Restenosis after Percutaneous Coronary Intervention (PCI): Experiences from the perspective of patients

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ABSTRACT

Background: The intention of this study was to clarify the patients perspective of what it means to suffer from documented restenosis after one or more Percutaneous Coronary Intervention (PCI).

Aim: The aim of this qualitative study was to ascertain the patients experience of restenosis.

Method: Nine patients were interviewed. They had undergone at least one PCI and two had also undergone Coronary Arterio Bypass Grafting (CABG). Data collection and analysis were done simultaneously according to Grounded Theory methodology and were continued until new interviews provided no additional information, i.e saturation was met.

Results: “Living with uncertainty” was identified as the core category and was related to four additional categories, labelled “fighting for access to care”, “moderating health threats”, “trying to understand” and “controlling relatives’ anxiety”. The categories formed a conceptual model, describing the experienced life situation of patients with restenosis following a previous PCI.

Conclusion: The perceptions of the patients regarding their illness and illness-related events, such as symptoms, diagnosis, treatment and prognosis, are considerably affected by uncertainty. This uncertainty infiltrates their struggle to acquire the care needed, their endeavour to comprehend and moderate health threats, and their way of caring for and protecting their family and relatives.

Key Words: Grounded theory, PCI, Restenosis, Uncertainty, Coronary artery disease, Revascularisation
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INTRODUCTION

Coronary artery disease (CAD), remains the leading cause of morbidity and mortality in the western world. Percutaneous Coronary Intervention (PCI) (1) with or without intracoronary stent placement has emerged as an effective treatment modality for the management of CAD. PCI offers immediate relief of symptoms, low risk and swift return to normal activities. Restenosis, however, that is to say the return of significant narrowing in the treated vessel, constitute a problem affecting 30-50 % of the treated patients (2). Restenosis may result in a reoccurrence of chest pain, with the outcome, in some of the patients, being a renewed need for revascularisation. The risk for restenosis is greatest during the first 6 months following a PCI. Major efforts have been made in the prevention of restenosis (3). To date, however, no systemic pharmacological treatment has been found to be effective. The risk of restenosis has, in many randomised trials, been demonstrated to be reduced following stent implantation as compared to after plain balloon angioplasty (4-12). It has been shown that in a cohort of unselected “real world” patients, the composite of death, Acute Myocardial Infarction (AMI) and/or revascularization procedures are significantly less after stenting, but the frequency of death or myocardial infarction was not, however, affected (13).

In-stent restenosis still constitute a problem. However, new and promising developments with drug eluting stents (DES) are in progress (14-17). Although a substantial part of the investigative and research funding is invested in the prevention and resolving of the restenosis problem, little is known about its clinical significance apart from the need for further revascularisation.

These psychosocial issues require more in-depth exploration. The aim, therefore, of this qualitative study was to elucidate what it means to patients to suffer from documented restenosis after one or more PCI.

METHOD

Qualitative approach
Grounded theory - a general methodology and way of thinking about and conceptualizing data for theory development - was used (18-21). The purpose of such a method is to gain a deeper understanding of concerns, actions and behaviours of a group of individuals and, through their own language, explain those patterns of behaviour on a higher level of abstraction. Charmaz (21) argues that interviewing is an appropriate method to gain access to individuals’ language and interpretations of their social reality. A strategic (open) sampling of participants was done to maximize the variations of experiences in the group studied, which was followed later in the process by theoretical sampling (18). Theoretical sampling means that the emerging results direct where data will be sought next, and which probing questions would be asked. As well as constant comparisons, the methodology also included a systematic hierarchical coding process (18). Another central feature of grounded theory is constant comparisons of data (18-21). Data collection and analysis were done simultaneously and continued until new interviews provided no additional information, i.e. saturation was reached.

