery for these children and have not

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been previously done in Thailand. The objectives of the present study were to study 1) the waiting time for cardiac surgery and 2) the mortality occurred during the waiting period in Thai children attending 3 of the major cardiac centers in Thailand: King Chulalongkorn Memorial Hospital (a university based tertiary center in Bangkok), Queen Sirikit National Institute of Child Health (the largest referral center for children operated by the Ministry of Public Health), and Chiang Mai University Hospital (a university based tertiary center in the northern provinces). The combined number of pediatric heart surgeries at these 3 hospitals was approximately 46% of the total number of pediatric heart surgeries in Thailand in the year 2003 (unpublished survey, the Society of Pediatric Cardiologists of Thailand).

Material and Method

This observational study was conducted at King Chulalongkorn Memorial Hospital (also known as Chulalongkorn Hospital or Chula), Queen Sirikit National Institute of Child Health (also known as Childrens' Hospital, CH) in Bangkok, Thailand, and Chiang Mai University Hospital (CMU), Chiang Mai, Thailand. The subjects enrolled were children (age 0-15 years) who were referred for cardiac surgery at Chula and CMU during January 1999-December 2000, and children (age 0-18 years) who were referred for cardiac surgery at CH in the year 2000. For the purpose of the present study, the patients who were referred from Childrens' Hospital for heart surgery at Rajavithi Hospital, Bangkok, Thailand was considered the same group as the patients who had heart surgery at the Childrens' Hospital. Indications for surgery and the procedure proposed were decided by the local pediatric cardiologists and cardiac surgeons at each center. Medical records were reviewed and the status of the patients was determined in the year 2003-2004. For those patients who did not come for the scheduled follow-up appointment, phone contacts were attempted twice, followed by mail contact if the patient or his/her parents could not be contacted by phone. The patient who could not be contacted by 2 phone call attempts and 2 letters were considered uncontactable. The status of the patients (whether the patient had undergone the proposed cardiac surgery or the patients had died while waiting) were collected according to the criteria in Table 1. Surgical waiting time and mortality during waiting were analyzed using Kaplan-Meier survival curve. Difference of survival curve between groups was analyzed by Log-Rank test. A p value of < 0.05 was considered significant.

Table 1. Criteria used in the construction of Kaplan-Meier survival curve

1. Surgical waiting time curve
   - Event = the date that the patient underwent the car diac surgery he/she was referred for
   - The patient was censored at
     i. If death occurred, at the date of death or
     ii. The date the patient was last known to be alive, If he/she was still alive and was waiting for sur gery (i.e. event = none)
        1. in patients who kept follow up appoint ment, on the date of last appointment
        2. in patients who did not come for follow up appointment, on the last date the pa tient came to clinic, or the date that the patient was know to be alive by phone contact or by mail, whichever was later.
2. Mortality (while waiting) curve
   - Event = death related to underlying heart disease and/or its complication
     i. Deaths from other disease such as accidental death, malignancy, etc. were excluded and the patient was censored at the date of death
     ii. All sudden deaths (death within 24 hours of symptoms) of unclear cause and/or unexpected deaths were assumed to be related to the under lying heart disease
   - The patient was censored at
     i. The date of cardiac surgery, if it was done, or
     ii. The date of death unrelated to underlying heart disease or
     iii. The date the patient was last known to be alive, If he/she was still alive (without event) and was waiting for surgery
        1. patients who kept their follow up appoint ment, on the date of last appointment
        2. patients who did not come for follow up appointment, on the last date the patient came to the clinic, or the date the patient was known to be alive by phone contact or by mail, whichever was later.

Results

The number of patients referred for surgery at King Chulalongkorn Memorial Hospital and Chiangmai University Hospital in the year 1999 and 2000 (2 years) was 410 and 358 patients, respectively. The number of children referred for surgery at Queen Sirikit National Institute of Child Health in the year 2000 was 462 patients. These figures made the annual referral for cardiac surgery at Chula, CMU, and CH = 205,179 and 462 respectively. The averaged number of annual referral for cardiac surgery at these 3 hospitals = 846 cases during these periods. The mean age for the whole group

was 4.3±4.2 years, of whom 51% were male. Collections of data up to the time of censored point were complete in 96.3%. Forty-six patients (3.7%) were lost to follow up while waiting for surgery and could not be contacted by phone calls and mails. These patients were censored at the time of the last clinic visit.

