Exploring the information needs of patients with unexplained chest pain

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Background: Unexplained chest pain is a common condition. Despite negative findings, a large number of these patients will continue to suffer from chest pain after being investigated at cardiac outpatient clinics. Unexplained chest pain covers many possible complaints, and diagnosing a single cause for a patient’s pain is often described as difficult, as there are a number of possible factors that can contribute to the condition. For health professionals to meet patients’ expectations, they must know more about the information needs of patients with unexplained chest pain. The aim of this study was to describe information needs among patients with unexplained chest pain and how those needs were met by health professionals during medical consultations.

Methods: A qualitative design was used. Data were collected by means of seven individual interviews with four women and three men, aged 21–62 years. The interviews were analyzed by qualitative content analysis.

Results: The results are described in two subthemes, ie, “experiencing lack of focus on individual problems” and “experiencing unanswered questions”. These were further abstracted under the main theme “experiencing unmet information needs”.

Conclusion: Existing models of consultations should be complemented to include a person-centered approach to meeting patients’ beliefs, perceptions, and expressions of feelings related to experiencing unexplained chest pain. This is in line with a biopsychosocial model with active patient participation, shared decision-making, and a multidisciplinary approach. Such an approach is directly within the domain of nursing, and aims to take into account patient experience.

Keywords: information needs, qualitative research, unexplained chest pain

Introduction

Many people will experience unexplained chest pain within their lifetime, although the majority will not have it investigated.¹ Bass and Mayou² claim that noncardiac chest pain is a common condition worldwide. Jonsbu et al³ indicate that the majority of people referred to cardiac outpatient clinics for chest pain in Norway will be told that their pain is not due to a cardiac condition. Unexplained chest pain covers many possible complaints and diagnosing a single cause for a patient’s pain is often difficult because there are a number of possible factors that can contribute to the condition.³ Common causes are described as esophageal disorders, musculoskeletal problems, and pain referred from the thoracic spine, hyperventilation, and psychologic disorders. However, the risk of death from coronary heart disease is not significantly different to that in the general population,⁴ but there is substantial morbidity attached to unexplained chest pain, with work absenteeism rates around 29%.⁵
According to research, people with unexplained chest pain are often more anxious, with a higher prevalence of panic disorder than people with heart disease, and a high percentage continue to take cardiac drugs. Many have a similar level of functional disability and use health services as frequently as people with a positive diagnosis of heart disease. Persons with unexplained chest pain experience fear and anxiety, feelings of uncertainty, stress, and loss of strength. Fagring et al point to the fact that men and women had more similarities than variations in their descriptions of chest pain.

The traditional biomedical model has guided the assessment and treatment of persistent pain for many years. An extension of this understanding, the biopsychosocial model, including interaction of biological, psychologic, and social factors causing noncardiac chest pain and subsequent disability, is suggested. According to this comprehensive model, all diseases have biopsychosocial components that contribute to the experience of unexplained chest pain and the response to treatment.

Thus, there are a variety of challenges related to the complexity of living with unexplained chest pain, which presumably indicates a need for more knowledge and understanding in order to handle everyday life. Information needs are defined by Knowles as the gap existing between specific competencies and the ability of the learner to achieve these specific competencies at present. According to Timmins, it is difficult to extrapolate from the literature an exact definition of information needs for acute coronary syndrome patients because no clear definitions or consensus upon terminology is found. There are few studies about information needs from the perspective of persons with unexplained chest pain. However, in a qualitative study, Price et al aimed to understand the needs and experiences of attendees at a rapid access chest pain clinic and to determine the acceptability and effectiveness of the procedural changes. Changes in procedures helped patients to understand their pain, practice self-management, and consider altering their lifestyle. Another interesting aspect which points to the need to explicate knowledge needs further is the deviation between patients’ actual needs and health care workers’ expectations of those needs, as documented for coronary syndrome patients. The studies indicate that participants focused on stress and symptom management rather than modifying health habits.

