

Experience of patients with Asthma from the role of social support in self-care: A qualitative study

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Research

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Abstract

Background

Asthma is one of the biggest challenges of health systems. One of the most effective ways to control this chronic disease is self-care. Self-care can be affected by social support. This study aimed to explain the experience of patients with Asthma from the role of social support in their self-care.

Methods

This study was qualitative and phenomenological and conducted in 2019. Data collected through semi-structured interviews with 40 patients using purposive sampling. It is noteworthy that the implemented interviews were analyzed using the seven-step Colaizzi method.

Results

Findings presented two main themes (patient communication network, self-care of asthmatics) and ten sub-themes. Some of the sub-themes included motivating peers as a reason for self-care, lifestyle and self-care advice, add exercise to the life plan, and therapeutic recommendations are a factor in following a treatment regimen.

Conclusions

It seems that self-care with social support and establishing a communication network between people with Asthma to transfer information and experiences and identify their needs in the management and control of this disease at the community level can be very serious.

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Background:

Asthma is one of the main problems of health care systems in many countries, including Iran and unfortunately, the prevalence of this disease and its associated risk factors is regularly increasing [1]. This chronic, non-communicable inflammatory disease of the lungs will affect 400 million people by 2025 [2]. Chronic means that the disease is always present even when the patient does not feel unwell [3].

Chronic diseases, in particular, affect the quality of life of people, social and economic issues, and they can lead to poor health outcomes in individuals, families, and communities and cost a lot [4]. In addition to adequate treatment, self-care in patients with chronic diseases in long-term life plays the principal role [5] because when the patient is present in the care and treatment process as a primary element, Participation, satisfaction with treatment, and quality of life increase, and anxiety decreases [4]. Self-care behaviors include activities that a person starts and does to maintain life, health, and well-being. Self-care is a turning point in proper Asthma control, and self-control programs are the most effective way to

control the disease [6]. It could influence by factors related to the patient, the community, and the environment, including social support and care staff [7].

Social support is one of the emotional coping mechanisms to have a potential impact on the quality of life [8]. Studies show that social support has positive effects on various aspects of self-care activities. It is affected in controlling the disease through two main processes: 1. the direct impact of social support through health-related behaviors such as encouraging healthy behaviors 2. The moderating effect of social support helps to moderate the results of acute and chronic stress on health as well as increase adaptation [9]. Satisfaction with the patient's social support is associated with reducing anxiety and depression and overcoming self-morbidity, and increases self-confidence and the development of social relationships, and improves the quality of life [10]. The Owen study found that patients with social support had higher confidence to perform self-care behaviors [11]. One study also showed that having social support was effective in preventive health behaviors, and sick people who need more support could have more effective self-care processes with this support [12].

This study aimed to investigate the effect of social support on self-care activities as an effective activity to control and manage Asthma. Also, with a qualitative study, a deeper understanding of patients' views about the social network is involved in their treatment process will be possible. This process can explore the social network in-depth, and since there is a close relationship with the participants, the concept of support and understanding of patient support could explore with greater transparency.

Methods:

Study design, site, and participants

The present study was a qualitative study conducted phenomenological with the Colaizzi approach in 2019 in Kerman. The research environment included the offices of pulmonologists and clinics. The subject's selection was from the patients of these centers using purposive sampling. Patients were satisfied with the sound recording and the use of their opinions. The interviews continued until the data were saturated. Semi-structured interviews were with 40 patients with Asthma. Inclusion criteria were, patients who had been diagnosed with the disease for at least three years and their Asthma has been confirmed, their health is acceptable enough for participating in the interview, and their willingness to participate in interviews and answer questions.