The characteristics of the patients at the 3 hospitals are summarized in Table 2. There were significant differences in the age and types of heart surgery required for patients at the 3 hospitals with more neonates and infants at Chula > CH > CMU. The types of cardiac surgery reflected the age-related diagnosis of the heart diseases typically seen in these children.

The waiting time by hospitals and by diagnosis in all patients are shown in Fig. 1A, 1B (left, top) and Fig. 1 (left, bottom), respectively. The median time from referral to cardiac surgery in all patients was 195 days with significant difference of waiting period for the 3 hospitals ($p < 0.01$, Log-Rank test). The initial decline of the waiting time curve appeared similar among the 3 hospitals with difference which appeared after a wait of more than approximately 1 year. For patients waiting more than 1 year, the waiting time appeared to be longer at Chula > CH > CMU with approximately 10% of patients at Chula and CH who had a waiting time of more than 4 years (Fig. 1A, left top panel). The waiting time was shortest for complex neonatal surgery and was longest for total repair of tetralogy of Fallot (TOF) (Fig. 1B, left bottom panel). The median waiting time for patients with TOF was 452 days (1.24 year) and more than 10% of these patients waited for more than 4 years for total correction.

The mortality during waiting by hospitals and by diagnosis are shown in Fig. 1C (right top) and Fig. 1D (right bottom), respectively. While there was no patient died of cardiac cause during waiting at CMU, approximately 5% of patients at Chula and CH died within 2 years of waiting. For the patients who were able to wait for more than 2 years, no further mortality was seen (Fig 1C, right top panel). Patients waiting for systemic-to-pulmonary shunt procedure had the highest mortality while waiting, followed by patients waiting for total correction of TOF and VSD closure, respectively (Figure 1D, right bottom panel).

Discussion

It is generally accepted that approximately 8 out of 1000 live born children have some kinds of congenital heart defects regardless of race and ethnicity[4]. In approximately one-third to one-half of these children, cardiac surgery will be needed to correct their heart defects [5,6]. In Thailand, with a population of 60 million and annual birth rate of 1.2% [7], approximately 6,000 children will be born with congenital heart defect each year. This translates to approximately 2,000-3,000 patients who will require at least 1 cardiac surgery during their lifetime. The number of procedures needed to be performed is likely to be higher because some children will have to undergo a staged surgery or additional surgery to correct for residual lesions.

Like many other developing countries, it has long been recognized that the number of heart surgeries for children in Thailand lags behind the number of patients in need of this treatment modality. In the

Table 2. Characteristics of patients referred for heart surgery at 3 hospitals

	Chula	Children	Chiangmai	p
Number of referral per year	205	462	179	
Age (years)	3.2 ± 3.8	4.8 ± 3.9	5.0 ± 4.9	< 0.001
Age < 2 months	18.3%	4.1%	3.1%	< 0.001
Age < 1 year	36.4%	20.0%	17.6%	< 0.001
Missing Case (lost to follow up and not able to contact)	3.8%	5.2%	1.1%	0.006
Procedures (%)				
PDA ligation/division	9.8	17.0	15.0	< 0.001
Shunt +/- PA banding	14.7	6.3	9.2	
ASD,VSD and AV canal total repair	20.0	38.0	44.4	
Total correction of TOF	21.7	19.7	17.0	
Fontan or bidirectional Glenn	6.8	4.1	5.0	
Complex and neonatal surgery	6.8	4.8	0.6	
Valve repair & Ross procedure	1.7	2.3	2.0	
Others	18.5	7.7	6.8	

ASD = atrial septal defect closure, AV canal = total repair of complete atrioventricular canal, PA banding = pulmonary artery banding, PDA = patent ductus arteriosus, TOF = tetralogy of Fallot, VSD = ventricular septal defect closure

