

Living with a chronic disease: A quantitative study of the views of patients with a chronic disease on the change in their life situation

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Abstract

Objectives: Chronic diseases have an impact on and change patient's lives which means that they need to find ways to cope with the new situation. The aim was to describe how the chronic disease has influenced patients' views of their life situation.

Methods: The study was quantitative in design with data collected using a semi-structured questionnaire. Descriptive statistics were used to compare similarities and differences between patients with asthma-allergy, diabetes mellitus, cancer and inflammatory rheumatoid arthritis.

Results: Changes in their life were experienced as a negative outcome for the majority of participants. Support can be in the form of interpersonal support from various persons, but also from activities and beliefs/religion. Family and friends as well as healthcare professionals were identified as being most supportive. Sadness and worry were the most common emotions among the participants and their surrounding networks.

Conclusion: People with a chronic disease have to live with the consequences the disease has for their life situation. They need to find strategies to cope with the negative outcome in their new life. Support from their own network and healthcare professionals can be helpful in the new life situation.

Keywords

Chronic disease, emotions, life situation, strategies, support

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Introduction

Chronic diseases have an impact on and change patients' lives, and the way they experience their bodies alters. Patients may struggle with identity and self-esteem, a shrinking lifeworld and a challenging reality.¹ The chronic diseases become part of the patients' lives, whether they affect their physical health and functions, autonomy, freedom and identity, or threaten their life.² The patients are forced to change their lifestyle, which they often experience as losing control, and to minimise loss of control they feel a need to mobilise resources, and plan and prioritise their life.³ Having a chronic disease can lead to stressors such as life-threateningness, progressive deterioration and controllability. It has previously been identified that there are stressors that are common to different chronic diseases.⁴ Patients who have a chronic disease have to find new ways to cope with their changed situation and develop coping strategies that relate to the way they think and act in order to manage stressful situations. This may involve problem- or emotionally focused coping, depending on the individual's

personality.⁵ Being given information is important, as is learning how to talk to others. The patients' own thoughts about their new situation can also influence how they cope.^{6,7} Another aspect of coping with the new life situation is the type of support the patients can receive. The social support received depends on the patients' available network of people, and the need for social support will vary depending on the patients' age and need. Overall, social support has been seen as a buffer against the risks to the well-being of chronically ill patients.⁸

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A stressful life situation also gives rise to different emotions. These emotions can be interpreted as an expression of behavioural and physiological regulation. The emotions can promote adaptive responses or social communication and provide information about internal states.⁹ Patients with a chronic disease experience different emotions depending on the factors on which they are based.¹⁰

This study focuses on four chronic diseases: asthma-allergy, diabetic mellitus, cancer and inflammatory rheumatoid arthritis. We chose these diseases because they all affect patients' daily lives practically and emotionally. They may appear different, but they all have a potentially life-threatening component, though public opinion on this may vary. So, even if they differ in terms of risk factors, treatment and progression, we will focus on those parts that are important and similar, irrespective of the other parts of the diseases. There are many other diseases that can lead to a similar view of life, life-changing needs and influence on life. These four diseases are common in health care, which has enabled us to reach such patients, and this knowledge may be helpful to other patients with one of these life-changing diseases. Asthma-allergy affects the physical and psychological well-being of sufferers. They experience limitations and have to develop strategies to increase their level of functioning in daily life. Asthma-allergy can also cause anxiety and affect physical well-being.^{11,12}

Patients with diabetes mellitus may have to change many areas of their life. This may be due to them trying to maintain good glycaemic control and monitoring their food during the day. Diabetes can also be experienced as a loss of control that can lead to an acute crisis or reduced quality of life.^{13,14}

Cancer has been documented as a traumatic disease that can develop to become chronic and life changing, bringing a new reality to which cancer survivors must adapt, and can have both positive and negative impacts on life.^{15,16}

Inflammatory rheumatoid arthritis causes fatigue, pain and stiffness. The disease also leads to psychological distress and impairs emotional well-being.¹⁷⁻¹⁹

The aim of the study was to identify the life-changing aspects of chronic disease,⁷ and this article describes how chronic disease has influenced the participants' views of their life situation. The study focused on the kind of support that the patients experienced as helpful and who provided the support. The study also aimed to identify the kinds of emotions that were experienced by persons living with a life-changing chronic disease. The result may help us learn more about what it is like to have a chronic disease and its influence on the daily lives of the people with it. The study focuses on four diseases that can be life changing both practically and emotionally.