In order for health professionals to create person-centered communication to meet patients’ expectations, there is a need to know more about the information needs of patients with unexplained chest pain. Person-centered communication seeks to elicit and satisfy the needs, preferences, and values that patients express themselves. Therefore, the aim of the present study was to explore information needs and how those needs were met by health professionals during medical consultations.

**Materials and methods**

A qualitative design was used to gather in-depth knowledge about experiences related to the information needs of people living with unexplained chest pain.

**Participants**

The participants were selected from a cardiac outpatient clinic at a university hospital in Norway. The inclusion criteria were diagnosis of unexplained chest pain (a cardiologist should have ascertained that patients’ symptoms had no apparent organic cause), age at least 18 years, and ability to understand and speak Norwegian. All eligible participants had a symptom-limited bicycle test in the cardiac outpatient clinic, and were given information about their test results. They also received standard information about risk factors and lifestyle factors related to the development of heart disease. Exclusion criteria were the absence of chest pain symptoms and having pathologic cardiac findings after the bicycle test. Patients who met the inclusion criteria were consecutively invited to take part in the study via a letter distributed by the head nurse in the cardiac outpatient clinic. This consecutive selection continued for a 6-month period. Those who were interested in participating contacted the head nurse. Four women and three men agreed to participate. The men were aged between 58–62 years and the women were aged 21–60 years. Five participants had also been assessed for chest pain once or twice before, in this or another cardiac outpatient clinic, and were told that their chest pain was unexplained.

Two participants had an academic qualification, one was studying to obtain an academic qualification, and four had a vocational qualification. Three were working full-time, two were working half-time, and two were receiving disability compensation. Two of the participants’ jobs involved physical work. Five participants lived in cities and two lived in rural areas.

**Ethical approval**

The persons who agreed to participate received both verbal and written information about the study, and were assured that the data would be treated confidentially and that they were free to withdraw at any time. They were asked to sign a written informed consent at study entry. Approval was sought from the regional ethics committee (2009/2243-7),
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and the investigation conformed to the principles outlined in the Declaration of Helsinki.

Data collection

Data were collected from semistructured individual interviews using an interview guide (Table 1). The interviews were narrative in form and were conducted as a conversation in which the informant was encouraged to talk freely. The interviews were carried out by the first author under the same conditions in accordance with patient preference in an undisturbed room in either the cardiac outpatient clinic or in a room at the university. All interviews lasted for approximately one hour.

Data analysis

Interview texts were analyzed using qualitative content analysis, which included identifying meaning units, categories, subthemes, and theme, to provide new knowledge and insights into the topic under investigation (Table 2). The analysis followed several distinct steps, from the interview situation to the validation of findings (Table 3): audiotaping and transcribing the interviews; reading the text several times; performing content analysis; selecting quotes; and validation.

Results

A main theme of “experiencing unmet information needs” was formulated. This illustrates the latent content. To retain the authenticity of the participants’ experiences, direct quotations from the interviews were selected to illustrate the most commonly reported aspects of each category or variation within the subthemes (Table 3). The two subthemes of “experiencing lack of focus on individual problems” and “experiencing unanswered questions” form the subheadings in the following presentation of results.

<table>
<thead>
<tr>
<th>Table 1 The interview guide</th>
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</thead>
<tbody>
<tr>
<td><strong>Interview sequence with topics or questions asked</strong></td>
</tr>
<tr>
<td>Opening</td>
</tr>
<tr>
<td>Main question</td>
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<tr>
<td>Can you tell me something about the information you received at the cardiac outpatient clinic?</td>
</tr>
<tr>
<td>Closing</td>
</tr>
<tr>
<td>Summary of main topics with the most important remarks</td>
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</tbody>
</table>

Experiencing lack of focus on individual problems

Not being seen as a person

The participants attended the cardiac outpatient clinic with uncertainties regarding their chest pain. They wondered how it would affect them in the future, and what treatment was needed. Most were positive towards the health professionals, but wanted them to focus on their individual problems. The majority of the participants perceived that the information was very general. One participant stated:

“[…] they don’t think that every person has individual questions and things they would like to know.” (Woman, 21 years)

The bicycle test was perceived to be rather generic as well. They were not reassured by a negative result. The tests were not found to be tailored to them and their particular problems.