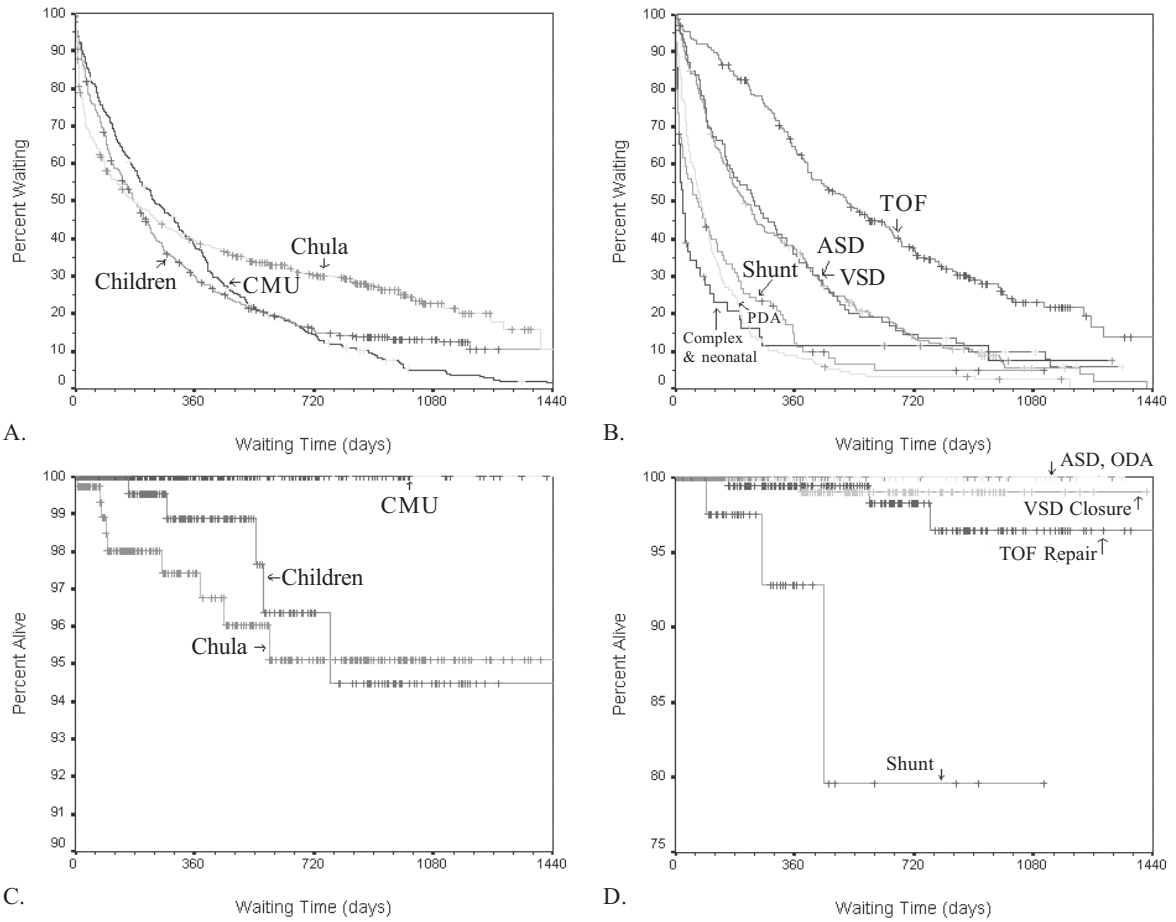

Fig. 1 Waiting time for heart surgery and mortality while waiting in children at the study hospitals. A = waiting time divided by hospitals. B = waiting time divided by the proposed surgical procedures. C = mortality (during waiting) divided by hospital. D = mortality by the proposed surgical procedures

past, during which time when no organized plan was in place to solve this problem, most cardiac center put all these patients on a waiting list with an exception for cases that required surgery emergently or urgently by varieties of reasons. Because of the large mismatch between the demand (number of patients waiting for surgery) and the supply (the number of surgeries that can be provided) one can probably expect that some patients may die while waiting for surgery. The purpose of this study was to serve as the baseline health status for children waiting for heart surgery in Thailand's three of the major referral centers for pediatric heart surgery in the country. Improvement (or deterioration) in the health status of these children because of institutional or national health policy changes (such as the national health insurance policy, etc.) can then be followed by the median time of waiting for surgery and also by the mortality and survival curve of children waiting for heart surgery.

