

SPICI-studien

Study of Patient Information after Coronary Intervention

A scientific survey of how coronary patients treated with Percutan Coronar Intervention(PCI) interpret the information given at hospitals, what they think caused the coronary disease and how they view the possibilities of influencing their condition.



The survey is funded and implemented by the Swedish Heart and Lung Association in collaboration with Linneaus University, Uppsala University, Swedish PCI AB, Falu Hospital, Mid Sweden University and The Swedish Research Institute for Disability Policy AB (HANDU).

Swedish Heart and Lung Association

Box 9090 • SE 102 72 Stockholm

+46 (0)8-55 606 206 • +46 (0)8-668 23 85



HJÄRT- OCH LUNGSJUKAS RIKSFÖRBUND

Reflection

There is strong evidence that points to the significance of a person's lifestyle in the progression of coronary diseases.

Furthermore, today there are well-documented measures of secondary prevention after a heart attack that reduce the risk of relapse and death, and improve the quality of life.

The number of patients taking part in hospitals' rehabilitation programmes, so-called Heart Schools and heart exercises, is alarmingly few. According to the latest survey presented by SEPHI, national quality register, only 3 out of 10 patients participate.

SEPHIA shows further that only 2 out of 10 patients reach all goals set for exercise, smoking, blood pressure and blood fats, twelve months after the heart occurrence.

Lately, Sweden's cardiac care and the Swedish Heart and Lung Association have wondered - why?

We now know the answer!

The majority of patients treated with balloon angioplasty (PCI) interpret the information they receive at hospital as meaning that they are in good health.

The majority also believe that they cannot prevail over the disease because it is inherited, caused by age and stress.

Swedish cardiac care needs to look at how patients are being informed. It is facing a big, new, and for heart patients, considerable challenge.

Summary

The survey is based on response from 1073 patients treated with balloon angioplasty performed between 1st March 20011 and 13th January, 2012. 29 hospitals are included in the survey.

Patients who answered the questionnaire are an average 66 years of age. The youngest is 34, the oldest 89.

The average woman is 67, the average man slightly younger at 65. The majority, 76 percent, experienced balloon angioplasty for the first time. Emergency surgery was performed in 86 percent of cases.

A majority of 57 percent interpreted the information given them by the staff who performed the operation as meaning they are in good health.

67 percent feel well on their follow-up visit to hospital 6-8 weeks after surgery.

Seven out of ten, 71 percent, did *not* partake of the information in connection with angioplasty with a close relative present. And more than six out of ten patients, 63 percent, did not have a close relative with them on the follow-up visit for advice as how to prevent future cardiac trouble.

57 percent of patients give hereditary reasons for their cardiovascular disease. 45 percent say stress and 41 percent say age. Hence, factors that cannot be influenced. Less than three out of ten thought the explanation was habits of exercise, smoking and diet.

The majority, 60 percent, have not improved their diet and 69 percent have not improved their exercise habits.

Eight out of ten, 80 percent, were given information about the hospital Heart School. It is mainly the oldest, 75 plus, who say they did not receive any information about the hospital Heart School, 30 percent.

Six out of ten, 58 percent, say that they have not been told that a close relative may also attend the hospital Heart School

One out of ten, 11 percent, say they perceive themselves as being very overweight while calculated BMI indexes show that double as many, 21 percent, are very overweight.

Younger people, up to 60 years of age, are more likely to feel stressed and tired out, run-down, depressed etc. Four out of ten, 39 percent, of people up to the age of 60 feel stressed several times a week, or even every day.

A fifth, 18 percent of the entire group of patients, have, on their follow-up visit to hospital, been offered stress management by taking part in a programme that helps reduce stress.

Over a third, 35 percent, say they wish they had had more information from healthcare staff about how to avoid and prevent future heart trouble. However, two thirds, 65 percent, are quite happy with the information they have been given.

In six out of ten cases, 61 percent, the only source of information about their illness was healthcare staff, while 37 percent have also received, or looked for, information elsewhere.

Description of the Survey

Background

Strong evidence points to the significance of lifestyle in developing cardiovascular disease. Today we also have well-documented measures for secondary prevention, following coronary thrombosis, that reduce the risk of relapse and death and improve the quality of life.

In The Interheart Study¹, 15000 heart patients from 52 countries were compared to persons without heart conditions, and shows that more than 90 percent of all coronary thromboses in a population could be explained by lifestyle factors such as smoking, poor diet, lack of physical activity and psychosocial stress, together with biological factors such as high blood fats, high blood pressure, central obesity and diabetes - all of which in their own way are related to lifestyle.

The very significant role lifestyle plays in the risk of relapse, was recently shown in a study of almost 19000 patients suffering from coronary thrombosis² in 41 countries. The study showed that drugs cannot replace lifestyle. The risk of recurrence of cardiovascular disease was almost four times lower among patients who had changed their lifestyle, compared to those who had not succeeded in changing their habits in a more heart-friendly direction. Good advice and information to patients is therefore one of the most significant parts of healthcare after an emerging cardiovascular operation – PCI, Percutan Coronar Intervention.

