Perceived Problems of Patients with Chronic Respiratory Failure: a Qualitative Study

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ABSTRACT

Chronic respiratory failure is one of the concerns of the World Health Organization because of its widespread prevalence in the world. This disease has led to individual, family, and social dysfunction in these patients with a wide impact on physical, mental, and psychological dimensions. Considering the importance of this issue, the present study was conducted to explain the patients’ perceived problems with chronic respiratory failure. The present qualitative study was performed using the conventional content analysis approach. Targeted sampling selected chronic patients with respiratory failure from Shahid Sawayd Shirazi Hospital in Gorgan, Iran.

Semi-structured face-to-face interviews were conducted with 15 patients. Graneheim and Lundman content analysis approach analyzed data. Data management was performed by MAXQDA 10. Data analysis was summarized in 2 main categories and eight subclasses. Patients’ perceived problems with chronic respiratory failure were extracted in two main categories and eight subclasses. The first main category of “perceived economic problems” with the subclasses of treatment costs, unemployment and insufficient income, unable to cover expenses, and the second main category of “unable to measure basic needs” with the subclasses of sexual dysfunction, defecation problems, eating disorders, sleep disorders and health problems. Policymakers and stakeholders, health system planners, welfare organizations, and support organizations should use supportive strategies to reduce or eliminate the problems of patients with chronic respiratory failure using the knowledge and understanding of their perceived problems.

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INTRODUCTION

The rise of chronic illness sufferers is one of the health system’s greatest issues in the twenty-first century because of rising life expectancy and scientific advancement.¹ It is anticipated that by 2050, the number of persons with chronic illnesses will have tripled to 300 million, accounting for over half of the global disease burden.²³ Chronic respiratory failure is a priority for the World Health Organization and is regarded as one of the chronic diseases that burden the healthcare system the most.⁴ One of the most frequent causes of patient hospitalization in specialist respiratory departments is this illness.⁵ According to statistics, this illness kills over 9.5 million people a year and accounts for more than 3% of all fatalities worldwide.⁶

In Iran, many people are susceptible to chronic respiratory failure because of the country’s climate, air pollution in some cities, cigarette smoking, and other causes.⁷ Chronic obstructive pulmonary disease is one of the main causes of chronic respiratory failure, and the Center for Respiratory Diseases estimates that 8.3 percent of Iranians have this condition.⁸ Asthma is the additional factor that contributes to chronic respiratory failure; Iran has a reported incidence of 13.4%.⁹ Another common cause of chronic respiratory failure in neuromuscular diseases, such as Myasthenia Gravis and amyotrophic lateral sclerosis, which have a prevalence of 1 to 10 per 100,000 people in various societies. During their illness, 17 percent to 30 percent of these patients require respiratory support.¹⁰ One of the main conditions that contribute to chronic respiratory failure is pulmonary fibrosis, which affects 3 to 9 persons per 100,000 people in different cultures but whose incidence is unknown in Iran.¹¹

Patients with this disease frequently experience problems in physical, mental and socio-economic health in their lives because of the high prevalence and variety of diseases that cause chronic respiratory failure, as well as the progressive and chronic nature of this disease and the exacerbation of respiratory symptoms that occur in chronic patients with respiratory failure.¹² ¹³ Additionally, Jones et al. (2018)
noted in their study that individuals with chronic respiratory failure experience a number of issues related to respiratory symptoms, dysfunction, significant negative effects on their finances, psychological symptoms, and social isolation as a result of the disease.\textsuperscript{14} Furthermore, according to Carreiro et al. (2016), chronic respiratory failure patients experience a reduction in quality of life, particularly in the physical, psychological, and social domains. They also regularly deal with discomfort, exhaustion, sleep and rest issues, anxiety, and despair.\textsuperscript{15} Despite the fact that chronic respiratory failure impacts every part of patients’ lives, the majority of research on this condition concentrates on its treatment and side effects, and little is known about the worries and alleged issues generated by the condition. If service providers can better understand patients in order to assist, encourage, and educate them, then they will be able to better comprehend their worries, limits, and issues with chronic respiratory failure patients. Therefore, in the current investigation, the researchers chose to use a qualitative study to describe the perceived issues of patients with chronic respiratory failure.

