

Original Article

## Intra-operative imaging in paediatric cardiac surgery: the reactions of parents who requested and watched a video of the surgery performed on their child

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**Abstract** *Objective:* Our previous work demonstrated that digital video recording of operations is the best way to describe the morphological features and complex dynamic physiology of surgical treatment of congenitally malformed hearts. Parental consent is required for video recording, and some parents have requested, and obtained, a copy of the video of the operation performed on their child. Our present aim was to explore their feelings and opinions having viewed the recording of the surgical procedures. *Design and participants:* This exploratory study examined the views of 17 parents, comprising 7 couples, 2 mothers, and 1 father, after requesting, and then watching, the recording of the operation performed on their child. The audio-taped, semistructured interviews were analyzed for the thematic content. *Results:* All parents watched the videos at least once, and no parent exhibited distress as a result. Curiosity and desire for learning, and wanting to know what exactly happened to the child during the operation, were the most common reasons for requesting the video. Parents reported that the videos were also useful in sharing the experience with family and friends. The videos had no effect on the attitudes of the parents towards the surgical team. Parents made recommendations to increase the length of the edited videos and add labels and voice-overs. *Conclusion:* Parents of children with congenitally malformed hearts want to watch the recording of the operation performed because of their need for information, and to understand the experience of their children when separated from them. Research is needed to assess the potential value of operative videos in facilitating parental knowledge and coping when children undergo major cardiac surgery.

Keywords: Intra-operative video; congenitally malformed hearts; parental attitude; parental knowledge; thematic content analysis.

THE BIRTH OF AN INFANT WITH A CONGENITALLY malformed heart is stressful for parents. Surgical intervention typically occurs in early infancy, when parents may still be struggling to understand and accept the diagnosis.<sup>1,2</sup> Parental stress may be compounded by the fact that congenital anomalies of the heart, and the procedures needed to treat them, are extremely difficult to describe. There is variation within a diagnosis,

and each diagnosis may be a combination of more than one defect. Studies in the United States of America and Israel have shown that parental knowledge about the cardiac condition of their child may be incorrect in up to one-third of cases.<sup>3,4</sup> Conventional explanatory diagrams are commonly used to demonstrate to patients and families the pathology of congenital cardiac disease. Videos of real hearts might improve our ability to demonstrate the complex three-dimensional morphology, and the surgical procedures used to correct or treat them, or to convey depth and perspective in explaining the procedures and relating the morphological features to the complex and changing physiology.

Previous research has indicated parents seek more information to gain a better understanding of the

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Accepted for publication 29 November 2006

congenital cardiac condition suffered by their child through written information and the Internet.<sup>5,6</sup> A thorough search of the literature, nonetheless, revealed only two published studies of new media for helping parents understand or cope with the congenitally malformed heart of their child,<sup>7,8</sup> with neither of these addressing the specific issue of parental understanding of the surgical intervention.

Two simultaneous developments precipitated our present investigation. Firstly, we decided to film, for the purposes of teaching and research and with parental consent, all the operations we performed.<sup>9</sup> Secondly, as a consequence of being asked to give consent for filming, parents became aware that they could obtain a copy of the video of the operation performed on their child. We wanted to learn more about the reaction of these parents to watching the videos, and to ascertain if they could be used to assist in explaining the nature of congenitally malformed hearts to parents in the future. We initiated this research project, therefore, to explore the feelings and opinions of the parents after having obtained a personal copy of a video of the cardiac surgery performed on their children.

## Methods

### Design

This qualitative and exploratory study was approved by the Local Research Ethics Committee.

### Sample

There were 107 parents who had requested and received a copy of the intra-operative video of the cardiac surgery performed on their child, representing 19% of the overall films made. English speaking parents of 10 randomly selected children living in the greater London area were invited to participate in the study, and all agreed to do so. One mother subsequently declined due to illness. The

10 children, 7 males and 3 females, had a palliative or corrective cardiac surgical procedure within the first 5 months of life (Table 1). The 17 parent participants included 7 couples and 3 single parents. The mean age of parents was 35 plus or minus 6 years. Except for the 1 divorced and 1 single mother, all were married. Education level varied, with 2 mothers having higher degrees in biology.

