Self-Management of Chronic Diseases: Descriptive Phenomenology Study

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Abstract: Chronic diseases are the priorities for the health care system and patient-centered care. Because, chronic diseases could cause a disabling which has impacts physically, socially and psychologically. Chronic diseases needs to ongoing care and support to assist patients' self-management. The aim is to understand the experiences of the treatment of patients with chronic conditions who were able to practice self-management. Within the scope of the phenomenological approach, was carried out in Izmir/Turkey province 10 patients with a chronic disease (e.g., hypertension, diabetes, arthritis) who attended a family health care center. Three main themes were identified, namely social support, disease management, and self-awareness and empowerment. It was determined that the disease management, self-awareness and empowerment sub-themes (chronic disease definition, perceived barriers, emotional and spiritual state, self-monitoring, dietary and medication management) had a significant effect on the self-management. The results have demonstrated that patients' health outcomes can be affected patients' experiences and behaviors in the chronic conditions self-management. Planning for self-care programs should be provided by health care professionals, taking into account the variables that affect patients' self-management of their disease.

Keywords: disease management; self-management; chronic disease; qualitative research; phenomenology

1. Introduction

Longer life spans, the increased prevalence of chronic diseases (for example, diabetes, rheumatoid arthritis and coronary heart disease) as well as the increased burden of illness have led to the need for more treatment and care. The health care system has been greatly impacted by major chronic diseases [1] increasing the risk of mortality and morbidity as well as negatively affecting the patients' self-care and quality of life. This situation shows the current, worldwide significance of controlling chronic diseases and implementing disease management programs within communities [1-6]. Success in the control and treatment of chronic diseases involves a self-management approach involving patient-centered decision-making and care. Self-management of a chronic disease is improved by adjusting patients’ treatment to ensure that self-care can be carried out at the highest level by the patients themselves. A patient needs to have the specific knowledge to be able effectively manage the disease but also needs to acquire self-care skills (medication management, dietary management, self-testing, self-monitoring, psychological and spiritual states) [1,6,7]. If patients consult their doctor/nurse when necessary, they can participate actively in increasing their knowledge and skills, and also acquire competence in independent decision-making, increase their ability to cope with problems, perform their own follow-ups, and carry out self-management [7]. Healthcare providers increasingly recognise the importance managing patients who have chronic diseases; they are also frequently involved in primary care in collaborative arrangements with specialised services [1].
Research has discussed the importance of patients being successful in their self-management [2-11]. Jerant et al. [2] carried out qualitative research which found that patients with chronic diseases have difficulties in self-managing, including depression, difficulties losing weight despite dietary programs, difficulties in doing regular physical exercise and aches and pains experienced as a result of disease. In addition, fatigue, inadequate communication with healthcare providers, inadequate social support and economic problems are also barriers to disease management.

The problems patients experience during the treatment process and the specific skills required for disease management were investigated using the following question:

What are the characteristics of patients’ lived experience in the self-management of chronic conditions?

The aim of this study is to understand the experiences of the treatment of patients with chronic conditions who were able to practice self-management.

2. Materials and Methods

The descriptive phenomenological research method was used from qualitative research design [12]. Phenomenological approach widely provides an in-depth perspective to reveal the phenomena, lived experiences, describing human experiences, perceptions and durations [13]. The study was carried out in İzmir (Turkey) province with patients with a chronic disease (e.g., hypertension, diabetes, arthritis) who attended Primary Health Care Services (two Family Health Centers) from February and June 2018. Interviews continued until the data reached the saturation point, and 10 participants (PI-10) were interviewed for this research.

Participants were selected for the study using the criterion sampling method in two different Family Health Centers and those with at least one chronic disease, such as diabetes, hypertension or rheumatoid arthritis, and those who used medication to treat these were included. Only those who were literate, were in good mental health, could communicate in and understand Turkish participated in the study. Illiterate, mental dexterity and could not communicate individuals were excluded from the study.

