

Chapter 9



THE FUTURE OF PEDIATRIC CARDIAC SURGERY AND THE WESTERN CANADIAN CHILDREN'S HEART NETWORK

INTRODUCTION

The checkered history of the pediatric cardiac surgery at the HSC since the 1950s and the tragic events of 1994 convinced the Review Committee that renewal of a program for Manitoba alone would involve variable outcomes and higher than acceptable risks for patients.

Research literature indicates that larger pediatric cardiac surgery programs around the world tend to deliver better results than smaller programs. The evidence suggests that pediatric cardiac teams that perform fewer than 100 open-heart cases per year have more difficulty in maintaining the surgical and other competencies necessary to ensure high-quality care and a ratio of positive outcomes, which compares favourably to standards within the field. The HSC program was usually slightly below or just at this threshold of 100 cases annually. Research suggests that the optimal number of cases per year to ensure continued competencies and the best ratio of positive outcomes is in the 150–200 cases per year range. Never in the history of the pediatric cardiac surgery program was the optimal number of surgeries performed at HSC on an annual basis.

The Review Committee is mindful of the fact that caution must be exercised in interpreting the numbers presented above. The “success rate” of a surgical program can be measured in various ways, but the tendency in public commentaries is to focus on the number of deaths. Also, success rates for surgical programs must be adjusted to take account of a number of factors, such as the severity of the illnesses involved and the mix of different types of procedures undertaken. In summary, to suggest that there is a precise minimum and a precise optimal number of cases which will guarantee positive outcomes in pediatric cardiac surgery would be misleading. There will always be risks and untoward events in pediatric cardiac surgery programs.

Nevertheless, the problems and the fluctuations in the quality of care documented in the Sinclair Report provide compelling evidence that the patients and families were exposed to an unacceptable level of risk in the pediatric cardiac surgery at HSC during 1994. Rather than restart the program, the Review Committee

recommends that the Province of Manitoba participate in the proposed Western Canadian Children's Heart Network (WCCHN).

PEDIATRIC CARDIAC SURGERY IN WESTERN CANADA

The proposal for the WCCHN emerged out of discussions among Deputy Ministers of Health from the four western provinces that took place in 1997. An Ad Hoc Committee to address collaboration among the provinces in health care was established and the first area selected for examination was pediatric cardiac surgery.

There are five pediatric cardiology programs in Western Canada, located in Vancouver, Edmonton, Calgary, Saskatoon and Winnipeg. Pediatric cardiac surgery is currently performed in Vancouver and Edmonton. Between the suspension of pediatric cardiac surgery at HSC in February 1995 and August 2000, approximately 550 patients were referred out-of-province, at a total cost of approximately \$7 million. Patients were sent to a number of locations, not all in Western Canada, but the greatest number of referrals were to Saskatoon's Royal University Hospital and to Toronto's Hospital for Sick Children. In the past, there has been competition between facilities and provinces for the approximately 600 cases of pediatric cardiac surgery that arise annually for all of Western Canada. Interprovincial cooperation and partnership must occur to provide optimal care and maximize the benefits of specialized expertise and professional collaboration.

THE WESTERN CANADIAN CHILDREN'S HEART NETWORK

A number of meetings and reports led to the production of The Final Report of the Western Canadian Children's Heart Network Implementation Committee (March 2000). The WCCHN involves a formal affiliation of the five centres with expertise in pediatric cardiology. The network will have the following functions:

- to assess results of clinical care (surgery and interventional cardiac catheterizations) at all centres on an ongoing concurrent basis in order to identify potential problems as they arise;
- to compare the results of clinical care to North American standards;
- to collaborate between centres on complex clinical cases;
- to share educational activities including morbidity and mortality rounds;
- to share patient/family related support resources;
- to collaborate on future research and educational endeavours;
- to share and discuss plans that will have impact on children's cardiac care from all member institutions, providing feedback as necessary.

