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FROM HOPE AND EXPECTATION TO UNEXPECTED DEATH AFTER CARDIAC SURGERY

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Abstract

Objective: Relatives of patients undergoing cardiac surgery expect successful outcome but sometimes complications cause death. The aim was to interview relatives of patients who have died in connection with cardiac surgery, and describe their experiences of information, reception and care.

Methods: Data were obtained from semi-structured interviews with 18 relatives of deceased patients and then analysed using qualitative content analysis.

Results: Two main groups emerged: “Analysing the situation” with the sub-groups: knowledge of cardiac disease, the road to operation, hope and despair, information and choice; and “The thin thread of life” with the sub-groups reception, life is over, care, death as a relief, cause of death and support.

Conclusion: Most relatives were satisfied with the information and care in connection with the operation and at the end of life. However, some aspects such as inadequate pain control and transportation of critically ill patients to other wards and hospitals could be improved. One way is to introduce a co-ordinator in order to better support patients, next of kin and colleagues without experience of cardio-thoracic surgery who need help during the patients’ way from diagnosis and acceptance of cardiac surgery and through the treatment and postoperative care.

Keywords: Heart, complication, death, next of kin, information,

Introduction

A family member's serious illness influences and puts limitations on the entire family, especially on the patient's spouse (Allen et al. 1991; Kuyper and Wester 1998). The time from confirmation of the need for cardiac surgery until the operation takes place is a time of worry not only for the patient but also for the next of kin (NoK) (Bengtson et al. 1996; Bresser et al. 1993; Ivarsson et al. 2005a; Ivarsson et al. 2005b; Mark et al. 1997; Staples and Jeffrey 1997). During the waiting time they all have the expectation that the operation will be successful, and they do not expect that the patient will die during the operation or soon after (Lindsay et al. 2000; Mark et al. 1997; Staples and Jeffrey 1997). NoK play an important role for the patient and thereby can also influence the course of the disease and consequently the patient's risk of death. Despite the significance of NoK, the health services focus to a great extent only on the need of the patient and not that of the NoK (Rankin 1992). However, most patients want their NoK to be fully involved in all parts of the care.

Giving correct and relevant information to the patients and their NoK is of profound importance. When waiting and in connection with cardiac surgery a patient receives care from several different health care providers, and the information given is often varied and not well synchronised (van Weert et al. 2003). One study showed that 23% of cardiac patients were dissatisfied with the information given to the relatives regarding the disease and the intended surgery (Koivula et al. 2002) and another study showed that relatives of cardiac surgery patients lacked information, sometimes because they had few opportunities to have personal contact with the health care professionals (Davies 2000).

During 2003 we introduced extended written information about possible complications in connection with cardiac surgery at our department (Ivarsson et al. 2005a). The information has since then been sent by ordinary mail to the patients, optimally 4–6 weeks before elective surgery or as soon as possible if the waiting time is shorter. As the extended information covers all types of complications, from tiredness to death, it ought to generate thoughts and questions in the patient and their NoK. It has been shown that the extended information serves as a useful basis for fruitful conversations between the health care professionals and the patients and also gives rise to discussions between the patients and their NoK (Ivarsson et al. 2005a).

Mortality after cardiac surgery is not negligible. In Sweden around 2.6% die during the first 30 days after CABG (Herlitz et al. 2004). The relatives interact on various levels with the health care professionals during the time patients are alive, but after a patient has died most relatives draw aside to take care of themselves. NoK often lack information and have a lot of unanswered questions when their loved one dies unexpectedly inside or outside the hospital (Merlevede et al. 2004).

The aim of this qualitative study was to interview the NoK of patients who have died in connection with cardiac surgery, and describe their experiences of information, reception and care.

Material and methods

At the cardio-thoracic surgical unit in question, 1217 major cardiac surgery procedures were performed during the 12-month study period (September 2005 – August 2006) and the 30-day

mortality during this period was 2.1% (26 patients). The study group consists of NoK of all patients going ad mortem within the first 30 days after cardiac surgery. Exclusion criteria were: emergency surgery cases where no written information was given (5 cases), cases where patients did not understand our language (1 case) and cases where the NoK could not participate due to their own health status (2 cases).