Patients and procedure
The study was conducted at the Department of Cardiology at Sahlgrenska University Hospital in Göteborg, Sweden, during twelve month (2003-2004). During the sampling period, approximately 1300 PCI’s and approximately 1500 coronary angiographies were
performed annually at this department. Patients in this study were not only from the Göteborg area, they came also from other hospitals in the west region of Sweden. All PCIs’ and angiographies of the patients included in the study were performed at this hospital including continued contact of patients belonging to the Göteborg area. After the initial procedure the patients who were from other hospitals in the west region of Sweden, continued their contact with the hospital in their home district.

Patients with documented restenosis after one or more previous PCI’s (two of them had also undergone Coronary Artery Bypass Grafting CABG) were approached and asked to participate in an interview. The patients selected showed a reoccurrence of their angina pectoris and had undergone a new coronary angiography, which showed a significant restenosis thereby requiring a new intervention. The patients included were of both sexes and different ages to validate and illustrate variability in the interview data (Table 1). Their informed consent was obtained and an agreement was made for time and place of the interview. The open taped interviews were conducted by the first author (AO), who has considerable experience in communicating with patients suffering from heart disease. The interview questions were focused on the patients’ thoughts, behaviours and feelings regarding the restenosis problem, and covered the time from first being aware of their coronary disease up to the time of completion of the interview. The interviews were conducted prior to discharge from the hospital and after mobilisation following coronary angiography, and did not include information regarding the patient’s name or date of birth. All interviews were conducted in an appropriate room at the clinic and took approximately 60 minutes, a digital tape recorder was used and the text was transcribed verbatim. Data collection and analysis were carried out simultaneously and in line with guidelines for grounded theory (18-21). The participants will be called “patients” in this paper.

Analysis of data
The analytic process included open, axial and selective coding processes (19). The definition of open coding is thus that the substance of the data was captured and segmented into substantive codes, which were specifically labelled. Labelling segments of the data served to open up the text. In line with suggestions by Glaser (20), questions guiding the analysis were: “What are these data a study of?” and “What category does this incident indicate?” “What is actually happening in the data?”. The process of open coding led to the clustering of substantive codes with similar content into summerizing categories. In axial (theoretical) coding, each category was further developed and subcategories identified. Relationships among categories were sought and data assimilated into new entitles. In the selective coding, categories were saturated with additional information assessed with new theoretical samplings, or added to by re-coding previously assessed data. During the entire process of analysis, ideas, preliminary assumptions and theoretical reflections were written down in notes or memos to keep track of the analysis (20). The interview transcript was finally re-contextualized to verify that categories were supported by the data, i.e. that the categories were grounded in the data. According to Charmaz (21), the unit of analysis in a grounded theory study concerns events and actions in the data rather than the separate individuals per se. Therefore, the number of informants is of less interest than the content and quality of the data.
Ethics
The study design was approved by the local ethical committee at the University of Göteborg and informed consent was given and signed by the patients and confidentiality was also met for the patients.

RESULTS
“Living with uncertainty” was identified as the core category which is the central process of these patients’ experiences. “Living with uncertainty” was closely related to four other categories which were labelled “fighting for access to care“, “moderating health threats”, “trying to understand” and “controlling relatives anxiety”. The categories formed a conceptual model (see Figure 1). According to the model, the experienced uncertainty infiltrates their struggle to acquire the care needed, their endeavour to comprehend and moderate health threats, and their way of caring for and protecting their family and relatives. All categories are shown in Table 2 and are further described below.

Living with uncertainty:
It was obvious in the data that uncertainty and lack of control were realities the patients had to face. The uncertainty they felt was related to the seriousness of their illness and their not knowing when or if they were going to be sick again. Will they be all right now, will the pain come back, and if the pain returns, how long time will it take before it happens? This is a major uncertainty for the patients as pain in the heart is perceived as threatening. The patients uncertainty also concerned their daily habits, for example, if they could take a holiday with their family or not, visit friends, go shopping or even to do something so mundane as being able to take the dog out. This unpredictability in life was expressed as living one day at a time: “I have learnt to take each day as it comes”. The uncertainty of not knowing how they will be feeling the next day causes hesitation in making decisions and waiting until the last moment to do things. This lack of decision-making effects their whole daily structure regarding both their own and the expected demands of others.

