Winnipeg's Pediatric Cardiac Inquest:

The Patient's and Parent's Advocate

By Joan Borton, RN, BN

What happened in 1994 is an extreme example of what could happen to any nurse, in any health care institution anywhere in Canada. It is amazing to me that people now want to interview us and hear us speak, because in 1994 it seemed that no one looked upon us as someone to be listened to, respected or even believed.

My presentation is comprised of other nurses' perceptions, actual patient charts, transcripts from the inquest, but mostly from my own experiences and memories.

During 1994, I was a nurse clinician at the Variety Children's Heart Center, a position I had held since 1987 except for one year during which I taught in the Pediatric Intensive Care Unit.

The role of the nurse clinician, [1] in theory is :

A - Patient Care

- provide clinical expertise to nursing staff;
- provide continuity of patient care by follow up of the patient between ambulatory care and in-patient service; and,
- collaborate with the physician, unit manager and other members of the health care team.

B - Education

- provides education to patients, family and staff in designated ambulatory care and in-patient units.

C - Research

- identify problems for clinical research.

(1. Source: Health Sciences Centre Nurse Clinician Job Description.)

As nurse clinician for the pediatric cardiac surgical program, I was responsible for the slating of the surgeries, the preoperative preparation of the patients and parents, the follow-through of the patients during hospitalization, and coordination of their care upon discharge. As nurse clinicians, (there were two or three of us), we met every parent of every child diagnosed with heart disease. We accompanied the pediatric cardiologist who would explain the anatomy, proposed medical treatment and surgical options. The exception to these patients were the critically ill newborns who were admitted to the Neonatal Intensive Care Unit and subsequently diagnosed. For these babies, the nursing support for the parents was provided by the neonatal nurses and we were peripheral at that point. But upon discharge of these infants, along with other children diagnosed at different times, nursing was present for the outpatient visits, heart catheterizations and preoperative preparation for elective surgery. We would follow the parents and child during the day of surgery, immediately post-op in the PICU, and then on the ward. I stress that the professional relationship between the parents and the nurses was intense and involved, and will illustrate this relationship later when I talk about two of the children. We knew these families, often for years.

The support of the parents was paramount to me in my position. Parents give their child to the doctors and nurses and trust that they will give their child the best possible care. Unfortunately, there is a mortality rate in pediatric cardiac surgery and there is no grief comparable to that which is experienced with the death of a child. Barbara D. Rosof writes:

> "Losing a child is a different kind of loss. Its dimensions are more profound, the swath it cuts across families lives is much broader than any other loss."

You can never prepare a parent for their child's death, but you can given them the knowledge that this is a possibility when the child undergoes cardiac surgery. Along with this knowledge you give them the trust and confidence they require to endure the experience, the surgery, and the hospitalization.

Author

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With the previous surgeon, I used to say to parents: "Dr. Duncan could operate on my child. I don't have children, but if I did, I would have the confidence in him to do the surgery". This trust was violated in 1994. I came to a point where I could no longer look into the parents' eyes and give them this confidence.

Dr. Jonah Odim started operating at the end of February,1994. After the first death in early March, I felt that this was one of those unexpected post-operative deaths that is part of a cardiac surgical program-any program. After the second death, I went to the other nurse that I worked with and said I had concerns about the program. She also had concerns, but she did not think that either of us could do anything about them. I agreed, but said that I felt since she was my immediate supervisor she should know my concerns. I also asked her to relay them to the medical director. She said she would.

Later on in April, an incident arose that caused me to have a meeting with this nurse and the medical director, Niels Giddins. After the discussion finished, I asked her if she had spoken to him. She said she had not. I turned to him and repeated my concerns. He basically said that he did not have any concerns. I could not believe that he did not perceive any problems. Carol Youngson and Irene Hinam and myself had been meeting by then and talking about the program and the surgeries. I had seen morbidity and mortality that I had not seen before. I knew that Carol had certain issues in the OR, as did Irene.

Talking to Dr. Giddins,Chief of Pediatric Cardiology, did not work, so I went to Isobel Boyle, the Director of Patient Care Services. I walked into her office, sat down, and started to cry. I could barely get the words out. I said: "I want you to know that I have concerns about the surgical program." She acknowledged my concerns and was very supportive. Someone finally listened! She also said: "You've got to get out of there", and I agreed.

Five- month old Alyssa Still

One of the children who died in early May, 1994 was Alyssa Still. She was a five- month old baby girl who was seen in the Cardiology Clinic in March, 1994. Her mom was a young single girl who lived with her own mother in Thunder Bay, Ontario.

