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Published in:
Journal of Nursing Management

DOI:
10.1111/j.1365-2834.2004.00400.x

2004

Citation for published version (APA):

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Postponed or cancelled heart operations from the patient’s perspective

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Introduction

For most people, the heart is strongly connected with both life, for which cardiac function is essential, and with the soul, as a centre for feelings (Davenport 1991). The time before patients with heart disease receive their diagnosis is filled with anxiety. The fear of a possible operation is felt even before the patient undergoes coronary arteriography and receives a diagnosis (Heikkinen et al. 1999) and the time that elapses from decision concerning operation and the operation itself is considered by most patients as a time of worry and insecurity (Bengtson et al. 1996, Jonsdottir & Baldursdottir 1998, Perski et al. 1998, Fitzsimons et al. 2000). Most patients feel a sense of impotence, as their capacity to make decisions regarding their own well-being is minimal (Burchiel 1995). To the patients, big surgical interventions can mean strong psychological and psychosocial reactions connected with thoughts about death, pain and risk of complications (Lazarus &
Prolonged waiting time for a cardiac patient probably increases the risk of a new myocardial infarction and the patients are worried about whether they will have their treatment in time (Bengtson et al. 1996). Research has shown that waiting for transportation to the operating room is one of the most frightening experiences for patients in connection with surgery. Patients also worry that their operation may be delayed (McCleane & Cooper 1990, Cobley et al. 1991). Should the waiting time be complicated by a sudden postponement or cancellation of the heart surgery, then most patients feel this to be a strongly negative experience (Davenport 1991, Bresser et al. 1993, Ivarsson et al. 2002).

Review of the literature

More than 9300 open heart surgery procedures are performed in Sweden annually (National Board of Health and Welfare 2000). Patients are usually admitted to hospital 1 day before the scheduled operation. On the day of arrival, the patients are given information by nurses, the ward doctor, the anaesthesiologist and the surgeon who is going to perform the operation. The patients are also instructed about the importance of postoperative physiologic activity by a physiotherapist. Furthermore, they undergo physical examination, ECG and radiography of the heart and lungs. A variety of blood tests are taken and a preoperative assessment made on the basis of the findings. The incision area is shaved and the patients are asked to shower using a special disinfecting soap. Sometimes a planned operation is postponed or completely cancelled during or after all these procedures. A survey of the literature shows that the frequency of postponements/cancellations for elective, inpatient operations varied from 8.6 to 30% (Lacqua & Evans 1994, Pollard & Olson 1999, Ivarsson et al. 2002), with a variety of different reasons for the postponement or cancellation. In a project addressing the issue of planning and completion of operations in Sweden (Dagmar 1992), cancellations were divided into three groups depending on the reason for the postponement/cancellation:

- Patient-related reasons: the patient does not keep the appointment or suddenly refuses the operation.
- Medical reasons: the patient’s health deteriorates, or the preoperative investigations are not complete.
- Organizational reasons: These are the major reasons for postponements/cancellations. There are many possible causes, for example the arrival of emergency patients, lack of staff, including surgeons, lack of space in the operating theatre, lack of space in the intensive-care unit, missing or faulty technical equipment and lack of time because of previous operations exceeding the scheduled time.

Studies showing the problems of postponements/cancellations from the inpatient’s perspective are few (Kennedy 1969, Davenport 1991, Bresser et al. 1993). In a previous quantitative study, we showed that 61% of the patients reacted negatively to the fact that their operation was postponed or cancelled and this reaction continued for an extended period of time (Ivarsson et al. 2002). In that study, anxiety and depression were assessed using the hospital anxiety and depression scale (HAD) and it was found that women were significantly more depressed than men in the same situation, but there was no significant difference regarding anxiety. The aim of the present qualitative study was to achieve a deeper perspective, by describing inpatients’ perceptions of a postponed or completely cancelled heart operation and of the reception they receive from the staff in connection with this.