Methods

Study design

The study was quantitative in design with data collected using a semi-structured mixed questionnaire with an option for patients to add their own comments to the questions. A

mixed questionnaire can facilitate data analysis with a low *dross or bias* rate and provide probability samples.²⁰ The open-ended responses were used to illustrate the similarities and differences between the diagnoses according to the main answers to the questions. Descriptive statistics were used to compare similarities and differences between patients with asthma-allergy, diabetes mellitus, cancer and inflammatory rheumatoid arthritis. A pilot study was conducted with in-depth interviews with three patients with different diagnoses. The results of the interviews were analysed by the research group to identify crucial experiences of having a chronic disease. The research group then constructed the questionnaires based on the results. The questionnaire was tested for comprehensibility on five patients. The final questionnaire comprised 21 questions and an option for comments.²⁰ In this article, we concentrate on the following areas: whether the disease changed the patients' view of life; who provided support and what was experienced as helpful; and the emotions of the patients and the people in their social networks with regard to the situation.

Settings

The study was conducted in the medical, rheumatology, lung, palliative and oncology clinics of a university hospital in western Sweden. We recruited patients affected by asthma-allergy, cancer in the curative stage as well as early and late palliative stages, diabetes mellitus and inflammatory rheumatoid arthritis. They were all patients at the hospital, which meant that the disease was serious and needed treatment on the open ward at the hospital. The study was approved by the Regional Ethical Review Board in Gothenburg (423-15).

Data collection

Data were collected over a 7-month period between October 2015 and October 2016. Information about the study was presented in a brochure in Swedish that was available in the various waiting rooms at the hospital where the patients were being treated. Those who were willing to participate completed the questionnaire and sent it back to the researcher in a prepaid envelope. The questionnaire had closed questions, and the participants were able to tick between 3 and 5 options. Some questions had between 7 and 10 options, of which more than one could be ticked. After each question, the participants could add their own comments on the question topic. The questions covered the information that the patients had received, their feelings about their diagnosis and life situation, the impact on their life situation, their experiences of having a disease and their need for support.⁷ The emotions of the people in the patients' social networks were evaluated through the patients' own views of their reactions. A power analysis was performed in order to carry out a statistically complete comparison between the different diseases. Although we did not receive enough questionnaires to

provide a statistical result for the differences between the diseases, we can present a description of life-changing diseases in general and identify some differences. The patients took 498 brochures from the waiting rooms, and 215 questionnaires were answered and sent back, giving a response rate of 43%.

As the information and invitation to participate in the study were open in the form of a brochure in a waiting room, it was not possible to send a reminder to the patients. This meant that only those who felt that they wanted to participate returned the questionnaire. The inclusion criteria were that the participants had one of four diseases: asthma-allergy, cancer, diabetes mellitus and inflammatory rheumatic arthritis. The participants had to be over 18 years and able to understand the Swedish language. The invitation to the study was open, and only those who wanted to participate gave their consent. All of the participants who answered were over 18 years and understood the Swedish language. Consequently, no one was excluded by the researcher.

Data analysis

The questionnaires were analysed using descriptive statistics comparing proportions, similarities and differences between the diagnoses according to the questions. Descriptive statistics were also used for analysis of frequencies for categorical variables. Analysis was carried out using IBM SPSS Statistics Version 22. The open-ended responses were used to illustrate the similarities and differences between the diagnoses according to the questions. The analysis of the open-ended answers which were presented in the form of quotes. The quotes were chosen by examining closely the topics of the questions in the questionnaire and comparing in order to describe them with the main results of the answers.²⁰

Results

Participants' characteristics

All the participants who answered the questionnaire were aged over 18 years. Most were female with a high level of education. There were unequal numbers of participants in the diagnosis groups: most patients had cancer (53%) or diabetes mellitus (18%). For participant characteristics, see Table 1.

