Ivarsson, Bodil and Larsson, Sylvia and
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EXTENDED WRITTEN PREOPERATIVE INFORMATION ABOUT POSSIBLE COMPLICATIONS AT CARDIAC SURGERY - DO THE PATIENTS WANT TO KNOW?

Bodil Ivarsson, RN, PhD (1), Sylvia Larsson, RN, PhD (2), Carsten Lührs, MD (1),
Trygve Sjöberg, PhD (1).

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Department of Cardiothoracic Surgery, University Hospital of Lund, Sweden (1) and Department of Nursing (2), Lund University, Sweden.

Short title: Preoperative information regarding possible complications

Address reprint requests to:

Bodil Ivarsson

Department of Cardiothoracic Surgery

University Hospital of Lund

SE-221 85 Lund

Sweden

Phone: +46-46-17 70 16

Fax: +46-46-17 72 07

Email: bodil.ivarsson@med.lu.se

ABSTRACT

Objectives*:* It is important that patients for whom cardiac surgery is planned are supplied with structured oral and written information regarding their disease and its treatment, so that they can understand and discuss the coming operation and the risk of complications. The aim was to describe patients' experiences of information regarding possible complications related to cardiac surgery, both before and after the operation. A comparison was made between patients who received detailed written information (intervention group) regarding possible complications and patients who received conventional information (control group).

Methods*:* One hundred eighty-two patients were included in the intervention group and 156 in the control group. Questionnaires were distributed and experiences, anxiety and depression (the Hospital Anxiety and Depression Scale, HADS), and avoidance or intrusion distress (the Impact of Event Scale, IES) were measured before and 8 weeks after the surgery.

Results*:* Seventy-two percent of the intervention group and 69% of the control group wanted information about both common and rare complications. Patients in the intervention group were significantly more satisfied with all aspects of the information compared to the control group both pre- and postoperatively. There were no significant differences between the groups for either the HADS or the IES.

Conclusion*:* Most, but not all, patients in the present study were positive to the extended written detailed information about risk of complications in connection with cardiac surgery. Detailed information can be a useful base for fruitful conversations between the health care personnel and the patients. The patients and their next of kin are informed, and better prepared if complications occur.

Keywords: consent information, preoperative information, cardiac surgery, complications

INTRODUCTION

It is well documented that coronary artery bypass graft and/or valve surgery alleviate the symptoms of heart disease, and due to continuous improvement in surgical and anaesthetic techniques and nursing, good clinical effect is obtained in most cases. However, there is a risk of pre- and postoperative morbidity and mortality due to complications in both younger and older age groups [1, 2]. Patients have different opinions regarding whether they want information about risks or not. One study showed that in 50 patients facing cardiac surgery, 42% wanted no information at all about the risks associated with the surgery and 50% did not want any information about the risk of death [3]. Even though the decision regarding cardiac surgery is crucial, most patients leave the decision to the surgeon. The patients feel that the information they receive and their knowledge regarding alternatives is inadequate to decide whether surgery is appropriate or not [4, 5]. In a previous qualitative study we showed that some patients waiting for cardiac surgery felt that the information could be both insufficient and incorrect [6]. Another study showed that during the night before cardiac surgery, 78% of the patients were informed about possible risks connected with the operation, and 75% of the patients were informed at the same time about the consequences of not having surgery [7].

It is unclear whether sparse or absent information about pre- and postoperative risk is a result of paternalism, but according to Shinebourne and Bush [8], it can be seen as a form of paternalism when a doctor makes a decision for the patient, or does not give full information on the grounds that it is better for the patient not to know.

Few studies have been carried out to evaluate the effect of different types of information regarding the complications that may occur in patients undergoing cardiac surgery. The surgeons have stressed that information about all aspects of possible complications could be frightening for the patients, and thereby increase anxiety and distress. Therefore, the aim of this study was to investigate patients' experiences of information regarding the risk of such complications and how the information affects the patients. A comparison was made between patients who preoperatively received new extended written information regarding possible complications connected with cardiac surgery and patients who received conventional, more superficial and less substantial information.

MATERIALS AND METHODS

Design and setting

The study had a non-randomised design with one intervention and one control group. The data collection for the control group was completed first, and the data for the intervention group after an intermission of 10 weeks. This strategy was chosen to avoid “leakage” of information between patients. Both groups consisted of adult elective, consecutive patients admitted for coronary artery bypass and/or valve surgery, with or without extracorporeal circulation (EEC), at a cardiothoracic surgical centre in Sweden. Approximately 1400 heart operations are performed each year at this centre.

The study was approved by the Committee of Ethics in Medical Investigation of Lund University, Sweden (LU 713-02). The patients received a questionnaire by mail, which they were asked to complete if they chose to participate in the study. The patients also received written information about the questionnaire and the aim of the study, and were told that all data would be treated as confidential.

A power analysis was carried out to determine the required sample size [9] and calculations were based on a two-sided α of 0.05 with a power of 0.80. To detect a difference of 25%, the target sample for the study was 244, with 122 in each group.

Intervention

The patients in the control group received written standard information about transportation to the hospital, procedural information and hygienic preparation etc., and a booklet compiled in 2000 at the cardiothoracic surgical centre about the preparation for and performance of the cardiac surgery, including some practical advice. The booklet contains information on different cardiac diseases and technical description of surgical approaches, information on medication, postoperative minor changes in pulse rate and possible wound infections, information about possible psychological reactions such as anxiety and depression and health related information of recommended life style post operative. The patients in the intervention group were given the same information as patients in the control group, as well as a brochure compiled in 2003, with extended information about common and rare complications, simple and severe, organ by organ, including information about life threatening situations that can occur in connection with cardiac surgery. The extended information focuses on the effects on different organ systems and possible complications. The brochure contains information of the possibility that severe illness and major complications can lead to death. It also contains information of the opportunity to call the clinic for discussion and questions with a nurse or surgeon and that the patient should bring the written information and discuss this at the preoperative meeting with the surgeon. The content of the brochure was based on current, clinical knowledge and studies of several patient information materials [10]. The brochure was discussed with a wide range of clinical experts.