**MATERIALS AND METHODS**

The goal of the current qualitative study was to use a content analytic technique to understand the patients with chronic respiratory failure who foresee concerns in 2021. The participants were chosen from the chronic respiratory failure patients, including those with neuromuscular disorders and obstructive and non-obstructive lung illnesses, who were aware of and had experienced the desired phenomena. The participants were chosen among the patients enrolled in the Shahid Sayad Shirazi Medical Education Center at Iran’s Golestan University of Medical Sciences by targeted-sampling. In the current study, data were collected via in-depth semi-structured interviews with participants who were as diverse as possible in terms of age, gender, employment, type of respiratory failure, and educational attainment. Ages 20 to 70, a history of sickness lasting at least six months, and a desire and capacity to discuss their experiences are the requirements for participation in the study. The inpatient ward or another location of the patient’s choosing was where the interviews were held. Can you recognize the difference between a typical day and a day when you have a problem with shortness of breath? is one of the interview guide questions. 2. How does breathing difficulty generally impact your life? Can you recognize the difference between a typical day and a day when you have a problem with shortness of breath? is one of the interview guide questions. 3. How does breathing difficulty generally impact your life? 4- Which activities can be troublesome for your problem? The next questions were asked given the answers, and some searching questions like explain more, or can you give an example, were used.

Within the first 24 hours, every interview was meticulously transcribed verbatim. After interviewing 15 subjects, data saturation, or the point at which no new code was discovered and data repetition, was reached. As a result, 12 interviews with patients who had the obstructive illness and 3 interviews with patients who had neuromuscular problems were undertaken (Table 1).

The interviews took place between May and October 1400. Depending on the participants’ tolerance, the interview lasted between 40 and 60 minutes. By getting informed consent before the interviews began, the goal of the study and the subjects’ freedom to withdraw from participation at any time were described, and they were given the assurance that the data would be kept private. To analyze the data, the qualitative content analysis approach of Lundman & Graneheim (2004) was used (16). The interviews and the semantically connected clauses, phrases, and paragraphs in the interview text served as the study’s analytical building blocks. After repeatedly listening to the recorded files, the researchers transcribed what they had heard word for word, line for line. In order to better understand the data and assess them appropriately, the texts were examined and reread numerous times.

Following the first level’s coding procedure, groupings of primary codes with comparable characteristics were put together to create the primary classes. Subclasses were then created by classifying homogenous primary classes,
and related subclasses were then combined by constant comparison. Finally, classes having overarching themes were removed, increasing the degree of abstraction. The MAXQDA (v. 10) program was employed in this study to handle the data.

To improve the quality and strength of the data in this study, four Guba & Lincoln criteria—credibility, dependability, confirmability, and transferability—were applied. For six months, the researcher was actively involved with the data in the study setting to assure validity. In-depth interviews were conducted with participants who were as diverse as possible in order to get rich data. Peer review was employed in this work to strengthen its verifiability. In order to guarantee the compliance of the codes and classes with the data, the research’s data, as well as the steps taken to code the data and create the classes, were checked by two specialists in the area who were not involved in the study. To transfer the data, the researcher made an effort to fully outline the work’s implementation procedures so that others may assess the data transferability and follow the study’s methodology.

The researcher made an effort to meticulously and accurately document all of the events, actions, and choices connected to the various stages of the study, including the interviews and data analysis, in order to make the study more reliable and allow others to verify it.

Participants in the current study observed all ethical guidelines, which included obtaining informed consent, outlining the purpose of the study, maintaining the confidentiality of all information, giving participants the option to withdraw from the study, and choosing the location and time of the interview. The research was also approved by the Golestan University of Medical Sciences Research Ethics Committee under the study’s approval code of IR.GOUMS.REC.1398.391.

RESULTS

In the current study, 15 important participants between the ages of 24 and 70 were questioned, with 8 males (53.3%) and 46.7% women (46.7%). (7 people). Participants made consisted of 53.3 percent (8 individuals) with a diploma or less, 40 percent (6 people) with COPD, and 33.3 percent (5 people) with asthma. Two hundred ninety-eight main codes were obtained after the interviews were examined and the codes were retrieved. Two hundred thirty primary codes were left after combining the codes with comparable meanings and concepts. Following that, 16 subcategories were created from the core codes based on similarities in meaning and idea. The final refinement was reduced to 8 subclasses following repeated analysis of the manuscripts and subclass extraction, and the subclasses were then summarized into two primary classes (Table 2).

The Main Class of Perceived Economic Problems

Due to the semantic similarity and appropriateness, the subcategories of “instability of treatment costs,” “unemployment and insufficient income,” and “ability to cover costs” that express economic problems were combined under the umbrella term of “perceived economic problems” in a more abstract concept.

The majority of participants in the study discussed their financial difficulties in terms of paying for medical expenses, struggling to make ends meet, losing their jobs and going unemployed, owing money to others, being unable to make payments, feeling ashamed in front of their families because they couldn’t pay bills, not adhering to treatment, and substituting complementary therapies for conventional ones in order to save money.