A summary of the results is shown in Table 2.

Has the disease changed their view of life?

The past. Changes to their *view of life* were experienced as a *negative* outcome by 67% of the sample when they received their diagnosis. The asthma-allergy patients felt most negative about their *view of life* with a result of 83%. Only 4% of the sample had a positive view of their life situation. The negative outcome was described as difficulties managing work, many medical check-ups, and that the

Table 1. The participants' characteristics.

	Total, n=215	
	n	%
Gender		
Male	43	20
Female	171	79
Missing	1	1
Age		
20–29 years	14	7
30–39 years	23	11
40–49 years	24	11
50–59 years	51	24
60–69 years	50	23
70–79 years	37	17
80–89 years	14	6
Missing	2	1
Employment		
Employed	88	41
Sick leave	33	15
Retired	69	32
Partly retired and partly sick leave	10	5
Missing	15	7
Highest level of education		
Primary school	23	11
High school	49	23
University degree	133	62
Missing	10	4
Living situation		
Living alone	68	32
Cohabiting	136	63
Missing	11	5
Parenting		
Have children	150	70
Have no children	60	28
Missing	5	2
Diagnosis		
Asthma-allergy	18	8
Cancer	113	53
Diabetes mellitus	38	18
Inflammatory rheumatic arthritis	36	17
Missing	10	4
Years since diagnosis		
0–2 years	74	34
2–4 years	28	13
4–6 years	18	8
6–8 years	12	6
>8 years	73	34
Missing	10	5

disease controlled how they lived their lives. The family was involved and sometimes all the family members needed to make changes to their lives. For many, the negative experience was that the disease gave them various symptoms that affected their life situation:

Table 2. Summary of the results.

View of life	Support provided	Emotions of the patient	Emotions of the participants in the social network
Most thought the disease had had a negative effect on their life situation both in the past and in the present.	Family and friends provided most support.	Sadness, despair, relief and incomprehension decreased over time from the time of diagnosis until the present. Feelings of hope increased over time.	Sadness and worry were the most common feelings.

I was on sick leave. My employment was terminated because of my disease and my whole life changed. (Affected by asthma-allergy)

It was a burden on my life, I felt trapped and I always had to watch myself. I am never on holiday. (Affected by diabetes mellitus)

The present. At the time of the study, 66% still experienced their *life situation as negative*, regardless of the disease. Their life had not be better according to that they tick the negative outcome in the question. A minority of participants, 8%, reported a positive view of their life situation. This meant that some, especially those with asthma-allergy, had been able to turn negative thoughts into something positive:

I had to make many changes to the way I live, and this affected me and my family. But at present I have a better balance in life. (Patient affected by inflammatory rheumatoid arthritis)

I thought everything triggered the asthma and I had a lot of problems. Now I try to take care of myself and have a pretty good quality of life. (Patient affected by asthma-allergy)

In order for the participants to describe a part of their life situation, they were asked whether they thought about their disease in their daily life, given a view of how the disease influences the life situation. The results showed that 69% of the participants thought about their disease always or often, and only 9% seldom or never had their disease on their minds. Here, the asthma-allergy participants also stood out from the patients with the other diagnoses in terms of thinking about their disease often or always, as was reported in 83% of cases. These patients needed to be aware of what could cause allergy symptoms throughout the day. On the other hand, participants with diabetes mellitus had the highest score for never or seldom thinking about their disease with a result of 21%. They reported that they focused on other things.

Always

As an allergic person I always have to think about my surroundings, smoke, food and so on. (Patient affected by asthma-allergy)

Table 3. Experienced as supportive (more than one alternative could be selected).

	Percent (N)
Family	84 (182)
Friends	62 (136)
Healthcare professionals	60 (131)
Physical activities	49 (105)
Leisure-time activity	38 (82)
Working	34 (73)
Hope	33 (70)
Beliefs/religion	31 (66)

Often

Sometimes I try not to think about my disease, but it is difficult because of the pain. (Patient affected by inflammatory rheumatoid arthritis)

Seldom

I think about everything I can do instead of the things I can't do. I find new ways of doing the things I can't do. (Patient affected by diabetes mellitus)

Who provides support and what is experienced as helpful? Support can be both interpersonal from various people and in the form of activities and beliefs/religion. Family and friends as well as health care professionals were identified as most supportive. There were some differences between the participants in relation to the different diagnoses, for example, the participants with cancer or inflammatory rheumatoid arthritis described more often that they had more support from family and friends than the participants with other diagnoses did.