Procedure

Patients were asked to complete a questionnaire focusing on their experiences regarding the information they received about different complications that can occur in connection with a heart operation. They were also asked about their emotional state and subjective distress. The patients received the first questionnaire within 10-14 days before the planned heart operation and the second questionnaire 8 weeks postoperatively. Both questionnaires were sent by ordinary mail. Patients not answering the first questionnaire were not included in the study and those not answering the second questionnaire were reminded once by mail. Exclusion criteria for patients to this study were emergency heart surgery or surgery planned within two weeks, and inability to understand, read and write Swedish.

Instruments

Self-assessment questionnaires were developed specifically for this study to evaluate satisfaction about the pre-operative information before heart surgery. They were designed on the basis of a literature review [3, 11, 12]. The questionnaires consisted of Likert-type questions and multiple-choice questions about information on complications (14 items), personal attitude to information (2 items), and possibility for support (3 items). The patients were also asked questions of a socio-demographic nature, such as age, education and family situation. Content validity was checked by clinicians (a surgeon and nurses experienced in surgery and care) and researchers who were not otherwise involved in the development of the questionnaire. In addition the questionnaire was distributed to five patients. This pilot study showed that patients had no difficulties to fill in the questionnaire and only minor changes had to be made.

The Hospital Anxiety and Depression Scale (HADS) was used to investigate degrees of anxiety and depression [13]. The HADS is a self-reported instrument and consists of 14 questions, 7 relating to anxiety and 7 to depression. Each multiple-choice question has 4 response categories, with a possible score of 0-3. Responses reflect the patient's emotional state during the preceding week. A total score of 7 or less of the maximum of 21 in each category indicates non-cases, 8 to 10 indicates doubtful cases, and 11 or above indicates definite anxiety or depression [13].

The Impact of Event Scale (IES) was also used. It is a self-reported instrument assessing current subjective distress [14]. The IES measures reactions to a specific stressor, in this case defined as concern about the heart operation. The questionnaire consists of 15 items, discriminating between 8 questions related to avoidance distress (range 0-40 for total score) and 7 questions related to intrusion distress (range 0-35 for total score). Responses reflect distress for the preceding week. The level of distress is considered to be low if the total score is 8 or less, medium at 9 to 19 and high at 20 or above.

Statistical analysis

For comparison of the proportion of Yes and No answers in 2 groups, Fisher's exact test was used, and for comparison of more than 2 groups, the Chi-square test was used. For graded answers and other ordinal scales, the Mann-Whitney U-test was used for comparison of 2 groups and the Kruskal-Wallis test for comparison of more than 2 groups. Spearman's test was used when assessing the correlation between 2 variables measured on an ordinal scale. The analyses were made with help of the SPSS software (SPSS Inc. Chicago, Il, USA). The chosen level for statistical significance was $p < 0.05$. All significance testing was two-tailed.

RESULTS

A total of 338 patients consented to participate and were enrolled in the study. The response rate to the first questionnaire was 83% (n=182) in the intervention group and 73% (n=156) in the control group. A flow chart of the trial profile is shown in Fig. 1. Socio-demographic data and other characteristics of the patients are listed in Table 1.

Experience of the information

Results from the preoperative questionnaire are given in Tables 2 and 3. Preoperatively, awareness of the legal right to information about complications was significantly higher in the intervention group than in the control group (p<0.001) (Table 2).

There was no significant difference between the groups regarding whether the patients wanted to know as much as possible or nothing at all about complications. Patients in the intervention group experienced to a significantly higher degree that they had the possibility to call to the nurse at the clinic where the heart surgery was to take place (84% versus 63% for the intervention and control groups, respectively; p=0.004). Thirty-nine percent of the patients in the control group called the nurse at the clinic compared to 28% in the intervention group, but the difference was not statistically significant (p=0.065) (Table 2).

Preoperatively, patients in the intervention group were significantly more satisfied with the written information about both common and rare complications (p<0.001) (Table 3). They were also more satisfied with the oral information about expected surgical outcome (p=0.010). More patients in the intervention group experienced a possibility to discuss the written information with their next of kin (p=0.058) (Table 3).

Preoperatively, patients in the control group with higher education were significantly more sceptical to the written information than those with lower education(p<0.001) and men were significantly more interested in receiving information than women (p<0.001). These differences were not found in the intervention group. In the intervention group, more patients did not want to know about possible complications (p=0.053) and women called the nurses at the clinic more often than men (p<0.001). These differences only existed in the intervention group.

Results from the postoperative questionnaire are given in Tables 4 and 5. Postoperatively, patients receiving extended information (intervention group) were significantly more satisfied with both the written and oral information about common and rare complications than patients in the control group (Table 4). The patients in the intervention group experienced that they could discuss alternative treatment methods with their surgeon to a significantly higher degree than patients in the control group (p=0.017) (Table 5). Most patients in both groups were satisfied with the information about expected surgical outcome (Table 4) and to a high degree experienced that the information was in accordance with their postoperative health (Table 5). Postoperatively, the younger patients (≤50 years) in the intervention group, but not in the control group, felt less satisfied with the oral information about rare complications than the older patients (>50 years) (p=0.029). Civil status had no significance for the results of any question either pre- or postoperatively in any group.