Data collection

After explaining the objectives of the research and presenting a letter of introduction and reminding patients of ethical considerations, giving them the right to choose to accept or reject participation in the study, keeping information confidential (using code instead of participants' names), and about time and obtaining permission To record the interview, their consent obtained to start the interview. Each interview lasted about 20 minutes. Attempts were made to manage the interview conditions to get much information as possible in a way that has minimal irritation for the patient while obtaining an interview. In

this study, to protect the privacy of patients in the interview process, an attempt was made to conduct the process in a way that patients could participate in it without worries. For example the interview was transferred from the waiting room to the secretary's room and provided with a chair where patients could sit and do the interview. The objectives of the study explained to a pulmonologist clearly and concisely to involve him, and coordination took place before the researchers arrived at their workplace.

A number of general questions were used to collect information and clarify specific cases. These questions were designed by reviewing relevant literature and scientific articles [13–18] and by consulting with experts in the field of patients and health care providers. The Guba and Lincoln criteria of reliability, validity, fitness and confirmability were used to determine the trustworthiness of the questions. To ensure the reliability of data, samples with maximum variation in age and education level were selected. Validity means that whether the result apply to other groups. For this purpose, attempt was made to select informed and opinionated samples. To meet the criterion of fitness, the study process was provided to qualified experts with experience in conducting qualitative research, as well as to the supervisor and specialist physician to be confirmed by them. Given that the three criteria of credibility, transferability, and dependability of qualitative studies had been met in this study, it can be concluded that the criterion of confirmability had also be ensured [19].

Data processing and analysis

The Colaizzi's seven-step method was used to analyze the data [20]. In the first step, all the descriptions given by the patients were repeatedly studied in order to get a general sense of understanding. In the second step, the transcripts of the notes were reviewed and the sentences directly related to the phenomenon under study were extracted. In the next step, an effort was made to understand the meaning of each of the important sentences (this is known as formulation). In the fourth step, the above stages were repeated and the formulated and related units were grouped into classes and categories (the original codes). In this step, first the validity of classes was examined by referring to the original manuscript and then, the inconsistencies between or within classes were reviewed. The inappropriate data or categories were not ignored. Step five involved combining the results into a comprehensive description of the study topic. In the sixth step, the comprehensive description of the subject under study was formulated as an explicit statement of the phenomenon structure, often referred to as the inherent structure of the phenomenon. Finally, in the seventh step, by referring to each participant and conducting a single interview, the opinions of participants about the findings were considered and the final validation of the findings was done.

Results:

The analysis of interviews resulted in the identification of two main categories and ten sub-categories (Table 1). For each of the main categories and sub- categories, relevant statements and quotation made by the interviewees will be presented.

Table 1: Main categories and sub-categories related to the impact of patient social network on Asthmatic patients

No	Main category	Sub-category
1	Patient's communication network	1. Motivating peers is a reason for self-care
		2. Advice on lifestyle and self-care
		3. Psycho-emotional support of the patient
		4. Advice to avoid risky behaviors
		5. Supporting position of experienced and committed medical staff
		6. Get psychological counseling
2	Strengthen self-care behaviors	1. Pay attention to consumption and considerations of drugs
		2. Add exercise to the life plan
		3. Therapeutic recommendations are a factor in following a treatment regimen
		4. Prevention of other aggravating diseases

1. Patient's communication network

Patient communication is one of the most important factors associated with the disease and recovery of Asthmatic patients. Therefore, to identify the position of each member of the communication network of Asthmatic patient, it is important to know the characteristics of the members of communication network.

Motivating peers is a reason for self-care

Each asthmatic patient has his or her own social network. These patients' social networks are tangible and affective in each other's healing process. These contributions can be from other patients as well as from people on others' social networks.

Since patients are sensitive to disclosure of their health and medical information to others, they tend to communicate more easily with people they trust and talk to them about their illness. One patient in this regard said:

"I try not to talk too much about my illness, and only my husband and my father know about it. (P.7).

Without effective communication, no solid communication network will exist. People who have more communication abilities can be trusted by patients and gain their satisfaction. They also make patients to communicate more comfortably and talk about their problems more easily. One patient mentioned:

"Stress is very effective in asthma, so having a physician and a nurse who can communicate well and have a good morale helps you to control your asthma (P. 15).