The activities that were experienced as providing most supportive were physical, at 49%. A higher number of participants with asthma-allergy and diabetes mellitus regarded activity as supportive. Leisure-time activity and work as well as hope, beliefs and religion were seen as supportive, coextensive with the diagnosis, at between 31% and 38% (see Table 3).

The participants' emotions

Sadness, worry and despair were the most common emotions at the time of receiving the diagnosis, and this was

reported irrespective of diagnosis. The descriptions of the changes in emotions showed that four had decreased similarly and one had increased. Sadness (−12%), despair (−13%), relief (−12%) and incomprehension (−11%) decreased from the time the participants received the diagnosis to the time of the study, irrespective of diagnosis. All the participants, irrespective of diagnosis, had more than doubled their feelings of hope (+13%). However, there were some differences between the diagnoses. The participants with asthma-allergy had a higher score than the participants with the other diagnoses for anger (+16%) and hopelessness (+22%) at the present time. The participants with diabetes mellitus had a lower score for relief and the participants with cancer a lower score for despair. The participants with inflammatory rheumatoid arthritis had a lower score for sadness and relief. These differences between the different diagnoses were not seen for the other emotions (see Table 4).

Table 4. Participants' emotions at the time of diagnosis and at the present time (more than one alternative could be selected).

	Percent (N)	
	At the time of diagnosis	At the present time
Sadness	53 (109)	41 (83)
Worry	42 (90)	48 (100)
Despair	31 (63)	18 (35)
Anxiety	26 (54)	23 (49)
Relief	21 (44)	0.5 (1)
Anger	20 (41)	21 (43)
Hopelessness	19 (39)	21 (43)
Incomprehension	17 (34)	6 (12)
Hope	15 (33)	33 (69)
No reaction	8 (18)	14 (30)

Emotions of the people in the participants' social networks at the present time

Emotions. The most common emotions experienced by the people in the participants' social networks (family, friends) were sadness (52%) and worry (51%). They have to comfort their loved ones even if they do not feel good themselves.

With regard to the different diagnoses, the social networks of the participants with cancer had higher scores than those of the participants with the other diagnoses for sadness (65%), worry (62%) and hope (36%). The cancer disease evoked thoughts of death and dying, which may have made the people in their social networks feel sad and worried. Despite this, the people in the social networks of the participants with cancer felt more hope (24%) than those of the participants with the other diagnoses. This hope was linked to support from the people in the social network. For the

Table 5. Emotions experienced by participants' surrounding networks (more than one alternative could be selected).

	Percent (N)
Sadness	52 (112)
Worry	51 (110)
Incomprehension	31 (67)
Despair	30 (65)
Hope	24 (51)
Anger	19 (41)
Anxiety	15 (32)
No specific feeling	14 (30)
Hopelessness	10 (23)
Relief	5 (11)

other emotions, similar reactions were reported by the people in the social networks for all diagnoses (see Table 5).

Discussion

Summary of key findings and comparisons with the literature

This study examined how patients experienced receiving a chronic diagnosis such as asthma-allergy, cancer, diabetes mellitus or rheumatoid arthritis. All these diseases influenced the patients' social and physical environment, and either enhanced or impeded management efforts.²¹ The participants in this study had a negative view of their life after receiving the chronic disease diagnosis. Why so many had a negative view of their life is up for discussion, but it could be because they had been ill for a while before they received their diagnosis and the way they were able to prepare themselves for having a serious disease.⁷ They had to live with the consequences of the disease for their life situation even before the diagnosis. When they had had the diagnosis, they were still affected by the influence of the chronic disease on their daily life. Asthma-allergy participants described that they needed to be aware of not being exposed to certain allergens, in line with the description by Foster et al.²² This negative feeling could change when a patient became accustomed to the disease, in the time between the past and the present, but only a minor proportion of the participants in this study turned their negative feelings into a positive view. However, this is their life situation and they have to find strategies to manage the negative outcome of their new life in order to create as good a quality of life as possible. Di Tella et al.²³ report that patients with fibromyalgia syndrome, another chronic disease, often use problem-focused coping to help control or solve the problems the disease can cause. On the other hand, this did not seem to be helpful when it was beyond the individual's control to remove the source of distress, as may be the case when the patient depends on other people and as the disease progresses.