Anxiety and depression

There were no statistically significant differences between the groups for anxiety or depression, as measured by the HADS, either before or after the operation (Fig 2). Mean scores for anxiety and depression decreased after the surgery in both groups, in relation to pre-surgery values, but these differences were also not significant (Fig 2). A score of 8 on the HADS is recommended as a cut-off point for identifying potentially clinically important cases of anxiety or depression [13].

A total of 47 patients (30%) in the control group and 56 patients (31%) in the intervention group scored 8 or higher before surgery regarding anxiety compared to 20 patients (15%) in the control group and 32 patients (20%) in the intervention group 8 weeks after the operation. Regarding depression, a total of 29 patients (19%) in the control group and 30 patients (17%) in the intervention group scored 8 or higher before surgery, as compared with 17 patients (13%) in the control group and 19 patients (12%) in the intervention group 8 weeks after the operation.

The women in the intervention group had symptoms of definite anxiety to a significantly higher degree than the men before the operation (p=0.023). The women in the control group had symptoms of definite depression to a significantly higher degree than the men after the surgery (p=0.044). The higher the agreement between the information about expected result of the operation and postoperative health, the lower was the degree of anxiety and depression, both in the control group (p=0.036 and p<0.001 for anxiety and depression, respectively) and the intervention group (p=0.002 and p<0.001 respectively).

Avoidance and intrusion

There were no statistically significant differences between the groups for avoidance or intrusion distress, as measured by the IES (Fig 3). Mean scores for intrusion distress decreased after the surgery in both groups but the difference compared with pre-surgery values was not significant for either group. Mean scores for avoidance distress also decreased in both the intervention and the control group after surgery (not significant).

Before the operation, the women in both the intervention group and the control group had symptoms of avoidance distress to a higher degree than the men, p=0.028 and p=0.002, respectively. Eight weeks after the operation the situation was the same, ie, the women in both the intervention group and the control group had symptoms of avoidance distress to a higher degree than the men, p=0.012 and p=0.033, respectively.

Before the operation, the women in the intervention group had sympomts of intrusion distress to a higher degree than the men (p=0.017). The better the agreement between the information about expected result of the operation and postoperative health, the lower was the degree of symptoms in the intervention group (p=0.008).

DISCUSSION

During the preparatory work for this study, cardiac surgeons at the clinic were worried that the extended information to the patients was too detailed, describing several serious conditions that can appear in connection with all the necessary procedures taking place at a heart operation. It was speculated that this could have a strong negative impact on the patients, and could lead to impaired confidence between the responsible surgeon and the patient. Before questionnaires were distributed to the intervention group, a regional (southern part of Sweden), half-day information meeting was arranged at the hospital, to which cardiologists, general practitioners, anaesthesiologists, cardiac surgeons and nurses involved in the care of these patients were invited. The content of the extended information and the set-up of the study were presented. The viewpoints raised by the audience at this meeting were not all positive. It was thought that the detailed information could be frightening for the patient and that many patients would refuse to undergo the recommended and life saving treatment.

In contrast to the expressed fears, this study shows that the extended written information about complications in connection with heart surgery did not cause increased anxiety, depression or subjective distress, as measured with the HADS and IES. The mean values of the scores for anxiety and depression are congruent with the values for the normal Swedish population [15]. Furthermore, the patients in the intervention group were significantly more satisfied than the patients in the control group with all aspects of the information. They were more aware of the possibility to call the nurse at the clinic (even if they actually did so less often), and they experienced to a higher degree that they could discuss their illness and treatment methods with their surgeon.

Regarding the concern raised at the hospital meeting that patients would refuse surgery, a direct measurement of the number of patients refusing the operation due to the extended information could not be made. However, only 17% of all eligible patients in the intervention group did not reply to the primary questionnaire, as compared with 27% in the control group (Fig 1). After the introduction of the extended information, the cardiac surgeons found that they met much better prepared patients, leading to more useful discussions before the operation. The warnings and negative attitudes towards the content of the extended information have ceased.

In the present study, 89% of the patients in the intervention group and 68% in the control group were aware of their legal right to information about the treatment, expected outcome and risk of complications. The majority of patients (69% and 72% for control and intervention groups, respectively) waiting for cardiac surgery preferred to receive information about the risks. According to a British study from 2001, 58% of cardiac surgery patients wanted complete information about risks (42% did not want any information at all) [3]. In older studies from Scotland and Canada (1991) and Australia (1994), where patients were asked about their desire for information about anaesthesia before general surgery, 43%, 72% and 92%, respectively, preferred to know about all possible risks of complications [11, 12]. The divergence in results may reflect differences in culture, trust in the health care system, level of paternalism and differences in the types of surgery. It can be speculated that patients are better informed today, both by health care personnel and by means of the wide access to all types of information on the Internet. Today it is well established that patients want to be involved in decisions regarding their care [16]. Yet it is possible that we give the patient adequate information about the treatment but fail to mention the risk of complications, with the intention to have a calm and satisfied patient. An obvious problem with this approach is that if complications occur, they will come as more of a shock to the patients and their next of kin than if they had been informed of the risks in advance.

In the present study the patients in the intervention group experienced to a higher degree that they could discuss alternative treatment methods with their surgeon than the patients in the control group, but the younger patients in the intervention group were postoperatively less satisfied with the oral information about rare complications than the older patients. This is congruent with findings by Lonesdale & Hutchison and Farnill, who reported that younger patients desired to know more about complications then older patients [11, 12]. This may indicate that younger patients want to play a more active role in their care than older patients. Whether younger patients are more prone to discuss individual risks than older patients has not been the topic of this study, but regardless of age, it is known that individual risk varies with the severity of the condition, mode of treatment, and comorbidity [3].