When selecting of the participants, medical records were guided after contacting registered nursing practitioners from the Family Health Centers, who were informed about the objectives and selection criteria of the study. Subsequently, public health nursing practitioners selected participants and participants were invited to participate in the study and referred to the researcher. The interviews were also observed by the nurse practitioners and the feedback or response continued between the researcher and nurse practitioners throughout the study.

The data collection instruments consisted of two parts. The first part contained socio-demographic questions and an information form about the characteristics of the disease; in the second part, a semi-structured interview form was used, consisting of eight problems relating to the process of the chronic disease management which had been formulated using the literature [2,4,8,10,11]. The open-ended questions are to allow to describe the lived experience of the participants. This form contained questions about perceptions of social support related to chronic disease, general health and disease management, barriers arising from the disease, trust, beliefs about the disease, disease information, communication with patients, their skills and abilities, and the management of disease. Prior to data collection, pilot interviews were held with three people for the semi-structured interview form and changes were made to the interview form following these interviews.

The face-to-face interviews were held in the Family Health Centers in prepared rooms using in one-to-one interviews last 45 and 60 minutes of qualitative data to explore the experiences of participants. Those agreeing to participate in the study were told that their voices would be recorded on the voice recorder and their verbal permission was obtained. The researcher recorded the interviews by voice recorder and recorded the observations in a notebook. The semi-structured interviews were conducted by the researcher who graduated PhD in Public Health Nursing area and experienced over 10 years in Public Health Nursing. The meetings were held between February and June 2018, and the interviews lasted approximately between 45 and 60 min. The participants expressed in their own words in a dialogue with the researcher. Conversations were recorded on a voice...
recorder and transcribed verbatim. The interviews were described in detail and direct quotations were frequently cited. The text comprehensively read two times. Firstly, the meaning identified. In second reading, categories and themes extracted. The themes and subthemes were clearly identified and analysed the documents. The documents were uploaded to the NVIVO 8 statistical program and content analysis was implemented. Documentation was produced approximately 12-14 pages and the data obtained were converted to a written document within 24 days totaling 1440 minutes (60 hours). All interviews were held in the Family Health Centers.

In order to improve the validity and reliability of the study, the criterion sampling method was deployed [13,15]. Consolidated Criteria for Reporting Qualitative Research guidelines were followed [14]. The data reliability method consisted of: a) For the analysis of the data was received opinion independently by three experts (two of them were PhD in Public Health Nursing, one of them was PhD in Psychiatric Nursing department) as well as the researcher according to Giorgi method [15]; b) 10 randomly selected participants were defined by the registered Family Health Center nurse practitioners; c) The interviews were also observed by the Family Health Center nurse practitioners. To confirm the participants’ responses, they were asked whether they wished to give any further information or remove any comments. In accordance with the research questions, a framework is created in order to help provide a structure to data analysis using the conceptual framework included in the interview/observation [12,13,15].

In order to carry out the work, written permission was received from the Izmir Katip Celebi University Non-Invasive Research Ethical Committee (IRB No: 31829978-050.01.04-E.170092115 date: 22.12.2017) and the Provincial Health Directorate in Public Health (IRB No: 77597247-604.02). Verbal informed consent was obtained from the patients.

### 3. Results

The socio-demographic characteristics of the participants and their histories of disease were first determined. In the study, the average age of the ten participants was 56.7 and ranged between 30 and 83 years. The sample comprised ten participants eight of the subjects were male, five of them were primary school graduates (see Table 1).