The number of patients taking part in hospital rehabilitation programmes, so-called Heart Schools and heart exercise, is alarmingly few. According to the survey presented by SEPHI, national quality register, in 2008 only 44 percent took part in Heart Schools and only 42 percent participated in physical training.

At The Heart and Lung Association's meetings with members with heart disease who have undergone PCI, also called balloon angioplasty, it has emerged that many consider themselves in good health and do not need to indulge in lifestyle changes. They have no symptoms of angina and in connection with the PCI operation feel they have been led to believe that their cardiovascular condition is rectified and their blood flow is normal and will continue to be so. They found the

¹Salim Yusuf, Steven Hawken, Stephanie Ôunpuu et al. Effect of potentially modifiable risk factors associated with myocardial infarction in 52 countries(the INTERHEART study): case-control study. *Lancet* 2004; 364:937-52

²Clara K Chow, Sanjit Jolly, Purnima Rao-Melacini et al. Association of Diet, Exercise and Smoking Modification With Risk of Early Cardiovascular Events after Acute Coronary Syndromes. *Circulation*. 210;121:750-758.

actual PCI operation painless and unspectacular, followed by a short stay at hospital. This attitude is corroborated by coronary nurses as the reason why many patients choose not to partake in hospital secondary preventive programmes.

Patients who have undergone PCI treatment are seen to differ from those who have had by-pass surgery, where the operation is decidedly more stressful. By-pass patients are also more motivated to change their lifestyle.

Aim

The aim of the survey is to map lifestyle behaviour, knowledge and attitudes towards lifestyle, and risk factors of patients who have been treated with balloon angioplasty, PCI. The aim is also to investigate how these patients have understood the information given to them by healthcare staff at hospitals.

The survey will form the basis for better heart care after PCI where lifestyle is more distinctly highlighted. By way of an action plan, the results will be referred back to healthcare in order, together with hospitals, to contribute to improvements of existing programmes for prevention and heart rehabilitation.

Target group

The survey includes patients with coronary diseases who have undergone emergency or planned balloon angioplasty PCI.

Method

The survey consists of a written questionnaire. The questionnaire and the terms of the study have been approved by The Ethics Committee.

Data was collected between 1st March 2011 and 13th January 2012 by:

The Swedish Research Institute for Disability Policy (HANDU AB)

(<http://www.handu.se>)

The Heart and Lung Association sent a letter to the chief executives of selected hospitals requesting their participation in the survey.

The questionnaires were distributed, together with information, to coronary nurses at the 29 hospitals included in the survey. The nurses were asked to hand out the questionnaire in connection with the patients' follow-up visits about 6-8 weeks after PCI treatment.

The patients took their questionnaire home, together with instructions, in order to answer without disturbances. They then sent the questionnaire back anonymously, in the envelope provided, to The Heart and Lung Association. There was a sticker on the envelope that revealed from which hospital the answer came. This was to make it possible to account for results and any analysis by district and and/or hospital if requested.

Patients have been given the opportunity to express their interest in having the results of the questionnaire sent home to them when the survey is presented.

The questionnaire answers will be presented and discussed at a seminar for the hospitals that have taken part.

The Questionnaire

The questionnaire is divided into various areas of questions.

- Firstly the patient's background and questions concerning balloon angioplasty.
- One area is aimed at the situation in connection with PCI treatment, i.e. how the patient interpreted the information given by the hospital (PCI department) when the balloon angioplasty was done.
- Another area of focus is how the patient interpreted the information given by the hospital staff at the heart reception/heart ward at the time of their follow-up visit after the operation.
- Questions concerning participation in hospital exercise groups and Heart Schools.
- The questionnaire includes questions about lifestyles, such as diet, exercise and smoking.
- Questions concerning patients' mental well-being.
- One area of questions touched on how a person, in general, understands information.
- Lastly at the end of the questionnaire the patient is asked whether he or she wishes to advise or recommend anything to the healthcare staff.

Selecting the hospitals

There are 29 hospitals in Sweden that perform PCI. Ten of these have been randomly chosen from regions divided into seven.

Hospitals from these towns that were approached and have taken part in the survey:

Malcolm (Trelleborg, Ystad), **Karlskrona** (Karlshamn), **Halmstad** (Varberg), **Östra sjukhuset i Göteborg** (Mölndal, Kungälv), **Linköping** (Motala, Norrköping) **Eskilstuna** (Nyköping, Katrineholm), **KS i Solna** (KS/Huddinge, Danderyd, Norrtälje) **Akademiska i Uppsala** (Enköping), **Falun** (Avesta, Ludvika, Mora), and **Umeå** (Skellefteå, Lycksele).

Selecting the patients

A calculated total of 1800 patients were to be asked to participate in the survey. This is the equivalent of the around 18000 patients a year that are treated with PCI. While the survey was ongoing, all patients were given the questionnaire by the coronary nurse at their follow-up visit. Patients who were unable to take in the information were not given the questionnaire.