Preoperatively, patients in the intervention group were significantly more satisfied with all aspects of the information than patients in the control group. More patients in the intervention group also expressed that they had a very good possibility to discuss the information about risk with their next of kin. This was also shown in an intervention study by Edwards [17], where patients preoperatively received a leaflet with information on complications. It was found that the patients who received the leaflet were significantly more satisfied than the patients who did not. The Edwards study also showed that the leaflets were read by the patients and their next of kin about five times before the surgery. The next of kin play a crucial role for patients waiting for cardiac surgery, and it has been shown that they experience support when they receive information and attention, and are involved in the care [18].

Even if a significant difference could not be detected between the groups for symptoms of anxiety, depression and distress in the present study, using the HADS and IES, it was found that particularly women need support and encouragement from the health-care personnel, both before and after the surgery. It is true that Bengtson et al [19] reported more nervous reactions by men waiting for coronary revascularization, as compared with women, but the women were more frequently treated with diuretics, and reported a higher frequency of various cardiovascular symptoms, including chest pain, dyspnoea and more sleeping disorders. The women in the control group in the present study were significantly less interested in receiving information, but in the intervention group, the women made telephone calls to the nurse significantly more often than the men. However, regardless of gender, it has been shown that uncertainty about the future and fear were experienced as the major disruptive symptoms by patients waiting for cardiac surgery [20].

The present study did not study the best time for the patients to receive information about risks, but the need for information begins when illness starts and illness does not start when the patient meets the health care personnel at the hospital [21], e.g. the surgeon. To merely relay written information to the patients is not enough. One solution is to set up patient education web sites, with easy access to experienced nurses or other health care professionals. Personal communication can be arranged by supplying patients with personal passwords to interactive web-sites, or via e-mail, mail or telephone. A programme for information, pre-surgical advice and support could also include a nurse-led pre-admission clinic. The nurse could detect and take care of problems and, when needed, mediate contact to various other specialists. A previous study showed that nurse-led web-based education and support through e-mail was useful to patients waiting for heart surgery [22], and another study highlighted the advantages of a web-based patient information system for patients waiting for cardiac surgery [23].

One limitation of this study is that the patients were not randomized. The reason for this is that it would be difficult to mix control and intervention patients in the same ward at the same time, because patients meet and discuss the information they have been given with each other. Another possibility would have been to use one ward for the control group and one for the intervention group. However, as there are different responsible surgeons in the two wards, and some degree of specialization regarding diagnosis in the different wards, this strategy was not optimal. The two experienced nurses answering all phone calls from the patients were the same, as were all surgeons and most of the nurses in the wards when the control and intervention groups were being studied. The patients were not aware that the intention of the study was to investigate the response to different types of information. Both groups received identical questionnaires, but different information. Another limitation of the study could be the generalizability to other countries. Some countries have laws regulating patients' rights to information not only about the treatment and care but also the potential risks, and they require verification of consent in the form of a signature from the patient. In Sweden there is no such law. Furthermore, the written extended information was not adapted for minority groups, e.g. persons with dyslexia or visual handicaps, and those unable to read Swedish.

In summary, the risk of complications in connection with cardiac surgery is not negligible and comprehension of these risks is related to the information provided to the patient before the surgery. Provision of extended information describing most of the possible complications did not have any negative effects on the patients. The patients receiving the extended information were more satisfied and experienced to a higher degree that they could discuss alternative treatment methods with the surgeon. The health care organization must supply the patients with detailed information about their disease and different possible treatment methods, including information about the risk of complications. It must also be possible for the patients to choose not to have this information. If the patients and their next of kin are well informed, this can constitute the basis for fruitful conversations between them and the health care professionals, and they can be better prepared if complications occur. Ever since the collection of data for this study was completed, the extended information is sent to all elective patients on the waiting list for cardiac surgery at the study site.

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REFERENCES

[1] Fruitman DS, MacDougall CE, Ross DB. Cardiac surgery in octogenarians: can elderly patients benefit? Quality of life after cardiac surgery. Ann Thorac Surg 1999: 68: 2129-35.

[2] Avery GJ, 2nd, Ley SJ, Hill JD, Hershon JJ, Dick SE. Cardiac surgery in the octogenarian: evaluation of risk, cost, and outcome. Ann Thorac Surg 2001: 71: 591-6.

[3] Beresford N, Seymour L, Vincent C, Moat N. Risks of elective cardiac surgery: what do patients want to know? Heart 2001: 86: 626-31.

[4] Kennelly C, Bowling A. Suffering in deference: a focus group study of older cardiac patients' preferences for treatment and perceptions of risk. Qual Health Care 2001: 10 Suppl 1: i23-8.

[5.] Jonsdottir H, Baldursdottir L. The experience of people awaiting coronary artery bypass graft surgery: the Icelandic experience. J Adv Nurs 1998: 27: 68-74.

[6] Ivarsson B, Larsson S, Sjöberg T. Patients' experiences of support while waiting for cardiac surgery. A critical incident technique analysis. Eur J Cardiovasc Nurs 2004: 3: 183-91.

[7] Vohra HA, Ledsham J, Vohra H, Patel RL. Issues concerning consent in patients undergoing cardiac surgery-the need for patient-directed improvements: a UK perspective. Cardiovasc Surg 2003: 11: 64-9.

[8] Shinebourne E, Buch A. For paternalism in the doctor-patient relationship. In Gillon R, editors. Principles of health care ethics. New York: Wiley, 1994: 399-408.

[9] Altman D. Practical statistics for medical research. London: Chapman and Hall, 1999.

[10] Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? BMJ 1999: 318: 318-22.