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>&lt; 49</td>
<td>2</td>
</tr>
<tr>
<td>50-69</td>
<td>6</td>
</tr>
<tr>
<td>&gt; 70</td>
<td>2</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>5</td>
</tr>
<tr>
<td>High School</td>
<td>2</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>3</td>
</tr>
<tr>
<td>Job Profession</td>
<td></td>
</tr>
<tr>
<td>Government official</td>
<td>3</td>
</tr>
<tr>
<td>Tradesperson</td>
<td>1</td>
</tr>
<tr>
<td>Retired</td>
<td>3</td>
</tr>
<tr>
<td>Private sector employee</td>
<td>1</td>
</tr>
<tr>
<td>Housewife</td>
<td>2</td>
</tr>
</tbody>
</table>

Five of the participants lived with their spouse and child and had a total of three people living in their homes. The remaining individual lived with an adult son, the son’s wife and their children.
All participants had full social security and all of them defined their income as adequate. The participants’ medical conditions are shown in Table 2. Six of the participants in the study described their health status as being moderate, two of them as good, one as very good, and one as bad. They all stated that they were supported by their families (wife/husband and child). All those who participated in the study had a chronic disease and all of them used medication.

Table 2. History of illness of the participants (n = 10).

<table>
<thead>
<tr>
<th>Variables</th>
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</thead>
<tbody>
<tr>
<td>General health status</td>
<td></td>
</tr>
<tr>
<td>Bad</td>
<td>1</td>
</tr>
<tr>
<td>Medium</td>
<td>6</td>
</tr>
<tr>
<td>Good</td>
<td>2</td>
</tr>
<tr>
<td>Very good</td>
<td>1</td>
</tr>
<tr>
<td>Participants’ diagnoses</td>
<td></td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>2</td>
</tr>
<tr>
<td>T1DM</td>
<td>1</td>
</tr>
<tr>
<td>T2DM</td>
<td>2</td>
</tr>
<tr>
<td><strong>Multiple Sclerosis</strong></td>
<td></td>
</tr>
<tr>
<td>Mechanic heart valve replacement patient</td>
<td>1</td>
</tr>
<tr>
<td><strong>Mixed</strong></td>
<td></td>
</tr>
<tr>
<td>Hypertension, T2DM, Rheumatoid Arthritis</td>
<td>1</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1</td>
</tr>
<tr>
<td>T2DM, Rheumatoid Arthritis</td>
<td>1</td>
</tr>
<tr>
<td><strong>Hypertension, Rheumatoid Arthritis</strong></td>
<td>1</td>
</tr>
</tbody>
</table>

Analysis of the interviews resulted in the emergence of the three themes: (1) social support, (2) disease management, self-awareness and empowerment (with subthemes including definition of chronic disease, perceived barriers, changes in emotional state and spiritual state, medication management, self-monitoring and dietary management) and (3) information sources (Table 3).

Table 3. Themes and subthemes emerging from the study.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social support</strong></td>
<td>-</td>
</tr>
<tr>
<td><strong>Disease management, self-awareness</strong></td>
<td>Definition of chronic disease</td>
</tr>
<tr>
<td><strong>Perceived barriers</strong></td>
<td>-</td>
</tr>
<tr>
<td><strong>Changes in emotional state and spiritual state</strong></td>
<td>-</td>
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<tr>
<td><strong>Medication management</strong></td>
<td>-</td>
</tr>
<tr>
<td><strong>Self-monitoring and dietary management</strong></td>
<td>-</td>
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<tr>
<td><strong>Information sources</strong></td>
<td>-</td>
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</tbody>
</table>

3.1 Social support
Participants described family member's function to their commitment to life, expression of adaptability and dependency of chronic conditions. Three people who participated in the research were not dependent on anyone, they did not consider themselves as dependent, but the rest (seven people) did think that they were dependent on their spouses and children with regard to their diseases.

My wife reminds me about my medication and I have meals according to my illness lets me eat (P1).

My disease does not mean I am dependent, I don’t need anyone in my illness (P2).

One of the participants lived in a large family. This individual stated:

I feel good, and my granddaughter makes me happy, and when I’m happy my sugar levels do not rise; if I’m sad and alone I don’t eat a lot of food but my sugar level goes up (P5).

One of the participants with T1DM who had an 18 month-old son stated:

When I go home and see him I feel I have to pay more attention to my illness and I become more attentive to my diet. I feel I’m tied to my disease (P3).