"My mother can only calm me down whenever I get nervous and get short of breath. Otherwise I get angry and my asthma gets worse, so I think my mother has good communication skills (P. 22).

Advice on lifestyle and self-care

Lifestyle is a combination of behavioral patterns and individual habits throughout life, including nutrition, physical activity, stress, tobacco use, and quality of sleep that result from socialization. Lifestyle is a multifaceted phenomenon that encompasses all aspects of daily life such as sleep, food, health, customs, work, play, entertainment, leisure time, social relationships, mindset, behavior, and emotions. All patients, depending on their condition and level of illness, have some people on their social network who give advice on healthy lifestyle and how to improve it. One patient in this regard stated:

"My doctor has given me all the advice about the lifestyle I should have and has helped me a lot (P. 20).

"Everybody thinks that those with asthma can't exercise, but there are some sports that asthmatic people can do and I always suggest them to others (P. 26).

Patients use a variety of resources to protect and promote their health, including their own, other people, information available in the environment and specialists. There are several ways to perform self-care in patients with asthma. For example, one patient stated,

"My doctor has given me most of the education about self-care and diet. At home, my children tell me to wear mask when cooking and when is dusty. They tell me what to do so I don't feel bad (P. 30).

"All the things that I have to do for treatment, my daughter have asked the doctor and do them for me (P. 5).

Psycho-emotional support of the patient

The secret of patient care is the patient's emotional support. In asthma, the patient's mental state plays an important role in patient's health and asthma attacks, and psychological support reduces patient's stress. Patients with poor mental health are more likely to develop asthma attacks and have a life-threatening illness. One patient stated:

"When my children and my husband take care of me and do not stress me at home, I do not feel bad at all. If I get nerves and stressed, I feel so bad" (P. 10).

"Nothing like the family can make a person calm and lift his/her moral in the stressful situations" (P. 36).

People and patients who are on another patient's social network can provide strong emotional support for that patient and give him hope that his illness can be cured by going through the course of treatment.

Specialists also play an important role in providing emotional support for their patients. Emotional support of patients reduces stress and asthma attacks. One patient stated:

"I was very scared of asthma before and thought that it is an incurable disease. But when the doctor talked to me and said that with the use of sprays, my lungs would be repaired, I became less worried" (P. 15).

Stresses and psychological moods that Asthmatic or Allergic patients have are especially important, because they can play a role in exacerbating their disease. Most patients have a social-familial support network, but nonetheless, physician's control and treatment of Asthma and allergies provides an additional source of support. Regular visits and easy access to doctor for unforeseen issues will definitely reduce anxiety. It also creates a sense of security and confidence in patient. For example, one patient said:

"I need medication and no stress and argument at home. I get really sick and short of breath when I get nervous. I get so much better when my daughters come to visit us from their towns" (P. 29).

Advice to avoid risky behaviors

In the patient's social network, there are people who engage in risky and harmful behaviors that are harmful to patient and these behaviors should be avoided as much as possible. Such high risk behaviors are also reported by the patients themselves and may pose a serious health risk to them. For example, one patient stated:

"Many people in the family ask me to quit smoking as I use opium" (P. 23).

"In relation to high-risk behaviors, I have been advised to stop smoking, and avoid going to places where there is smoke, or wear mask when I am cooking" (P. 22).

Patients' awareness of environmental stimuli has either been empirically tested or trained by experts. People who have just been diagnosed with asthma get their information through other patients on their social network. One patient in this regard stated:

"I can teach, for example, I say, don't smoke, don't walk in the dust, don't go anywhere where people are smoking, do not keep a pet, or don't use feather-filled pillow. We have asthmatic people in my mom's family" (P. 7).

"In regard to the environmental stimuli, the physician told me to wear mask when the air is polluted, leave the places where there is smoke, and do not eat fast food" (P. 34).