An estimate was made of how many PCI patients at the hospitals had taken part in the survey. The hospitals were divided into "large", "middling large" and "county regional hospitals". This was to facilitate the handling of questionnaires at the various hospitals. Large hospitals were given 144 questionnaires each, middling large hospitals 70 questionnaires and county regional hospitals 30 questionnaires to hand out to patients.

Response Rate

The survey's response rate is 69 percent. The questionnaire was answered anonymously hence no reminders could be sent. Some hospitals have, however, contacted their patients and reminded them to send off the questionnaire.

A total of 1073 patients have sent in their answers.

Response rate per hospital and total percentage of survey

| Hospital location | QUESTIONNAIRES HANDED OUT | ANSWERS TO QUESTIONNAIRES | RESPONSE RATE per HOSPITAL % | NUMBER CURRENT ANSWERS FOR SURVEY | RESPONSE RATE IN SURVEY'S RESULTS % |
|-----------------------------|---------------------------|---------------------------|------------------------------|-----------------------------------|-------------------------------------|
| Akademiska Hospital Uppsala | 124 | 102 | 80 | 99 | 80 |
| Avesta | 30 | 22 | 73 | 22 | 73 |
| Danderyd | 70 | 47 | 67 | 47 | 67 |
| Enköping | 30 | 20 | 67 | 20 | 67 |
| Eskilstuna | 70 | 47 | 67 | 47 | 67 |
| Falun | 70 | 43 | 61 | 43 | 61 |
| Halmstad | 70 | 49 | 70 | 49 | 70 |
| Huddinge KS | 72 | 47 | 65 | 46 | 64 |
| Karlskrona | 45 | 32 | 71 | 31 | 69 |
| Karlshamn | 30 | 26 | 87 | 26 | 87 |
| Katrineholm | 30 | 20 | 67 | 19 | 63 |
| Kungälv | 30 | 20 | 67 | 20 | 67 |
| Linköping | 132 | 93 | 70 | 93 | 70 |
| Ludvika | 30 | 20 | 67 | 20 | 67 |
| Lycksele | 30 | 23 | 77 | 23 | 77 |
| Malmö MAS | 144 | 61 | 42 | 58 | 40 |
| Mora | 30 | 19 | 63 | 19 | 63 |
| Motala | 30 | 19 | 63 | 19 | 63 |
| Mölnadal | 46 | 27 | 59 | 27 | 59 |
| Norrköping | 70 | 63 | 90 | 63 | 90 |
| Norrtälje | 30 | 21 | 70 | 21 | 70 |
| Nyköping | 30 | 20 | 67 | 20 | 67 |
| Skellefteå | 30 | 21 | 70 | 21 | 70 |
| Solna KS | 58 | 39 | 67 | 39 | 67 |
| Trelleborg | 30 | 18 | 60 | 18 | 60 |
| Umeå | 116 | 72 | 62 | 62 | 53 |
| Varberg | 30 | 24 | 80 | 24 | 80 |
| Ystad | 30 | 21 | 70 | 21 | 70 |
| Östra Göteborg | 89 | 55 | 61 | 52 | 58 |
| Unknown hospital | | 4 | | 4 | |
| Total | 1626 | 1096 | 67 % | 1073 | 66 % |

THE SURVEY'S ORGANISATION

Research leader: Professor Joep Perk, cardiologist, Linneaus University, Kalmar

Project leader: Project leader Pelle Johansson, Heart and Lung Association

Reference group: Associate professor Kristina Hambreaus, cardiologist
Associate professor Roland Carlsson, cardiologist
Associate professor Jan Lisspers, psychologist
Associate professor Gunilla Burell psychologist

Analysis/statistics Irene J. Westerlund, HANDU AB

Research partners: Britt Bergh and Ingrid Allermo

The PCI survey is funded by The Heart and Lung Association.

Results

Answers from a total of 1073 PCI patients form the basis of the results, representing a result response of 69 percent.

The tables in this account show the answers in actual numbers of responding units and vertical percent, i.e. the sum of each column is 100 percent. However, depending on the rounding of margins, the sum can diverge slightly in percentage. Moreover, the sum is usually higher than 100 percent when respondents were able to give more than one answers.

Comments on the results are included in the course of the text and follow the order of the questionnaire, the questions asked are included in the tables' titles.