[11] Lonsdale M, Hutchison GL. Patients' desire for information about anaesthesia. Scottish and Canadian attitudes. Anaesthesia 1991: 46: 410-2.

[12] Farnill D, Inglis S. Patients' desire for information about anaesthesia: Australian attitudes. Anaesthesia 1994: 49: 162-4.

[13]. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983: 67: 361-70.

[14] Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. Psychosom Med 1979: 41: 209-18.

[15] Lisspers J, Nygren A, Söderman E. Hospital Anxiety and Depression Scale (HAD): some psychometric data for a Swedish sample. Acta Psychiatr Scand 1997: 96: 281-6.

[16. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol 1992: 45: 941-50.

[17] Edwards MH. Satisfying patients' needs for surgical information. Br J Surg 1990: 77: 463-5.

[18] Ivarsson B, Sjöberg T, Larsson S. Waiting for cardiac surgery - support experienced by next of kin. Eur J Cardiovasc Nurs 2004: In press.

[19] Bengtson A, Karlsson T, Herlitz J. Differences between men and women on the waiting list for coronary revascularization. J Adv Nurs 2000: 31: 1361-7.

[20] Bengtson A, Herlitz J, Karlsson T, Hjalmarson Å. Distress correlates with the degree of chest pain: a description of patients awaiting revascularisation. Heart 1996: 75: 257-60.

[21] Morse J, Johnson, J. The illness experience: dimensions of suffering. Newbury Park: SAGE, 1991.

[22] Scherrer-Bannerman A, Fofonoff D, Minshall D, Downie S, Brown M, Leslie F, McGowan P. Web-based education and support for patients on the cardiac surgery waiting list. J Telemed Telecare 2000: 6 Suppl 2: S72-4.

[23] Hassling L, Babic A, Lönn U, Casimir-Ahn H. A Web-based patient information system--identification of patients' information needs. J Med Syst 2003: 27: 247-57.

Table 1

Demographic data and other characteristics at baseline of the patients in the intervention and control groups (n = 338).

	Control (n=156)	Intervention (n=182)
Men (n)	113 (72%)	130 (71%)
Age		
Mean ± SD	66±11	66±10
Median (range)	68 (25-83)	68 (39-83)
Women (n)	43 (28%)	52 (29%)
Age		
Mean ± SD	70 ± 10	66 ± 12
Median (range)	72 (43-84)	66 (38-91)
Civil status:		
Single (n)	43 (28%)	39 (22%)
Married/Cohabiting (n)	112 (72%)	142 (78%)
Missing	1	1
Education:		
Elementary school	83 (53%)	82 (45%)
High school	57 (37%)	63 (35%)
College/university	16 (10%)	37 (20%)
*Occupation**:		
0 Armed forces	2 (1%)	5 (3%)
1 Legislators, senior officials and managers	14 (9%)	15 (9%)
2 Professionals	15 (10%)	36 (21%)
3 Technicians and associate professionals	21 (14%)	18 (10%)
4 Clerks	6 (4%)	12 (7%)
5 Service workers and shop sales workers	31 (20%)	18 (10%)
6 Skilled agricultural and fishery workers	14 (9%)	20 ((12%)
7 Craft and related trades workers	23 (15%)	24 (14%)
8 Plant and machine operators and assemblers	16 (11%)	17 (10%)
9 Elementary occupations	10 (7%)	6 (4%)
Missing	4	11
Planned cardiac surgery:		
CABG† (n)	89 (57%)	100 (55%)
CABG reoperation (n)	4 (3%)	6 (3%)
Valve (n)	10 (6%)	25 (14%)
Valve reoperation (n)	1 (1%)	3 (2%)
CABG + valve (n)	38 (24%)	37 (20%)
CABG + valve reoperation (n)	4 (3%)	3 (2%)
Another (n)	10 (6%)	8 (4%)
Waiting time (days):		
Mean ± SD	119 ± 81	115 ± 92
Median (range)	96 (4-517)	74 (15-630)

*Occupation is grouped according to the Swedish Standard Classification of Occupations 1996 (SSYK 96). www.scb.se/grupp/ekonomi/dokument/englishsummary.doc

† CABG = Coronary artery bypass grafting

Table 2

Preoperative standpoint and handling by the patients in the intervention and control groups.

	Yes (%)	No (%)	Don´t know (%)	p-value*
Aware of legal right to information about complications				
Control group (n=154)	67.5	18.8	13.6	
Intervention group (n=181)	89.0	6.1	5.0	<0.001
Wishes to know as much as possible				
Control group (n=154)	68.8	18.8	12.3	
Intervention group (n=177)	71.8	20.3	7.9	1.000
Wishes not to be informed about complications				
Control group (n=148)	16.2	72.3	11.5	
Intervention group (n=173)	11.0	80.3	8.7	0.139
Possibility to contact the nurse to talk about possible complications				
Control group (n=144)	63.2	18.8	18.1	
Intervention group (n=173)	84.4	9.2	6.4	0.004
Phoned to the nurse at the clinic				
Control group (n=112)	39.3	58.9	1.8	
Intervention group (n=160)	28.1	70.6	1.3	0.065
Received help from the nurse at the clinic				
Control group (n=53)	69.8	17.0	13.2	
Intervention group (n=60)	66.7	16.7	16.7	1.000

*p-values for comparing the proportion of Yes- and No-answers using Fisher’s exact test.

Table 3

Experiences of preoperative satisfaction with the information given to the patients in the intervention and control groups.

