

Adherence to Treatment in Patients with Chronic Diseases: From Alertness to Persistence

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ABSTRACT

Background: Adherence to treatment is a process that begins with alertness about the disease and has to end with staying in treatment. It is a concern to all health care disciplines. The aim of this study was to explore the experience of adherence to treatment patients with chronic diseases.

Methods: This qualitative study was conducted during a period of 6 months in Golestan province in Iran in 2017. In-depth semi-structured interviews were done with a purposive sample of 15 patients with chronic disease (i.e. Chronic renal failure (CRF), Hypertension (HTN), Multiple sclerosis (MS) and Diabetes). Data were analyzed using qualitative content analysis in MAXQDA Software.

Results: The analysis of the data in this study led to the development of ten subthemes and four themes emerged as follows: motivation, cohesion, commitment and empowerment which are necessary components for adherence to treatment in patients. "Moving from alertness to persistence" emerged as the main theme.

Conclusion: The findings of the study offer helpful insights into the concept of adherence to treatment and its components for health care providers, which can be used to develop the best possible care plan and may help health care providers to support the patients to have an active role for following treatment rather than just doing it.

KEYWORDS: Chronic disease, Qualitative research, Treatment adherence

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INTRODUCTION

Subsequent to advanced public health and prevention of communicable diseases, the rates of fatality are reduced; afterwards, the prevalence of chronic diseases increased dramatically.¹ The term chronic disease refers to the illness the course of which lasts for more than three to six months. Common chronic diseases include arthritis, asthma, chronic obstructive pulmonary disease, and diabetes.² Chronic diseases have extremely become notable as mortality rates and disease burden.³ It remains the leading cause of death in the world.⁴ Chronic diseases in Iran accounted for 63% of all deaths.²

It is expected that the burden of chronic diseases will have increased up to 57% by 2020.⁴ The burden of chronic diseases is wasting more resources in the health care systems; these economic consequences are estimated to rise in the future.⁵ Adherence to treatment would be improved by modifying the lifestyle to reduce the symptoms and complications of the disease.⁶ As a result, adherence to treatment can increase the quality of life and improve the life style.^{2,7}

Following the treatment may begin from from “making effort for treatment” to “commitment to treatment” which is diseases even during absence or lack of symptoms.^{2,8}

A great number of patients do not follow the prescribed treatment, and the rate of adherence to treatment in chronic patients is low, ranging from 0 to 100 percent. In Iranian population, it has been reported to be between 12.7% and 86.3%.^{2,3,9-13}

Inadequate adherence to treatment may limit the efficacy of prescribed therapeutic regimen; in consequence, it leads to unmet treatment outcomes which are expected. Promotion of adherence is one way to prevent worrisome consequences of chronic disease.^{2,10,11,14-16}

It is recognized that the control of chronic diseases is not directly in the power of health care providers; somehow, it is in the hands of patients¹. Thus, it is necessary for health care providers to support the patients for enhancing

adherence and successfully providing them with a healthier life. Understanding the perceptions and experiences of patients seems to be necessary; a good design to achieve this goal is the qualitative research.

Adherence to treatment affects the management of chronic diseases¹⁷ although published articles addressing adherence have increased during the last decades. Nonetheless, the problem of adherence is remained unresolved.³ Most of the studies have been conducted primarily in medicine.^{18,19} Many researchers have also focused on taking medication and other components of treatment mentioned in the definition of world health organization, which was previously ignored in most adherence research. Such an investigation has rarely been done as a whole and these issues increase the lack of clarity and detailed information concerning adherence. On the other hand, there is an avoidance of discussions in the articles as to “what is the patients’ experience for taking treatment?” while understanding the experience of patients is required to expand adherence to treatment. The aim of this study was to explore the experience of adherence to treatment in patients with chronic diseases.

MATERIALS AND METHODS

This qualitative descriptive design with conventional content analysis was undertaken in hospital of Golestan province which is located in the Northeast of Iran.

The participants consisting of 15 patients were interviewed from April to October 2017. A purposive sampling method was used to recruit a maximum variation of patients in regard to social background, disease characteristics and treatment. The inclusion criteria were age over 18 years, affliction with a chronic disease at least for 1 year and ability to communicate. The exclusion criterion was lack of willingness to continue participation in the study.