One aspect experienced as helpful in the life situation was the support that the participants felt they were able to receive. Family were described as giving most support, which is also in line with the results in this study.⁸ The process of integrating the disease into their lives as an inner process consists of a complex co-existence between living a life and living an illness.²⁴ Social support from the family network can be experienced as helpful in this process, and this was mostly described by the participants with cancer and inflammatory rheumatoid disease in this study. Why this phenomenon occurred here is difficult to say, and we have not found any discussion on this in the literature. Support with daily tasks as well as emotional support can be helpful, given that the new life will not be the same as life before the diagnosis. The new element seen in this study was that activities and work were seen as providing support. This may be because they were able to think about something other than the disease, which, as far as we know, has not previously been reported in the literature.

In this study, the participants gave their view on which emotions were common and how they changed with time. Although it cannot be known if these changes are influenced only by the disease, the disease is part of their life and will influence their emotions. The most common emotions at the beginning of the period of illness were sadness, worry and despair. As time passed, the participants indicated a possibility of finding ways of managing their situation, which could be the reason sadness, relief, despair and incomprehension decreased. It was interesting that hope increased from the time of receiving the diagnosis to the present time among all the diagnosis groups. This means that if they are able to focus on a better future and have greater choice/will, as seen earlier by Duggleby et al.,²⁵ this can be helpful in coping with the new life situation. The experience of having a chronic disease can change to create positive emotions after some time. Nevertheless, the emotions influenced the participants' life, and a decrease in sadness and an increase in worry could both result from having a chronic disease and from not being able to fulfil their expectations in life.²⁶ There were some differences in emotions described by the diagnosis groups that may be related to the way the participants experienced that the chronic disease had influenced their life.

The emotions experienced by the people in the patients' social networks affected the participants and their view of their life.^{9,27} The most common emotions were sadness and worry. The participants with cancer described the people in their social networks as more hopeful than the other diagnosis groups did, and the reason for this may be that the longer the cancer patient survives, the stronger the belief that they will not die in the near future. Sadness and worry were common among the participants and the people in their social networks. Sadness can result from an experience of something having happened that no one wanted and life having

changed in a way the person had not chosen. The worry can be about an unknown future and how life will turn out and be affected by the disease.

Strengths and limitations

Our study aimed to identify how a chronic disease is experienced. Despite the study covering four diseases, the result pointed to similarities between them.

The result showed the participants' views of life after developing the chronic disease. They had to live with the consequences of the disease for their life situation, and they experienced having a chronic disease as negative. Support can be helpful in the new life situation and was reported as being mostly from family and friends as well as health care professionals. Support was identified for both daily tasks and emotions. The new element found by this study was that activities and work were experienced as support. This also generated much emotion among the participants and the people in their social networks. The negative emotions were common and remained, even if some positive emotions, in particular hope, increased.

This study has some limitations. Most of the patients were highly educated women, and the numbers of participants for the diseases differed. These factors may have influenced the result; it is difficult to say. However, the patients were all in the same situation in that they had a chronic disease. The patients completed a questionnaire with closed-ended questions but had the opportunity to enter their comments in an open-ended area on the questionnaire. Further studies in the subject could be carried out to deepen the knowledge of ways to support patients with a chronic disease.

Implications for future research and practice

The study focused on how the participants felt that the disease had influenced their view of life, who provided support and what was experienced as helpful. The study also examined the participants' emotions and those of the people in their social networks regarding the situation. The knowledge gained from this study may be helpful in different ways to all health care professionals who meet patients with chronic diseases, for treatment and giving practical and emotional support to them to help them live as good a life as possible. Further research is needed to obtain a deeper understanding of how a chronic disease influences the way people live.

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Ethical approval

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