Supporting position of experienced and committed medical staff

One of the needs of patients is the need for qualified medical staff. If the hospital treatment staff perform their duties properly and provide proper diagnosis and treatment, patients will be satisfied with their

treatment. Most concerns of patients about the treatment staff is that, when they pay for their treatment, they want to see positive outcomes. Naturally, patients whose physicians have a high level of expertise are more satisfied with their physician, and they introduce them to other patients on their social network. Introduction of specialist physicians is also seen by other people on patient's social network who are not ill, including family, friends, etc. One patient stated:

"I was hospitalized for my asthma. I live in another city, so I came to see a doctor in Kerman and she admitted me in the hospital and thanks to God I got better. The nurses worked very hard for me" (P. 5).

One patient in this regard stated: *"A friend of mine introduced a physician to me for my asthma, and she has become my doctor since and I am very satisfied with her. So if I see someone who needs a specialist physician, I introduce her"* (P. 7).

Get psychological counseling

Psychosocial factors play an important role in asthma. Psychological factors are often considered to be the underlying cause of the disease. Anxiety and depression, whether contributing to the onset of asthma or occurring during asthma, can cause asthma attack and affect quality of life. One patient in this regard stated:

"I have a lot of problems in my life. I need counseling. My husband left and I brought up four children alone. I always fought with myself. I really need a peaceful place" (P. 11).

Another patient stated: *"I really have stress and problems at home. I need someone to really calm me down. I have a bad condition at home"* (P. 28).

"I have a problem with my husband. Most of the time I get nervous and have asthma attack because I argue with my husband. I really need a psychiatrist" (P. 7).

2. Strengthen self-care behaviors

All diseases have their own care process and support needs, and asthma is no exception. Among the needs of asthmatic patients are the perceived and essential need for disease treatment. Perceived needs are the needs that patient require and may not be necessary, but essential needs that are often diagnosed by a physician are the needs that improve patient's condition and if neglected, they may endanger the health of patient.

Pay attention to consumption and considerations of drugs

One of the most basic needs of patients is the need for effective medications. Prescription of effective medications depends on accurate diagnosis, and the experience and expertise of the physician. One patient in this regard stated:

"I think you must first find a good asthma specialist to find out what makes you sick and give you good medication, not the ones that make your illness worse" (P. 33).

Most patients do not have enough information about the use of drugs that are harmful to asthma and allergies. So it can be said that, pharmacological counseling is one of the few important and effective measures in the treatment of asthma and all patients obtain their information from their doctor. One patient in this regard stated:

" I used to take ibuprofen or acetaminophen when I had a headache, but I did not know both of these pills would make me worse until I asked my doctor and he gave me a replacement medicine for my headache" (P. 27).

"Since I have had open heart surgery, I have to consult both my heart doctor and my asthma doctor, so that there would be no interference with my drugs" (P. 14).

Add exercise to the life plan

Exercise is beneficial for people with asthma and reduces the frequency of asthma attacks. The exercise of choice should be consistent with the patient's physical condition and health. People should consult their doctor before performing any exercise. In the area of exercise counseling in the patients' social network, information is provided to patient through a specialist physician. One patient in this regard stated:

"I can't do exercise. My doctor said I should only take a short walk in days when the weather is not polluted and in places where there is no flowers and plants. I have allergies and it gets worse if I don't follow these rules" (P. 9).

Another patient stated, *"My friend is studying medicine and says I can do swimming and cycling, so I go for swimming once a week" (P. 19).*

"My doctor told me I can do some light exercises and I could go for a short walk" (P. 12).

Therapeutic recommendations are a factor in following a treatment regimen

Nutrition is one of the factors that contribute to the increase in the number of people with asthma. Proper nutrition can help relieve and improve asthma condition. The need for proper diet is seen in all asthmatic patients. Specialist nutrition for these patients is provided only by a specialist physician and nutritionist, and in some cases it is suggested to asthmatic patients empirically by others on their social network. One patient remarked:

"The diet and treatment that the doctor prescribed me (avoid eating certain foods) has helped me more than the things others suggested me. If I follow the regimen, I will feel much better during the day" (P. 34).

