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# Living with a Chronic Disease: Preparation, Information, Talking and Thoughts about the Disease

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## ABSTRACT

*Chronic diseases have an impact on and change the lives of people with them. The chronic disease is part of coping strategies relating to the way a person thinks and acts in order to cope with a stressful situation. The study focuses on four chronic diseases: Asthma-allergy, diabetic mellitus, cancer, inflammatory rheumatic arthritis. All the diseases influence daily life in a practical as well as emotional way. The diseases may seem different, but they can all have a life-threatening component, even if the focus on this may vary in common opinion. The objectives of this article are to describe how patients with a chronic disease were prepared for having a chronic disease, experienced the information they receive if they can talk about the disease and what they think about the disease. Despite there being four diseases in this study, the result pointed to similarities between them. Talking to others about their disease can help patients cope with the situation of having a chronic disease. For all health care professionals meeting patients with chronic diseases, the knowledge from the study can be helpful when the treatment in different ways as well as practical and emotional support to help those patients live as good a life as possible.*

**Keywords:** Chronic diseases, Talking, Thoughts

## INTRODUCTION

Chronic diseases have an impact on and change the lives of people with them [1]. The chronic disease is part of their life, whether it affects their physical health and functions, autonomy, freedom, and identity, or threatens their life [2]. They have to change their lifestyle, which is often experienced as a loss of control. To cope with the new situation, they have to develop self-management skills as a process to bring order back into their lives [3,4].

Coping is about finding a way forward when there is a change in one's life. Coping strategies relating to the way a person thinks and acts in order to cope with a stressful situation [5,6]. The study focuses on four chronic diseases: Asthma-allergy, diabetic mellitus, cancer, inflammatory rheumatic arthritis. All the diseases influence daily life in a practical as well as emotional way. The diseases may seem different, but they can all have a life-threatening component, even if the focus on this may vary in common opinion.

Asthma-allergy influences the physical and psychological well-being of sufferers. They experience limitations and have to develop strategies to increase their level of function in daily life. Asthma-allergy can also cause anxiety and affect physical well-being. Asthma-allergy control is related to treatment effectiveness and the way the patients behave to avoid allergenic materials [7,8].

Patients with diabetes mellitus may have to change many parts of their life. It can be weight loss, always having good glycaemic control and monitoring 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 [9,10].

Cancer has been documented as a traumatic disease and developed into being chronic and life-changing, and it brings about a reality to which cancer survivors must adapt, and it can influence life in both a positive and a negative way [11,12]. Inflammatory rheumatic arthritis causes fatigue, pain, and stiffness, and swelling of peripheral joints is common. The disease also leads to psychological distress and reduces emotional well-being [13-15].

The objectives of this article are to describe how patients with a chronic disease were prepared for having a chronic disease, experienced the information they receive if they can talk about the disease and what they think about the disease.

## PATIENTS AND METHODS

### Study Design

The study was quantitative in design with data collected with a semi-structured questionnaire using descriptive statistics comparing similarities and differences between patients with asthma-allergy, diabetes mellitus, cancer, and inflammatory rheumatic arthritis. A pilot study was conducted with in-depth interviews with patients with different diagnoses. The results from interviews were analyzed by the research group, which identified the crucial experiences of having a chronic disease. From these results, the research group constructed the questionnaires. The final questionnaire comprised 21 questions and an option for comments [16]. The questions covered the information received, feelings about the diagnosis and life situation, influence on the life situation, experiences of having a disease and the need for support. In this article, we concentrate on these different areas:

1. Being prepared for having a disease
2. Receiving the diagnosis
3. Talking about the disease and
4. Thoughts about the disease

### Settings

The study was conducted at the medical, rheumatologic, lung, palliative and oncology clinics at a university hospital in western Sweden. We recruited patients affected by asthma-allergy, cancer in the curative stage as well as the early and late palliative stages, diabetes mellitus and inflammatory rheumatic arthritis. The study was approved by the Regional Ethical Review Board in Gothenburg (423-15).