Questions about the background of those who have undergone treatment with balloon angioplasty (PCI)

Sex

Table 1. Sex, number and percentage distribution

| | Percent |
|--------|---------|
| Female | 26 |
| Male | 74 |

Total number of respondents: 1068 (99 percent of those who answered the questionnaire)

Education

Table 2. Education, number and percentage distribution

| | Total percentage |
|------------------------------|------------------|
| Primary school | 42 |
| Secondary school | 23 |
| College | 5 |
| University, higher education | 24 |
| <i>Other schools</i> | 7 |

Total number of respondents: 1065 (99 percent of those who answered the questionnaire)

Occupation

Table 3. Occupation, number and percentage distribution

| | Total percentage |
|---|------------------|
| Full-time/part-time work | 37 |
| Temporary activity or sickness compensation full-time/part-time | 2 |
| Study | 0 |
| Job seeker | 2 |
| Full-time early retirement due to illness | 4 |
| State pensioner | 57 |
| Other | 1 |

Total number respondents: 1109 (97 percent of those who answered the questionnaire)

Living conditions

Table 4. How do you live? Number and percentage distribution

| | Total percentage |
|------------------------|------------------|
| Live alone | 24 |
| Live with other/others | 76 |

Total number respondents: 1073 (100 percent of those who answered the questionnaire)

Time passed since balloon angioplasty

Table 5. How long is it since you had your balloon angioplasty? Number and percentage distribution

| | Total percentage |
|--------------------|------------------|
| 1 – 4 weeks | 35 |
| 5 – 8 weeks | 44 |
| 9 – 12 weeks | 13 |
| More than 12 weeks | 8 |

Total number respondents: 1070 (100 percent of those who answered the questionnaire)

Number of balloon angioplasties

Table 6. How many times have you had a balloon angioplasty? Number and percentage distribution.

| | Total percentage |
|-------------------|------------------|
| once | 76 |
| twice | 18 |
| 3 times | 4 |
| More than 3 times | 2 |

Total number respondents: 1070 (100 percent of those who answered the questionnaire)

Emergency or planned balloon angioplasty

Eight cases of ten, 83 percent, were performed acutely, 17 percent were planned.

Table 7. Was your balloon angioplasty... Number and percentage distribution.

| | Total percentage |
|---------------------------------------|------------------|
| Emergency | 83 |
| Planned (referred from waiting list) | 17 |

Total number respondents: 1064 (99 percent of those who answered the questionnaire)

The reasons given for cardioid-vascular problems

Table 8. Why do you think you suffer from angina? Number and percentage distribution.

| | Total percentage |
|--|------------------|
| Age | 41 |
| Environment | 3 |
| Hereditary | 52 |
| Smoking | 25 |
| Lack of exercise | 22 |
| Diet | 31 |
| Stress (i.e. pressure, worry, anger, helplessness, depression) | 45 |
| Other | 8 |

Total number respondents: 1039 (97 percent of those who answered the questionnaire)

Status after balloon angioplasty

Table 9. Do you still have trouble with your heart after balloon angioplasty? Number and percentage distribution.

| | Total percentage |
|---|---------------------|
| No, no chest pains or other worries | 73 |
| Yes, chest pains, but they do not limit taking part in average physical activities | 17 |
| Yes, chest pains that slightly limit participation in average physical activities | 7 |
| Yes, chest pains that definitely limit participation in average physical activities | 2 |
| Yes, cannot participate in any physical activity without discomfort/chest pains | 2 |

Total number respondents: 1059 (99 percent of those who answered the questionnaire)

Information given at hospitals (PCI-units) in connection with balloon angioplasty treatment

Advice from PCI unit

Table 10. Were you given advice by the staff of the PCI unit in connection with your treatment as to how to prevent future heart trouble? Number and percentage distribution.

| | Total percentage |
|----------------------------|---------------------|
| Yes | 71 |
| No | 19 |
| Do not remember/don't know | 10 |

Total number of respondents: 1064 (99 percent of those who answered the questionnaire)

Knowledge of state of health at the time of balloon angioplasty

Table 11. What were you told by the staff about your state of health in connection with your balloon angioplasty treatment? Number and percentage distribution.

| | Total percentage |
|---|---------------------|
| I am healthy and do not need to change my lifestyle/habits | 19 |
| I am healthy but should change my lifestyle/habits | 38 |
| I still have the disease and need to change my lifestyle/habits | 20 |
| I was not given any information | 14 |
| I don't remember/don't know | 9 |

Total number of respondents: 1054 (98 percent of those who answered the questionnaire)

Information together with close relative

Tabell 12. Were you given information with a close relative present in connection with your balloon angioplasty treatment? Number and percentage distribution.

| | Total percentage |
|---------------------------|---------------------|
| Yes | 27 |
| No | 71 |
| Don't remember/don't know | 2 |

Total number of respondents: 1068 (99 percent of those who answered the questionnaire)

Information from hospital staff at heart reception/heart ward in connection with follow-up visit after balloon angioplasty treatment

Preventive advice

Table 13. What concrete advice were you given at your follow-up visit after balloon angioplasty treatment by the staff of the heart unit at your hospital, concerning how to prevent future heart trouble. Number and percentage distribution

| | Total |
|---|-------|
| I was not given any concrete advice at my follow-up visit | 16 |
| Don't remember/don't know | 6 |
| Was given concrete advice | 78 |

Total number of respondents: 1068 (99 percent of those who answered the questionnaire)