### Procedure

As a standard part of the process of informed consent for planned cardiac surgery, all parents were also asked to give consent for video recording of the procedure. It was explained that the video recordings would only show internal organs, would be completely anonymous, and would be used for training or research purposes only. Parents were also told that an edited copy of the video could be made available for them after the operation. All parents gave consent for the video recording. Before discharge of the child, those families who requested a video were given an edited version of the video recording the surgery performed on their child.

The digital videotapes were edited by a Specialist Registrar using Final Cut Pro software (Apple Inc., Cupertino, CA, USA) on a dual processor Apple PowerMac G5.<sup>9</sup> The videos were edited to exclude opening, routine cannulation, and closing steps, and aimed to show the anatomy and the surgical repair of the major defect. Each video began with an introductory image, to allow orientation of the image by demonstrating the relative positions of head, feet, right and left. During our pilot work, we found that an average of 10 minutes of edited video was long enough to show the surgical repair of the major defect. After completion of editing, digital video images were transferred to video home systems tapes.

After obtaining written informed consent from each parent, semi-structured interviews were conducted,

Table 1. Patient characteristics.

Patient	Diagnosis	Age at operation	Operation
1	Transposition	15 days	Arterial switch
2	Tetralogy of Fallot	3 months	Repair of tetralogy of Fallot
3	Ventricular septal defect	3 months	Patch closure
4	Ventricular septal defect	5 months	Patch closure
5	Tetralogy of Fallot	4 months	Repair of tetralogy of Fallot
6	Pulmonary arterial sling	3 months	Repair of pulmonary arterial sling
7	Atrioventricular septal defect	4 months	Repair of atrioventricular septal defect
8	Tetralogy of Fallot, long segment congenital tracheal stenosis	7 months	Repair of tetralogy of Fallot, slide tracheoplasty
9	Tetralogy of Fallot	4 months	Repair of tetralogy of Fallot
10	Ventricular septal defect	5 months	Patch closure

Table 2. Interview guide.

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How long has it been since your child's operation?  
 Can you tell me a bit of background about yourself?  
 How did you find out that your child had a heart problem?  
 What did you think when it was first explained to you?  
 Did you understand the explanation well enough to describe it to others?  
 Have you done any additional searching for information about your child's heart problem other than what you received from doctors or nurses?  
 Which information did you find most useful?  
 Why did you ask for a copy of the operation video?

- How many times did you watch it?
- How did you watch it?
- Where did you watch it?
- With whom did you watch it? Why did you show it to others?

What did you feel after watching the video?  
 Did the video alter your relations with the surgical team in any way?  
 What did you find most helpful/interesting about the video?

- Least helpful/interesting?

What did you think about the technical aspects (image quality, duration, etc)?  
 Do you have any recommendations about how the videos are edited to give to parents?

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either in the homes of the parents, or in private rooms in our clinic. If the interview was with a couple, mothers and fathers were interviewed by asking the same questions to each parent separately. The principal investigator conducted all interviews, which were audio-taped and lasted between 40 to 67 minutes. An interview guide (Table 2) was used, based on the purpose and objectives of the study. Probing questions were asked further to explore parental responses. Field notes reporting the observations of the interviewer were recorded immediately after each interview. The travel expenses of the parents were paid from charitable funds.

### *Analysis of data*

Audio-taped interviews were transcribed verbatim, and transcripts and field notes were examined by analysing the thematic content, also known as thematic content analysis, using the methods of Boyatzis.<sup>10</sup> This methodology is a process for systematically and objectively encoding qualitative data into categorical data, extracting patterns, and describing or organizing observations. The units of analysis were the message characteristics encoded within the comments of the parents. Data were initially organized using open coding, without regard for relative importance. In this way, the

breadth of conceptual possibilities across parental comments was appreciated. Conceptual categories that were salient across participants were created and validated by a second investigator (LF). Coding and conceptual categories were defined precisely, and illustrated with verbatim quotes to ensure completeness, inter-rater reliability, and validity. The findings, process, and products of analysis, specifically coding, preliminary, and final thematic categories, were independently developed and later compared by two investigators (EK and LF). Inter-rater reliability was greater than 80% for all categories.

