

Living with a Chronic Diagnosis

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Abstract

Introduction: More and more people are diagnosed with a chronic disease. The socioeconomic consequences have been analyzed, but the results are all numbers. How do the patients really experience life with a chronic diagnosis? This qualitative study look into chronic patients' lives to find items that can form the basis for further reflection.

Methods: A qualitative case study of six patients with different chronic diseases (type 2 diabetes, chronic obstructive pulmonary disease, familial hypercholesterolemia, ischemic heart disease and hypertension) is presented. All patients were recruited from different general practices. The interviews were semi-structured, face-to-face, and performed by six medical students in the patients' own homes. Analyses were made according to systematic text condensation as described by Malterud K.

Results: Several interesting themes were discovered, and we decided that illness perception, perception of treatment and of consultations with the doctor were the most relevant for the doctors. The information we got led us to emphasize the need to see the patient behind the diagnosis.

Conclusion: Patients perceive living with a chronic diagnoses differently. This depends on his/her common beliefs about the illness, its prognosis and its treatment. It should be considered and explored when treating patients with chronic diseases where treatment is often lifelong.

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Introduction

A chronic disease is a disease that has a long duration or is recurrent. One third of all people in Denmark have a chronic diagnosis [1]. The number of people with chronic diseases is increasing due to longer life spans in better conditions and the improved ability to treat many life-threatening diseases [2]. A chronic illness can induce changes in a person's life, and may result in negative effects on quality of life and wellbeing. From a socioeconomic point of view and from the doctor's perspective, there is vast knowledge about chronic diseases. But what about the patient's perspective? Shifting perspective model shows that living with chronic illness is a dialectical, constantly shifting perspective in which either illness or wellness is in the foreground. The illness-in-the-foreground perspective focus on the sickness, suffering, loss, and burden associated with living with a chronic illness. The wellness in the foreground perspective is characterized by seeing the chronic illness as an opportunity for meaningful change in relationship to the environment and others [3].

During the medical curriculum six medical students have been involved with chronic patients and wondered about the patients' behavior. One of the medical students worked in a GP clinic, where she met a lot of chronic patients, and wondered why they did not always adhere to treatment. Three students wanted to explore living with a chronic disease because of a family history of chronic obstructive pulmonary disease (COPD), familiar hypercholesterolemia (FH) and type 2 diabetes mellitus (DM). In order to seek diversity, we asked two students to interview the patient with the cardiovascular disease and the patient with hypertension.

For all doctors in hospitals as well as in GP clinic is it relevant to understand the impact of the patient's personal perception on their personal disease management.

Patients are confronted with a new situation when they are diagnosed with a chronic disease which can challenge their coping strategies. According to Lazarus and Folkman, coping is a psychological mechanism to handle stressful situations [4]. Successful coping does not necessarily have the same meaning for patient and doctor.

Albrecht et al. talks about a disability paradox, finding that patients with chronic diseases do not perceive themselves as ill as their caretakers. Another good reason to explore their thoughts [5].

A lot of discussion is going on for the time being about using data from the patients to be sure guidelines have been followed. It might be a problem for the doctor, if quality in work will be assessed by the numbers in the data and a problem for the patient if his prognosis gets worse because of bad adherence.

The aim of this study look into chronic patients' lives to find items that can form the basis for further reflection

Methods

Participants

Six patients were randomly chosen from six different general practice clinics in 2013-2014. The patients were contacted by telephone by their GP and asked if they would consent to an interview. None refused. They should have a chronic diagnosis, and be able to communicate. Semi structured, interviews were performed by six medical students. Before the interview each interviewer constructed an interview guide with six to eight questions, that the student wanted the patient to answer, but the patient was also allowed to talk freely. This is done to achieve greater diversity, getting different answers and find different topics. Each interviewer made his own interview guide just to get new experiences for each and not to do it from a theoretical background. The participants were interviewed in their homes. The interviews were all tape-recorded, lasting around one to two hours,

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and were afterwards transcribed by the individual interviewer. See table 1. The patients did not look through or comment the interview. Only the interviewer and the patient were present at the interview, but the last author participated in the analysis.

She finds that the disease in itself takes less and less part in her life, but taking medicine, also reminds her of being a heart patient.

The woman aged 83 with hypertension and no symptoms finds it acceptable and very common to have problems at her age and says:

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6
Sex	Man	Woman	Woman	Man	Woman	Woman
Age/years	50	47	59	60	59	83
Diagnosis	Type 2 diabetes	Type 2 diabetes	Chronic obstructive pulmonary disease (COPD)	Familial hyper cholesterol e-mia (FH)	Ischemic heart disease COPD	Hypertension
Year of debut	2008	2008	1999	1980	2013	2012

Table 1: Shows the patients' sex, age, type of chronic disease and the duration of the disease.