A few interesting observations were found in the present study. The initial portions of the curves for surgical waiting time (Fig. 1, left top panel) were quite similar between the 3 hospitals which probably represented the procedures done in patients with relatively urgent indications for surgery. The initial decline was more rapid at Chula than CH than CMU, probably because there were proportionally more urgent neonatal and infant heart surgeries at Chula > CH > CMU. The logarithmic nature of the curves demonstrated the ability of the surgical team to increase its capacity to match the demand of the cardiac surgery (i.e. the chance for each patient to get to surgery was constant or in another words, was not affected by the number of patients waiting). The latter parts of the curves (after waiting for more than 1 year) appeared to flatten out for Chula and CH, and were finally lagging behind the

waiting time curve of patients at CMU. The authors postulate that the more complex and more urgent nature of surgeries at Chula and CH contributed to the delay of the more elective heart surgeries at these hospitals. The waiting curve after 1 year at Chula and CH also appeared to be declining at a constant rate (rather than logarithmic) which imply that only a fix number of elective heart surgeries could be done regardless of the number of patients waiting. A large proportion of patients in this section of the curves were probably patients waiting for TOF repair since its surgical waiting time were the longest and more than 60% of them waited for more than 1 year before undergoing cardiac surgery (Fig 1B, left bottom panel). These data demonstrated that the capacity to operate was probably at its limit for this group of patients (or the capacity to clear these patients from waiting list was saturated if one compares this curve to a drug elimination curve). These results may assist the particular cardiac center or national health authority to look into possible solutions for the long waiting list problem.

The second observation is related to the effect of waiting upon mortality of these patients. The results were striking that there was no mortality while waiting at CMU but there was approximately 5% of mortality at 2 years of waiting at the other 2 hospitals despite similarly long waiting time at all centers. The results imply that decreasing waiting time may not have to be the top priority in improvement of health care delivery at every hospital. Hospitals that do relatively well may have certain patients' or institutional characteristics that account for the low mortality. Thus, each institution should have and monitor their data in order to find the best strategy to improve the heath care at each center. For example, Chula and CH may find a median waiting time of 6 months too long since patients succumbed while waiting as little as 2 months but similar duration may be appropriate for CMU. The more complexity of heart diseases at Chula and CH compared to CMU (Table 2) may be one of the reasons for this difference. National registry of patients waiting for heart surgery will be particularly helpful in this regard.

The survival curve based on cardiac surgical procedure to be done showed the highest mortality in patients waiting for BT shunt, followed by patients waiting for TOF repair and patients waiting for VSD closure, respectively. The data can be used to change the pattern of referral or to classify the urgency for each procedure. For example, from the present study, any patient who is cyanotic enough to be sent for a BT shunt should probably have a shunt placed within a few weeks to months while patients referred for ASD closure may be able to wait for a few years.

The waiting time curve and mortality curve classified by surgical procedure demonstrated one important problem of pediatric cardiac surgical care in Thailand. Patients waiting for TOF repair had the longest waiting time of all and were second only to cyanotic patients waiting for BT shunt in terms of mortality. Patients with TOF died as early as a few months while waiting for surgery and the mortality continued during the first 2 years of waiting (Fig. 1D, right bottom panel). On the other hand, less than half of these patients had cardiac surgery within one year of waiting (Fig. 1B, left bottom panel). These data imply that although total correction of TOF accounted for a large portion of cardiac surgery to be performed for children with CHD (approximately 20% of all cases), the number of surgeries that can be done was limited. This is in contrast to the generally good long-term outcome of patients with TOF who had undergone surgical repair [8-11]. These data can be used as a guide for the cardiac centers and the local health authorities in improving health care delivery for children with heart disease in the future.