### **Results**

All parents received an edited version of the intra-operative video of 6 to 12 minutes duration, and watched the video at least once, with a range from 1 to 5 times. We extracted 6 major themes as characterizing the responses. Parents first described their search for information on learning the diagnosis for their child, including their feelings when told that their child had a congenitally malformed heart, their need for information, and the value of the first explanation they were given. Second, they described their reasons for requesting the intra-operative video. Third, parents described their responses to the video, such as the meaning of the recording to them, and what they learned. Fourth, parents discussed sharing the experience by showing the videos to other family members or friends. Fifth, they described the effects of the intra-operative videos on their attitude toward the surgical team. Finally, parents gave constructive criticisms and recommendations for how the tapes could be made more useful for parents in future. Detailed descriptions of these themes follow, with some direct quotes from the parents for illustration.

### *Search for information*

All parents first described their emotional state of shock, panic, and worry when they were first told of the congenital cardiac malformation, and the stress they experienced because they were being asked to make decisions about the treatment of their child. Six couples described how they did not accept the diagnosis at first, and experienced denial.

Only 2 parents, of the same child, thought that the information from booklets and leaflets that they were given was the most useful pre-operative information. All other parents felt that the information given in person prior to surgery by a cardiologist or a surgeon was the most useful

compared with the booklets, General Practitioner or local hospital information. For some parents, the face-to-face information was enhanced by diagrams of the defect or the proposed surgical procedure drawn by the surgeon or the cardiologist. Even though parents considered that all the information they were given was useful, no matter whether it was in different institutions or given by different doctors and nurses, they all reported that the information was insufficient, and they had wished for more.

...I think when your child is ill, you just never have enough information, and you always want to know more. If we were told that you have a baby with a hole in the heart, we feel that we are all the same, no matter how different it is, every heart operation is not the same but feelings of parents are all the same...

One couple did not have a computer, and had never used the Internet. Another couple thought that the baby had a unique defect, and so did not search for more information on the Internet. All of the other parents performed a detailed Internet search based on the diagnosis of their child. Parents did not remember the names and the addresses of the websites that they had visited, but some recalled that the website developed by the British Heart Foundation was the most useful. Google was the most used search engine, and parents estimated they viewed approximately 20 to 30 websites. Two couples reported that they had talked to other family members or friends who had similar experience or knowledge to find out more information.

#### *Reasons for requesting a copy of the intra-operative video*

Curiosity and desire for learning, seeing what exactly happened to their child in the operating theatre, and the option of having it, were the most common reasons for requesting a copy of the intra-operative video. One mother learned about the filming of cardiac surgery from another parent in the ward, and asked to have a copy of the recording of the operation before the surgeons asked for consent to make the recording.

...Curiosity, you know, you want to see, you don't want to see how operations are done, you just want the choice of having it on the shelf so that if one day you choose to watch it, then you watch it, you can learn. The parents will have a clear mind that everything was carried out clear, clean and fine. I recommend that you should at least let all parents have their own copy...

Seven couples, and 1 mother, mentioned that the period of the operation was the only time that they

could not be with their children. They all felt that by having and watching the video, they were able to fill this otherwise lost time.

...So when doctors came to talk to us, we were sitting there and people came to talk to us and we looked at each other and we didn't know what they're saying, we didn't know what words, what parts. We did not understand. You know what I mean? So we want to see, so we know, that's what she's going to have and extra things. I didn't want to miss anything. To have a kid with a problem is bad; to not fully understand what happens is worse...

#### *Response of the parents to the videos*

All parents used the same term 'emotional' when describing their reactions on first watching the videos. When probed further, they focused on the positive feelings, and used terms such as 'gratefulness', 'respect' and 'admire'. No parent described negative emotions, squeamishness, or inability to watch the video because of its graphic nature.