Instability of Treatment Costs

The unpredictability of medical expenditures, including drug costs, was one of the economic issues that the majority of patients brought up. This, along with the exorbitant price increases, has made it impossible for these patients to obtain several medications. The following was mentioned by the participants in this context:

“My spouse is a freelancer. Therefore he truly can’t afford my bills, which is why I take my prescriptions less. I tell myself that because my medications are so expensive, the cost will be reduced if I take less of them. Naturally, this reduces the costs when I need to visit the hospital “ (P5).

“... Now the price of medicine has grown in comparison to previously, and these medications are frequently altered, or comparable ones are developed or made in Iran, or certain medications are hard to get and have high pricing” (P2).

When my shortness of breath becomes really bad and bothers me, I attempt to utilize the doctor’s medicine, but most of the time, I try to use herbal remedies because they are cheaper (P9).

Unaffordability to Meet Expenses

The majority of patients, particularly males, who are responsible for covering costs, struggle to cover both their daily expenses and medical care. These folks experience several issues since they are unable to work and generate money due to a lack of breath. The participants said the following with regards to the inability to pay the expenses:

“I’m in this hospital right now, and I ask the doctor to let me go so I may go. The doctor says you will recover, but with this expensiveness and financial problems, it is not conceivable. I’m here, and I’ll lose my work. Due to my shortness of breath, I am currently hospitalized here, and people are phoning to

Table 2: Main categories and subcategories of perceived problems of chronic patients with chronic respiratory failure

<table>
<thead>
<tr>
<th>Maincategory</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived economic problems</td>
<td>• Instability of treatment costs</td>
</tr>
<tr>
<td></td>
<td>• Unemployment and insufficient income</td>
</tr>
<tr>
<td></td>
<td>• Unaffordability to meet expenses</td>
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<tr>
<td>Impaired assessment of basic needs</td>
<td>• Sexual dysfunctions</td>
</tr>
<tr>
<td></td>
<td>• Excretory problems</td>
</tr>
<tr>
<td></td>
<td>• Disturbance in nutritional activities</td>
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<tr>
<td></td>
<td>• Sleep disorder</td>
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<tr>
<td></td>
<td>• Health problems</td>
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Two major categories—‘‘perceived economic concerns’’ and ‘‘disturbance in the assessment of fundamental needs’’—emerged as a result of the content analysis.
inform me that we will execute the check. However, I am unable to do anything because I am hospitalized.”(P4).

“When I get to work, I put in a little time, and then I start to feel out of breath. I have to pay my paycheck for that day and go to the pharmacy and the doctor to obtain some medicine to help me breathe again. Or perhaps I went to work and worked for 50,000 tomans because I was sweating profusely, feeling hot and chilly, and having trouble breathing. When I got home, I laid down for three days and was unable to move from beneath the blanket. That implies that regardless of whether I get better or not, I will have to spend twice as much money in the hospital. I'm unsure about what to do with the money I made and whether to use it to support myself or to pay a doctor (P6).

Unemployment and Insufficient Income
The majority of patients, particularly the males, concurred that there is no support group in this sector that can address the issue since their ailment hinders them from completing work-related tasks and has caused them to quit their occupations. The following was mentioned by the participants:

“This illness has rendered me unable to work, and when you can’t work, you don’t have any money. Therefore my financial condition is devastated, and I am a weak person,” the patient said. I have five kids since I am unable to work, and I am responsible for paying for their schooling. Sadly, they were also unable to attend school since they needed to work in order to support themselves. If a person is well today, do you really believe that he would be able to afford these living expenses? What am I supposed to do with this disease, no job, and no one to care for us? (P13).

“... When I go to work, I work for a little while, and then I get out of breath. I have to come and spend my money for that day on the medicine and the doctor to restore my breath. Or perhaps I went to work and worked for 50,000 tomans because I was sweating profusely, feeling hot and chilly, and having trouble breathing. I then returned home.

The Main Category of Impairment in Estimating Basic Needs
The subcategories of “excretion problems,” “disorder in dietary activities,” “sleep disorder,” and “health concerns” show the participants’ failure to gauge fundamental needs. They were included in a more abstract notion called “disturbance in assessing fundamental demands” because of their semantic resemblance and suitability. A person’s ability to achieve their fundamental requirements is limited by the issues brought forth when hospitalized are the main causes of the disturbance in excretory activities. For instance, the participants in this discussion started:

“Because of the extreme worry and terror it causes me, I am unable to control my urination even when I have acute shortness of breath. I feel a lot of embarrassment about my urine incontinence, and my family is also affected by it “ (P11). My stomach is swollen, and since I haven’t done any walking, my stomach hasn’t functioned in five or six days, so I’m reluctant to eat too much. I have to go a few steps to the service because otherwise, I don’t enjoy going there, and this shortness of breadth” (P7).