### Data Collection

Data were collected over a seven-month period between October 2015 and May 2016. Information about the study was presented in a brochure in Swedish that was available in the different waiting rooms at the hospital where the patients were treated. Those who were willing to participate answered the questionnaire and sent it back in a prepaid envelope to the researcher. Patients took 498 brochures in 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 was open, in the form of a brochure in a waiting room, there is no way to send a reminder to the patients. This means that only those who felt that they wanted to participate returned the questionnaire.

### Data Analysis

The questionnaires were analyzed using descriptive statistics comparing proportions, similarities, and differences between different diagnoses according to the different questions. Descriptive statistics were also used for frequencies for categorical variables. The analysis was carried out using IBM SPSS statistics version 22. The open-ended responses were used to illustrate the similarities and differences between the different diagnoses according to the different questions.

## RESULTS

### Participants Characteristics

All of the patients who answered were over 18 years. Most were female with a high education level. There were unequal numbers of participants in the diagnostic groups and most had cancer or diabetes mellitus (Table 1).

**Table 1 Participant's characteristics**

| Parameters | | Total (n = 215) | |
|---|---|---|---|
| | | n | % |
| Gender | Male | 43 | 20% |
| | Female | 171 | 79% |
| | Missing | 1 | 1% |
| Age (Years) | 20-29 | 14 | 7% |
| | 30-39 | 23 | 11% |
| | 40-49 | 24 | 11% |
| | 50-59 | 51 | 24% |
| | 60-69 | 50 | 23% |
| | 70-79 | 37 | 17% |
| | 80-89 | 14 | 6% |
| | Missing | 2 | 1% |
| Employment | Employed | 88 | 41% |
| | Sick leave | 33 | 15% |
| | Retired | 69 | 32% |
| | Retired and 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% |

Chronic diseases have an impact on and change the lives of a people affected by the. In this article, we concentrate on these different areas: Being prepared for having a disease, Receiving the diagnosis, Talking about the disease, and Thoughts about the disease.

### Being prepared for having a disease

The majority of patients in all four diagnoses (52%) had felt that they had some kind of disease, but 40% had not had any feelings that they might have had a disease, and 6% were unsure whether they had a disease.

Looking at the differences between the different diagnoses, a higher number of cancer patients than the other patients had not felt they were ill before they were informed of their diagnosis. They described that they may have had some diffuse symptoms but did not associate them with a chronic disease. Most of the patients with the other diagnoses had symptoms and felt that something was wrong in their bodies, making them afraid that they had some disease (Table 2).

*"It was my daughter who was home over Christmas who thought that something was wrong. I just thought I was old and tired, as I do a physical, heavy job." (Patient affected by cancer).*

**Table 2 Being prepared for having a disease**

| Diagnosis | Yes | No | Don't know | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 109 (51%) | 38 (38%) | 10 (5%) | 14 (6%) |
| Asthma-allergy | 10 (55%) | 5 (28%) | 3 (17%) | - |
| Cancer | 49 (45%) | 58 (53%) | 3 (21%) | - |
| Diabetes mellitus | 22 (59%) | 13 (35%) | 2 (6%) | - |
| Inflammatory rheumatic arthritis | 28 (78%) | 6 (17%) | 2 (5%) | - |

### Receiving the diagnosis

Receiving the diagnosis of a chronic disease comprises several parts: whether the patients thought they had been informed in a good or a bad way, had been informed with clear words, and had received satisfactory information.

**Informed in a good or a bad way:** The first part concerned whether the patients thought they had been informed in a good or a bad way (Table 3).

In all of the diagnoses, 40% thought they had received the information in a good or very good way. About 20% perceived that the information was given in a bad or a very bad way and 32% had no opinion about the way the information was given. The participants described that giving the information with empathy influenced their feelings of whether they thought the information was provided in a good or a bad way.

"*I had a specified doctor and nurse with professional and empathic ability." (Patient affected by cancer).*

Dividing the participants into the four diagnoses showed that the patients with diabetes mellitus were most satisfied with the information (50%), but they also had a higher proportion who were not satisfied with the information (28%). Many of the patients with diabetes mellitus were diagnosed as children, and this can influence how they answer the question as adults, depending on whether they remember the information.

Of the participants with the other diagnoses, 30-44% felt that the information they received was good or very good. It was almost the same frequency as for those who evaluated the information as neither good nor bad. An example of this was the way the information was delivered, and a bad way was being informed by telephone.