Participants and information

NoK of 18 consecutive patients who had undergone major cardiac surgery fulfilled the inclusion criteria for the study and all agreed to participate. All NoK were family members or close relatives and will be referred to below as relatives. The patients had received standard written information about the transportation to the hospital, pre-operative showering etc., and a booklet compiled in 2000 at our department about the preparation for and performance of the cardiac surgery, including some practical advice as well as extended written information about possible complications in different organ systems and their consequences. They also received extended written information concerning possible common and rare complications, simple and severe, organ by organ, including information about life-threatening situations. Each topic discussed possible complications in a straightforward manner, without hiding the fact that several complications can be life-threatening and even cause death.

The patients were classified for risk by means of EuroSCORE, which is an additive risk algorithm developed on patients operated on in 128 surgical centres in eight European countries. When a risk factor is present in a patient, a weight or number is assigned. The weights are added to give an approximate percentage predicted mortality (EuroSCORE).

Data collection

Four weeks after the patient had died the relatives were invited by letter to participate in the study. Names and addresses of the relatives were extracted from the department's patient register and the deceased patient's case record. The relatives were defined by the patient at the registration on arrival in hospital before the operation. Demographic and clinical characteristics of the deceased patients and relatives are shown in table I.

The relatives were informed by the letter about the purpose of the study and of our intention to conduct a personal interview. It was stated that their participation was voluntary. Then the relatives were contacted by phone and asked if they agreed to participate, and if so they could decide the place for the interview.

Before the interview, the relatives gave their consent and were guaranteed confidentiality. They were told that they could withdraw from the study at any moment if they wished. For this type of interview study with NoK formal permission from an ethics committee was not required, but the intention outlined in the Declaration of Helsinki was followed. The interviews were semi-structured and covered the following topics: (a) demographic details such as age, relationship, length of relationship, profession; (b) questions about the patient's general health before operation; (c) questions about information; and (d) aspects of the reception by the health care professionals. The interviews took between 10 and 38 minutes and were conducted in their home (10), at their work (1) or done as telephone interviews (7). The interviews were undertaken in dialogue form and were tape-recorded. A verbatim transcription of each interview was made afterwards.

Data analyses

The qualitative data were analysed systematically using content analyses inspired by Burnard (Burnard 1996). The process of analysis of the content was done in several steps by one of the authors, who has much experience with this method. First, to obtain a sense of the whole, the raw material was read through several times, looking for similarities, differences, and extremes. It is important that the researcher is “immersed” in the text. Second, statements made by the respondents were identified as expressions with a certain limited significance, whether a single word, a phrase, or several phrases. The numbers of statements provided by each relative varied between seven and 36. At this step it is important that the researcher realizes that the method is a time-consuming process and really let the statements reflect almost all of the interview data. There is a risk of self-delusion or that an inexperienced researcher will try to use elements of the interviews that are unusable or cut strings of words and thereby alter the meaning of the statement. Third, the statements were systematised and coded into themes, i.e. sub-categories relating to the aim of the study. The statements from all the interviews should be reduced by grouping them and removing doublets. Fourth, the results were abstracted and condensed. This gave categories of description, i.e. citations of statements made by the respondents (Burnard 1996). This is a reductionist process. Content analysis of this type involves breaking down the transcripts and reports only parts of them. However, we considered this method useful to achieve the aim of the study. The analytical model inspired by Burnard (1996) is well known and has been used in several studies with similar aims. Using this model allows the interpretation to go beyond the surface level, i.e. reveals the unspoken, but does not go to a deeper level. To ensure that the classification was as free from bias as possible and could be replicated, the data were assessed by inter-rater agreement between two of the authors classifying the same data independently. This strengthens the validity of the analyses.

Findings

All of the deceased died in hospital, either where the heart operation was performed or at their home hospital. Death occurred in one case in the operation room, in 14 cases at cardiac intensive care units or general intensive care units, and in three cases at cardiac wards or ordinary wards. The analysis displayed two main groups: “Analysing the situation” and “The thin thread of life”, containing four and six sub-themes, respectively (Table 2).