The participants were given written informed consent including permission to tape-record the interview and the objective

of research was explained to them. They were ensured that their information would remain confidential and that they could leave the study whenever they wished. After selecting the potential participants, according to the interviewees' preferences, the time and place which was convenient for them was set in the hospital for interview.

Prior to the interview, the patients' characteristics were recorded. In-depth semi-structured interviews were begun with a broad question (Would you please talk about your disease and treatment?). Uncertainties in interviews were elucidated with additional follow-up questions. Probing questions were then asked to explore the experience of applying the treatment and to provide an opportunity for clarifying the misunderstanding of the interviewer. Finally, the interviewer asked if there were additional key points which needed to be explained.

All of the interviews were done by the corresponding author. The interviews lasted 45-80 minutes. Following the interviews, the audio-taped interviews were transcribed verbatim for subsequent analysis. Two patients were interviewed twice.

The data were analyzed using qualitative content analysis approach concurrently with data collection. Initial codes were made by the corresponding author and the remaining members agreed on the coding process, labeling and interpretations. MAXQDA 10.0 software was used for data organization. Based on the aim of the study, to describe and interpret the concealed message within the data, first was read the interviews transcription line by line several times for immersing the researcher in the data and recognizing meaning units which constituted a single meaning. After extracting the meaning units, in relation to the aim of the study, they were condensed to shorter meaning units. Then, condensed meaning units were abstracted and labeled with a code after examining for similarities and differences and sorting according to meaningful connections. Then, subthemes and themes emerged sequentially. In order

to preserve the core meaning during the process of falling to more abstract and deeper meaning, meaning units were compared with subthemes and themes continually.

To assure the trustworthiness of the data, continuous data comparison and prolonged engagement with data, peer debriefing, and member checking by patients were done for credibility. Dependability of data was evaluated by presenting of the data to the research team to make appropriate decisions. For data conformability, other researchers confirmed the accuracy of the coding process through reviewing some quotations, codes and categories. To ensure the transferability of the data, we considered maximum variation in sampling method.

This research was approved by the Ethics Committee of Golestan University of Medical Sciences with the code of IR.GOUMS.REC.1396.76.

RESULTS

Fifteen adult patients with confirmed chronic disease participated in this study. The majority of them 11 (73.30%) were married and their mean age was 46.06 ± 9.43 years. The time period since diagnosis ranged from 4 to 23 years (Table 1).

The results of the present study revealed that four themes emerged as follows: motivation, cohesion, commitment, and empowerment. "Moving from alertness to persistence" emerged as the main theme (Table 2).

1. Motivation

Motivation was one of the themes that emerged from the patients' expression. They emphasized that it was an important issue at the beginning of treatment. The theme motivation consists of two subthemes including "alertness" and "willingness".

1-a. Alertness: The patients described their concerns about health after facing with some disease-related problems. They expressed their intention to request for help after being aware about the risks of disease. Lack of knowledge leads to delay in seeking care.

Table 1: Characteristics of the participants

Code	Age (year)	Gender	Occupation	Marital status	Disease duration (year)	Disease
P 1	45	Female	employee	Married	15	Rheumatoid arthritis
P 2	46	Male	Self-employed	Married	12	Diabetes & CRF ^a
P 3	53	Female	Housewife	Married	10	Hypertension & IHD ^b
P 4	54	Female	Retired	Married	21	Hypertension - CRF - Osteoarthritis
P 5	48	Male	employee	Married	13	Diabetes
P 6	26	Male	Unemployed	Single	4	Systemic Lupus Erythematosus
P 7	40	Female	Self-employed	Divorce	6	Hypertension & CRF
P 8	59	Male	Farmer	Married	21	CRF
P 9	32	Male	Worker	Married	8	COPD ^c
P 10	52	Female	Housewife	Widowed	15	CHF ^d
P 11	46	Male	Disability Pensioner	Married	5	Cirrhotic liver failure
P 12	38	Female	Housewife	Married	8	Hypertension
P 13	42	Female	employee	Married	3	CRF
P 14	60	Male	Retired	Widower	23	Diabetes
P 15	50	Male	employee	Married	7	IHD

a: Chronic renal failure; b: Ischemic heart disease; c: Chronic obstructive pulmonary disease; d: Congestive heart failure

Table 2: An overview of the main themes, themes and sub-themes

Main themes	Themes	Subthemes
Moving from alertness to persistence	1. Motivation	a. Alertness b. Willingness
	2. Cohesion	a. Patient-health care provider interaction b. Patient-health care provider congruency
	3. Commitment	a. Fidelity b. Participation c. Responsibility.
	4. Empowerment	a. Competence in self-care b. Adaptability c. Persistence in practice

In order to promote the health literacy, they were eager to obtain information and share their concerns with health care providers because they needed more information on their conditions, when they were warned of a disease threat.