Table 14. Concrete advice given to prevent future heart trouble. Number and percentage distribution

| | Total |
|--|-------|
| Exercise | 74 |
| Diet/drinking habits | 58 |
| Stop smoking | 20 |
| No stress | 15 |
| Take drugs recommended/regular health check-ups/ask for help when needed | 11 |
| Live normally | 7 |
| Lose weight/thinner waistline | 5 |
| Other/attend Heart School/Heart rehabilitation | 6 |

Total number of respondents: 789 (99 percent of those given concrete advice)

Table 15. Were you given information by the staff with a close relative present at your follow-up visit? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 36 |
| No | 63 |
| Don't remember/don't know | 1 |

Total number of respondents: 1054 (98 percent of those who answered the questionnaire)

Information about state of health in connection with follow-up visit

Table 16. What were you told about your state of health by staff of heart unit at your follow-up visit? Number and percentage distribution

| | Total |
|--|-------|
| That I am healthy and need no other care or rehabilitation except medicine | 38 |
| That I am healthy but should change my lifestyle/habits | 29 |
| That I still have the disease and need to change my lifestyle/habits | 27 |
| I was not given any information | 4 |
| Don't remember/don't know | 3 |

Total number of respondents: 1026 (95 percent of those who answered the questionnaire)

Information about hospital exercise groups (physical training in groups) and Heart Schools (information about heart conditions)

Information about hospital exercise groups

Table 17. Were you given information about the hospital's exercise group (physical training in groups)? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 78 |
| No | 20 |
| Don't remember/don't know | 2 |

Total number of respondents: 1060 (99 percent of those who answered the questionnaire)

Taking part in the hospital exercise group

Table 18. Have you taken part in hospital's exercise group? Number and percentage distribution

| | Total |
|--|-------|
| Yes | 24 |
| No but I am going to | 19 |
| No I shall not be taking part | 35 |
| No, I don't know whether I shall take part | 22 |

Total number of respondents: 1026 (95 percent of those who answered the questionnaire)

Table 19. If you have not participated in the hospital exercise group, what is the main reason for this? Number and percentage distribution

| | Total |
|---|-------|
| Didn't know there was an exercise group | 14 |
| Long way to the hospital | 27 |
| The time wasn't suitable | 7 |
| Don't have the time | 2 |
| Have no need of exercise group | 7 |
| Do my own exercise | 51 |
| Other, namely | 24 |

Total number of respondents: 755 (97 percent of those who as yet have not taken part in an exercise group)

Information about hospital Heart School

Table 20. Were you given information about the hospital Heart School? (where information about heart disease is given)? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 80 |
| No | 17 |
| Don't remember/don't know | 3 |

Total number of respondents: 1062 (99 percent of those who answered the questionnaire)

Table 21. Have you taken part in the hospital Heart School? Number and percentage distribution

| | Total |
|--------------------------|-------|
| Yes | 30 |
| No but I am going to | 25 |
| No I am not going to | 21 |
| No, don't know if I will | 23 |

Total number of respondents: 1033 (96 percent of those who answered the questionnaire)

Table 22. If you haven't attended the Heart School, what is the main reason why? Number and percentage distribution

| | Total |
|--------------------------------------|-------|
| Didn't know there was a heart school | 25 |
| Long way to the hospital | 27 |
| Time is not suitable | 9 |
| Do not have the time | 3 |
| Have no need of information | 7 |
| Have other access to information | 24 |
| Other, namely | 21 |

Total number of respondents: 624 (87percent of those who have not yet attended heart school)

Offer to close relatives about the hospital Heart School

Table 23. Has anyone close to you been asked to attend the hospital heart school? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 35 |
| No | 58 |
| Don't remember/don't know | 8 |

Total number of respondents: 1053 (98 percent of those who answered the questionnaire)

Patients' Lifestyles

Weight

The patient is asked in the questionnaire to state his or her weight status. This means they were asked if they are "not overweight", "slightly overweight" or "very overweight". They were then asked their height in centimetres and their weight in kilograms. By using the two, a BMI rate was calculated (BMI= body mass index, a measure of body fat based on height and weight) that was then compared to patients' own opinion about their weight.

Table 24. How would you describe yourself? Number and percentage distribution

| | Total own calculated weight | Total calculated BMI index |
|---------------------|-----------------------------|----------------------------|
| Not overweight | 39 | 29 |
| Slightly overweight | 50 | 50 |
| Very overweight | 11 | 21 |

Total number of respondents: 1052 (98 percent of those who answered the questionnaire)

Smoking and the use of snuff

Smoking habits

Table 25. Do you still smoke? Several choices were possible. Number and percentage distribution

| | Total | Percentage of smokers before PCI | Percentage of those who still smoke |
|-----------------------------------|-------|----------------------------------|-------------------------------------|
| No, I neither smoke nor use snuff | 84 | 53 | - |
| Yes, I smoke every day | 6 | 19 | 39 |
| Yes, I sometimes smoke | 2 | 6 | 12 |
| Yes, I smoke a pipe/cigar | 1 | 1 | 3 |
| Yes, I use snuff | 7 | 23 | 48 |