Methods

Informants

All adult inpatients scheduled for elective bypass and/or valve surgery with extra corporeal circulation (ECC) at a Department for Cardiothoracic Surgery in southern Sweden, during 1999, whose operations were postponed or completely cancelled, were eligible to participate. During this period, 1212 heart operations were performed and 94 patients experienced a total of 104 postponements/cancellations. Some patients thus had their operation postponed more than once. Of these 94 patients, 74 (14 women, 60 men) participated in the study. Of the others, four patients died, six were excluded for medical reasons and 10 were unwilling to participate.

Demographic information on the patients completing the survey is summarized in Table 1. Reasons for postponements/cancellations were classified as patient-related, medical or organizational (Dagmar 1992) and characteristics of the postponements/cancellations are summarized in Table 2.

Ethical considerations

The Ethics Committee of the Medical Faculty of Lund University, Sweden approved the study (LU 705-98). Study patients received a letter with information about the aim of the study, stating that participation was
voluntary and that all data would be treated as confidential. Included was a questionnaire, which they were asked to complete if they chose to participate in the study.

Procedure

The questionnaire was designed in-house on the basis of a literature survey. Besides direct socio-demographic questions, the patients were allowed to express themselves freely and to answer open questions about their experiences in connection with the postponement or cancellation of the operation and also about the reception they received from the staff. A specific question relating to feelings about the waiting time from the postponement until the operation was completed was also included. A pilot study, including two patients, was conducted to test the content validity of the questions and which was shown to be satisfactory.

Patients for whom heart surgery was found unsuitable received the questionnaire together with an invitation to participate in the study, by mail. Patients with postponed operations received the questionnaire after surgery. The time ranged from 1 to 12 weeks after the postponement/cancellation (median 4 weeks). The patients that did not answer were reminded by mail once.

Data analysis

The chosen qualitative analyses were inspired by content analysis according to Burnard (1996) and Burns & Grove (1997). Content analysis is based upon communication and systems theory and is used to describe the manifest message of a text as well as the latent message (Carlsson 1991). In manifest content analysis, the investigator looks for words, phrases, descriptions and terms in the textual data that are important to the context. Latent content analysis means that each passage is reviewed within the context of the entire text, to identify the relationship between major intents and indirect meanings (Burns & Grove 1997). Both manifest and latent content analysis were used in this study.

Analysis used five steps based on the thoughts and experiences expressed in the questionnaires inspired by Burnard (1996).

Step 1: After repeated reading of the inquiries we looked for similarities, differences and extremes of these.

Step 2: Statements describing the patients’ perceptions of cancelled heart surgery and staff reception in connection with this were identified. A ‘statement’ was identified as an expression with a certain limited significance, whether a single word, a phrase, or several phrases. A total of 246 statements were identified.

Step 3: The statements were systematized and memos written to find patterns and associations resulting in recurrent themes relating to the aim of the study.

Step 4: Thirty-three themes were identified and through reading and reflection a further abstraction of perceptions was made.

Step 5: Abstraction and condensation resulted in five categories of description. These are illustrated using quotations from the questionnaires.
Our purpose was not to generalize the results to apply to every patient who had the operation postponed or cancelled, but to acquaint ourselves with patient opinions that might be expected to cover a majority of the variations in patients’ opinions (Starrin & Svensson 1994).

Findings
The results are not structured according to the causes of postponement/cancellations but according to the patients’ perceptions of the experience and of treatment by medical staff in connection with this. Five categories of description emerged. Most of the patients in all categories felt anxiety, depression, disappointment and worry. Figures in brackets (n) refer to the number of statements within the respective categories.