“When you find out that you have the disease and they talk about the cure, you don’t know exactly what is going on! How important it is. You are confused.”(P6)

“You can’t believe it because there are just some small signs and your life is going on without any change. Till you gradually find out that how careless you were about your health.”(P4)

1-b. Willingness: Willingness refers to the patients’ tendency to enter and stay in treatment. Some patients pointed that when they knew what was required to be done, they tried to seek out treatment intentionally. Then, they are more likely to be involved in treatment.

“So, I try to consider everything, but I’m not anxious because I know the way to protect myself. I can, I can control everything in my life because I am willing to do that.”(P15)

2. Cohesion

The participants pointed that the cohesion of patients and health care providers will help

the patients to take their advice. Based on the patients' delineation, the theme cohesion comprised the following subthemes:

2-a. Patient–health care provider interaction: Patients explained that they felt secure if they could count on health care providers when they needed help. Patients believed that health care providers, as the most reliable source of support, should spend more time in providing continued care. Although health care providers are ostensibly interacting with the patients, they have to consider some important issues such as empathy and respectfulness in their relationship. Health care providers should initiate an effective communication with respect to the patient's rights. They focused on how it can affect the patients' behavior to follow the treatment. When they have effective interaction, health care providers can develop care plan based on the patients' needs.

“A doctor prescribes you a medicine and another contradicts it; this makes you confused. You know what's annoying? When I asked, they didn't reply me!”(P3)

“When the doctor doesn't examine me and he only writes a prescription...! You have to just take medicine! He doesn't try to find out what the problem is. Sometimes, I just need to talk and to be calm.”(P1)

“He didn't ask me! Nothing! He just looked at my medical records. Medicine isn't all to be considered. Words are mostly like a miracle which makes the patients tranquil.”(P4)

2-b. Patient–health care provider congruency: Congruency between patients and health care providers means to decrease disparity between them regarding the treatment. Participants referred to their right to self-determination and their need to autonomy as a part of establishing a therapeutic relationship. Some participants felt inferior because of their role as a powerless recipient of care. They pointed that the doctor takes the sole responsibility for treatment decisions as an absolute authority and just prescribes drugs without providing any information about the potential risks and

benefits of all treatment choices based on his/her own condition and ability. They pointed to the importance of sharing of power between health care providers and patients. With mutual decision making, patients are given the opportunity to express their preferences. Patients should be empowered to make active and collaborative decisions.

“He doesn't allow me to explain my condition. How can he decide about my treatment without knowing about my lifestyle, financial issues, facilities, etc.?”(P2)

3. Commitment

The theme “commitment” included three subthemes: fidelity, participation and responsibility.

3-a. Fidelity: Fidelity implies a sense of duty to prescribe treatment without wavering allegiance to them. To achieve the goals, patients have to trust in health care providers. Also, the greater fidelity toward the treatment causes a greater intention to follow the treatment. This sense of faithfulness to a duty in treatment is also inherent in patients' commitment.

“I never give up my medicines, diet and ...; it's so interwoven with my life; it's part of my life and I do them as a routine. I owe my health to them.”(P5)

“It's no wonder I refused their recommendation at first. When disease occurs, problem will spread across all aspects of life. You lose lots of your routine, but life goes on. When you find out you take your life in your hands, there's no choice. You promise to stay on treatment over the rest of life.”(P7)

3-b. Participation: Participants revealed that patients expected to be viewed as active participants in their own health care. They explained their need to be more involved in treatment; their active role in treatment process should be continuous. They state that active and ongoing participation in treatment enables them to achieve health-related goals, but it requires the participation of health care providers as well.