The uncertainty was also related to the possibility that they themselves might be responsible for the relapse, or to the reason or explanation of why they have restenosis: “I think it is my fault that it has come back again, as I am obliged to say that I have smoked”. Uncertainty with regards to if they were responsible for the restenosis, what they could possibly have done, or not done, to find themselves in this situation again and why it came back in the same place: “maybe there is a reason why... it comes back in the same place” and “... is it because of diabetes?” The patient’s questions concerned how many times one can have restenosis and if it is possible to be treated with PCI repeatedly? Uncertainty and fear regarding CABG was also obvious in the interviews, as well as questions such as will the next treatment be of help and if not what “the next step” would be: “Why was it just me that got this, be sick I mean, how is it going to be ... when I am sixty, how will that be, that will be the end of me, I mean, that’s how one thinks...?” The uncertainty was also related to the question of if they can find some structure in their life, to be able to take control again and thereby be able to reduce the feeling of uncertainty. This is where uncertainty for the future creeps in, how it will be when they are older, what will happen then: “Even if I need to have a big operation,
they can’t guarantee that it will last ...I think ...” and “Just because uncertainty is awful and that’s how I think, if they help me now... how long will it last?”.

Fighting for access to care
The category “fighting for access to care” was related to uncertainty in several illness-related situations, i.e. when trying to obtain treatment at the hospital but were, however, sent home again and instructed to come back if they continued to feel ill or got worse. The uncertainty felt by the return of pain and the insecurity of eventually not being believed by the hospital staff was worrisome also when, for example, the information given by the doctor was not compatible with the patients own perception of his/her illness when seeking help at the emergency department. “… but according to the doctor, it was still nothing to do with the heart as the doctor said that the ECG looked really good, therefore it must be something to do with the muscles and that I can be overwrought, and then I was told to go home!” and “I felt it after one month, but they said that it can’t be, as before 3 months one can’t feel anything, and if you manage to get through 6 months then you will manage”. If the information given states that there is nothing seriously wrong, the patient has no alternative but to believe this and await further developments. To be met with the information that everything is normal but the patient still is in pain leads to a feeling of mistrust. “I went through quite a lot of agonising, that they didn’t admit me into the hospital and that I had to go home with angina for 4 weeks”. To be old leaves the patient with a feeling of inadequacy. “Then I felt that they didn’t believe that I had pain and that I was a bothersome old woman”.

The continual problem for a patient to explain symptoms that were not congruent and which were not specific for angina pectoris resulted in a situation where the patient’s symptoms were not taken seriously. “… and then there is the problem with explaining the unclear symptoms such as, being uncomfortable in my back, the pinched feeling in my neck, and such signs one shouldn’t have with angina pectoris”.

“Fighting for access to care” can be further illustrated by patients who have undergone a new coronary angiography and have been told that there was a need for a new PCI treatment. They again contacted the hospital after a delay and were told that they were on a waiting list as there was still no time available. The uncertainty of what to do and the feeling of rejection, not being able to reach the responsible hospital staff by phone and even to reach someone that can give them an answer to their queries and uncertainties left them feeling even more vulnerable. “...and the second thing was the hell of trying to get hold of some doctor”. The citation mentioned below is from a patient that had no time booked at the hospital and was told to come back after he received a reservation, whereby he threatened to have a “sit-down strike” and would refuse to move until he had his exercise-ECG as he was aware that he was having a reoccurrence. “I’m telling you - I will sit down on the floor - I am feeling so poorly”. The patient implied that money could be saved if they were not on an extended sick leave, with the added feeling that nobody cares about their sickness. “If I have been treated earlier I could have saved a lot of sick leave”. The uncertainty caused by being on a waiting list leaves the patients with the feeling that they may be forgotten. “It has been a very drawn-out process, in the end I thought that I had been forgotten”.