Total number of respondents: 1066 (99 percent of those who answered the questionnaire)

Number of respondents who smoked before treatment: 345. Number of respondents who say they still smoke: 164

Table 26. Average smoking habits

| | Average smoking habits |
|--|------------------------|
| Yes, smoke x cigarettes every day | 9,5 |
| Ja, I sometimes smoke, about x cigarettes a week | 7,0 |
| Yes, I use snuff, about x boxes a week | 2,2 |

Changed tobacco habits

Table 27. Have you changed your habits? Several choices were possible. Number and percentage distribution.

| | Total | Percentage of those who were tobacco users before PCI |
|--|-------|---|
| I have never used tobacco | 53 | - |
| I have stopped using tobacco after balloon angioplasty | 22 | 59 |

| | | |
|--|----|----|
| I use less tobacco now than before balloon angioplasty | 12 | 33 |
| I have not changed my tobacco habits | 12 | 9 |
| I use more tobacco than before balloon angioplasty | 0 | 0 |

Total number of respondents: 891 (83 percent of those who answered the questionnaire)

Number of respondents who were tobacco users before PCI: 155

Table 28. Were you offered help to stop smoking when you came for your follow-up visit? Number and percentage distribution.

| | Total |
|---------------------------|-------|
| Yes | 48 |
| No | 45 |
| Don't remember/don't know | 7 |

Total number of respondents: 316 (81 percent of those who have said they use/have used tobacco)

Diets

Vegetables and/or root vegetables

Table 29. How often do you eat vegetables or root vegetables (fresh, frozen or cooked)? Number and percentage distribution

| | Total |
|----------------------|-------|
| Every day | 55 |
| Several times a week | 32 |
| Once or twice a week | 11 |
| Less than every week | 2 |
| Never | 0 |

Total number of respondents: 1064 (99 percent of those who answered the questionnaire)

Fruit and/or berries

Table 30. How often do you eat fruit and/or berries? (fresh, frozen, tinned, juice etc.)? Number and percentage distribution .

| | Total |
|----------------------|-------|
| Every day | 56 |
| Several times a week | 28 |
| Once or twice a week | 13 |
| Less than every week | 2 |
| Never | 0 |

Total number respondents: 1062 (99 percent of those who answered the questionnaire)

Changed diets

Table 31. Which statement fits you? Number and percentage distribution

| | Total |
|---|-------|
| My diet is more healthy now than before balloon angioplasty | 40 |

My diet is the same now as before balloon angioplasty 59
 My diet is less healthy now than before balloon angioplasty 1

Total number respondents: 1005 (94 percent of those who answered the questionnaire)

Diet information

Tabell 32. Were you given information about diet at your follow-up visit? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 71 |
| No | 26 |
| Don't remember/don't know | 3 |

Total number respondents: 998 (93 percent of those who answered the questionnaire)

Exercise

Effort used when exercising

The question "How often do you exert yourself in exercise, sports and outdoor activities?" was divided into three levels of exertion of at least 20 minutes at a time.

- **Strenuous** exercise for at least 20 minutes at a time; your pulse is high, you are breathless and perspiring – for example from running or strenuous gymnastics
- **Moderate** exercise for at least 20 minutes at a time: your speed allows you to converse with someone during the activity – for example jogging, light aerobics, brisk walks or other hard work.
- **Low** impact exercise for at least 20 minutes at a time; for example slow walks and bicycle outings.

Table 33. Number and percentage distribution

| Strenuous exercise | Total |
|----------------------------|-------|
| Never | 33 |
| Less than once a week | 19 |
| Once a week | 14 |
| Twice a week | 15 |
| Three times a week or more | 19 |

Total number respondents: 877 (82 percent of those who answered the questionnaire)

Table 34. Number and percentage distribution

| Moderate exercise | Total |
|----------------------------|-------|
| Never | 10 |
| Less than once a week | 10 |
| Once a week | 14 |
| Twice a week | 19 |
| Three times a week or more | 47 |

Total number respondents: 932 (87 percent of those who answered the questionnaire)

Table 35. Number and percentage distribution.

| Low impact exercise | Total |
|----------------------------|-------|
| Never | 6 |
| Less than once a week | 9 |
| Once a week | 13 |
| Twice a week | 18 |
| Three times a week or more | 55 |

Total number respondents: 853 (79 percent of those who answered the questionnaire)

Changed exercise habits

Table 36. How have you changed your exercise habits compared with before you underwent balloon angioplasty? Number and percentage distribution

| | Total |
|--|-------|
| I am more physically active now than before balloon angioplasty | 31 |
| I am just as physically active now as before balloon angioplasty | 57 |
| I am less physically active now than before balloon angioplasty | 12 |

Total number respondents: 1002 (93 percent of those who answered the questionnaire)