**Table 3 Informed in a good or a bad way**

| Diagnosis | Very good/good | Neither good nor bad | Bad and very bad | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 86 (40%) | 72 (32%) | 46 (20%) | 11 (8%) |
| Asthma-allergy | 7 (39%) | 8 (44%) | 3 (17%) | - |
| Cancer | 47 (44%) | 37 (34%) | 24 (32%) | - |
| Diabetes mellitus | 18 (50%) | 8 (22%) | 10 (28%) | - |
| Inflammatory rheumatic arthritis | 13 (30%) | 15 (45%) | 7 (19%) | - |

**Informed with clear words:** The majority of the participants, irrespective of the diagnosis (83%), preferred clear information about the disease at the time of receiving the diagnosis. Only 10% were uncertain of whether they wanted to have the disease described in a clear way. The patients with cancer and rheumatic arthritis answered to a higher degree than the others that they wanted the information in a clear way. They gave the reason for this as needing to know their prognosis as a prerequisite for their dealing with their future life situation. The patients with asthma and diabetes mellitus were less sure about how the information should be provided but did not comment on why (Table 4).

*"I want to know the prognosis and treatment possibilities." (Patient affected by inflammatory rheumatic arthritis).*

The majority of the participants, irrespective of the diagnosis (99%), preferred clear information about the disease in the present time.

**Table 4 Informed with clear words**

| Diagnosis | Yes | No | Don't know | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 179 (83%) | 5 (2%) | 20 (10%) | 11 (5%) |
| Asthma-allergy | 11 (61%) | 3 (17%) | 4 (22%) | - |
| Cancer | 106 (95%) | 1 (1%) | 5 (4%) | - |
| Diabetes mellitus | 29 (76%) | 1 (3%) | 8 (21%) | - |
| Inflammatory rheumatic arthritis | 33 (92%) | 0 (0%) | 3 (8%) | - |

**Received satisfactory information:** The study contained two questions on how the patients experienced the information: one at the beginning of the disease and one now. The majority experienced that they had received satisfactory information both in the beginning and now (54% in the beginning, 59% now). Comparatively between the different diagnoses, however, the cancer patients were more satisfied (65%, 72%). The patients with asthma-allergy were more satisfied with the information about their disease that they had received now than with the first information they had received. This could also be seen in patients with rheumatic arthritis but to a lesser degree. The diabetes mellitus patients experienced the information as more satisfactory earlier than now. They explained this by them needing to search for further information later on that the health care staff did not provide (Tables 5 and 6).

*"I received the practical information I needed in the beginning, but later on I had to find my own information. (Patient affected by diabetes mellitus).*

**Table 5 Satisfactory information in the beginning**

| Diagnosis | Yes | No | Don't know | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 115 (54%) | 54 (25%) | 34 (14%) | 15 (7%) |
| Asthma-allergy | 6 (33%) | 8 (44%) | 4 (22%) | - |
| Cancer | 72 (65%) | 24 (22%) | 14 (13%) | - |
| Diabetes mellitus | 21 (57%) | 9 (24%) | 7 (19%) | - |
| Inflammatory rheumatic arthritis | 16 (46%) | 13 (37%) | 6 (17%) | - |

**Table 6 Satisfactory information now**

| Diagnosis | Yes | No | Don't know | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 133 (59%) | 55 (26%) | 16 (7%) | 8 (18%) |
| Asthma-allergy | 11 (65%) | 6 (34%) | 0 (0%) | - |
| Cancer | 78 (72%) | 20 (18%) | 11 (10%) | - |
| Diabetes mellitus | 18 (50%) | 16 (45%) | 2 (5%) | - |
| Inflammatory rheumatic arthritis | 20 (57%) | 13 (37%) | 2 (6%) | - |

### Talking about the disease

Another question in the study asked whether they could talk to other persons about their disease. Half of the participants (51%) felt that they could do so. One reason for talking about the disease was to be open about their situation and to spread information about the disease (Table 7).