In order to fulfill these functions, a coordinator will be selected to arrange meetings, to review and circulate data, to manage collaborative projects and to maintain telecommunications links.

THE ROLE OF TELEMEDICINE IN THE WCCHN

Telecommunications will play a key role in the operation of the Network. The WCCHN will involve the use of high-speed telemedicine links for real-time interactive assessment of clinical cases by specialists from multiple sites advising, supporting and sometimes mentoring one another regarding appropriate treatments. Information and telecommunications technology to support this level of sophisticated interaction in the health field is not presently available. With the Province of Manitoba playing the lead role, a request for consulting services to provide an inventory of current technology and the necessary upgrades to make the network concept viable was issued in October 2000. The contract was issued to KPMG and a work plan is to be ready by the end of June 2001.

OUTCOMES DATA FROM THE WCCHN

The WCCHN is a complex project and numerous issues could be raised for discussion. We will restrict ourselves to features which seem most germane to the mandate of the Review Committee. We will begin with the matter of quality medical care. The Review Committee is convinced that the Network will facilitate the provision of high-quality care to children with heart disease in Western Canada. It will do this by creating the necessary volume of cases and the opportunities for the participating surgeons to refine their skills in an extremely challenging specialty. It will provide an expanded pool of knowledge, peer review of performance and advice on outcomes through monthly video-conferencing arrangements. Data from the program will be collected and stored electronically, shared with other member institutions and be submitted to the Pediatric Cardiac Care Consortium for comparison to the outcomes in similar programs in North America. The Network will allow for specialists to be licensed in more than one province and it will support travel for specialists to other cities for purposes of training and filling-in for vacationing specialists.

THE HEALTH SCIENCES CENTRE AND THE WCCHN

Membership in the WCCHN will be based on the referral nature of the program and not on the presence of a pediatric surgery program at the member institutions. What this means for Manitoba is that the Pediatric Cardiology program at HSC in Winnipeg, which has not operated a pediatric cardiac surgery program since 1995, will be part of the Network. Pediatric cardiologists in Winnipeg will be able to refer patients to the two centres where surgeries are performed. The pediatric cardiologist selected to represent HSC will serve on the Network Steering Committee and will participate in discussions with professional colleagues on topics such as diagnosis, treatment, data development, quality care initiatives and evaluations.

For the foreseeable future, it is not recommended that there be a resumption of pediatric cardiac surgery at HSC. Longer term consideration should be given to conducting high volume, low risk surgical procedures at HSC. The Review Committee recognizes that there are hardships for families involved, with travel to referral centres out-of-province. But we believe that the Network represents the best option to ensure safe,

high-quality care in the challenging field of pediatric cardiac surgery. In some respects, participation in a four-province regional network follows the same logic that led to regionalization in a Manitoba context, namely that it provides the scale of operation necessary to enable high-quality, full service programs.

ITINERANT SURGEONS AND THE WCCHN

There is one aspect of the medical component of the network proposal that requires clarification – that is, the movement of surgeons to other surgical and non-surgical centres in the network to conduct operations. This arrangement would seem to contradict the importance usually assigned to continuity and teamwork in the surgical process. It may be the intention to have itinerant surgeons conduct only high volume, low risk procedures outside of their “home” institutions and away from their own surgical teams, however the impact on the patient must be recognized. Care of a patient undergoing surgery begins prior to and extends past the completion of the surgical procedure. Ideally, post operative care should be managed by the attending surgeon to allow for a continuity of care and consistent management of said patient. Within an itinerant surgery model, fragmentation may occur given the limited time frame that surgeon is present at the host facility. This creates the potential of risky situations and will need to be addressed.

There is also the issue of licensing physicians to practice in other jurisdictions. Some provinces, like British Columbia, require that physicians regardless of the circumstances, be fully licensed to practice within their borders. There are provisions in the Medical Acts of other provinces, such as Manitoba, for limited practice by physicians, usually in medical-education settings or to fulfill health needs in medically underserved areas. These jurisdictional issues can probably be resolved. If successful, the WCCHN could become a model of both constructive collaboration among governments to improve health services and contribute to a reduction in the current restrictive barriers to physician practice among the provinces.