“That bicycle test for me is like, I did not get breathless or tired […] I bike so much [usually] that I did not feel any of that […] but they [the health professionals] are doing their program, even when they don’t get anything out of it. So to have gotten a result, I should have cycled properly.” (Man, 58 years)

Some indicated that they did not feel that the professionals listened to their individual history of pain. The participants regarded their perceived information needs as individual ones and expected the health professionals to look into their daily life. They wanted the physician to prescribe a more facilitating job situation, for example, including breaks, reduced working hours, and avoidance of night shift work with increasing age. One participant said she would have asked more questions if she felt there was room for this. The participants also said that they wanted to understand their chest pain. Some were confused after seeing the cardiologist and were no closer to understanding their problems after the consultation. However, one of the participants said the information was very useful.

Lack of time for asking questions

Some participants became confused because of the short consultation session.

“I didn’t [have time to] ask any questions or anything like that. They told me I could ask, but in a way, yes, it went like quick, quick, quick. So, it’s obvious, they do it [consultations] many times.” (Woman, 21 years)
The participants felt unable to think things over and to ask appropriate questions within the time frame. Limited opportunities to discuss the diagnosis, particular worries, and further management were reported. One of the participants suggested that a website about chest pain should be set up so she could get more answers to her questions.

**Alone with their problems**

Most of the participants felt they were alone with their problems. Some felt that social contacts were difficult to maintain because the pain was bothering them so much.

“So often you just loaf about at home, you don’t go out to a single thing, as crazy it may be. It’s terribly wrong, I know myself. You have to pull yourself together, but it isn’t always easy. It’s not.” (Woman, 55 years)

They also talked about the pain causing depression. One participant said:

“Because of that [the pain], I think it is very easy to get depressed, and it [the situation] feels as heavy as stones.” (Man, 62 years)

The pain situation was a troublesome burden. This participant also blamed himself for the situation because he had been working too hard for too long. He thought it would be easier to deal with if he had someone in the same situation with whom he could talk. Further investigation and referral to a cardiologist every second year were suggested as a follow-up preference by the participants. In such follow-up consultations, they could be investigated with the opportunity to share experiences of pain on a continuous basis.

**Experiencing unanswered questions**

**Uncertain about how to formulate questions**

The participants reported that it was difficult to ask questions when they did not know why they were in pain, and could not find any pattern to the level or intensity of the pain. They wanted the staff to inform them about what was important to know.

“Because I am of the opinion that when you come to a doctor, then he knows what to do […] if he is good at informing, he just explains from the investigations.” (Man, 56 years)

Several participants wanted the health professionals to inform them without first asking questions. Due to difficulties in formulating their questions, the participants wanted the professionals to be alert to both verbal and nonverbal...
Still uncertain of the cause of pain

The participants’ most frequently mentioned need was to know what was causing the chest pain, and all of them considered this to be important. All but one of the participants thought they had a cardiac disease, even though their cardiologist told them that the test results were negative.

“The physician said he could not find anything wrong with my heart, but there is something. There is something, because I feel it.” (Woman, 58 years)

The participants still felt the same chest pain as before the consultation, and were not reassured about the result of the test.

“But I have something, somewhere in the cardiovascular system. I have no doubt.” (Man, 58 years)

There were no connections found. The participants did not find a pattern for their chest pain, which made them uncertain. They wanted to understand their chest pain, why it fluctuated over time, and why it changed without understandable reasons. The participants wanted to be able to help themselves and to know what to do.