Trying to understand:
The category “trying to understand” illuminates the difficulties for the patients to comprehend why they had become ill and why the restenosis had occurred: “Why me -

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why have just I been afflicted”. They attempt to find any reason for their illness. “…it’s the diabetes which causes all my problems”. The patients try to find some root cause why just they have been afflicted. They contemplate if it is the food they have eaten that is the cause, have a bad conscience due the fact that they smoke or have smoked earlier in their lives. If they have been too much under stress, some of them put the blame on themselves. What were apparent in the interviews was that most of the patients tried to find a reason “…that it just can’t appear - that there must be a reason!” “…but I don’t know if that is... there is surely an explanation as to why... it has come back in precisely the same place”. They have not understood that this can afflict them and not others. “Now afterwards it just feels so... why didn’t I understand that”. There is always the problem of explaining to patients about their basic illness, to discover how much they understand and are receptive to hearing. The problem can be that even though they receive all the information, they are simply not receptive to hearing it and can be in a state of denial. Some patients are simply not aware of, and are unable to separate progression of CAD from restenosis. “It is probably better that it comes in the same place than coming somewhere new”.

**Moderating health threats**
This category, “moderating health threats”, concerns not only the threats the patients feel and how they try to cope, but also that the patients do not seem to take their situation and illness seriously. “This is a part of life, it shouldn’t be so remarkable... because it doesn’t make me feel ill... I manage to walk and do the things I want to do except just when it becomes tight”.

Some patients diminish the severity of the illness of CAD, and when the symptoms have been treated, i.e. with PCI, they experience themselves as “healthy” again until the possibility of a recurrence of pain in which case the possibility of a new PCI will solve the problem. “Well okay, maybe you only have to blow it out again in the old stent then?”. This can be due to the fact that the patient does not understand the severity of the situation or that they are in a state of denial or minimization of their illness. “In some way I have thought... Okay, okay... this is something that I need to get used to”, “The last thing the doctor said was operation... I replied that I don’t want to... can we try something else - if there is something else?”,

We have described above that patients believed the situation to be not so serious and that they only has to repeat the PCI treatment, thus being healthy again. However, patients that are scheduled to undergo CABG seem at last to understand, as if for the first time, that it really is something serious to do with their heart. “The more we are in and fix and rebuild inside the body here and there, the less natural it is for the body, and to operate the heart, I am really a little nervous about, it is after all the heart! The people I have talked to have said that it isn’t so bad, you do have pain relief... one has to believe in it”.

**Controlling relatives’ anxiety**
The category “controlling relative’s anxiety” concerns the patients’ social life and how they try to mitigate the relatives from anxiety and worries. The patients’ perception is that they are the ones who need to be strong when the loved ones cry and are anxious. “My family and wife are sad”. According to our data, it seems to be the patient that comforts and reassures the relatives. The patients were aware of what they would be going through as they had done this i.e. PCI - before, it was the patient who consoled
the apprehensive relations and told their family that it was nothing to worry about and that everything would be all right. “My husband and my mother - they were the ones that were nervous and cried, but I knew what I would be going through”. The content of this category showed that besides their own uncertainty and trying to understand their situation, the patients were also forced to take care of their family and relations and explain and comfort them rather than contending with their own worries and feelings. Our data indicate that the patients were in need of support. “...and we all talk about it a lot we do... as soon as I have to go to the doctor... or something, then everyone gets together and talks about it”. Relatives were worried for a reoccurrence of the illness, which in itself resulted in a situation where the patients felt their need to console and calm their intimates. Many patients find themselves in the situation whereby they refuse invitations, as they are afraid that they may be ill and spoil the occasion for others. “No, and I don’t want to risk spoiling their holiday and as they have two small children with them who I love, they are wonderful, I really don’t want to ruin... no, I would prefer to be at home and lie down when I feel like it”.