Perceptions of postponements/cancellations caused by organization (n = 11)
This category describes the patient’s perception of the organization around the planning of the operation.
Some patients did not feel they could take part in the decisions concerning the postponed or cancelled operation; they did not feel that they received an acceptable explanation of what happened and why. Neither could they understand why, after being taken to hospital and all the preparations for surgery being made, just before the scheduled time for the operation it was suddenly postponed or cancelled.
‘I was X-rayed, shaved, had to have a special shower, spoke with a doctor (probably a ward physician), received instructions from a physiotherapist, met an anaesthesiologist who told me everything he was going to do. My wife was with me the whole time, but drove home at about half past four, only the surgeon was still there, and she was going to call and ask what he had said. Then I spoke to the nurse and was shocked to hear that I was not going to have the operation. She drove straight back to fetch me. My wife called Dr NN the next day, and was then told that he considered a second operation too risky, and since I hardly have any angina, it’s better to leave things the way they are. He then said that it was just too cruel that nobody had said this much earlier. How can I go back to a normal life after this? I know that two arteries need changing, and that my heart is not getting enough oxygen. It would have been better not to know anything, now I think about it day and night. My heart must be strong after all, to take all of this.’
There were also patients who said they could understand that emergency operations had to receive higher priority than their own, and that the postponement was justified. They abided by the decisions of doctors and nurses, and felt they had no other choice, which led to acceptance of the situation.
‘I consider it inevitable that consideration must be taken of the current operative situation.’
However, there were also patients who expressed anger at higher-level decision-makers, feeling that these persons were responsible for the time and money wasted because of the postponed operation. They had the impression that doctors and other staff members could do nothing but accept and follow the political decisions concerning health care, even if these decisions affected the patients in a negative way.
‘Let no shadow fall on the hospital and its staff. In my opinion, inadequate allocations from politicians and government are most to blame.’

Perceptions of medical aspects (n = 23)
This category describes the physical or psychosomatic problems suffered by the patients because of postponement/cancellation of their operation.
The patients reported chest pain, tachycardia, hyperglycaemia (in diabetes patients), nausea, sleeping disturbances and various nervous reactions were mentioned. The patients also reported a fear of having cardiovascular problems.
‘The fear of having a heart attack was there the whole time.’
The patients whose heart surgery was postponed considered this a matter of minor importance, as their sense of well-being was worse than expected after the operation, as the result of medical complications in connection with the operation. They described their symptoms, and the disappointment they felt, because of the medical complications.
‘In retrospect, I would have been glad if it had been postponed for ever.’
There were patients who felt that their sense of well-being improved after the heart surgery, and thereby their quality of life. Their experience of the operation itself and the care before and after the operation was very positive, and these positive experiences overshadowed the fact that the operation was postponed at first.
‘After the operation, everything went well, the staff and food were just perfect. I am very grateful
to the doctors and staff for their efforts, otherwise I would not be writing this today.’

Perception of information (n = 18)
This category describes how the patients perceived the information they received about the postponement/cancellation.

The patients said they had received inadequate information, and this made them feel uncertain about what was going to happen in the future. They felt that they were informed about the postponement or cancellation too close to the scheduled operation. They also brought attention to the fact that they received no new operation date in connection with the negative message about the postponement.

‘It was difficult to have my operation postponed only 1 hour before the scheduled time.’

However, there were also patients who felt that the information given was clear and objective and they were able to understand why their operation was postponed or cancelled. They felt ignorant about their disease and treatment options available, but trusted the professional information given to them.

‘The surgeon informed me that it was a better choice for me to insert a net, and shatter [balloon dilatation].’

Perceptions of waiting time (n = 84)
This category describes the experience of waiting for surgery.

The patients felt uncertainty and fear after having been put on the waiting list, and said the time of waiting felt long and distressing even before the operation was postponed.

‘From angiography on 30 November 1998 to surgery on 9 March 1999 is mental torture for a human being.’

The new waiting time, between the postponement and the operation, was described as long, heavy and dreary. The patients said they felt restless.

‘Too much time to think.’

The patients felt that the extra waiting time was difficult and frustrating. They could not understand why they had to be the ones affected.

‘Very frustrating, because you are mentally prepared for the operation, and then you have to start all over again.’

The patients described feeling fear and mental distress during the extra waiting time. They experienced worry, anxiety and depression and they were also disappointed. The patients also thought that the delay might put more pressure on the already sick heart.