Analysis

A qualitative case study was found eligible to explore phenomena. Systematic text condensation is a descriptive and explorative method for thematic cross-case analysis of different types of qualitative data, such as interview studies, observational studies, and analysis of written texts. The method represents a pragmatic approach, although inspired by phenomenological ideas, and various theoretical frameworks can be applied. The procedure consists of the following steps: 1) total impression - from chaos to themes; 2) identifying and sorting meaning units - from themes to codes; 3) condensation - from code to meaning; 4) synthesizing - from condensation to descriptions and concepts (6). The themes found in the different studies were examined, and here based were found themes that were similar in 6 studies and themes that were surprising and relevant to illuminate the angle of how it is to have a chronic illness. This led to the themes illness perception and treatment and seeing the doctor (see flow chart 1). There were many other findings, but it is limited to the purpose.

Results

Perception of illness

We found themes relating to perception of illness, treatment and seeing the doctor, which could lead to reflections and further exploration. We chose to discuss the themes that we found most relevant for the aim of our study.

Having a chronic diagnosis does not necessarily mean that you perceive yourself ill but having daily symptoms made a patient feel more ill. The patient with COPD says:

"I feel more ill when I have the flu, than from just having the COPD." (pt. 3)

In her daily life, she did not have many symptoms from her quite severe lung disease, as she had adapted her life to living with a restricted lung capacity, but when she had the flu, she felt ill.

The patient with familiar hypercholesterolemia knows he has a serious condition, having familiar hypercholesterolemia and coronary arteriosclerosis. He has had a coronary thrombosis and has seen the consequences of the condition in his closest family. He feels very ill.

The woman aged 59 with ischemic heart disease and COPD had a father and mother that died young from cardiovascular disease. Even though she has undergone a by-pass operation, she does not consider herself ill, until she sees the scar on her chest.

"Actually I think I haven't quite yet realized that it's a chronic disease, I have." (pt. 5)

"I cannot feel anything different, so I am not ill. At my age most peoples have problems." (pt. 6)

The Turkish woman with diabetes perceives herself ill as a consequence of bad behavior:

"If you do som ething bad, Allah will punish you with a disease" (pt. 2)

She does not find the disease serious, it is Allah's will and she does not want to exhibit her disease (and Allah's punishment) to others, so when eating together with friends and family she had a tendency to overeat.

Treatment and seeing the doctor

A 50 years old diabetic describes himself as addicted to sugar. He cannot stop eating.

"I love candy, cakes and fat food. When I have taken the first piece of chocolate or candy, something happens with my body." (pt. 1)

Actually he perceived a control over the condition in the beginning after being diagnosed and had the belief that he could work it out and reach the goals. He trained a lot but at Christmas he left his good intentions behind and ate a lot. He started out refusing invitations, even if it should not be necessary, if he could manage his overeating.

The 59 old year's woman with COPD also felt like an addict. Could it be an excuse as we all know how difficult it is to be addicted?

Social and cultural backgrounds influence the illness behavior of our Turkish diabetic:

"... and if I do not eat a lot with them (guests), they might think we haven't plenty of food or have financial problems." (pt. 2)

Being prescribed an inhaler for COPD made it too much for the 59 years old woman with the heart disease. She says:

"when you don't feel bothered by the disease... why should I use it..." (pt. 5)

The patient with familiar hypercholesterolemia did a lot of physical training, but stopped. He now spends a lot of hours in front of the computer instead, trying to find information and recipes. Definitely an adverse coping strategy and might cover up a lot of anxiety.

Patients seek information on the internet. Our patient with hypercholesterolemia trusts his doctor but prefers to find the dietary advice and prescriptions by himself. It could be difficult for a doctor to fulfill his immense need for information. The woman aged 59 living

with COPD does not want to talk to the doctor about the disease:

Or it could be that she is afraid to admit that she is still smoking, and that decreases her wish to see the doctor.

And the man with diabetes aged 50 says

"I am totally embarrassed, when I go to the doctor, and they can see that I have gained weight. I feel I am wasting their time." (pt.1)

The Turkish woman living with diabetes finds it difficult to make the doctor understand the situation:

"I think she finds me a liar, if I sayI really try to eat healthy food." (pt. 2)

The woman with the heart diseases tells how she gets scolded for not following the doctor's advice to use the medicine for COPD. On top of that she is frustrated that the doctor cannot tell her how long the effect of the operation (for coronary arteriosclerosis) will last.

The woman with hypertension relies on the doctor, who suggested she should measure her blood pressure at home three times twice a day:

"It reminds me about the hypertension all the time. I do not want to do it." (pt. 6)

Discussion

The aim of the study look into chronic patients' lives to find items that can form the basis for further reflection (Table 2). When people get diagnosed with a chronic disease they make their own common sense beliefs or illness perceptions, their own explanatory model. Illness perception includes five broad subjects: identity of their illness, causal beliefs, consequences, timeline beliefs and beliefs about control or cure. These perceptions are important determinants of behavior [7]. A study finds that illness perception and self-efficacy beliefs can be useful predictors of adherence and metabolic control concerning patients with diabetes mellitus [8].