Conclusion

Waiting time for heart surgery for children in Thailand is long and should be viewed as a problem in the public health policy. Mortality occurs while waiting especially in patients with cyanotic heart disease waiting for surgical treatment like BT shunt or total repair of TOF. However, mortality while waiting is likely to depend on many factors and optimal waiting time at each cardiac center may not have to be the same. These data should serve as a baseline for monitoring the health status of children with heart disease in Thailand.

Limitations of the study

1. Forty-six patients (3.7%) were lost to follow up while waiting for surgery and could not be contacted. These patients were censored and considered to be alive at the time of the last clinic visit. This method could potentially be biased toward less death because patients who died do not come for follow up appointment. The mortality while waiting in the present study would probably represent the best case scenarios.

2. The number of pediatric cardiac surgeries performed at these 3 hospitals plus Rajavithi Hospital (which operates almost exclusively on children referred from Childrens' Hospital) accounted for 46% of the

number of pediatric cardiac surgeries for the whole country in the year 2003. The data may not be entirely representative for the whole country. A national registry should serve as the better way to evaluate the health care delivery (and improvement) for children with heart disease in Thailand in the future.

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References

1. Hewitson J, Brink J, Zilla P. The challenge of pediatric cardiac services in the developing world. Semin Thorac Cardiovasc Surg 2002;14:340-5.
2. Abdulla RI. Congenital heart disease management in developing countries. Pediatr Cardiol 2002;23: 481-2.
3. Asou T, Rachmat J. Pediatric cardiac surgery in Indonesia. Cardiol Young 1998;8:437-9.
4. Abdulla R. What is the prevalence of congenital heart diseases? Pediatr Cardiol 1997;18:269.
5. Dickinson DF, Arnold R, Wilkinson JL. Congenital heart disease among 160 480 liveborn children in Liverpool 1960 to 1969. Implications for surgical treatment. Br Heart J 1981;46:55-62.
6. Mogyorosy G, Belicza E, Karacsonyi T, Szucs E. [Incidence and invasive treatment of congenital heart diseases in Hajdu-Bihar county]. Orv Hetil 2000;141:1287-92.
7. National Statistic Office. Statistical Thailand Year Book 2004. Bangkok: National Statistical Office, 2004.
8. Ternestedt BM, Wall K, Oddsson H, Riesenfeld T, Groth I, Schollin J. Quality of life 20 and 30 years after surgery in patients operated on for tetralogy of Fallot and for atrial septal defect. Pediatr Cardiol 2001;22:128-32.
9. Norgaard MA, Lauridsen P, Helvind M, Pettersson G. Twenty-to-thirty-seven-year follow-up after repair for Tetralogy of Fallot. Eur J Cardiothorac Surg 1999;16:125-30.
10. Morris CD, Menashe VD. 25-year mortality after surgical repair of congenital heart defect in childhood. A population-based cohort study. JAMA 1991;266:3447-52.
11. Owen AR, Gatzoulis MA. Tetralogy of Fallot: Late outcome after repair and surgical implications. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu 2000;3:216-26.

ระยะเวลาของการรอผ่าตัดหัวใจในเด็กไทย และอัตราการเสียชีวิตขณะรอผ่าตัด: การศึกษาที่โรงพยาบาลจุฬาลงกรณ์, สถาบันสุขภาพเด็กแห่งชาติมหาราชินี (โรงพยาบาลเด็ก) และโรงพยาบาลมหาราชนครเชียงใหม่

อภิชัย คงพัฒนะโยธิน, ธนะรัตน์ ลยางกูล, แรกขวัญ สิทธิวางค์กูล, ยุพดา พงษ์พรต, พรเทพ เลิศทรัพย์เจริญ, พีระพัฒน์ มกรพงศ์