Mental well-being

Stress levels

Table 37. How often do you feel stressed, for example rushed, under pressure, worried, lack of time? Number and percentage distribution

| | Total |
|---------------------|-------|
| Hardly ever | 37 |
| A few times a month | 21 |
| A few times a week | 21 |
| Many times a week | 14 |
| Every day | 7 |

Total number respondents: 1008 (94 percent of those who answered the questionnaire)

Fatigue levels

Table 38. How often do you feel tired out, run down, exhausted, depressed etcetera? Number and percentage distribution

| | Total |
|---------------------|-------|
| Hardly ever | 38 |
| A few times a month | 25 |
| A few times a week | 19 |
| Many times a week | 13 |
| Every day | 4 |

Total number respondents: 1006 (94 percent of those who answered the questionnaire)

Changed stress levels

A total of six out of ten, 61 percent, report the same stress levels now as before the balloon angioplasty. A third, 35 percent, say they are less stressed now and a few, 4 percent, are often more stressed now, after balloon angioplasty, than they were before.

Tabell 39. Which of these statements about stress fits you? Number and percentage distribution

| | Total |
|--|-------|
| I feel as stressed now as I did before balloon angioplasty | 61 |
| I am less stressed now than before balloon angioplasty | 35 |
| I feel more stressed now than before balloon angioplasty | 4 |

Total number of respondents: 976 (91 percent of those who answered the questionnaire)

Offer to take part in stress management programmes

Table 40. Were you given the opportunity to partake in a stress management program at your follow-up visit? Number and percentage distribution

| | Total |
|---------------------------|-------|
| Yes | 18 |
| No | 72 |
| Don't remember/don't know | 10 |

Total number respondents: 997 (93 percent of those who answered the questionnaire)

Channels of information

Information from hospital staff

More than a third, 35 percent, would have liked more information from the hospital staff about how to avoid and prevent future heart trouble

Table 41. Do you think you received adequate information from hospital staff about how to avoid and prevent future heart trouble? Number and percentage distribution

| | Total |
|-------------------------------------|-------|
| Yes, absolutely | 65 |
| Yes, some but would have liked more | 28 |
| No, had very little information | 7 |

Total number of respondents:: 1063 (99 percent of those who answered the questionnaire)

Information found elsewhere

Table 42. Did you find information about your heart condition elsewhere? Number and percentage distribution

| | Total |
|------------------------------|-------|
| Yes | 37 |
| No, only from hospital staff | 61 |
| Don't remember/don't know | 2 |

Total number of respondents: 1044 (97 percent of those who answered the questionnaire)

Table 43. If you answered yes to last question, where did you find information? More than one alternative can be given. Number and percentage distribution.

| | Total |
|--|-------|
| Through relatives, friends and acquaintances | 54 |
| Internet | 41 |
| Heart and Lung Association | 21 |
| Trade journals | 14 |
| Information from chemist | 15 |
| Other ways | 12 |

Total number of respondents: 419 (100 percent of those who found information elsewhere, not just hospital staff)

Sources in which the patients looked for information:

- 1177.se : health advice online
- Diabetes Association
- Doktorn.se : health advice online
- Hjärt-lung.se
- Fass : information to doctors, patients and veterinaries about drugs
- Medical care hotline
- Google – about drugs, blood tests and balloon angioplasty, PCI
- Re. coronary thrombosis
- Hälsosidorna.se : diet, exercise, mental training online
- The Heart and Lung Association's website
- The Heart-Lung Foundation
- Chemists
- Heart School online
- Läkartidningen: Swedish medical journal
- Internetmedicin : Swedish healthcare doctors' website
- Kostdoktorn.se : dietary advice online
- Advice on diets and websites i.e. Heart School
- Medscape : medical news online
- Hospitals' websites
- Socialstyrelsen: National Board of Health and Welfare
- Wikipedia etc
- Vårdguiden: Health advice online

Suggestions and advice from patients

There was room at the end of the questionnaire for respondents to make suggestions and advise hospital staff.

We have categorised the open answers in an attempt to present an overall picture of patients' mode of suggestions and advices . **We have identified three categories: 1. Information** is about how patients felt about the information they were given, for example a wish for more information about the side-effects, how to cope with life after the operation, advice about diet and exercise etcetera.

2. **Care** is about how patients felt they were taken care of and how improvement could be made, for example to be given more time for talking to healthcare staff who are responsive, understanding and empathetic. 3. **Follow-up and continuity** is suggestions and advice to hospital staff about how a patient views the time before and after being in hospital. Lastly there are some "Miscellaneous" suggestions.