‘Nervous and worried that something would go wrong in the meantime.’

In contrast, there were also patients who did not consider the extra waiting time a problem. They considered it relatively short and some used the time in a positive manner. They felt that the extra waiting time gave them respite and they found comfort either at home with relatives or from hospital staff.

‘During the waiting time, I had the chance to see that even elderly patients made rapid recoveries.’

Perceptions of reception (n = 110)
This category describes how the patients felt about the reception they received from the hospital staff.

The patients considered the reception from all categories of staff to be positive, and felt that they all showed a high level of social competence. Staff members were considered friendly, pleasant, kind, helpful, service-minded and professional.

‘They were kind, and really took care of me.’

The patients felt that staff members were careful, sympathetic and always available when needed. They also felt they were given due respect and that their needs were attended to.

‘The staff were very understanding, and could see things from my point of view.’

However, there were also patients who mentioned that they felt that the staff members were too busy and under too much pressure to take care of those who needed attention because of a postponed or cancelled operation. They felt that nobody took notice of their expectations and wishes and nobody asked if they needed some kind of support.

‘The staff, without exception, have too little time for the individual patient.’

Discussion
Discussion of method
As our aim was to get the largest possible range of patients’ perceptions of having their heart operation postponed/cancelled, our study included all patients in a department of cardiac surgery who had an operation postponed/cancelled. To collect information, a questionnaire was sent to the patients’ homes, so that the answers would not be affected by a feeling of dependence on the doctors and nurses who were caring for them. It was not practically possible to interview the
patient immediately after the postponement/cancellation since some patients had their operation postponed/cancelled for <24 hours or postponement took place in middle of night. Some patients also left the hospital immediately after they had been informed that their surgery was postponed/cancelled. Another way to collect information would have been to interview the patients in their homes but this would have taken too much time because of the wide geographical distribution. Considering the aim of the research and the number of patients participating, content analysis was considered an applicable method for collecting data and this method has been used in similar studies. To clarify the scientific problems regarding collection and analysis of data, the concepts of applicability, concordance, security and accuracy were used (Fridlund 1998). Concordance could be considered reasonable, as the authors have an understanding of this area of research, having long experience of acute somatic care, and formulated the questions together, afterwards testing them in a pilot study. Security was confirmed through a check of the description categories by co-authors and every category was illustrated using a quotation. In an effort to ensure accuracy, collected material was read and reflected on, and during analysis of data, similarities, differences and extremes were sought in the patients reports.

Discussion of results

Perceptions of postponements/cancellations caused by organization

In this study, the patients questioned the organization around planning of operations. They did not feel they took part in the decision to postpone or cancel or their operation, not having received a satisfactory explanation. To be able to participate in decision-making, patients must have knowledge about the alternatives available to them. Sometimes the patients dare not ask questions and express their doubts. A reason can be that when doctors and other members of the staff on the basis of their knowledge and proficiency are given the opportunity for disciplined exercise of power (Raatikainen 1994), the patients surrender to their decisions, in order not to be considered troublesome (Nordgren & Fridlund 2001).

In the present study, the patients expressed sympathy for the staff, saying they did not feel doctors and nurses were to blame for the postponement of the operation, but rather the decision-makers. However, a fundamental aim of both decision-makers and hospital staff must be to reduce the frequency of postponements/cancellations. Previous studies have shown that it is possible to reduce the number of postponements/cancellations caused by organizational problems by introducing a preadmission clinic (Nelson 1995, Lindsay et al. 1998), especially if the patient has waited a long-time for surgery and the health condition may have changed. Another way is to introduce a co-ordinator for hospital beds and operations (Fletcher & Hodges 1999), or to change the system for waiting lists and planning of operations (Morgan & Vaughan 1997) and thereby separate emergency and elective surgery.