SUPPORT FOR PATIENTS AND FAMILIES USING THE WCCHN

The advantages of the Network in terms of improved medical care are clear to the Review Committee. Less clear is whether the designers of the WCCHN have at this point given sufficient attention to ensure that the experience of patients and their families within the network will be trouble free and positive. The Final Report on the WCCHN mentions that video-conferencing will be used to allow patients and families “to meet” clinicians at the referral centre prior to transfer to provide background information and to relieve anxieties during a stressful period.

The WCCHN proposal also refers to the development of a common pamphlet/or consent form to be provided to patients and families. Patient satisfaction is designated as one component of the formal, in depth evaluations to be conducted every three years beginning after two years. Patient surveys would be used to complete this component of the evaluation.

Based upon the experience of the families involved with the HSC program and a small sample of families who travelled out of province to other centres, the Review Committee is concerned that to this point in

the development of the WCCHN, not enough attention has been paid to meeting the needs of families. For example, in our Chapter Five on Informed Consent we discussed the importance of patient-physician communication in terms of ensuring that consent was voluntary, involved full disclosure and resulted in the fullest possible understanding of all aspects of the surgery. In the technological context of a videoconference process generating trust and confidence between the patient and the physician will probably be even more intimidating and difficult than in a face-to-face meeting. The WCCHN proposal describes a combined handbook and consent form which seems designed to fulfill the strict legal requirements for informed consent, but does not address adequately the crucial and sensitive issues of communications between patients, families, physicians, nurses and other health providers within the consent process. This is an example of how telemedicine takes us into new, largely uncharted territory in terms of the need to develop new approaches to issues like informed consent.

A second area of concern involves the need to provide the fullest possible range of supports to the families facing the stressful situation of leaving the province for delicate and risky surgery on their children. A handbook alone will not be sufficient assistance to families. There has been a financial support program (covering airfare, accommodations, ground transportation and per diem allowances) operating out of HSC since the suspension of the pediatric cardiac surgery program in 1995. There is also an experienced neonatal transport team at HSC Children's Hospital. The Review Committee believes that when out-of-province travel for pediatric cardiac surgery becomes an institutionalized part of Manitoba's health care system, there should be a coordinating office established. This office would report to the physician selected to serve on the WCCHN Steering Committee. The office should be directed by a nurse from the pediatric field. The office should provide "one-stop" service to the families – including travel arrangements, coordination with the personnel at the receiving facility, the transfer of medical records, dealing with inter-jurisdictional issues, arranging follow-up care for families upon their return and, most importantly, dealing with the questions and concerns that families will inevitably face. In summary, the Review Committee sees it as essential that there be a well coordinated and integrated approach to service provision within the network and that there be a visible "human face" who embodies the qualities of professional, competent and empathetic care.

RECOMMENDATIONS

The Review Committee recommends that for the immediate future, there should be no restart of the pediatric cardiac surgery at HSC. Pediatric cardiac surgery programs are costly to support in terms of programming funding. Fiscal resources that would be utilized for a Manitoba pediatric surgery program should be redirected to support the WCCHN.

The Review Committee recommends that the Province of Manitoba continue to support and play a lead role in the development of the WCCHN as basis for providing high-quality pediatric cardiac surgery to Manitobans.

The Review Committee recommends that in the development of the WCCHN that attention be paid to the needs of families in terms of the concerns raised above. Patient experience and

patient satisfaction should be a larger component of the formal in-depth evaluation scheduled to take place several years after the launch of the program.

The Review Committee recommends that the WCCHN be seen as a possible model for extension of collaboration with pediatric surgical programs in Eastern Canada and for other specialty programs where Manitoba could benefit from participating in interprovincial programs.