“The only thing I missed [during the consultation in the cardiac outpatient clinic] was basically, what is it [the chest pain], and what can I do about it?” (Woman, 21 years)

Participants reflected over possible causes. Most of them had someone in the family with heart disease and wondered if their condition was related to heredity. They reflected on what information their family members had received regarding the cause of their pain, and wondered if their own chest pain was caused by the same thing. Others wondered if there could be psychologic causes. Even if they did not have problems like anxiety or depression, some participants reflected over possible psychologic causes. Causes in daily life were also reflected upon, such as various stressful events and burdens.

Uncertain about how to exercise in a safe way

Physical activity was emphasized by all participants. Advice on an adequate level of activity was of interest, as was advice on how to respond when the pain starts.

“I can sit normally, like I do now, and then lifting 100 kilograms here, and then down to the floor, quite a number times. So I think I can use my chest and all this here then. And then, there is no pain at all, there isn’t. I wonder if I have been using my muscles incorrectly, even though I don’t think so.” (Man, 60 years)

According to this participant, the pain comes and goes and is not associated with exercise. Some participants were confused by being told to exercise in spite of pain and expressed anxiety about doing exercise. Some admitted lack of physical strength and/or self-confidence in performing common daily activities. The physician in the cardiac outpatient clinic told the patients that they had less chance of developing heart disease if they were in good shape. Even well trained participants said that they had intensified their training after being told in the cardiac outpatient clinic that physical training can help them to avoid chest pain. Only one of the participants had limited exercise after the consultation and was striving to “get started”.

Uncertain if food is causing pain

Some of the participants wondered if their diet was causing chest pain, but could not find a connection.

“But on the other hand, you can only think: why do some get pain, and then I think; they can’t find anything [cause of the chest pain]. So I’m not so sure of anything. But then
I have to add: I’m not the world’s cleverest man when it comes to food, I must admit. So I could certainly been more careful with my diet. I could certainly have been more careful about many things, and maybe it has something to do with that, I don’t know.” (Man, 58 years)

Symptoms of heart burn were experienced. Four participants had been referred to gastroenterologists to look for esophageal sources of their pain. Two of them had gastrointestinal abnormalities. At that time, it was indicated that this could be the cause of the chest pain. The participants nevertheless wondered what in their diet could give chest pain.

“But I know at least that when I eat, it [chest pain] can come […] I’ve felt it with egg sometimes, but I don’t know why. But it can be other things as well […] like bread, so it’s a mystery.” (Woman, 54 years)

Some were careful about what they ate, and suggested that more information be given about ways of improving their health by dietary changes.

Discussion

The aim of this study was to explore the information needs of people with unexplained chest pain and how those needs were met by health professionals during medical consultations. The participants experienced that their information needs were not adequately met. The two subthemes of “experiencing lack of focus on individual problems” and “experiencing unanswered questions” form the subheadings in the following discussion.

Experiencing lack of focus on individual problems

The results of our study indicate that patients felt that they did not receive attention for individual problems when attending the cardiac outpatient clinic. This is supported by Price et al13 who pointed out that patients wanted a definite diagnosis, an understanding of the problem, and to learn about self-management. Laburnée et al18 argue that there are no standardized rules and methods to deliver information and education or to evaluate the results of therapeutic education. This clearly points to the responsibility of health professionals to identify patients’ information needs. In our study, all participants had received general information about their condition and risk factors for developing a cardiac condition. Timmins12 found in her study that a natural conflict existed between nurse and patient priority of information needs among acute coronary syndrome patients. According to Timmins,12 there is agreement that cardiac patients should have individualized teaching based on assessment of information needs, but there is no clear explanation of precisely what this is. This is in line with our findings, which indicate a conflict of needs priorities in terms of what health professionals and patients value as important information. Presumably, this may influence the level of uncertainty, as described in the study.