ANALYSING THE SITUATION

The first main group highlighted four different sub-groups: Knowledge of the cardiac disease, The path to operation, Hope and despair, and Information and choice.

Knowledge of cardiac disease

Most of the relatives knew that the patient had cardiac problems, but not all realised the impact and the size of the operation which their loved ones had been through. Some were also taken by surprise when the patient suddenly suffered a heart attack and had to undergo emergency surgery. However, to most of them it was clear that if the patient had not agreed to an operation, he or she would not have survived very long.

“So Mum knew that she would be in a bad way if she didn’t do it [the operation], and she didn’t survive it.” (4)

The path to operation

Most relatives had thoughts about what the outcome would have been if the operation had been performed earlier. In contrast, some had thoughts about what could have happened if the surgery had been performed at a later stage when the patient was more mentally prepared. Some of the now deceased patients had been waiting for an operation for a long time, while others had been offered surgery which they themselves had postponed for a long time. At emergency surgery there were also relatives who reflected on the fact that the time lapse between the onset of symptoms and the operation had been very short.

“So there are more things we wonder about, you know, if ... she'd been operated on or said yes back in December.” (4)

“If he'd been given a date later on and had been able to prepare himself for it mentally, but it felt as if he'd made up his mind that he didn't want to any more.” (17)

Hope and despair

Most relatives felt that both the now deceased person and they themselves were confident that the operation would cure the patient, and restore their health to a life they had not had in a long time because of the illness. They trusted the physicians and thought that they would never perform an operation if they were not certain it would turn out successful.

“I suppose he was hopeful, like me, that it would go well.” (16)

Some relatives felt despair when they thought about how life could have been if their now dead loved one had not undergone the operation. They brooded over the quality of life,

restricted lifestyle and over the suffering the deceased had endured before surgery, and whether that life could have been a dignified life. Some relatives thought that it was the patient alone who made the decision about the operation, while others struggled with the thought that they had encouraged the patient to go through an operation.

“I felt a bit responsible at first that I had pushed him to have the operation.” (17)

Information and options

Most relatives were aware of the fact that the deceased had received written and oral information about risks and complications in connection with cardiac surgery. Some relatives had read this information themselves, whereas others did not know about this kind of information until after the operation. Those who had studied the information felt it positive that they already knew of all the risks, whereas those who had no knowledge about the information thought that it was probably a way for the deceased to protect the relatives from unpleasant thoughts and anxiety. When it comes to the patients' potential for choice to consider an operation or not, the relatives looked upon this in different ways. Some thought it was the deceased's own choice and therefore they had not insisted on being present when the doctor gave the oral information. A few thought it was the health care professionals' task to make sure that the closest family were informed about the risks.

“Then I read [the risk information] aloud so that we both heard it. It must have been the first time he heard it too, but the doctor must have said something ... So I thought too that if you're persuaded to do something like that, it must be because there's no other alternative, for otherwise you don't force medical care on anybody. And in a way it's nice that I haven't been involved in any decisions.” (14)

Most relatives felt positive when the surgeon phoned them after the operation. Many felt that the health care professionals took the time necessary to inform them during the entire critical period and all the way to the death of the patient. Most of the relatives felt that, whether the information was given over the telephone or personally, it was sometimes difficult to understand, especially if the information was negative, as in the event of death and everything connected with this.

“When she came in, the nurse anaesthetist, and talked a bit to us and asked if we were wondering about something, but my head was completely empty.” (7)

THE THIN THREAD OF LIFE

This main group had six sub groups: Reception, Life is over, Care, Death as a relief, Cause of death, and Support.

Reception

Most relatives were satisfied with the way they had been received by all health care professionals. They felt that these cared very much by talking, listening, and urging them to eat and sleep. They never felt they were considered tiresome whenever they called the staff members at the ward; on the contrary, they were treated very well even if they knew that other relatives phoned as well. The nurses or nurse’s assistants wrote a diary for those patients who spent a long time in the intensive care unit, which the relatives thought was very positive. Furthermore, the relatives felt that the health care professionals were always ready to effectuate individual wishes, such as music, books, making arrangements for them to find a place to spend nights close to the patient etc.