**Table 7 Talking about the disease**

| Diagnosis | All | Some | None | Don't want to | Missing |
|---|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) | N (%) |
| Total | 108 (51%) | 86 (41%) | 1 (0%) | 6 (1%) | 14 (7%) |
| Asthma- allergy | 9 (56%) | 6 (38%) | 0 (0%) | 1 (6%) | - |

| | | | | | |
|---|---|---|---|---|---|
| Cancer | 69 (62%) | 42 (38%) | 1 (0%) | 0 (0%) | - |
| Diabetes mellitus | 19 (51%) | 14 (38%) | 0 (0%) | 4(11%) | - |
| Inflammatory rheumatic arthritis | 11 (31%) | 24 (67%) | 0 (0%) | 1 (2%) | - |

*"I have no problem talking to anyone who is interested because I think it is important to spread information about cancer." (Patient affected by cancer).*

On the other hand, almost 50% did not want to talk about their disease. The patients with rheumatic arthritis chose whom they wanted to talk to a higher degree (67%). For those who did not want to talk much about their disease, one explanation could be that they chose to talk only those who already knew about their situation because they could understand the problems they had. For those who did not want to talk about their disease at all, the reason could be that they had encountered a great lack of understanding of the effects the disease could have on their life situation, and they may also have had nasty comments made to them.

*"I mostly met people who didn't know much about diabetes and they made nasty comments, so I would rather not talk to anyone." (Patient affected by diabetes mellitus).*

*"People panic just hearing the word asthma or if I need to use the inhalator." (Patient affected by asthma-allergy).*

### Thoughts About the Disease

Of the participants, 50% felt negative about their disease. The patients with rheumatic arthritis were most negative about their disease, while the cancer patients had less negative thoughts. One reason for the negative approach was that the participants experienced a negative effect on their quality of life, including restrictions in daily life. The negative effects can also lead to increased anxiety.

*"It is scary that the disease affects the body negatively whatever you do." (Patient affected by diabetes mellitus).*

*"It is a chronic disease without a cure and it affects my daily life." (Patient affected by inflammatory rheumatic arthritis).*

A quarter of the participants had some positive thoughts about their disease, while 15% were unsure of their feelings about the disease. Those who had a positive view of their disease had found strategies to accept the disease and a way to cope in their daily life despite the limitations caused by the disease. They had some kind of hope for the future, for example, that research would find better treatments and even a cure (Table 8).

*"I feel positive about the future. I am grateful to the health care I have received and I have had a fantastic life experience." (Patient affected by cancer)*

*"It is a routine and a way of living and it does not play a prominent role in my life."(Patient affected by diabetes mellitus).*

**Table 8 Thoughts about the disease**

| Diagnosis | Positive | Negative | Don't know | Missing |
|---|---|---|---|---|
| | N (%) | N (%) | N (%) | N (%) |
| Total | 49 (23%) | 108 (50%) | 32 (15%) | 26 (12%) |
| Asthma-allergy | 3 (20%) | 9 (60%) | 3 (20%) | - |
| Cancer | 28 (26%) | 55 (51%) | 24 (22%) | - |
| Diabetes mellitus | 11 (33%) | 20 (61%) | 2 (6%) | - |
| Inflammatory rheumatic arthritis | 7 (21%) | 24 (71%) | 3 (9%) | - |

## DISCUSSION

This study examined how patients experienced receiving a chronic diagnosis such as diabetes mellitus, rheumatic arthritis, asthma or cancer. All these diseases are life changing and influences in the persons social and physical environments to enhance or impede managements efforts [17]. The study focused on how the patients experienced being prepared for being given a chronic diagnosis, how the information was provided and their thoughts on the disease. The study also examined whether they were able to talk about the disease and thought about their disease positively or negatively.

Patients with asthma, diabetes and especially rheumatic arthritis had been prepared for the possibility that they could have some disease even before they received their diagnosis. They had all felt that they had symptoms that had led them to contact health care. The cancer patients may have had similar symptoms, but those who were diagnosed after a screening check had all thought that it was just a routine check, and when they were diagnosed with cancer it was traumatic and preparation was not possible.

Information is important for patients to have some kind of control. Fishbain, et al., discussed how the way that information and health care are provided can influence feelings of uncertainty that a chronic disease can cause [18]. Information can also help patients to cope with their situation, as seen in an earlier study [19]. Fewer than half of the patients in our study described that the information on the diagnosis was either good or very good. The professionals need to discuss the patient's goals, fears and function Bernacki, et al., [20]. Evers, et al., point out that it is important that the patient is involved in the discussion about their disease [21].