วัตถุประสงค์: *เพื่อศึกษาระยะเวลาของการรอผ่าตัดหัวใจในเด็กไทย และอัตราการเสียชีวิตขณะรอผ่าตัด โดยทำการศึกษาที่โรงพยาบาลจุฬาลงกรณ์ (จุฬาฯ), สถาบันสุขภาพเด็กแห่งชาติมหาราชินี (โรงพยาบาลเด็ก) และโรงพยาบาลมหาราชนครเชียงใหม่ (ม.เชียงใหม่)*

วัสดุและวิธีการ: *ผู้ป่วยเด็ก (อายุ 1-18 ปี) ที่ได้รับการส่งตัวไปยังแผนกศัลยกรรมทรวงอก เพื่อทำการผ่าตัดรักษาโรคหัวใจ ในปี พ.ศ. 2542-2543 (โรงพยาบาลจุฬาฯ และมหาวิทยาลัยเชียงใหม่) และในปี พ.ศ. 2543 (โรงพยาบาลเด็ก) ได้รับการสำรวจในปี พ.ศ. 2546-2547 ในเรื่องดังต่อไปนี้ 1) สถานภาพของการผ่าตัด (ได้รับการผ่าตัดแล้วหรือไม่) และ 2) ผู้ป่วยเสียชีวิตไปก่อนการผ่าตัดหรือไม่ การแปลผลการศึกษาทำโดย Kaplan-Meier survival curve และเปรียบเทียบ survival curve โดย Log rank test ผู้ป่วยที่ไม่มาติดตามการรักษา และไม่สามารถติดต่อได้จะถูก censored ที่วันสุดท้ายที่มาพบแพทย์*

ผลการศึกษา: *เด็ก (อายุเฉลี่ย 4.3 $\pm$ 4.2 ปี, เป็นเพศชาย 51%) ที่ได้รับการส่งไปแผนกศัลยกรรมทรวงอกเพื่อรับการผ่าตัดหัวใจในปีดังกล่าวมีจำนวนเฉลี่ย 846 ราย/ปี (205 รายที่ จุฬาฯ, 462 รายที่โรงพยาบาลเด็ก และ 179 รายที่ ม. เชียงใหม่) สามารถติดตามผู้ป่วยได้ 96.3% ชนิดของการผ่าตัดได้แก่ ASD, VSD หรือ AV canal closure = 33.9%, การผ่าตัดหัวใจชนิดปิด (เช่น PDA ligation และ Blalock-Taussig shunt) = 29.9%, total repair of TOF = 19.6%, การผ่าตัดชนิดซับซ้อนในเด็กทารก = 4.2% และอื่นๆ = 12.3% ค่ามัชฌิม (median) ของเวลารอผ่าตัด = 195 วัน และมีความแตกต่างกันใน 3 โรงพยาบาล ($p<0.01$) ผู้ป่วยที่รอผ่าตัดถึง 2 ปีที่โรงพยาบาลจุฬาฯ และโรงพยาบาลเด็กเสียชีวิตขณะรอผ่าตัดประมาณ 5% ในขณะที่ไม่มีผู้ป่วยเสียชีวิตระหว่างรอผ่าตัดที่โรงพยาบาลมหาวิทยาลัยเชียงใหม่ ความแตกต่างของอายุและความซับซ้อนของโรคหัวใจ (อายุน้อยกว่าและโรคซับซ้อนกว่าที่โรงพยาบาลจุฬาฯ และโรงพยาบาลเด็ก) อาจเป็นสาเหตุของความแตกต่างของอัตราการตายระหว่างรอผ่าตัด*

สรุป: *ระยะเวลารอผ่าตัดหัวใจสำหรับเด็กไทยยังเป็นเวลานานและควรได้รับการแก้ไขในระดับประเทศ ระยะเวลาที่ยอมรับได้ในแต่ละโรงพยาบาลอาจจะไม่เท่ากันได้ ซึ่งอาจขึ้นกับปัจจัยต่าง ๆ เช่นลักษณะของคนไข้และความซับซ้อนของการผ่าตัดที่ทำได้ในโรงพยาบาลนั้น ๆ*