One person with multiple sclerosis stated:

I do not think I am dependent, I can eat my own food, I can walk with my cane, I do it myself, why do I feel bound by it? (P8).

3.2. Disease management, self-awareness and empowerment

Under this theme, the participants' awareness, attitudes and behaviors are explored, in addition to how they perceive the support nurses give patients so that they are able to manage their conditions.

3.2.1. Definition of chronic disease

Chronic disease refers to continuous disease (P2), unhealthy disease and continuous disease (P3) and lifetime medication use (P4). One individual with T2DM defined the disease as constantly avoiding dessert (P10).

3.2.2. Perceived barriers

Self-monitoring blood levels, difficulties in using diet programs for weight control were experienced as barriers of disease self-management. Of the participants emphasized that the illness negatively affected their quality of life.

I have to regularly check my blood sugar and take insulin, which almost always leads to half an hour in which I feel bad. I feel like I've lost this time in my life (P3).

I need to be careful not to eat constantly and not to skip my medications or my blood pressure goes up (P1).

Work load and time pressures were perceived negatively to quality of life, resulting in the training program participants felt that it was unsatisfactory.

Sometimes I do not understand clearly that if I do not eat I will get bad. Nurses have any time, have to more tasks... (P10).

After the diagnosis, doctor said something hurried but I did not really understand it. The education programme was insufficient... (P3).

3.2.3. Changes in emotional state and spiritual state

In particular, emotional state, morale, cultural and religious practices that is affecting health behaviors.

My morale is bad, you give up everything, sometimes the illness makes you feel bad. I do not see a negative side effect, for example bleeding, because I do not have a great negativity (P4).
Five were stated as no expectations about the treatment. Whatever Allah has destined for us (P1-P4, P7).

All the participants had religious beliefs (Muslim) and six of them performed religious practices (three people performed prayer, three people prayed and performed both).

3.2.4. Medication management

All of the participants used medication, also thought that the medicine was important, because it protected them from thinking negatively such as one of them was defined by their diseases:

- When I take medicine, my sugar level drops (P7).
- All of the participants thought that the treatment process had been positive for them and that treatment was necessary.

Two participants emphasized this along the following line:

- People are increasing resistance to life. Feel happy. People are so glad (P2).
- I need to take care of myself and my daughter for a healthy long life (P4).

3.2.5. Self-monitoring and dietary management

One particular issue emphasized that the participants gained more awareness to detect changes self-monitoring their chronic conditions, dietary management was viewed as a huge responsibility, expressed their own care in a dietary management.

- A man is his own doctor (P2).
- I have to figure out whether my sugar level is falling or rising and I have to do something (P3).
- I can inject insulin myself. When I do not pay attention to my diet, I understand that my sugar level goes up and down (P5).
- When I’m so tired my legs hurt I need to rest (P6).

3.3. Information Sources

The participants were not very positive about educational resources, they emphasized their reliance on doctors, the internet, neighbors and their own experiences as educational resources, expressed a fear of training:

- They [doctors/nurses] said something, but I didn’t understand this training (P2).
- I look on the internet for information about the illness (P4).
- My neighbor also has diabetes. I’m talking with her (P5).

It was also expressed that, given the lack of information and learn to cope with their diseases when faced with the problems of the participants, highlighting their own experiences:

- Now, I know myself that I am suffering from long-term hypertension and I’ve learned what to do. I also go to regular follow-up, but I am my own doctor (P1).
- After the doctor at the hospital made a diagnosis….Then I learned what to do to stay alive (P3).
- Over the years, going back and forwards to the doctor and the difficulties of the disease have taught me something. Now I eat unsalted food (P6).
- I suffer from long-term hypertension. At first the doctors said something then I learned what to do myself.
- They prescribe my medication (P9).
4. Discussion

The patient-reported outcomes obtained from the research showed evidence of changes in health outcomes. The quantitative data provided from the patients’ responses allow the researcher to measure changes about the assessment the health behaviour in chronic conditions [8]. It has been shown that the level of education is one of the important determinants of self-care and adjustment levels of patients and that as the level of education increases, the self-management of patients increases [2,6,10,11]. It is vital that people with chronic diseases know what their diseases are and the causes of them, as well as the necessity of treatment, its duration, the treatment plan, the anticipated and unexpected effects of medications, and that they know what problems might arise if the treatment is not followed [7].