**DISCUSSION**

Prior to commencement of this study, our belief was that the present data would illustrate that restenosis would be considered a negative experience due to patients having to repeat the same treatment. We believed that data also would show that patients were interested in discussing the problems appertaining to angina pectoris and their fear of myocardial infarction and death. We also assumed that patients would find it difficult to be supine for such a long period of time following the perforation of the femoral artery. However, our study convincingly showed that the most salient theme was their “living with uncertainty”, which accordingly was identified as the core category in the data. This concern is further illustrated and described in the conceptual framework (see Fig. 1) generated in the systematic analysis of the data. Our result showed that the patients’ perceptions of illness and illness-related events, such as relapse symptoms, disease diagnosis, treatment and prognosis, are greatly affected by uncertainty. The uncertainty arose from ambiguous or unclear information, medical jargon and difficulties in understanding given information on diagnosis, treatment and prognosis. “Living with uncertainty” might have increased the patients’ stress reactions and thereby decreased their active coping strategies. Before becoming ill, most people take their physical activities and bodily functions for granted.

According to Leventhal’s self-regulatory model (22), illness and symptoms are dealt with in the same way as other problems in order to re-establish a state of normality, *i.e.* to regulate oneself. Leventhal *et al* (22) argue that returning the balance back to normality will be done in three dynamic and interactive processes: (1) making sense of the problem through symptom perception and information from the doctor and nurses or other people, (2) dealing with the health status problem by coping strategies, *e.g.* taking medications or changing behaviour and (3) evaluating the effectiveness of the coping strategy and determine whether to opt for an alternative coping strategy or continue the chosen one. The model proposes that when an individual’s normal state is disrupted by illness the individual is motivated to return the balance back to normality. A chronic disease, which CAD is, often brings a disturbance of normal life. Therefore, patients strive to maintain a reasonable emotional balance and a satisfactory self-image, maintain a satisfactory sense of competence and master a sustained relationship with family and friends, and thus be prepared for an uncertain future. Using denial as a coping strategy may reduce symptom perception and thereby
moderate the disruption of normality and change illness cognitions. This is illustrated in
the categories of “moderating health threats” and “controlling relatives anxiety”, both
emerging from our data. “Moderating health threats” is due to the fact that the patient
does not understand the severity of the situation or, alternatively, that they are in a state
of denial or minimization of their illness. However, denial of reality cannot last forever,
and patients with diagnosis of serious illnesses must gradually face up to the reality.

The experiences between pain and distress from treatment, to avoid pain
and distress of the disease is also a part of solving the problem. This is part of the
patient’s attempt at trying to understand the severity of their illness. For many patients
returning to work is an important milestone in their recovery. The fact that patients fail
to return to work and resume a normal function represent a social and economic cost
and negative degree of life satisfaction (23). Coping strategies play a major role in
individuals’ psychological and physical well-being when they are confronted with
stressful life events (24, 25). One problem is that late in the rehabilitation phase, denial
can be related to non-compliance with care and treatment regimen (26). For patient who
undergo a PCI, work-related tasks might involve meeting demands such as modification
of lifestyle, carrying out complex medical regimens (i.e., multiple drugs therapies),
managing physical and emotional discomfort (e.g., pain, depression, anxiety, anger),
managing functional limitations and meeting demands from other chronic illnessness
(e.g., diabetes, hypertension, heart failure), successful management of these tasks
should contribute to improving quality of life (QoL). Coping actions and strategies for
managing everyday life; require that the clinician or nurse furnish both education and
emotional support. Nurses can work with patients to help them feel empowered to take
control of their condition.