	Very bad (%)	Bad (%)	Not good, not bad (%)	Good (%)	Very good (%)	p-value*
Written information about common complications						
Control group (n=142)	0.0	4.2	23.9	64.8	7.0	
Intervention group (n=179)	0.6	0.0	3.4	72.6	23.5	<0.001
Written information about rare complications						
Control group (n=137)	0.7	10.9	37.2	48.2	2.9	
Intervention group (n=178)	0.6	0.6	6.7	71.9	20.2	<0.001
Oral information about expected surgical outcome						
Control group (n=142)	1.4	6.3	22.,5	64.1	5.6	
Intervention group (n=173)	2.3	5.2	13.3	59.0	20.2	0.010
Possibility to discuss the written information with next of kin						
Control group (n=143)	4.2	4.2	21.7	44.8	25.2	
Intervention group (n=177)	0.6	8.5	11.9	46.3	32.8	0.058

*p-values for comparing graded answers in the two groups using Mann-Whitney test.

Table 4

Postoperative satisfaction with the information given to the patients in the intervention and control groups.

	Very bad (%)	Bad (%)	Not good, not bad (%)	Good (%)	Very good (%)	p-value*
Written information about common complications						
Control group (n=134)	1.5	4.5	23.1	60.4	10.4	
Intervention group (n=161)	1.2	0.6	7.5	62.7	28.0	<0.001
Oral information about common complications						
Control group (n=135)	1.5	7.4	19.3	56.3	15.6	
Intervention group (n=159)	3.8	1.3	14.5	50.3	30.2	0.004
Written information about rare complications						
Control group (n=133)	3.0	13.5	37.6	39.8	6.0	
Intervention group (n=160)	1.9	0.6	17.5	56.3	23.8	<0.001
Oral information about rare complications						
Control group (n=134)	3.0	14.9	32.1	41.8	8.2	
Intervention group (n=155)	5.2	4.5	23.2	43.2	23.9	<0.001
Information about expected surgical outcome						
Control group (n=136)	0.0	4.4	22.1	55.9	17.6	
Intervention group (n=156)	3.8	2.6	14.1	55.1	24.4	0.147

*p-values for comparing graded answers in the two groups using Mann-Whitney test.

Table 5

Postoperative experience of the information given to the patients in the intervention and control groups.

	Not at all (%)	To a low degree (%)	Not low, not high degree (%)	To a high degree (%)	To a very high degree (%)	p-value*
Did you experience that the surgeon made sure that you understood the information about possible complications correctly?						
Control group (n=130)	5.4	9.2	33.1	41.5	10.8	
Intervention group (n=157)	3.2	3.8	31.8	47.8	13.4	0.073
Did you experience that you could discuss alternative treatment methods with your surgeon?						
Control group (n=130)	11.5	13.8	30.0	35.4	9.2	
Intervention group (n=150)	8.7	8.7	26.7	37.3	18.7	0.017
Do you experience that the information about the expected surgical result has been in accordance with your health after the operation?						
Control group (n=132)	2.3	7.6	27.3	47.7	15.2	
Intervention group (n=151)	4.0	4.0	20.5	51.0	20.5	0.105

*p-values for comparing graded answers in the two groups using Mann-Whitney test.

Legend to figures

Fig. 1 Flow of patients through the study.

Fig. 2 Levels of anxiety (upper panel) and depression (lower panel) as measured by the Hospital Anxiety and Depression Scale (HADS) of the patients in the control and intervention groups before and after the heart operation. The broken and unbroken lines in each box indicate the mean and median values, respectively. The lower and upper levels of the box indicate 25th and 75th percentiles, respectively. The error bars indicates the 5th and 95th percentiles.

Fig. 3 Levels of intrusion distress (upper panel) and avoidance distress (lower panel) as measured by the Impact of Event Scale (IES) of the patients in the control and intervention groups before and after the heart operation. The broken and unbroken lines in each box indicate the mean and median values, respectively. The lower and upper levels of the box indicate 25th and 75th percentiles, respectively. The error bars indicates the 5th and 95th percentiles.