“The nurses have to know everything

about us and then develop a care plan. To treat the patients, they aren't doers; they are facilitators."(P14)

"It's clear that doing your treatment usually involves working long hours. I think both doctors and families have to allow us to take part in treatment."(P8)

3-c. Responsibility: Responsibilities are the voluntary roles to follow the goals of well being. One participant pointed that patients could take more responsibility for their care. Patients' awareness of their uniqueness of own circumstance and potential risks may lead to a heightened sense of responsibility for health. Responsibility should be shifted not entirely; the shared responsibilities of patient and health care professional should be considered because patients need more support for being safe. The responsibility should be allocated to the patient reasonably.

"I know. This is my problem. If I cooperate more and be more responsible, I can keep away from this difficult situation."(P3)

"You know what scares me? Lots of patients, who don't apply the treatment, take their own life. It's a kind of committing suicide gradually. I know it's your business! It's your life! But you can't deny it; you need help. Nobody can help you if you don't want!"(P12)

4. Empowerment

According to the tenets of the participants, "competence in self-care", "adaptability", and "persistence in practice" are subthemes of patient empowerment.

4-a. Competence in self-care: Some interviewees explained about their confidence regarding their ability to perform specific tasks. The sense of taking control and asserting their own authority came from the patients' own beliefs in their ability. They learned based on their personal experiences or by watching someone else in a similar situation. They reported that health care providers tend to undervalue their experiential knowledge and skill in self care. They explained about their need to participate in educational program. Insights in self care and feeling a mastery

of behavior for self-care may make it easier to believe in one's own self-management capacity and promote his/her self-efficacy. Afterwards, they can participate in treatment and can perform more challenging tasks. The finding revealed that the patients' attitude about their capabilities is an important factor in using their abilities to overcome disease-related problems and follow the treatment. Their perceptions of oneself to be independent are required to manage the wide range of unforeseen, novel and particular situation.

"After stroke, I tried to do my affaires by myself. I pushed my body to the wall to stand up and did my chore by lying on a cane. I believed that I could stand on my own."(P3)

"So, I think people can control everything if they want; life is ours. Why don't we direct it? We can change everything if we want. I know it's so difficult, but we can handle our lives and enjoy it."(P6)

4-b. Adaptability: Adaptability has a very important role in patients' empowerment. According to the tenets of the participants, following the treatment is closely related with the patients' ability to change their practices, or beliefs depending on the directions imposed by others. When patients set aside their own beliefs and yield to health care providers' recommendations, they can give up unhealthy behaviors. This flexibility is essential for implementing the treatment modalities, so that the goals are met. Patients explained about their need to expand the resources, especially their social support. They believed that the condition was partly controlled by themselves, but also partly by the social context, particularly the family members' support. They pointed to tangible support plus emotional and informational support, such as medical equipment, home facilities and other services in society which can persuade them to follow the treatment and maintain a new lifestyle.

"As you can see, most of the diabetic patients are old. They need their children to help them emotionally and financially!"(P5)

"There's no other alternative for me. I've

been under dialysis for 4 hours twice a week. It takes a long time; therefore, I do nothing for my family; I've to accept."(P13)

4-c. Persistence in practice: When patients learn to use all types of skills to control the disease, these skills will be maintained over time. It may allow them greater perceived control over their life with chronic disease and enable them to recover or withstand difficult conditions and change the lifestyle. Patient's tendency to persist as a result of mastery of knowledge may lead to maintain the new behavior for achievement of goals. They explained how their knowledge enabled them to identify new symptoms early on, and thus to deal with the new condition for preventing the exacerbation of the disease. Despite living with chronic disease, when they succeeded to turn life all into comfort, they were be persuaded to follow it in the same way constantly. Some participants referred to their steadfast and hardiness against some external forces such as lack of facility and family disagreement for treatment. All these efforts could prove useful when they insisted on staying in the new behavior for balancing life and disease. After mastery of healthier behavior, they could stay in new behavior and integrate treatment with the rest of life.

"Life's too short to worry about, I try to see the convenient side of treatment; and then it helps me to behave well according to my doctors suggestions completely, with no trouble for me. I try to be as good as I say."(P8)

DISCUSSION

According to the finding, adherence is a dynamic process from "motivation" to "empowerment". When patients struggle with the disease, the presence of undesirable consequences may render them aware as the result patients' attempt to consult and seek treatment as a useful solution, but some research finding pointed that greater concern about treatment was associated with non-adherence.²⁰

The finding of the research revealed that

lack of knowledge about the disease led to late alertness and intention to take action. Some researchers demonstrate that adherence is influenced by increasing knowledge about their medical condition.^{19, 21, 22} Contrary to our findings, a study indicated that more information about drugs and side-effects could lead to non-adherence to medications.¹² In the light of the participants' point of view; notice to problems can motivate the patients to seek treatment. As earlier studies revealed, willingness and motivation could play an important role in adherence to treatment.²³

Interviews with participants revealed that a sense of cohesion between patient and health care providers during treatment is required which consists of interaction and congruency between them.