In health care, the traditional biomedical model often guides assessment and information in connection with medical consultations.19 One main focus is to evaluate whether there is a physical condition present that may explain the symptoms. It is important to diagnose and treat pathologic pain conditions, because a diagnosis will indicate or guide treatment options. All participants in our study said that their chest pain was influenced by their own experiences and was unique to them. This is also in accordance with the biopsychosocial model2,10 which contributes to understanding of psychosomatic and environmental components in unexplained chest pain.

Participants expressed that it was not easy for them to communicate with anyone about problems related to their chest pain. Some also expressed anxiety and depression. Van Ravensteijn et al20 point out that diagnostic testing hardly impacts on the level of someone’s doubts and fears. Jerlock et al2 suggest nurses could talk to patients to elicit their illness narratives in order to have a deeper understanding of the patients’ experiences. This was also shown in our study. In a study by Price et al,13 communication problems were identified and interpreted as related to failure of clinical procedures to meet patients’ needs. According to Dammens et al6 and Jonsbu et al,1 psychologic factors may play a role in the pathogenesis of unexplained chest pain. It is indicated that there is a higher proportion of panic disorder and major depressive episodes among this group of patients. Depression and poor social support are significant risk factors for coronary heart disease21 and panic disorder,22 while stress and anxiety can trigger coronary events.22 It is also claimed that people experiencing such psychosocial difficulties are more likely to be physically inactive, which is also an independent risk factor for cardiac heart disease. Robertson et al23 reported that people with unexplained chest pain viewed their conditions as significantly less controllable and less understandable than those whose pain was cardiac in origin. As suggested by Robertson et al,21 a multidisciplinary approach to meet patients’ different information needs is required. In addition, a sympathetic appreciation by the health professionals to take psychologic factors into account in the communication
with the patients is suggested. Such approaches presumably promote active patient participation. They may reduce psychologic and psychosocial difficulties and help the patients to experience more control and understanding, and as such reduce cardiac risk factors.

**Experiencing unanswered questions**

The participants were uncertain about how to formulate questions and did not feel their questions were answered. In the cardiac outpatient clinic, they were informed that the results of the tests were negative but remained uncertain about the cause of the pain. The participants were uncertain about how to exercise in a safe way and about issues related to their diet. A definition of uncertainty, which is valid across disciplines, is proposed by Penrod, who indicates that people who are uncertain have a perception of being unable to assign possibilities for what to do or think. This was also true of the participants in our study, who felt pain but had no explanation for it. According to Penrod, this promotes a discomforting, uneasy sensation that may be affected through cognitive, emotive, or behavioral reactions, or by the time and changes in perception of circumstances.

The participants in our study had received information that a pathologic cardiac condition did not explain their chest pain, resulting in their uncertainty. However, their experience of chest pain may have forced them to search for alternative explanations which link chest pain with heart disease. Following Leventhal et al, the chest pain compels the individual to create a subjective perception of a heart disease, which subsequently inspires a search for specific bodily signs of cardiac pathology. These researchers point to the importance of modeling patients’ subjective perceptions of the investigation, procedures they use to manage their problems, questions they ask, and the criteria they use to evaluate outcomes. According to research, it is increasingly important to understand how the perceptions, experiences, and impact of having pain might influence a person’s interpretation and response, so that health professionals can, in turn, respond more appropriately. This is in line with person-centered care, which is focused on the patients’ narrative, partnership, and documentation of negotiated care and decisions.

The majority of the participants in our study were not reassured by the information that heart disease was not the cause of their chest pain. Some of the participants described the pain as “mysterious”. If the person’s pain beliefs are ignored, it may complicate or entirely undermine the reassurance of having negative findings of heart disease. This is in accordance with reports by several other authors, who found that if pain becomes persistent, patients may abandon previously held cultural or personal beliefs about pain to form new pain beliefs that are more consistent with their persistent pain experience. Preparing patients by means of information for negative test results is assumed and may make it easier for them to accept simple reassurance from a cardiologist or cardiac nurse.