Alyssa had been referred by her pediatrician in Thunder Bay. He had tentatively diagnosed the baby with Tetraology of Fallot, so mom and grandma were not intensely shocked or grieved by the diagnosis as explained by the cardiologist.

Because of the distance the family lived from Winnipeg, the plan was to admit Alyssa the next month for a heart catheterization followed by surgery, if the catheterization confirmed the clinical and echo diagnosis.

The heart catheterization went well and surgery was slated for two days later. However, Alyssa's chest x-ray showed right middle lobe infiltrates and the decision was made to postpone the surgery for two to three weeks. The family stayed at our Ronald MacDonald House in Winnipeg. The day prior to Alyssa's scheduled first operation, Daniel Terziski underwent a Norwood procedure and died.

Two weeks later, Dr. Odim performed a Repair of Tetraology of Fallot on Alyssa. She did well. I saw her immediately post-op. I was thrilled and thought that the cardiac team had 'turned the corner' and from now on things would go well.

The next day, I went to PICU to see how Alyssa was doing. She had died. I could not believe it. I went back to the Heart Centre and cried uncontrollably. That was the beginning of the end for me.

I had lost confidence in what the cardiac team was doing. I phoned Alyssa's mom and grandma to offer my condolences and later that day, the other nurse and I visited them at Ronald MacDonald House - a very sad and difficult meeting.

Alyssa's mother told me later that she had a bad feeling about the surgery. She said she was prepared and confident before the first date of surgery, but not at this one. The autopsy confirmed that Alyssa's death was unexplained.

By the middle of May, the anesthetists withdrew their services for high risk surgeries for the purpose of examining the program and ultimately improving it. As stated earlier, Isobel Boyle and I had agreed that I needed to get out of the Heart Centre because I was so upset about the program.

My job changed from doing the principle components of the surgical nurse clinician role to that of the medical nurse clinical role which included heart catheterizations, doing the cardiology clinics and following the cardiology patients in the hospital. This was an interim solution.

The summer of 1994 went fairly well for me. I had three weeks holidays in July and only low risk, closed and open cases were booked. I was looking at positive patient outcomes. However, Carol, Irene and Carol Bower continued to see problems in the OR.

Carol Bower attended a meeting of the Wiseman Committee in August where it was to be decided whether to continue with low risk cases or to start doing more complex cases. She stated the nurses'

decision that they did not feel comfortable moving on to more difficult cases. She explained that even though the patient outcomes were good, things had not been smooth. At the Inquest Carol testified about one case during the summer where a cannula was knocked out, and another case where the repair was not done correctly and had to be redone. Despite nursing's objections, the program returned to full capacity in September.

Marietess Capili

The first case to be done when the program resumed was Marietess Capili. I knew Marietess from her first week of age until she died post-op in September, 1994. I can remember meeting her parents at the initial clinic visit, both of them 17 years old and in Grade 11. I wondered how these parents could possibly look after this baby, but, they managed very well.

Marietess was of Filipino origin, and both extended families were very supportive and involved. Marietess almost had two mothers, Sara, her mom, who was an excellent student attending University doing a science degree, and Sara's sister. The sister cared for Marietess at home and the two of them would come to Marietess' appointments together. The baby was so spoiled - she had learned early in her life that if she cried, she would turn blue, and could always get what she wanted.

The day before the surgery I went to see Marietess. Ben, her dad, was quite relaxed about the surgery. I assume in his mind, he had been through two surgeries even though they were closed heart operations, and Marietess had done well. Later he would testify that he was told by Dr. Odim that the surgery would be like a " walk in the park".

The day of surgery I went to see the parents about mid afternoon. Sara had left the hospital for a break and Ben said he had a report from the OR that things were moving along.

The next day at work in the cath lab I was told that Marietess had died the previous night. I was stunned. I felt I had failed Marietess and her parents, not only because she died, but because I could not be there for the parents. The autopsy showed that one of the bicaval bidirectional shunts was sutured too narrowly, and caused obstruction to blood flow.

In 1998 after we made a presentation at the Manitoba Association of Registered Nurses annual general meeting, Ben came up to me and said that it helped to hear us speak, it helped with closure.

The program continued until December, 1994 with more morbidity and mortality. Eventually I had to leave my position. Undoubtedly, the worst outcome of all of this was that children died and their parents have to live with that and the circumstances that surround the deaths. For me, personally and professionally, the issue is that my obligation to the children and their parents was not able to be fulfilled. The system denied me that. The program failed the children it was meant to serve. A lot of people involved supported the program instead of the children which is the whole reason the program existed in the first place.