“They treated us well. I can’t imagine it being better. There’s nothing to complain about.”

(13)

A few relatives felt that the information they received over the telephone was too positive and they wished that the doctors and nurses had been more direct and honest. Some felt that the health care professionals did not appreciate when they expressed their opinions regarding the care of the patient. Some reacted negatively to the frequent changes of personnel and would have preferred more continuity, and they also felt insecure when different doctors expressed varying views about the same things concerning the care, the treatment and the prognosis of the patients.

“They didn’t agree about whether to operate ... and we thought, you know, that it was really problematic to be put in the middle from one person who was in favour to one who was against.” (2)

Life is over

Most relatives were convinced that the heart operation would turn out successfully and, therefore, the information that the patient would not survive or was already dead was an unexpected shock, and some felt that even the surgeon was surprised when the patient died. In a few cases the relatives were shocked, and even felt anger and despair when they were informed about the irreversible critical condition or about the death.

“So I went and when I came home they had phoned, that the end was near. They thought that we should come in, so I just returned and it was over when we came. I thought, oh, why didn’t I stay there [in the hospital]?” (16)

Care

Most relatives had been by the side of the patient during the critical period after the operation. Most of them were satisfied with the care and felt, especially when the death had occurred, that the deceased had not been left alone at all even when they were not present themselves, and that their loved one had been taken care of with the utmost consideration and dignity. The deceased was placed in a separate room and was washed, combed and shaved, and there were flowers and candles in the room. The relative thought that the most important thing was that the deceased looked peaceful and also that there were staff close by if they were in need of support when they said their last goodbye.

“So I said goodbye to her in there and it was very nice, they do it so nicely in the hospital.”
(5)

At some stage in the postoperative period the patients were routinely transferred to another ward or to their home hospitals. Some relatives were dissatisfied when the critically ill person had been transported from an intensive care unit to another ward and/or from one hospital to another. They did not consider it dignified and secure to be transported in this way, to have to meet new doctors and nurses and to take part in new discussions regarding the continued care. In some cases they also felt that the pain relief was insufficient at the receiving ward or hospital and that the patient therefore had to suffer unnecessarily:

“I didn’t think that was fair, you know, going back and forth with patients who were so ill, but I suppose it’s the money that dictates it, I don’t know.” (6)

Death as a relief

Most relatives had thoughts about pain during the final days of life. Some felt the patient had a peaceful death without pain, while others thought that the mitigation of pain and anxiety had not been efficient enough.

“... that she should suffer so when she had to die anyway, I thought that was terrible and she was in such pain.” (5)

Most relatives weighed death against a life with severe functional disorders as a consequence of the cardiac surgery. Although some said they would have preferred to have their relative still alive, they realised that death was a relief considering the prospects.

“I’ll look after him even if he’s in a chair. But I know that NN would never have accepted this life himself.” (8)

Cause of death

Most relatives thought that they had received sufficient information about the cause of death, but they were well aware of the fact that they might not have been able to receive all the information given to them right after the death. Many lacked written information, such as a certificate of death, and they did not know where to get one. As regards autopsy, most of the relatives were very negative about this.

“The doctor wanted to do a post mortem but I said definitely not. I thought they had operated once and broken her open three times and I thought that was enough.” (18)

Support

The relatives described various persons who had been of help and support to them after the death, such as family, friends, colleagues, the undertaker and clergymen. Some had been in touch with the hospital almoner and had found this valuable, but most of all this contact had been a matter of insurance and other paperwork. Many of the relatives had not really asked for more information or time to discuss the course of events but pointed out that they felt positive when they were called in connection with the present study. They were then able to express their feelings and thoughts and also to ask questions.

“If there had been resources that maybe some time a few months afterwards we could have talked through it again. Perhaps it would have been good, because it’s now that it’s coming up like this. They [the health service] could perhaps have offered anyway, maybe not everybody wants it.” (4)

DISCUSSION

The overall findings of this study showed that relatives will respond to death, information and reception from the health care professionals in a number of ways. This is congruent with earlier findings where the responses depend on a number of factors such as the strength of the relationship, timing of death, cause of death and the age of the deceased (Costello 1995).