Fig 1

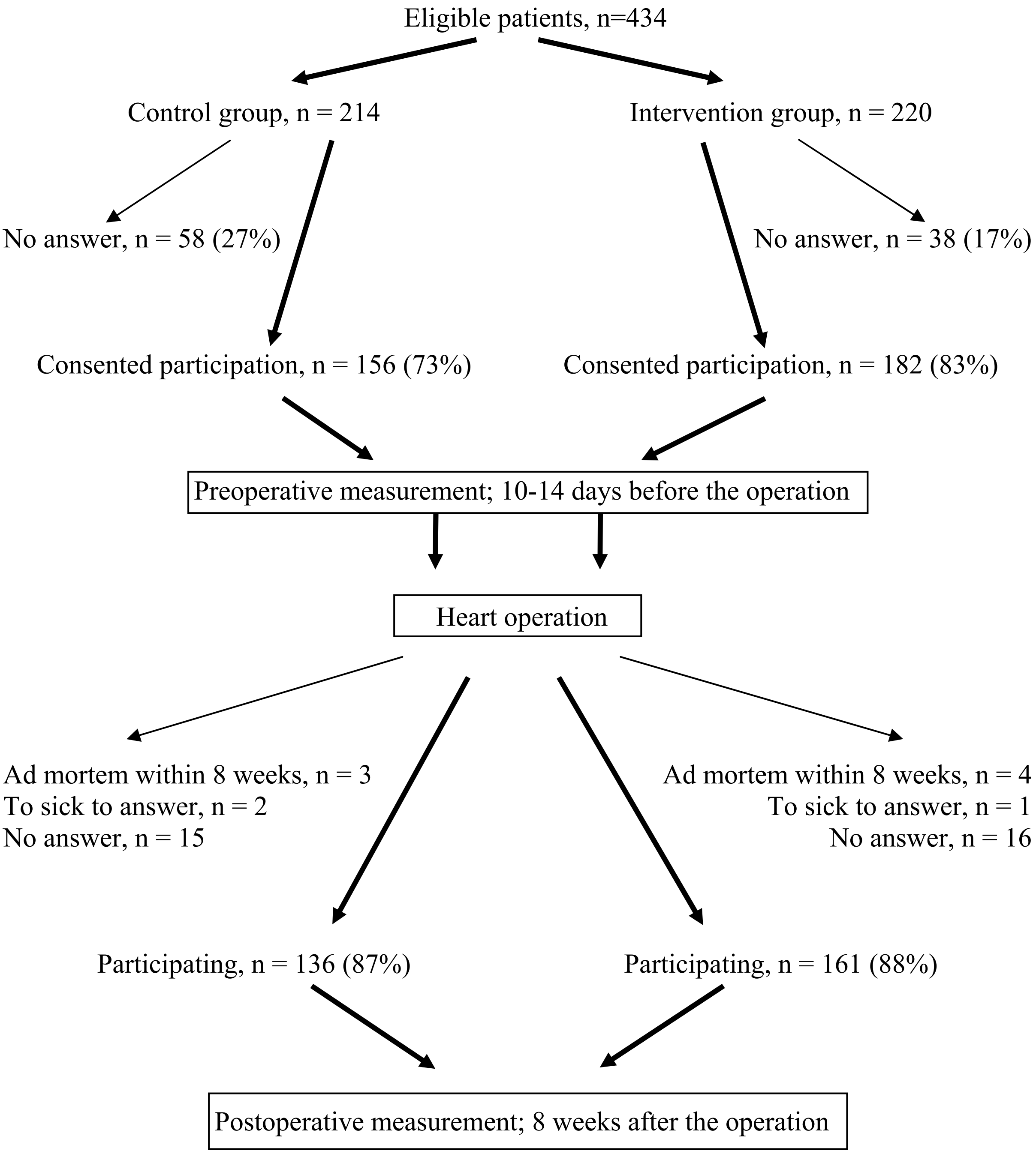

Eligible patients, n=434
Control group, n = 214
Intervention group, n = 220
No answer, n = 58 (27%)
No answer, n = 38 (17%)
Consented participation, n = 156 (73%)
Consented participation, n = 182 (83%)
Preoperative measurement; 10-14 days before the operation
Heart operation
Ad mortem within 8 weeks, n = 3
To sick to answer, n = 2
No answer, n = 15
Ad mortem within 8 weeks, n = 4
To sick to answer, n = 1
No answer, n = 16
Participating, n = 136 (87%)
Participating, n = 161 (88%)
Postoperative measurement; 8 weeks after the operation

Fig 2.