Perceptions of medical aspects

The results showed that the patients felt they had physical or psychosomatic symptoms caused by the postponement or cancellation of their operation and they were afraid of being affected by cardiovascular problems. This is in accordance with the results of another study, which showed that eight of 17 patients who had their operation postponed had at least one episode of chest pain during the extra waiting time; three of these patients needed treatment at an intensive care unit preoperatively (Bresser et al. 1993).

Although the patients were not asked about their experiences of the surgery they described this spontaneously. In many patients their feelings to the postponement and to the operation were closely intertwined and could not be separated. The patients described feeling a poorer sense of well-being than expected after heart surgery, because of complications. This problem is also seen in patients whose operation has been carried out according to schedule. According to a study in which 58 patients described the first 6 months after coronary artery bypass graft (CABG) surgery, more than 50% of the patients had problems with side-effects after the operation, emotional reactions and physical fitness. In the same study, 25% of the patients requested detailed information concerning potential postoperative problems (Jaarsma et al. 1995). It is probably more important to give information about potential complications to patients whose operation is postponed, since there may be thoughts that the complications are caused by the postponement. One study showed that postoperative follow-up telephone calls to patients who had undergone heart surgery were helpful (Roebuck 1999), and it is likely that this type of telephone call can be of advantage both to patients who have been operated on and to patients who have had their operation cancelled completely. Internet-based support systems for heart operated patients are also being built and tested (Flatley Brennan et al. 2001).

Other patients in the present study felt an increased sense of well-being, and an improved quality of life after
the operation, and the postponement of the operation was considered of minor significance. In a longitudinal study, 86% of the patients said that life had more or less returned to normal, 1 year after CABG, and 76% said they had recovered as well as expected, or better than expected (Jaarsma & Kastermans 1997).

Perceptions of information
To give the proper information is not easy, as staff and patients have different ways of seeing things. In the present study, the patients felt that the information they were given concerning the postponement or cancellation of their operation was not sufficient. Similar results were seen in previous studies, in which patients were dissatisfied with the explanation given for the postponement of their operation (Bresser et al. 1993), or did not understand the information (Davenport 1991). It is important for the staff members to be sensitive to whether the patients really have understood the information, which must be individually adapted to the patients, and repeated if necessary. One earlier study showed that cardiac patients expected the nurse to be an information provider, who would more fully explain the information they had not understood (Staniszewska & Ahmed 1998). A follow-up talk with the nursing staff could have been of great value in reassuring the patients and increasing their understanding of why the operation was postponed/cancelled.

In our study, the patients left it to the doctors, who were considered experts, to take the decisions regarding their care, and trusted the information given to them. Similar results were seen in previous studies, in which patients preferred doctors to make the decision but wanted to be involved in the decision-making process; for this extensive information giving to the patient is necessary (Kennelly & Bowling 2001, Robinson & Thomson 2001).

The findings show that patients felt they were informed about the postponement too close to the scheduled operation, and without receiving a new date for the operation, causing stress and frustration. In both the study by Ivarsson et al. (2002) and the study by Kennedy (1969), it was possible to see that the closer to the scheduled operation the patient was informed about the postponement/cancellation, the more negative were the reactions. The findings were significant in both studies.

In the present study, there were also patients who said they were satisfied with the information given in connection with the postponement or cancellation of the operation. We have previously shown that 54 of 72 (75%) answering patients were satisfied with the information they received about the postponement/cancellation (Ivarsson et al. 2002). In 1996, Larson et al. (1996) showed a clear connection between adequate information and the patient’s satisfaction with medical treatment.