Sometimes the first reaction of relatives hearing that a family member is in need of cardiac surgery is a shock because most people know that this type of surgery is not without risk and may therefore provoke ambiguous feelings. We found that, in line with other studies (Lindsay et al. 1997; Staples and Jeffrey 1997), relatives often felt uncertain at the beginning about the patient's cardiac disease and said that they had little or no ability to know or understand how seriously ill the patient really was. But later on, and especially after the death, relatives of patients with manifest heart disease said that they were fully aware that their loved one could not live a life of high quality without surgery.

“If” was a commonly used word among the relatives. Some relatives had thoughts about the scheduled operation. If it had been done earlier, would the surgery then have had a fatal outcome? Other relatives had thoughts like: if the time for surgery had been delayed so that the patient was in better mental condition, what would have happened then? Therefore, it is important for health care professionals to realise that the NoK should have information about complications, risks and expected outcomes of an operation as early as possible when planning elective or emergency surgery. The health care professionals must also be attentive to the patients' need for autonomy and respect whichever family member or friend the patient wants to be involved.

In this study the relatives trusted the doctors and for them the assurance that the patient would receive the best treatment was a source of hope and support, and they had no thoughts about death. Most of the patients were older, and Lynn et al. (1997) found that life-threatening illness may be easier to grasp for relatives of older patients. However, that was not obvious in the present study. Costello stated that the expectations of modern medicine in a culture that

does not fully accept the reality of death can result in a startling feeling being attached to death as a subject (Costello 1995).

Cardiac surgery is performed today on more seriously ill patients with an increasing number of risk factors and is therefore more complicated than before. The patients in the present study had high mean risk EuroScores, 11 ± 4 (Table 1), which should be compared with 6, the mean score of patients undergoing cardiac surgery in the clinic during the same period (EuroSCORE). Before the operation most relatives knew that the patient was fully informed, both in writing and orally, about risks and complications and that the patient participated in the decisions about the treatment. Furthermore, before the patients' death most of the information received by relatives concerned the illness and its treatment. The relatives said that they had been given many opportunities to ask questions and answers had been provided in an open and honest way, and often the information had been given in a separate area of the ward.

Most relatives had mainly good experiences of the encounter with the health care professionals. The relatives felt encouraged to call if they had questions or were anxious, and mostly the information was given in a clear and concise language which was of great value for the relatives. There were some relatives who were dissatisfied when negative information was given by telephone and not face to face. They felt that the health care professionals then acted as gatekeepers of information, as Main (2002) has also described in a qualitative study about management of relatives of dying patients. The present study shows that even if the state of the patient's health came as a shock the relatives wanted to hear the truth.

The divergent explanations about care, treatment and prognosis of the patient given by different doctors and other health care professionals lowered the relatives' hope and spirit and resulted in both trust and distrust. Azoulay et al. (2000) made similar findings in a study of families of intensive care patients, and they concluded that the reason was that the relatives did not understand the information given to them. This reflects a state of crisis inflicted by the news of their loved one's death. In the first phase, the shock phase, the individual normal way of solving problems does not work and the person feels blocked and excluded from the rest of the world. Information given to the individuals during this initial shock phase is often difficult to recall at a later stage (Cullberg 2000). This demonstrates that it is important for health care professionals to be sensitive as to whether the relatives really have understood the information, which must be individually adapted to the relatives, and repeated if necessary.

The relatives had positive opinions and feelings about the diaries written by the health care professionals at the cardiac intensive care unit and recalled tender memories afterwards. These feelings also have been highlighted by Bergbom et al. (1999) in a small pilot study with deceased patients' relatives at an intensive care unit.