The category “Trying to understand” illuminates the importance of the
patients comprehending how imperative it is to understand their disease. How are we
going to enable patients to understand the seriousness of the situation if we don’t follow
up on our own actions? We explain to the patients the seriousness of the situation,
however we sometimes delay the procedure, causing uncertainty and confusion for the
patients. This is even more important for the patients with risk factors, such as diabetes,
systemic hypertension and hyperlipidemia. For patients, illness perceptions are dynamic
conditions that change over time. For medical personnel, however, medical knowledge
is the main source of information on which perceptions and ideas regarding a certain
disease are based. Patients live with their illness every day so their own day-to-day
experiences with their disease and its symptoms are the main source of information on
which their perceptions are based. It is unfortunate that the medical personnel’s
explanations of symptoms and disease is not readily accepted by the patients as
replacement for their own ideas and preceptions (27).

That patients have more problems than just taking care of themselves is
even obvious in the category “Controlling relatives’ anxiety”, which includes even the
responsibility they feel in taking care of the uncertainty of their relatives. According to
the interviews, the patients need social support as well as professional help in their
struggles for readjustment to a new life situation. Generally, professionals are very good
in ruling out medical problems but ill-equipped to handle patients who are demanding
answers and solutions to their problems (28). It is an enormous uncertainty in an
individuals life not to be able to plan for the future or have no possibility to plan even
for the next step; to always need a plan B. They are forced to redesign their lives and
adjust to the new situation.

In a study by Lukkarinen (29), describing the life course of people with
CAD, and focusing on the process that overwhelms the patients at the onset of illness.
The author describes the subjective experiences after onset, during the in-patient period, and the one-year period of aftercare following PTCA or CABG. "The attitude to everyday life" was also described by the following characteristics: the health care personnel were unable to meet and recognize the patients' problems; everyday life was dominated by work; the illness separated patients from their families; the future was dismal and desolate; the patients lived one day at a time. The findings of our study also supports these conclusions.

Based on thirty-eight deep-interviews with patients in primary care, Kuzel et al (30) in line with the present study, found that preventable problems in primary health care led to physical or psychological harm. They found problems related to getting in touch with the doctor or the nurse, and even the problem of persuading the doctor to listen and understand what it was the patient was trying to describe. These are the same problems that we found in the present study, which we now assume to be of global character. It is important to note that a secure patient probably does not burden the health services as much as an insecure patient. One of the patients in our study described the health system as a "fortress"; when you are inside you feel safe with good care, but after discharge you are outside the fortress, the drawbridge is closed and it is in principle impossible to enter again unless one is carried in. In other words, one must be desperately ill to be attended to again.

As drug-eluting stents are now available, the restenos problem will most certainly be reduced quantitatively, however, the problems still remain for the patients that find themselves in the aforementioned situation.

**Conclusion and implications:**
Patients' perceptions of illness and illness-related events, such as symptoms, diagnosis, treatment and prognosis, are considerably affected by uncertainty. This uncertainty infiltrates their struggle to acquire the care needed, their endeavour to comprehend and moderate health threats, and their way of caring for and protecting their family and relatives.

We suggest, therefore, a surveillance system to ensure the availability for patients suffering from ischemic heart disease to communicate their problems related to their illness. This would also allow patients a more accurate and rapid assessment by having access to specialist competence regarding their chronic illness. We suggest that a patient administrative centre should be created for patients with cardiac diseases, including actual access to a database containing information on diagnoses, treatments and events. This patient administrative centre would be available around-the-clock manned by a competent and responsible nurse/coordinator at the cardiac clinic. By a telephone call, patients can be guided to the appropriate instance at the cardiac clinic. By this, the patient's illness-related uncertainty will be reduced and the accessibility to health care and caring will be improved.
REFERENCES


Table 1
Patients age, gender, previous interventions and CCS-class

<table>
<thead>
<tr>
<th>Patients</th>
<th>Gender</th>
<th>Age (Years)</th>
<th>Nr of CABG (prior interview)</th>
<th>Nr of PCI (prior interview)</th>
<th>CCS-Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>70</td>
<td>1</td>
<td>1</td>
<td>III</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
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<td>0</td>
<td>2</td>
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<td>0</td>
<td>1</td>
<td>III</td>
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<td>41</td>
<td>0</td>
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<td>III</td>
</tr>
</tbody>
</table>