1. Information

- ✓ I was allowed home so quickly that I missed some information. But it was all right, I got the information later on.
- ✓ The doctor did not have much time for me when I was in hospital. The doctor was stressed and the information insufficient. I don't mean the doctor who operated. But the doctor on the ward. Every thing was so quick. The nurses were better at giving information.
- ✓ More information about the illness after coronary thrombosis
- ✓ I was a patient not a person searching for information. I was given the opportunity to ask many questions if I wanted to. They talked a lot about the drugs I had been given, nothing else. Not more than 14 days to wait for the first follow-up appointment. Blood pressure checked at district nurse's.
- ✓ Excellent care! There is one thing though; it would be good to speak to a doctor in private before being discharged.
- ✓ Better information about the drugs prescribed, after-effects and how long you have to take them.
- ✓ More information about stress management
- ✓ Get heart patients together at hospitals before they go home! Pass on the message to a group.
- ✓ I was given far too many leaflets all with same content but put differently. It irritated me. It must be possible to print one brochure that says it all.
- ✓ More information in connection with balloon angioplasty – how you got it and how to prevent it. The run-through at my follow-up visit was very good and thorough. I was treated like royalty.
- ✓ More information about coming activities. More information to relatives.
- ✓ Nurses and auxiliary nurses were very good and willing to give information and answer questions. Met three doctors, on the other hand, who were hopeless at giving good, concrete information.
- ✓ A lot of random information today. Many people involved, doctors, nurses, physiotherapists etc., a total of 10-15 people they ought to give you one person to contact for help and to answer questions.
- ✓ Possibilities to get more information. It is, or can be, quite an overwhelming experience to suffer coronary thrombosis and it makes it difficult to digest all the information at one go.

- ✓ Explain in easily understandable language more about why a person has this problem and how they can do something about it. Comment on the things that are not good, for example weight, too little exercise, diets.
- ✓ Better information. More information before and after balloon angioplasty
- ✓ Tell how to change lifestyle after heart surgery
- ✓ To have a close relative present when given information on leaving the hospital
- ✓ To be told what a serious illness you have been through so that you realise you have to take care after the treatment.
- ✓ Repetition – you can't take it all in at once. It's enough trying to understand, at least if it is emergency treatment
- ✓ Ask/inform about lifestyle and stress
- ✓ Give more information about how to live after heart trouble, what you can do and what you should avoid
- ✓ More help for those who use snuff to give it up
- ✓ The book I was given when I left the hospital doesn't apply to me. I was well enough to start work.
- ✓ Make people stop smoking before treatment begins. My doctor was wise enough to make me. Smoked for 40 years 40-a-day, am now a non-smoker and feel fine.
- ✓ Distinct information. Important that close relative attends. The brochures you are given when you are admitted are not enough you are stressed and in shock and want the staff to give you the same information.
- ✓ More information from doctor at follow-up appointment about how much exercise is suitable after the treatment and in my case more information about how to stop smoking.

2. Care

- ✓ Better organisation/logistics on the emergency ward. Bad patient security!
- ✓ Keep on being cheerful and positive
- ✓ As a patient you feel quite small and scared. I have only ever been treated in a positive way. Important.
- ✓ To listen properly to what people say. I feel unlucky because the heart doctor I was given did not believe "there is anything wrong with you" like I was cheating. He didn't even look at me and I felt like something "the cat dragged in" I felt humiliated.
- ✓ As far as doctors are concerned, it feels like they are always slightly stressed and have too

little time to listen to the patient. You hardly ever see the same doctor twice.

- ✓ More time for information when you become ill. Help to contact healthcare and rehab staff that work with heart disease.
- ✓ The follow-up visit to the coronary nurse is very significant, you get answers to all your questions. You are visible, she cares!
- ✓ Listen to the patient, don't just use standard phrases. Cooperation between wards must be better. Relatives should be informed both when the PCI is an emergency or a planned operation.
- ✓ I don't really know whether I am ill or well. Side-effects of the drugs were not discussed, and not much was said about stress, it was mostly about exercise, smoking and eating habits. When they informed me of my health status they should have asked me to have a close relative present. I was somewhat in chock 3,5 days after the thrombosis.
- ✓ Keep on being as cheerful and positive as they were when I stayed. Thank you! And the consultant explained how serious it was with a twinkle in his eye...
- ✓ Straight after the treatment I would have liked to speak to someone about how life is going to be after this. And be given the chance to talk to a psychologist or someone similar.
- ✓ In my case it was all about my difficulties coping with the drugs after the operation and some other things were forgotten.
- ✓ More information about how to live and cope with the problems I have had. Dealing with the same staff, especially doctors. I was in for 5 days and met no less than 5 doctors. All good, but why?
- ✓ I think the doctor who performed the balloon angioplasty should come and talk to the patient the day after

3. Follow-up and continuity

- ✓ There should be more follow-up visits
- ✓ I would like to have a table diagram that shows my test results day by day so I can see how I am doing.
- ✓ Perhaps more check-ups. For example weight and diet. A good follow-up would be in connection with heart exercise they could ask about drugs, diet, exercise and side-effects.
- ✓ Follow-up visit with a repetition of the rules for diet, exercise and stress management would be good. It is easy to forget things after a while.
- ✓ Less time after balloon angioplasty before follow-up visit and doctor.
- ✓ I am satisfied but it took 4 weeks before I met a coronary nurse. It should not be more than 2 weeks at the most.