The relatives felt deeply insecure when their loved ones were moved from one ward to another and most of all when they were moved from one hospital to another. This was expressed by several informants and has also been found in a previous study by Magnusson and Granskär (2005), who found that next of kin were negative to patient transfer due shortage of beds. Nurses are also distressed and frustrated by this action of transferring dying patients between different wards (Nordgren and Olsson 2004). Shortage of beds is based on political decisions but it is important to give correct information as to why the patient has to be moved.

The relatives in this study were not always prepared for the worst, but those who understood that the patient would die started grieving while he or she was still alive. All wanted to be near the patient if there was any deterioration, but sometimes the death came suddenly even for the health care professionals.

Faced with the loss of a loved one after a relationship lasting in some cases up to 75 years, it was surprising that most relatives could accept the death. Most relatives observed with sadness that death was best for the person because his/her life was filled with illness, in many cases even before the surgery. This finding is in agreement with a study by Kaunonen et al. (2000).

After the death of a cardiac surgery patient, contact with the deceased relatives is often limited from the health care professionals' side. In this study none of the relatives needed or asked for help from the health care professionals and they described how they coped without help from the health care organisations. This was also found by Kaunonen et al. (2000), who showed that grieving spouses' opinion was that the most important source of support was families and friends followed by support from co-workers. It is not known whether the health care professionals offered any later contact with the relatives in the present study, but the relatives greatly valued being contacted in connection with this study. In a recent study (Fridh et al. 2007) describing routines for calls or visits at 94% of the Swedish intensive care units, only 51% answered that they often or almost always offered it, although in most cases the bereaved family had to initiate the contact themselves.

Conclusion

In this study the relatives who lost their loved one in connection with heart surgery were satisfied with information, reception and care at the operating hospital. They also expressed positive feelings when they were contacted for the present study. The relatives appreciated the opportunity to ask questions and to talk about the course of events. This finding shows the importance of a postoperative contact, perhaps also when the operation is successful. One important finding was that when the patients were transferred postoperatively to wards not specialising in heart surgery or to their home hospitals, the information and pain treatment deteriorated. Those relatives felt insecure when they received divergent information and they also felt that their loved one had to suffer pain and anxiety. Future studies should therefore contain topics such as development and evaluation by a nurse coordinator and a scheme to secure continuity in information, care and pain treatment to all patients irrespective of where they will be transferred postoperatively.

Methodological limitations

One of the major problems with this study was that it was impossible to do face-to-face interviews with all the relatives because they lived in a wide geographical area. The data in this study were collected from relatives at one cardio-thoracic centre. Because of the study's qualitative nature, our aim was not to generalise the findings to apply to all relatives whose loved ones had died in connection with cardiac surgery. However, it is reasonable to assume that the findings can show a part of the reality of relatives' experiences of bereavement and give a better understanding of the interaction between relatives and health care professionals.

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Table 1. Characteristics of the study population

Characteristics	Relatives (n=18)	Patients (n=18)
Sex (F/M)	13/5	6/12
Age (years):		
Mean \pm SD	55 \pm 15	72 \pm 11
Median	50	75
Range	30–80	50–87
From waiting lists:		10 (56%)
Emergency surgery		8 (44%)
EuroSCORE*		
Mean \pm SD		11 \pm 4
Median		12
Range		2–19
Days from operation to death		
Mean \pm SD		13 \pm 12
Median		11
Range		0–30
Type of cardiac surgery:		
CABG** (n)		7
CABG* + valve replacement (n)		7
Valve replacement (n)		2
Aneurysm		2
In gainful employment (yes/no)	12/6	
Healthcare knowledge (yes/no)	8/10	
Length of relationships (year)		
Mean \pm SD	46 \pm 14	
Median	45	
Range	75–24	
Relation:		
Husband	1	
Wife	5	
Son	3	
Daughter	5	
Brother	1	
Sister	3	

* <http://euroscore.org>.

**CABG = Coronary artery bypass grafting

Table 2. The main groups and sub-groups emerging from the data.

Main groups	Sub-groups
Analysing the situation	Knowledge of cardiac disease (18) The road to operation (16) Hope and despair (36) Information and choice (87)
The thin tread of life	Reception (52) Life is over (16) Care (36) Death as a relief (27) Cause of death (20) Support (31)