"I have not had any dietary counseling, but my uncle, who had asthma in the past, gave me some advice on foods" (P. 17).

Nutrition is one of the most important ways to control asthma attacks. The nutritional advice is first provided by the specialist physician on the patient's social network and then, by patient's experience and family. One patient said:

"I should not eat pickles and meat. There is smoke in the house that should not be. It is better not to smoke. Eating bad food will make me worse. Cold weather annoys me. I should adhere to diet that is given by my doctor" (P. 14).

"When I went to see the doctor, he wrote a dietary regimen on paper and told me what foods are not good for asthma. I follow them all" (P. 19).

Prevention of other aggravating diseases

Several factors are involved in exacerbation of asthma. One of these factors is other diseases that exacerbate asthma. These diseases can increase the incidence of asthma attacks and cause severe shortness of breath. Patients should prevent these diseases by adhering to health recommendations. One patient reported:

"In winter, when I get cold and my sinusitis worsens, I feel very bad and I get chest pain. The weather gets worse, so is my asthma" (P. 34).

"I just have to be careful not to get cold, because cold causes me to caught, and that makes my breathing worse" (P. 10).

Discussion:

Participants in this study believed that the patient's communication network was one of the most important factors associated with their disease and recovery. From the viewpoint of asthmatic patients, motivating peers is a reason for self-care, advice on lifestyle and self-care, psycho-emotional support of the patient, advice to avoid risky behaviors, supporting position of experienced and committed medical staff, get psychological counseling are effective in their treatment. In the study of Lorant et al., the most important features were emotional and psychological support and effective communication skills in patients with chronic disease [21]. In the study of Kahkonen et al., the highest participation in patients' social networks was related to lifestyle and drug counseling [22]. NaviPour's study also indicated that the extent and quality of people's relationships and their lifestyles should be considered in the promotion of healthy lifestyle in patients with chronic disease [23]. In the study of Robert et al, the most frequent form of communication was consultation on self-care [24]. The most important feature in the study of Levin et al was the reassuring communication in most families and receiving of psychological support for asthmatic patients [25] that finding is consistent with the results of present study. In Wright's research, emotional and psychological support was the most important form of communication [26]. In a study,

Loerbrocks et al., found that due to the low morale of patients, psychological need is a priority for asthmatic patients and after that the need for experienced clinical staff is prominent [27]. In the study of Lind et al., emotional support, and medicinal and medicinal consultations were the most effective form of communication [28]. In recent years, patients and their families have been increasingly involved in health promotion and health care activities, and also increased patient participation in care and follow-up has provided appropriate strategies for health promotion [29]. In the study of Ghazi Saeedi et al., smoking and indoor allergens (such as domestic dust, fungal spores and animals) were identified as contributing factors to asthma [30]. In the study of 128 asthmatic patients, Smyth et al., referred to counseling on environmental stimuli and high-risk behaviors as an important measure in asthma care [31]. In a study, Pedram Razi et al stated that nurses play an important role in patient education and they can be widely used to train asthmatic patients in the Iran's treatment centers. They also acknowledged that continues education, active follow-up system, and greater interaction between physicians and nurses can effectively meet the needs of patients with asthma and their families in Iran [32]. Based on the results of a study, psychological mechanisms and social practices throughout one's life influence the incidence of chronic diseases. In addition to the effective role of these determinants in the control and incidence of asthma, one can also point to the role of social environment in the adoption of health behaviors that have a significant impact on optimal disease control [33]. In Shemwell's research, the main role of service providers was to provide education and counseling on caring behaviors and self-care for patients with chronic diseases [34]. It seems that planning to involve patients as much as possible in health promotion instead of immediate or temporary treatment methods could provide appropriate educational and treatment strategies. Also, forming an effective communication network between people with chronic diseases could lead to emotional and psychological support. This support encourages and gives hope to patients, which plays a great role in creating and maintaining patients' self-care motivation. By conducting macro-related research, we could focus more on improving patients' mental health and support their needs in this area. Efforts to improve patients 'mental status through mental health and psychological interventions and education of patients' families and people with whom a patient is most in contact could helpful.