Perceptions of waiting time
In the present study, the patients found waiting time for scheduled heart surgery uncertain and filled with anxiety, a finding also seen in other studies (Bengtson et al. 1996, Fitzsimons et al. 2000). For those patients in the present study who had lived under severe strain for an extended period of time, the strain was further increased when the waiting time was prolonged, and the extra waiting time was seen as negative. Kennedy (1969) described also this in a study of adult inpatients, of whom 61% reacted negatively to the cancellation of their surgery. A previous study showed that patients felt uncertainty and a feeling of having lost control when their operation was postponed (Bresser et al. 1993). Another study showed that more than 50% of patients whose operation was postponed were tenser and more worried while waiting for the new operation date. The same study concluded that the more prepared the patient is for the possibility of the operation being cancelled, the less negative is the reaction (Davenport 1991), which indicates that preoperative information that cancellations cannot always be avoided should be increased. In addition to information in writing or by telephone, the patient can be informed at a preadmission clinic. Previous studies showed that preoperative anxiety was reduced in intervention groups of heart patients who had been to a preadmission clinic, compared with control groups who did not attend these clinics (Lindsay et al. 1998, McHugh et al. 2001). A preadmission clinic could also aim at identifying the patients’ mood, in order to be better able to support patients who need help, for instance when their operation is postponed or cancelled. Furthermore, the staff of such a clinic could identify cases where postponement absolutely should be avoided or cases where it would be very inconvenient for the patient (Schnetler 1992). In the present study, patients who did not experience the postponements/cancellations and the extra waiting time as troublesome could be persons of equanimity by nature. It may be possible to identify these patients at a preadmission clinic, and if necessary, to place them on a standby waiting list, with the possibility of being informed of the availability of an operation on short notice.

Perceptions of reception
In the present study, the patients felt that they received a very positive reception from hospital staff of all
categories, which is in accordance with the results of a previous study in which almost everyone, 67 of 70 (96%) answering, was satisfied with the reception received from the staff after notification of a postponement/cancellation (Ivarsson et al. 2002). Bresser et al. 1993 found that 82.4% of patients who had experienced postponements felt that the nurses had performed all they possibly could for them. Similar results were found by Davenport (1991). These results are gratifying, as a correct and respectful reception assumes that the staff has sufficient understanding of the patient’s situation and knowledge of their problem and also a humanitarian approach. The patient’s perception of the quality of the care given depends a great deal on the person-to-person interplay between patient and staff and this has significant effects on whether the patient is satisfied with the care (Fosbinder 1994). In 1969, Kennedy (1969) suggested that it was difficult for patients to express or admit their feelings and none of the patients had talked to a nurse about the cancellations (Kennedy 1969). Formerly, patients may have felt themselves in more of a subordinate position towards staff compared with today. However, the tendency is still there, although patients know a lot about their illness, its treatment, and their rights, because of increased possibilities of finding information, for example on the Internet. In the present study, the patients reported they felt that the personnel lacked time and they wished staff members would be more sensitive to their wishes and needs. Similar findings were obtained in another study (Nordgren & Fridlund 2001). Thus staff should remember that tone of voice, attitude and character in meeting with the patient are crucial in deciding how the relationship with the individual patient develops.

Conclusion
During data analysis, five categories of perceptions emerged: perceptions of organization, medical aspects, information, waiting time and reception. Overall, the findings indicate that the patients reacted negatively in the form of anxiety and disappointment to the postponement/cancellation, but were generally satisfied with the reception they received from the hospital staff. The patients’ perceptions, however, revealed a number of concerns, with possible implications for the healthcare system.

Clinical and research implications
An important implication for the health-care system is that the hospital staff need to have a better understanding of patients’ perceptions of postponed/cancelled heart operations so that they can provide them with the information and support they really need. The findings from this study can be used to design an intervention programme aimed at improving the situation of the heart surgery patient. The programme could include a preadmission clinic, a change in the system for waiting lists and planning of operations, and follow-up telephone calls and internet-based support system.

Further research is needed regarding the relative importance of the support patients receive from the healthcare system, and from their next of kin. Moreover, a health economics analysis to look at the cost of postponing and cancelling surgery would be beneficial for the individual patients, their next of kin, and not least, society as a whole.

Acknowledgements
This study was supported by grants from the Local Association for Heart and Lung Patients in Skåne, SSSH (Southern Sweden Nurse’s home), Swennenurse (SSF) and Lund University Hospital.

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