Abbreviations: CABG- Coronary Artery Bypass Grafting, CCS-class Canadian Cardiovascular Society class, PCI- Percuaneous Coronary Intervention.
### Table 2

**Five categories and subcategories describing the patient’s expectations**

<table>
<thead>
<tr>
<th>Core category:</th>
<th>Living with uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcategories:</td>
<td>To live with uncertainty</td>
</tr>
<tr>
<td></td>
<td>To live with indecisiveness</td>
</tr>
</tbody>
</table>

- "I have learnt to take each day as it comes"
- "I think it’s my fault that it has come back again as I am obliged to say that I have smoked."
- "...maybe there is a reason why... it comes back in the same place"
- "...is it because of diabetes?"
- "Why was it just me that got this, be sick I mean, how is it going to be... when I am sixty, how will that be, that will be the end of me, I mean, thats how one thinks..."
- "...even if I need to have a big operation, they can’t guarantee that it will last... I think...
- "...just because uncertainty is awful and that's how I think, if they help me now... how long will it last?"

<table>
<thead>
<tr>
<th>Category:</th>
<th>Fighting for access to care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcategories:</td>
<td>To be not believed waiting</td>
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- "...but according to the doctor, it was still nothing to do with the heart as the doctor said that the EKG looked really good, therefore it must be something to do with the muscles and that I can be overwrought, and then I was told to go home!"
- "...then I felt that they didn’t believe that I had pain and that I was a bothersome old woman"
- "I felt it after one month, but they said that it can’t be, as before 3 months one can’t feel anything, and if you manage to get through 6 months then you will manage"
- "...and the second thing was the hell of trying to get hold of some doctor"
- "I went through quite a lot of agonising, that they didn’t admit me into the hospital and that I had to go home with angina for 4 weeks"
- "I’m telling you - I will sit down on the floor - I am feeling so poorly"
- "If I have been treated earlier I could have saved a lot of sick leave"
- "...it has been a very dawn-out process in the end I thought that I had been forgotten"

<table>
<thead>
<tr>
<th>Category:</th>
<th>Trying to understand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcategories:</td>
<td>To comprehend</td>
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- "...it’s the diabetes which causes all my problems"
- "...now afterwards it just feels so... why didn’t I understand that?"
- "...but I don’t know if that is... there is surely an explanation to why... it has come back in precisely the same place"
- "...it is probably better that it comes in the same place than coming somewhere new"

<table>
<thead>
<tr>
<th>Category:</th>
<th>Moderating health threats</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcategories:</td>
<td>To deny/reduce the seriousness of the situation</td>
</tr>
</tbody>
</table>

- "...well okay, maybe you have to blow it out again in the old stint"
- "This is a part of life, it shouldn’t be so remarkable... because it doesn’t make me feel ill... I manage to walk and do the things I want to do except just when it becomes tight"
- "In some way I have thought... Okay, okay... this is something that I need to get used to"
- "The more we are in and fix and rebuild inside the body here and there, the less natural it is for the body, and to operate the heart, I am really a little nervous about, it is after all the heart! The people I have talked to have said that it isn’t so bad, you do have pain relief... one has to believe in it"
- "The last thing the doctor said was operation... I replied that I don’t want to... can we try something else - if there is something else?""

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<th>Category:</th>
<th>Controlling relatives’ anxiety</th>
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<td>Subcategories:</td>
<td>Family and work</td>
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- "My family and wife are sad"
- "My husband and my mother - they were the ones that were nervous and cried, but I knew what I would be going through"
- "...and we all talk about it a lot we do... as soon as I have to go to the doctor...or something, then everyone gets together and talks about it"
- "No, and I don’t want to risk spoiling their holiday and as they have two small children with them who I love, they are wonderful, I really don’t want to ruin... no, I would prefer to be at home and lie down when I feel like it"
Figure 1 A model of the categories whereby the double-edged arrows show how the categories are linked to each other.