...I can't watch programs about hospitals, things like ER or if they're having operations or injections, I can't watch that. But now, when my girlfriend phoned me at work and said the tape's here, the blood drained out of my head. I didn't know what to do, what to say, didn't know if I could watch it and the whole day I thought about it; couldn't think of anything else. How horrific would this video be? Would I see the cut? And it was scary and I had to put it on and straight away. I did think, when I played it, I sat there with my hand on the control. If I'd seen something I didn't like, I was going to stop it. I watched the whole thing, and I watched it again.

All parents also felt that that the videos would be a valuable resource in terms of describing the diagnosis and the operation to their children when they are older and as proof of what took place.

...I felt emotional. Some parents may choose not to remember any of it as it's such an emotional time for them but I like to have all the information there and it's mainly, well, for me and to explain to other people, but as my daughter gets older and looks at her scar, she's able to have all that information there for her. I can explain it to her and show her all the information...

...so that's (the video) like a concrete proof to say that it's been done and hopefully he will never have to have that done again...

All parents described the video as helping them understand more about the human body.

...because no matter how many books you read or pictures you look at and how things are explained to you,

when you actually see a human being cut open, it just looks like a complete and utter space that is choc-a-block of stuff. To me, my understanding before this incident about human body was that there was a lot of space inside it, and it's not, it's just full of vessels and tissues and this has changed my understanding of the human body...

### *Sharing the experience*

The most frequently reported reason for parents to show the video to others was that other people showed interest in it. Parents felt it was a useful method of explaining the operation to their families and friends, and for sharing the experience. Parents reported that everyone who watched the videos found them useful. Siblings were mentioned in particular, and 4 couples felt it was important to show them exactly what had happened to their sister or brother when he or she, along with mother and father, were away from home. The biology teacher of one child asked him to bring the video to school. Some of the friends of this child watched the video, while others refused because they did not like the sight of blood. After watching the video, the friends of the child who watched the tape told him how brave he was.

### *Attitudes towards the surgical team*

None of the parents thought that the videos had any effect on their attitudes toward the surgical team. They all spontaneously expressed that they already had respect and trust for the surgeons operating on their children, and this was not changed after watching the videos. One father commented that even if mistakes could be seen on the video, it would not change his overall view about the surgeon, because the important factor for a parent is the final result of the operation, and seeing their child is alive after surgery.

### *Criticisms and recommendations*

The videos were considered as potentially useful in understanding the congenital cardiac malformations, and were regarded by 6 couples and 1 mother as helpful in the consolidation of the information they received from the healthcare team. The pre-surgical period was considered by parents to be the most vulnerable period, and they all felt that any additional information, such as intra-operative video showing the defect and repair, would be useful. Parents indicated that videos were better than written information, and felt that they could

be beneficial, if certain recommendations (see below) could be implemented.

Except for 2 mothers, all parents commented that the 10-minute videos were too short. The 2 mothers considered the edited version of the videos 'good enough' to show the anatomy and the procedure. Other parents would have preferred to receive an unedited, full, version of the intra-operative videos so that they could see every step of the surgery.

...it was quite funny because when I had the tape, the tape was there (at home), the children were put to bed, a glass of wine got and I sat down to watch it and put it (the tape) on and before no time at all it had finished, and I thought "Oh! I hadn't even had a drink!"...

All parents described how they did not understand anything when they first watched the videos, and they all tried to 'guess' at what they were looking. The scientific background of 2 mothers helped them to have a somewhat better understanding than the others. Parents made a number of recommendations for improvement, including a voiceover, explaining the important steps of the operation, enhanced by labels and arrows to indicate the anatomy and the procedure. Two mothers also suggested that a live soundtrack from the operating room should be included.

Another concern while watching the videos, shared by 3 mothers and 1 father, was the lack of identifiable characteristics of the child in the video. In the videos, all patients were covered with sterile drapes and it was not possible to see their face during the operation, only the intrathoracic organs. This created some suspicion for these parents as to whether the patient was really their child or not. They recommended that some wider views of the operating theatre be included on the videos, including the face of their child, and a view of the surgeons operating, so as to reassure them.