According to the results, the participants were uncertain about how to exercise in a safe way. Thompson et al claim that important information for the participants must focus on the positive results of physical activity and that immobility might be far more harmful for them. A study by Williams et al indicates that patients’ perceptions of their own risks are often not a reflection of their true risks. The patients in their study overestimated their risk factors compared with an objective measure, regardless of whether they received information or not. In relation to our study, the participants did not receive explanations of cardiac origin for their chest pain. They were still uncertain about how to exercise in a safe way and expressed anxiety about doing physical exercise.

Some of the participants in our study expressed a lack of physical strength for daily living. Wise and Patrick stress that a modest increase in daily activities can improve health and quality of life for persons with unexplained chest pain. Jonsbu et al use the expression “noncardiac chest pain”. In their study, patients with noncardiac chest pain were exposed to physical activity as a part of a cognitive behavioral therapy intervention. According to Mayou, patients with noncardiac chest pain may have high levels of fear of body sensations, and it is assumed that a reduction of this fear will lead to a decrease in patient limitations, for example, with exercising. In the study by Jonsbu et al, it was therefore assumed that exposure to physical activity could be a useful element. When exposed to physical activity, the treatment group in their study showed significantly larger improvements in terms of reduced avoidance of physical activity, fear of bodily sensations, depression, and some domains of health-related quality of life. Some participants in our study expressed avoidance of physical activity and fear of physical activity because of the chest pain they felt.

Our participants also reported problems with digestion. Hershcovici et al claim that gastroesophageal reflux disease (GORD) is by far the most common cause of noncardiac chest pain. Further, they say that esophageal dysmotility is relatively uncommon among patients with non-GORD-related noncardiac chest pain. They argue that it is still unclear if longitudinal esophageal muscle contractions are a direct
cause of chest pain or if they represent an epiphennomenon that is associated with symptoms of such pain.

Some of the participants experienced anxiety and depression. Lillestøl et al19 claim that anxiety and depression are common in patients with self-reported food hypersensitivity. However, according to Lind et al,39 psychologic factors were not major predictors of symptom severity in patients with subjective food hypersensitivity. The participants in our study had chest pain and no cause of cardiac origin was found. They still believed they had a heart disease, but also considered other explanations for their chest pain. Notably, some were investigated for GORD.

Implications for practice
The results indicate that listening to patients’ beliefs, perceptions, and expression of feelings related to experiencing unexplained chest pain should be encouraged and acknowledged by health professionals. The patient’s narrative is thus a useful tool in the consultation when dealing with the complexity of living with information needs and uncertainty related to unexplained chest pain. Topics related to physical activity and diet seem to be important content in conversation. Dialoguing about pain as a normal and multifaceted phenomenon in life is also suggested as important. A multidisciplinary approach, such as team work among cardiologists, dieticians, specialized nurses, and physiotherapists, with a genuine focus on the patient perspective, and on shared decision-making is proposed.

Methodologic considerations
Because few individuals agreed to participate, we acknowledge that some data may be missing. However, the material gives important answers to the research questions and discloses both manifest and latent content. Although age and gender varied in the sample, the data analysis revealed only minor variations. To secure trustworthiness, several credibility of the analysis, categories, subthemes, and theme in the search for manifest and latent content were identified and formulated in the course of the research team’s discussion.

Conclusion
This study reveals unmet information needs, specifically a lack of focus on individual problems and unanswered questions during medical consultations as experienced by people with unexplained chest pain. Existing models of consultations should be complemented to include a person-centered approach meeting patients’ beliefs, perceptions, and expression of feelings related to experiencing unexplained chest pain. This is in line with a biopsychosocial model with active patient participation, shared decision-making, and a multidisciplinary approach. Such an approach is directly within the domain of nursing, and aims to take into account the patient’s experience of their condition.

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Disclosure
The authors report no conflicts of interest in this work.

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