In the present study, the interviewees believed that asthmatic patients have many needs, depending on the severity of their illness, their mental and physical condition and the environment in which they live in. Some of these needs include strengthen self-care behaviors, pay attention to consumption and considerations of drugs, add exercise to the life plan, therapeutic recommendations are a factor in following a treatment regimen, prevention of other aggravating diseases. The study of Augusta et al., concluded that drug therapy has several side effects and inter-professional treatment methods are more effective [35]. For optimal control of asthma, appropriate drug use is an important consideration, indicating that the drug should not be used arbitrarily [36–38]. Excessive use of antibiotics and arbitrary administration of vaccines have been identified as causes of asthma [39]. In the study of Martin et al., patients' noncompliance with medication regimen and misuse of medication were identified as the leading cause of failure in the treatment of asthma [40]. One study found that family support has a significant effect on diet and exercise. In cases where those around them have used positive reinforcing

behaviors (such as encouragement or accompaniment) to force the patient to carry out their treatment programs, they have achieved better results [41]. In studies, factors such as rhinitis in the individual, recurrent respiratory infections, rhinovirus infection have been identified as effective factors in asthma [42]. According to research conducted in Iran, social support has a significant effect on the treatment and control of diseases [43–45]. A study has shown that the more support a sick person has on their social network, the more loyal they are to following their self-care activities [46]. Asthma is a chronic disease that requires ongoing and continuous management [47]. Special attention should be paid to patient education as patients do not have sufficient information about the disease. Involving people in self-care in the disease process develops the skills necessary to adapt to the disease. It also reduces the patient's dependence and thus empowerment, which ultimately leads to self-care behaviors. It seems social network creates motivation and adherence to self-care behaviors by creating a spirit and hope. The interaction between the patient and others and accompanying the patient in the social network can ensure self-care behaviors of observance in patients with asthma.

Conclusions:

According to the results, it seems that educating patients, establishing a communication network between people with asthma to transfer information and experiences, and identifying their needs in the management and control of this disease at the community level can be very important. In future studies, it seems that by examining the status of depression, quality of life, absenteeism, self-care, and health care needs of asthmatics from the perspective of health professionals, more dimensions of the problem will clarify.

The present study was an attempt to identify the role of social support in self-care by using the experiences of patients with asthma. Limited research did on this subject in Iran. The present study is qualitative and performed on a small number of participants, so like all qualitative studies, it has little generalizability.

Declarations

Ethics approval and consent to participate

The ethical considerations observed in this research included obtaining informed consents from the participants before their participation in the research and recording the interviews, not listing the names of the participants in the transcribed texts, and observing the principle of confidentiality (ethical code: No. IR.KMU.REC.1399.357). Receiving informed consent in writing in order to participate in the interview, observing anonymity and secrecy in recording the interviews, and assuring the participants of the confidentiality of their information and the right to participate in or leave the study were some of the moral principles of the study. The participants could skip any question they were not willing to answer. In order to conduct the research, the researcher went to the participants' workplace and interviewed them

there. The participants were informed that they might be contacted again to complete the process. Moreover, they were told that if they wished, they could have the results of the study.

Consent for publication

Not applicable. The manuscript does not include details, images, or videos relating to an individual person.

Availability of data and materials

All relevant data are presented in this paper. The datasets generated and/or analyzed during the current study are not publicly available because the study uses primary data of interviews with participants.

Competing interests

All authors declare no competing interest.

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Authors' contributions

MAH, LV, RG, MS and RGh contributed conceptualizing the study, drafting the manuscript and finalization. MAH, LV, RG and MS contributed in data analyses and results write up. LV, RG, MS and RGh thoroughly reviewed the manuscript and contributed substantially for necessary revision. LV and RGh final reviewed the manuscript and prepared for submission. The authors read and approved the final manuscript.

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