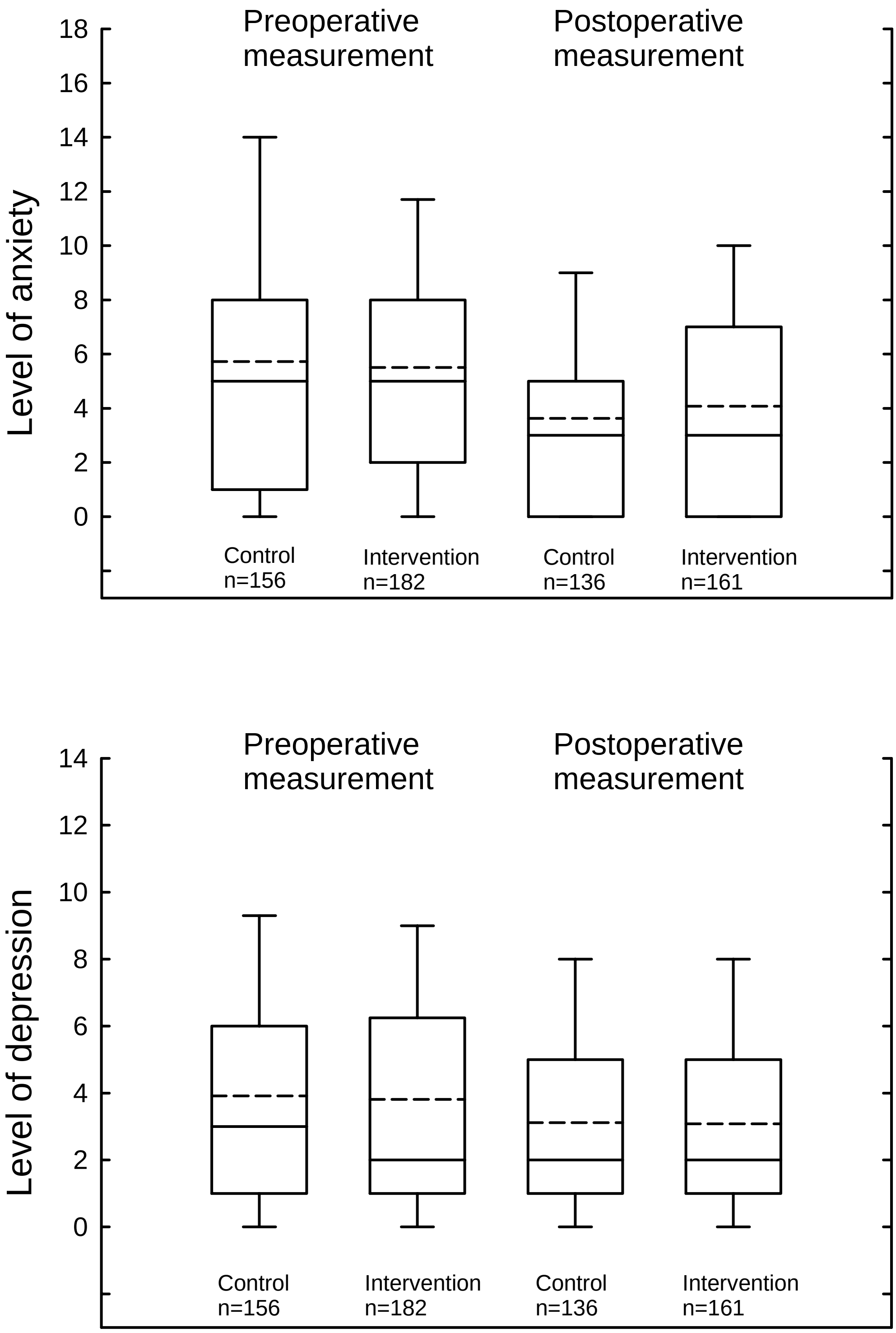
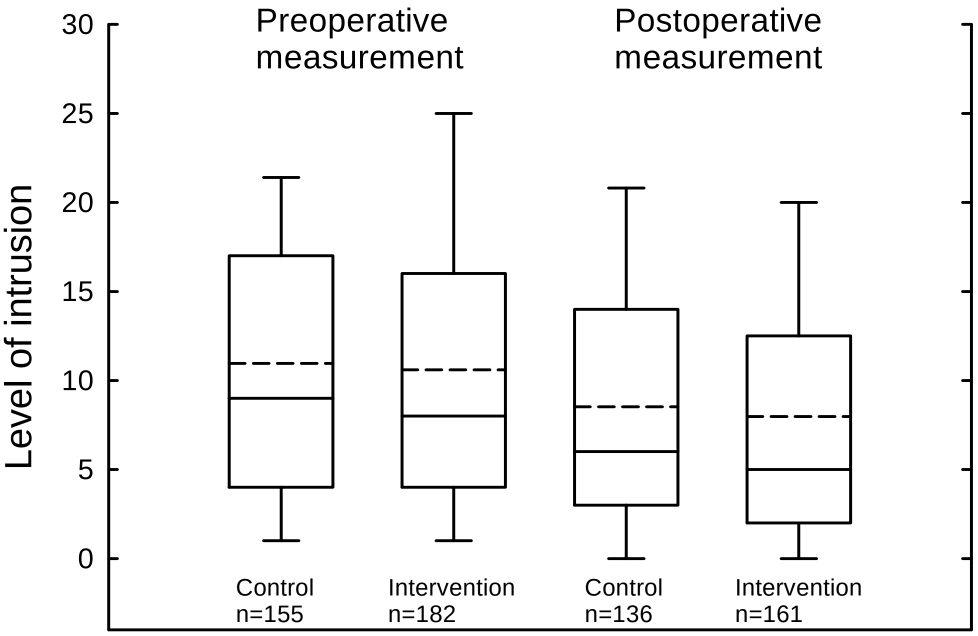
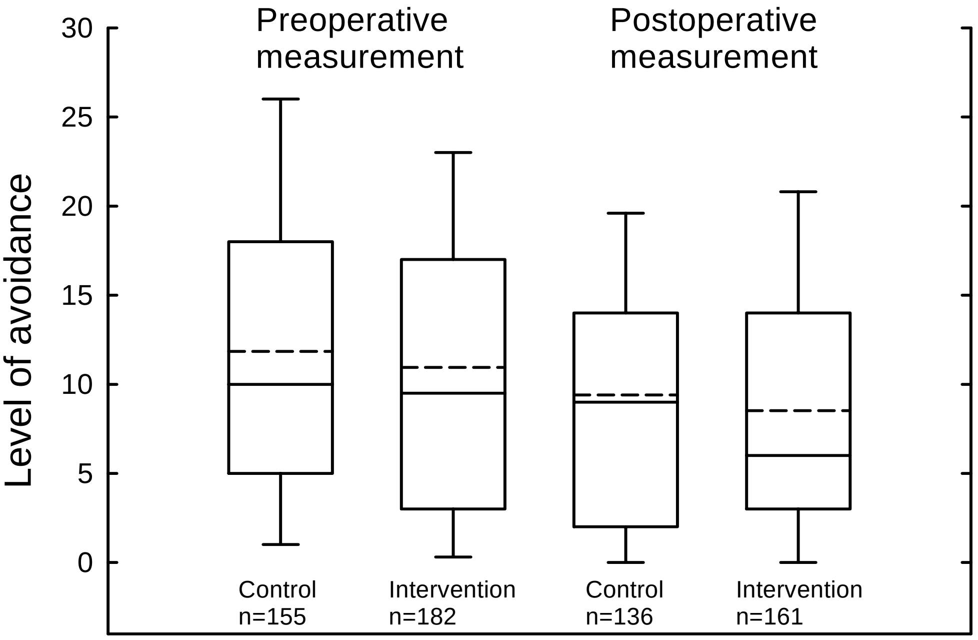

Preoperative measurement
Postoperative measurement
Level of anxiety
18
16
14
12
10
8
6
4
2
0
Control n=156
Intervention n=182
Control n=136
Intervention n=161
Preoperative measurement
Postoperative measurement
Level of depression
14
12
10
8
6
4
2
0
Control n=156
Intervention n=182
Control n=136
Intervention n=161

Fig 3


Preoperative measurement
Postoperative measurement
Level of intrusion
30
25
20
15
10
5
0
Control n=155
Intervention n=182
Control n=136
Intervention n=161


Preoperative measurement
Postoperative measurement
Level of avoidance
30
25
20
15
10
5
0
Control n=155
Intervention n=182
Control n=136
Intervention n=161