"I wanted to tell my truth in court"

The first, and I hope the only time I had contact with the legal system was in March, 1997 when I testified at the Pediatric Cardiac Inquest. I think that I was the only nurse in the group who actually looked forward to testifying. I wanted the opportunity to tell my truth in a court of law. In my view what happened in 1994 was wrong and unethical, in so many ways. It seemed there were problems within the program that everyone involved was aware of except the parents. After about a day and a half of questioning it became evident that lawyers for Drs. Odim and Giddins and the families had different perceptions. The doctors' lawyers seemed to think I had acted from an emotional basis rather than a factual one, and according to the families' lawyers, I perhaps did not act on their behalf enough. This was very stressful and disturbing to me. It shook my confidence and created self doubts for a while, but then I referred to the Mission Statement of the Health Sciences Center, my employer. Under Patient Care it reads:

> "To provide high quality and innovative patient care through programs that are responsive to the physical and psychological needs of the patients we serve, (including their rights to be informed and to be respected for their beliefs, religious practices and customs)".

The Mission Statement concludes with:

> "The Health Sciencs Centre will pursue this mission in accordance with accepted ethical values recognized by society as a whole as well as those ethical standards adopted by Professional organizations represented in the Centre".

I adhered to this Mission Statement to the best of my ability. One of my questions is: Did others in the organization do the same ? ■

Research on Positioning and Post-Op Pain wins award

A study to examine the relationship between surgical positioning and post-operative pain received the ORNAC Research Award of $5,000. The award was presented to Hilda Power, MN, the Principal Investigator, at the 16th National ORNAC Conference in Halifax in June, 1999. (See photo of presentation page 5, October, 1999 issue).

Hilda Power is Support Coordinator, Perioperative Care Team, Women's Health Program IWK/Grace Health Centre, Halifax, N.S. Other members of the team include Dr. Lorna Butler, School of Nursing, Dalhousie University and Mary Lee Hebert, BscN.

The purpose of the study is to determine if there is a relationship between surgical positioning and postoperative pain in the lower extremities and to compare if the incidence and severity of lower extremity post-operative pain differs between patients placed in the lithotomy position versus the supine position.

Objectives of the study are to determine:

- If there is a difference in the incidence and severity of lower extremity pain between patients placed in the intra-operative positions of lithotomy and supine.
- If there is a difference in the incidence and severity of lower extremity pain experienced between patients who undergo procedures for less than one hour versus those who undergo procedures of greater than one hour duration.
- If there is a difference in the incidence and severity of lower extremity pain experienced between patients placed in the Allen stirrup versus the Sims (candy cane) stirrup while in the lithotomy position.

It is anticipated that perioperative nurses will use the results of this study to examine the positioning guidelines used in the OR to determine the effectiveness of the guidelines in achieving a pain free outcome for patients post-operatively.

A sample of 350 women scheduled for gynecological procedures comprises the study sample. The women are divided into two groups. Group I consists of all patients admitted for gynecological surgery requiring the lithotomy position and Group II consists of all patients admitted for gynecological surgery requiring the supine position.

As of October, 1999 the study has accrued more than half of the required number of participants and hopes to accrue the total number within the next six months.

Correction

On page 5 of the October, 1999 issue the photo cutline - Speakers from the Heart Club, Winnipeg ..."*Events leading up to the death of 14 infants.*" Correct number of deaths is 12. The editor apologizes to readers for this unfortunate error. Please see full coverage of Winnipeg's Pediatric Cardiac Inquest in this issue.

Conference Calendar

May 3 - 6, 2000
BCORNG Conference
"A Peak Experience"
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Education Sessions include: • Computers (Hands On experience in the Cyber Bistro • Current Hot Nursing Issues • Heart Disease • Anesthesia • Day Surgery Dilemmas • Breast Cancer • Documentation • Nursing Abroad • Pediatric Facial Reconstruction • Dr. Laugh

Lots of entertainment & Fun, including dinner atop Whistler Mountain ! Great Exhibits.

Watch for more information from the British Columbia Operating Room Nurses Group and this 17th Biennial Conference.

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The Operating Room Nurses Association of Ontario

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17th ORNAC Conference - Banff, Alberta.
Conference Chairperson Gloria Nemecek.
Watch for details in the Feb/March, 2000 issue.

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Websites for Operating Room Nurses:
The Operating Room Nurses Association of Canada website: **www.ornac.ca**

American Operating Room Nurses: **www.aorn.com**