Denial used as a coping strategy does not work when you are confronted with a change in bodily appearance or shall take a lot of medicine, which reminds you of the illness. To have a scar can have psychosocial consequences and produce anxiety [9]. Culture could matter when it comes to finding the cause of the disease and influences the illness behavior and perception. And it is acceptable and normal to have health problems in old age [10].

If you are addicted to smoking and it may be difficult to seek help, especially if you feel guilty about this self-inflicted condition [11]. COPD patients can be anxious when they cannot breathe. Avoidance of situations that confronts breathing problems by not going out of the apartment can be one way of coping. But what about the good

Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6
Themes: - individual perception of the disease -difficult to adhere to treatment - childhood experiences - seeing the doctor	Themes: - religious influence on perception of the disease - adherence to treatment - doctor-patient relationship	Themes: - containment in daily life - feeling diseased by experience of new symptoms - blame - does not want to see the doctor	Themes: - change in illness perception because of serious disease - the need for being in control - adverse coping strategy - anxiety	Themes: - from healthy to heart patient - the need for being in control - feeling of powerlessness - no recognition of the family history - seeing the doctor	Themes: - being of old age -being reminded of the disease

Perception of illness: Four quotes
 Awareness of disease: One quotation
 Seeing the doctor: Two quotes
 Following the doctor's instruction: Two quotes

Table 2: Patients details with activities.

To sum up

Addiction is here said to be the cause and excuse for two patients. The social and cultural context influences our diabetes patient's illness behavior when it comes to follow advice from the doctor. Our heart patient did not want to take medicine for a disease she had no symptoms from. Our patient with hypercholesterolemia exhibits an adverse coping strategy. Barriers for seeing the doctor and adhere to treatment is guilt, embarrassment, disappointment, different culture, an unacceptable advice (from the patient's point of view).

impact of social support on chronic patients, if you get more and more isolated [12]. As doctors we need to know the effect the disease has on the patient's function.

A review about patients with coronary heart disease concluded that illness perceptions were found to predict quality of life and mood [13]. Studies about an illness perception, perceiving low sense of control, and strong emotional perception as for example anxiety and depression, appear to be associated with poor outcomes regarding experience of disability, lower quality of life and psychological

characteristics [14,15]. But if we as doctors do not clarify the patient's feelings, we do not get the whole picture.

It might be difficult to relate to risk factors. A study finds that complications of diabetes in the later state are the most important disease-specific determinant of quality of life, the more symptoms the less quality of life [16]. But knowing intellectually that diabetes can have consequences, does not lead to adherence. When it comes to treatment the adherence mechanism is complex. Symptoms are a good reason for accepting treatment. As doctors we need to explore the patient's perception of the risk factors for better understanding.

If the underlying problem of non-adherence is obsession with eating, it should be treated in another way. Obsession can be so overwhelming that all fear of future complications might get swept away.

A study finds that patients who experience disease symptoms alter their self-care management according to their disease-related knowledge [22]. Seeking information is a well-known coping strategy [23]. But it does not work well for all of us, it depends on who we are.

According to shifting perspective theory you can have the illness in the foreground, and you may get isolated and do not cope with illness. The wellness in the foreground makes it possible for the patients to act. In our study it is much more complex.

So seeing the patient behind the disease and his or her specific needs could be a way to reduce the use of healthcare.

Strength and limitations of this study

The aims of qualitative interviews are not finding universal truths, but clarifying meanings by in- depth interviews and thus getting new information. The interaction between the interviewer and the respondent gives the possibility for pursuing the answers for further in-depth knowledge.

We have haphazardly chosen six patients with a chronic disease and found themes for reflection and further exploration. All the patients were past the first year after being diagnosed and had had an opportunity to adjust. We chose the patient mainly according to their disease so no presumption on the patient's personal management could influence the results.

Our aim was to interview patients with the most common chronic disease. We found some useful themes, but we will not claim that we have found all themes in every chronic disease.

It could be strength as well as a weakness that the interviewers were six different medical students, who all were driven by a curiosity for different reasons.

What this study adds to previous knowledge

We demonstrate the complexity in treating chronic patients with different perception of their disease and treatment, and the need for exploring the patient's illness perception, feelings, psychological reactions, the impact on daily life and the patient's values.

Conclusion

We have looked into the life of six haphazardly selected patients with a chronic diagnosis. Behind any chronic diagnoses is a person, who has his/her common beliefs about the illness, its prognosis and its treatment. It should be considered and explored when treating patients with chronic diseases where treatment is often lifelong.

Competing Interests

The authors have no competing interests with the work presented in this manuscript.

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