Health care providers need to be aware of the fact that their communication skill has a strong effect on interaction and consultation. Another researcher considered counseling as part of treatment and better adherence will occur due to the effect of greater psychosocial support and counseling.¹³ The roles assumed by health care providers in our study both facilitated and constrained communication. A communication skill within health systems is necessary for developing meaningful engagement. Research findings have indicated that interaction with health care providers, as an influential resource, can impact the consultation process which helps the patients to understand their condition and perceive medical advice helpful.^{20, 24, 25}

Health care providers' authoritarian relationship was the patients' most concern. They stated that they need to be listened and understood. Patients who had more empathic relationship with health care providers were more likely to be congruent with them. Effective communication and power sharing are two interrelated factors. Balance in patients and health care providers' power can help them to get involve in informed and shared decision-making about treatment. The participants reported that congruency between health care providers and patients are

reinforced by power sharing. The relationship between mutual decision-making and compliance has been addressed in the studies implicitly. Using participatory approaches by involvement of the patients persuades them to achieve treatment purposes.²⁶ When decision-making processes are initiated or facilitated by health care providers, patients cannot trust in the information which leads to less information gain.²⁵ The concept analysis of adherence reveals that there is no definition for adherence with focus on a patient-centered approach and the power balance.²⁷

The findings indicated that commitment to treatment is considered as a most important step in treatment. It is worth noting that patients cannot be forced to follow a lifestyle dictated by others; they should be more convinced by prescribed treatment and they should rely on the health care providers' advice. Fidelity is the cornerstone of commitment for patients. For being faithful in treatment, patients should identify the benefits of treatment as well as any barriers; after that they assume all or part of the prescription and try to take an active role in the care. Active participation of patients may help to achieve an agreed plan and expected outcome.²¹

The finding suggests that adherence is facilitated by empowerment that includes competence in self-care, adaptability and persistence in treatment. Although less attention has been paid to the studies to find the impact of empowerment on adherence in a direct manner, the components of empowerment (motivation, power opportunities and ability) were frequently cited as the critical determinant of adherence.^{25, 28} However, some research finding indicates that patients' socio-demographic characteristics and clinical variables did not affect the adherence.¹³

For enhancement of the patients' well-being, sufficient skills to manage the condition and utilize resources are pivotal. To bring about this purpose, patients should be flexible. In this situation, they can change their behavior and social situations that influence their lives with disease.

In the process of behavior change, health care providers have to know how to help the patients to develop their skills to take control over their conditions, while they experience disruptions of routines due to treatment restriction. Adaptability as a core component of empowerment is helpful for adopting the new situation and getting help from others. The literature has focused on the relationship between adherence and social support which can help the patients to cope with the new situation.^{19, 21}

Patients with good treatment outcomes have described how they succeeded in changing their lifestyle. In fact, the components of adherence have had a decisive role in the patient's behaviors in treatment. They put effort in their practice for perpetuating this change, despite many obstacles that hinders progress. For changing the lifestyle, patients should both adopt the new behaviors and adapt to the existing behaviors, but for changing lifestyle, the patients did not receive enough information.^{19, 28}

The findings of this study can provide insight to health care providers to find out the process and components of adherence to treatment. However, these findings cannot be generalized to all chronic patients in other settings because of the small sample size. Also, the limitation of our study was selection of the patients from Golestan province. Therefore, the finding may be applied in a comparable context which is extremely influenced by culture and religion.

CONCLUSION

Understanding the views of health care providers about the concept of adherence might enable them to develop the best possible care plan for improving the outcomes of treatment. Based on the findings, they may encourage the patients to modify their lifestyle according to medical recommendations; as a result, it may help the health care providers to support the patients to have an active role in following treatment rather than just doing it.

In future studies, it would be more effective to include health care providers to find out their experience which is an influential factor in the process of adherence. Also, future studies are recommended to be conducted in other contexts and in patients with specific diseases.

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