All parents reported that they preferred digital versatile disc format to video home systems, although all were happy with the quality of the edited videos. One participant suggested that it would be particularly useful if the digital versatile disc could have chapters on it according to the steps of the surgery. Two parents suggested that it would have been better for them if they had had the opportunity to watch pre-operatively a similar operation on another patient before the operation was performed on their own child.

## **Discussion**

To our knowledge, this is the first investigation of the reactions of parents to watching an intra-operative video recording of the surgical procedures

carried out on their own children. We found that, in a random sample of 10% of parents who take up the offer to obtain a copy of the intra-operative video recording, all of them, and in some cases their family and friends, watched the videos and felt it was a beneficial experience without apparent adverse effects. The findings suggest there may be benefits to providing the intra-operative videos to parents.

First, the use of intra-operative videos may help parents, the children themselves, and other friends and family members to better understand the cardiac malformations and the corrective surgical procedures. Parents in this study used all available sources of information, including the Internet, and yet all described the need for more information presented in an understandable manner. Despite the raw format of the intra-operative videos in this investigation, parents perceived they learned something positive about the surgery, and considered them to have potential advantages in delivering information in comparison with conventional pictures, diagrams, or written information. Parents were enthusiastic about the potential improvements that could be made to enhance the quality of video information to help parents understand more fully what happens during cardiac surgery. Many of their recommendations are technically achievable, such as adding voiceovers, labels, and chapters to explain anatomy and steps of the procedure, but significant cost would be incurred if this is done individually for each video. Cost would be less of an issue if a generic set of videos of the most common operations were demonstrated to enhance parental understanding.

Second, the videos appeared to play an important role in helping parents come to terms with the emotional trauma of the surgery undergone by their child. Parents appeared to feel distress at not being able to be with their child during this most significant of life events. They found the videos allowed them, and others, to bear witness and have greater empathy for the experience of their child. Parents experience high levels of stress in relation to cardiac surgery, irrespective of the severity of the disease,<sup>11,12</sup> and parental stress has been linked to behavioural problems of the child up to four years after cardiac surgery.<sup>13</sup> Further research is needed to understand the emotional impact on parents, and to determine if the intra-operative videos could be useful in preventing or reducing post-traumatic stress or other symptoms experienced by parents, or by the children themselves.

Interestingly, some families wished to receive a recording of the full 3 to 4 hour surgery, motivated by their desire to fill the void in time they were separated from their child. In our experience, at

least some editing is necessary because of the movement artifact that occurs when using a head camera. The cost of editing was not measured in this study, but is an important consideration because of the limited resource of surgeon time. Although customized videos for each child may be desirable, it is unlikely ever to be feasible. Nevertheless, the length of the videos could be doubled for little additional time or cost. Furthermore, the full version is currently considered part of the permanent medical record and permanently archived at our institution. Parents, or the child when older, can request and obtain a copy at any time.

The desire to share the video with other family members, friends, and the school of the child, was an unexpected finding. Previous research, nonetheless, has highlighted the difficulties parents and children encounter in giving information about the congenital cardiac malformation in social and school settings.<sup>2,5</sup> Intra-operative videos may be useful as part of an initiative for the classroom or public education in improving awareness, understanding, and sensitivity to children who have had cardiac surgery.

Parents did not feel the videos altered their relationship with the surgical team. Further studies are needed to determine if having a video of the surgical procedure alters the views of the parents when they have less positive relationships with the surgical team, or when the outcome is less favourable than expected.

The findings from our preliminary study must be interpreted with caution because of the small sample size, potential selection bias, and exploratory design. More research is needed to confirm the needs for information and emotional support suggested by the parents in our study. In light of the obvious superiority of videos in displaying three-dimensional concepts and motion compared to other methods of giving information, and the high level of need for information of parents in the pre-operative period, it may be useful and feasible to provide parents in pre-operative period with generic disease-specific digital versatile discs, which show all the main anatomic variations and common surgical approaches with voice-over and labels. This standardized information could also decrease the variation in information given to families during the stay in hospital, which often causes distress or miscommunication. Comparative trials will be needed to determine if the videos offer sufficient improvement over current methods. Further research is also needed to examine the impact of viewing intra-operative videos for the children themselves or their siblings, as suggested by parents in our study.

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