Some patients describe that a good way of being given information is with empathy, which has been seen in earlier literature [22]. The patients requested that the information is given in a clear way, especially the patients suffering from cancer or rheumatic arthritis. They commented that they needed this to be able to plan for their life situation. The patients with rheumatic arthritis found it valuable to plan for their everyday life situation according to their disability. The cancer patients wanted to know their prognosis to help them deal with questions of death. Many of the diabetes mellitus and asthma-allergy patients were young when they received the diagnosis and were unsure if they understood if the information was clear. In the present time, all of the participants wanted clear information.

It was important for all the patients to continue to receive information so they could have current knowledge about the disease and prevent medical errors [19,23]. The study showed a higher degree of dissatisfaction among diabetic patients than among the patients suffering from other diseases. One reason could be that the patients contracted the disease as children and now did not remember, or did not understand the information at the time, but now as adults do not think that the information was good. This may indicate that information to patients who become sick in their youth needs to be repeated when they grow up [24].

Talking to others about their disease can help patients cope with the situation of having a chronic disease. Those participants who talked to others about it did so so that they could spread information about the disease. This also allowed them to explain and increase knowledge about the effects of the disease on their daily life. Those who did not want to talk about their disease gave the reason as wanting to protect themselves from others' negative responses [25]. Irrespective of whether they talked about it, this can be seen as a strategy to cope with the situation [5]. Another study shows that patients need special strategies to talk about a severe disease to their family and friends [26]. In this study, it was more common among patients with rheumatic arthritis not to want to talk to others about their disease. Surprisingly, this was less common with the patients suffering from cancer, which is often linked to death. Maybe there has been a change in the way cancer is seen. Nowadays, it may not always be seen as a fatal disease: it may be seen more as a chronic disease, like the other diseases in this study [11,27].

Most of the participants think their disease will have a negative effect on their future life. This is not surprising as these are all life-changing diseases. The participants with rheumatic arthritis were more negative than the others [28]. This study does not verify why this was the case. The participants suffering from diabetes mellitus or asthma were less negative than the patients with rheumatic arthritis but the majority of them had negative thoughts about their disease. This can be explained according to that the disease influences their daily life. The diabetes mellitus participants needed to control their food and blood and be observant throughout the day. The participants suffering from asthma also needed to be observant so they were not exposed to allergens that would cause them problems. Surprisingly, here too the participants suffering from cancer had the lowest level of negative thoughts. There is now much information indicating that many cancer diseases have a better prognosis than before, and because cancer is so closely linked to death the possibility of being cured or having a long life with good treatment may give those participants a more positive view of their situation. To reduce the negative thoughts that can influence the quality of life, positive information strategies may help the patients to have a more positive view of their disease, which may give them a better view of their life [19,29].

## Limitations

Nonetheless, our study has limitations. Most of the patients were highly educated women, and it is difficult to say whether this influenced the result. There were also different numbers of participants for different diseases. However, the patients were all in the same situation with a chronic disease. Patients filled in a questionnaire with closed-ended questions, but they also 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.

## CONCLUSION

Our study aimed to identify how chronic disease is experienced. Despite there being four diseases in this study, the result pointed to similarities between them. Having the possibility of being prepared helped the patients to find strategies to cope with the new situation. When they have had symptoms and felt that something was wrong in their bodies prepared them for having a disease. It also showed that patients suffering from a chronic disease need information on the diagnosis and if they were informed in a good or a bad way. Talking to others about their disease can help patients cope with the situation of having a chronic disease. Talking to others can be experienced as positive or negative depending on how they will be met. Talking to others can also be an opportunity to inform about the disease which points out the necessity that patients receive sufficient information about their disease. The negative experience of having a chronic disease is an indicator of the risk of future ill health. The participants felt either negative or positive about their disease and this can influence their view of their new life, experienced as being better or worse. For all health care professionals meeting patients with chronic diseases, the knowledge from the study can be helpful when the treatment in different ways as well as practical and emotional support to help those patients live as good a life as possible.

## DECLARATIONS

### Conflict of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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