For the social support; families played a key role in creating an environment that allowed for support and engagement within the family. This kind of support included maintaining good relationships between members of the family and the normalisation and contextual understanding of the chronic disease [3]. Many dimensions of how family members function can have an impact on a patient who suffers from various chronic conditions as well as how the family functions with regard to resources such as money, the burden of care (e.g. events, activities and daily routines) and its ability to cope with chronic conditions [4,16] and in strengthening self-management behaviors [2,17] of dietary and medication management [18]. The patients’ perception of their dependency can be evaluated as having two different meanings in this research. The first is the perception of family members and their commitment to life. It can be said that it is related to adherence to daily life and affects the patient’s attachment to life. In the process of disease, this relation positively affects the health of the patient and their framing of the disease as a spiritual matter. One of the participants in the study reported that he was living within a large family and was happy that his family ties included grandchildren. He reported that feeling alone was a stressor which increased blood sugar. The second perception is the perception of being subject to the disease process and having to receive help from others in disease management. This has been seen as a negative result of self-managing diseases [11]. Most family members can exert a high degree of influence on patient behaviour, they help to promote autonomy, harmony and provide support for the maintenance of chronic disease management [4]. Having members of one’s family present during consultations promotes understanding and increases knowledge, and, as a result, changes how the family functions for the better.

For disease management, self-awareness and empowerment; there are challenges related to disease management within the health system and service provision, in terms of healthcare providers’ attitudes and behavior, patients’ adherence to medication and lifestyle changes, patients’ individual and clinical experiences and their choice of self-management tools [6,11,19,20]. It is important to provide a window of opportunity for the development of contextually-adapted self-management programs for community health nursing in developing countries [11] because in general people have been living with chronic disease for many years, self-management by the patient is part of everyday life and patients motivation play the central role in their own care [17,19].

The management of chronic diseases involves the patient learning to live with the treatment and disease, and the strengthening of these self-management skills through education. The patient’s feeling of self-esteem and how they cope with a chronic diseases influenced by his/her past family relationships, self-confidence, human relationships, personality, self-esteem and life experiences, which all affect how they cope with loss. There is a relationship between the patient’s personality and perception of their disease and their reaction [2,9]. Patients ‘showing an increasing awareness and increasing and strengthening their participation in treatment is an important index of self-management [2,11,19]. In this study, chronic disease is defined as an ongoing process requiring lifelong drug use and a disease that cannot be healed.

In the study, participants reported perceived barriers that their quality of life was adversely affected by the disease. As seen in the literature, it is possible to say that many variables influence quality of life (follow-up blood glucose levels, dietary management, medication management, difficulties in exercising regularly, related-disease complications or healthy lifestyle behaviours)
In the context of perceived barriers to self-management, a T1DM patient stated that it was a waste of time to do regular blood sugar follow-up tests, one of participants experienced complications from bleeding, two of them felt they should be careful with what they ate but were still frustrated and another interviewer had to make sure not to miss the right time for their medicine to be administered, otherwise they would experience tension.

Changes in emotional state are shown to be an important variable affecting self-management in the research. If a person’s morale is broken, they lose hope and feel bad about the disease, this may lead to a decrease in the perception of quality of life. Depression, sadness and fear have also been shown as emotional barriers to life in the research findings [2,9,18,19]. In other researches, the adverse effects of treatment were associated with a lack of confidence in changing their medication and issues with dietary management in diabetes, hypertension and rheumatoid arthritis patients [11,21].

Similarly to these research findings, Reed et al. [1] found that patients who were involved in a Flinders chronic disease management program perceived their general health status as well and that patients' diseases were affected by the following variables: pain, fatigue, depression, disease intrusiveness, and walking as a form of exercise. Religious or spiritual attitudes is important to manage of the disease. It can be said that the participants who said “Whatever Allah has destined for us” is approaching to the end of life and that they had no expectations about the treatment. Since the perceived seriousness leads to opinions about possible consequences such as death, disability, pain, social losses, the sensitivity on this will lead the individual to take precautions (treatment compliance, monitoring, compliance to the treatment, nutrition, physical activity and spiritually) against the disease [2,17]. The fact that all of the participants included in the research had a religious belief and the fact that some of them performed a religious practice (such as prayer) improve the coping mechanism related to the disease, affect the participation to the treatment positively and have influence on maintenance of self-care.

All of the participants believed that using medicines was important for treating their disease and they thought that the medication protected them from any complications related to disease. Depressive illness, weight problems, difficulties in taking exercise, chronic pain, tiredness, problems communicating with the doctor, a lack of support from the family and financial problems were the most common obstacles to self-management. The most frequently reported obstacles to finding resources about self-management were physical symptoms, a lack of knowledge, transport issues and a lack of insurance [2,5,6,21]. Similar to other research findings, the difficulties that patients had with changes to their medication in the research can be understood by using the extended self-regulatory model, which involves their beliefs about the need for treatment and worries about the negative effects of treatment [11,21].

All of the participants thought that the treatment process made a positive difference and that it was necessary to get treatment. A participant with cardiac valve surgery noted the importance of coordinating treatment in order to be with their family, and another one defined life as joy and happiness. Evaluating self-management has focused on the perceived clinical benefits to patients and looked at how it positive affects their acceptance and understanding of what they are experiencing. However, a recent study has reported that clinicians may find it difficult to share responsibility for managing conditions with their patients [11].

In the research conducted sources of information, it has been reported that chronic disease is not effectively managed and the expectations of the participants are not adequately met due to barriers related to the patients, and that the expectation of healthcare providers is not adequately met due to reasons such as lack of personnel, lack of time, and the traditional care approach [2,11,20]. It is a quite remarkable finding of the study that patients learn to cope with their diseases themselves when faced with the problems caused by them without becoming aware of disease management. The attitude and knowledge of the nurses and the establishment of effective communication techniques has an important role in the management of chronic diseases [20,21]. In a comprehensive and coordinated care delivery system that is accessible to everyone, the patients’ want to be able to learn how to cope with diseases, to maintain the continuity of care, to keep in constant communication with the healthcare professionals [2]. In this study it is possible to say that the participants had been educated
by healthcare providers but that this did not go beyond a few suggestions. The self-management of any disease is taught and the nurses needs to provide support and training to the patient.

Only a limited sample participated in the research. The author freely accepts that her own presuppositions may have had an effect on the data analysis. In order to limit this, the adopted an inductive approach, basing the themes on the data, maintaining a transparent record of these themes and seeking common points of view by discussing the data with others on a regular basis.

5. Conclusions

The present study has been defined social support, awareness of information sources, self-awareness and empowerment of disease self-management. It has been determined that patient-centered perceived barriers to disease management negatively affect the health consequences and self-management and demonstrate requirement changes planning of chronic conditions delivery system. It can be concluded that the role of nursing professionals is important in increasing the awareness of patients and nurse managers make a plan to change chronic disease management procedure.

In the light of this study, healthcare professionals can investigate individual patients’ self-management behaviors and progression of conditions. Especially, nurse professionals can be offered evidence-based self-management programs which teach strategies, practical skills and give patients the confidence to manage their health condition in clinical practice to encourage healthy behaviors, thus enhancing the patient’s self-management skills (medication management, dietary management, self-monitoring, self-testing). Future studies, especially in nurse-led clinics chronic care models should be apply patient-centered care by the nurse professionals.

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