Disturbance in Nutritional Activities
The impact of the disease’s restricting conditions on the patients’ diet was one of the experiences that the majority of chronic patients with respiratory failure reported. These patients had to limit their diet and consume less food than their bodies required. Regarding this, the participants said:

“Even eating might be challenging for me at times. A few spoonfuls of food leave me gasping for air, and it frequently occurs that I was hungry and wanted to eat but couldn’t “ (P11). “You lose consciousness when eating when you are out of breath. You put a slice of bread in your mouth, but because of the shortness of breath, you are unable to chew and swallow it. As a result, you will lose weight and have stomach pain ” (P12).

“... The weakness has made it difficult for me to even eat; I don’t have the power to chew food, and I have difficulties swallowing it. Sometimes, food or water quickly leaps into my throat; this causes me to start coughing, which makes my shortness of breath worse and makes me irritable. I occasionally have to consume more soft things since I lack the strength to chew food when my weakness is at its worst. I eat less because of this, and my body weakens as a result”(P5).

Sleep Disorder
According to the majority of study participants, sitting or partially sitting positions for ease of breathing, body pain
from maintaining a particular position to reduce asthma, stretched devices and connections, oxygen therapy, and sitting or semi-sitting positions all cause problems with falling asleep, waking up early or late, and disrupting sleep continuity. Consequences of nocturnal sleep problems that were mentioned by the majority of individuals were daytime fatigue and sleepiness, headaches, loss of attention while doing everyday tasks, irritability, and mood disorders. Regarding this, the participantssaid:

“If it is a little lower beneath my head, my shortness of breath is stronger, and my head should be higher, and this upsets my sleep, and this shortness of breath impacts my sleeping posture, and I have to sleep in one position all the time,” the author writes. Additionally, my left side hurts and causes me to sleep on my left side since I have to sleep on it most of the time, despite not wanting to be in this situation. If the cushion beneath your head is a bit lower than it should be, you may have shortness of breath when you have it” (P2).

“I have trouble falling asleep at night. I cannot lie down comfortably, I cannot sleep soundly, and I am scared that I may have shortness of breath while sleeping. Therefore I either sit or sleep on my side to take a nap “ (P6).

“I have to lean against the wall to breathe easier at night when I am out of breath since I can’t sleep otherwise. I was lying down and had trouble breathing because yesterday night I didn’t get any sleep and stayed awake till morning “ (P15).

“I have to sleep on one side at night. Even if I doze off and roll over, I still wake up with breathing difficulties. The same oxygen hose either gets trapped in my hand and causes me to wake up when I turn, or it is stretched out and causes me to wake up when I turn “ (P8).

Health Problems
The majority of the research participants stated the experience of disruption in matters relating to their personal health as one of the subcategories connected to the disturbance in everyday activities. The participants in this situation, for instance, state:

“I find it really challenging to take a bath since the steaming water makes me feel claustrophobic and out of breath. At this age, I rely on my mother to carry me to the bathroom. While a typical person would wash in the shower, I couldn’t stand up, so I sat on a chair while my mother washed me. Even the shampoo and soap that I put on my head must be odorless; else it makes me suffocate” (P3).

“I go to the restroom, but I can’t bring myself to wash my face since I feel so out of breath. Or I go to the restroom, I’m out of breath, I can’t stand up for ten minutes, and I have to have assistance with all of this. I don’t have the energy or air to get up and straighten my face, so even kids do it (P11).

DISCUSSION
The primary objective of the study was to discover and interpret the perceived problems of patients with chronic respiratory failure, which was done in order to gain a deeper and richer understanding of this phenomenon. The main classes and sub-classes that emerged from the participant interviews are an attempt to accomplish this goal. “Perceived economic issues” was one of the major classes in this study’s extraction of information from the participants’ talks. There are three subcategories under this primary category: “inability to cover expenses,” “unemployment and inadequate income,” and “instability of treatment costs.” The economic challenges faced by patients with chronic respiratory failure are a result of the rising prevalence of the disease, the direct and indirect costs associated with treating its acute and chronic complications, unemployment, and inadequate income on the one hand, and regulations and economic pressures on the other. The results of this study demonstrated that economic factors help individuals in a way that lessens anxiety, boosts self-confidence, and also helps them feel productive by raising the amount of access to resources and making it easier for people to access services. These patients’ social functioning, bodily health, and mental health have all been negatively impacted by the economic issues they are now dealing with. In his study, Oates (2019), which addresses the topic of “financial struggles,” claims that physical exhaustion and diminished work capacity with a detrimental effect on the economic situation cause poor access to medical care and incomplete treatment of these patients. This finding is consistent with the findings of the current research. 18

In his study, Nedjat-Haiem (2021) also demonstrated that chronic patients with respiratory failure brought on by frequent hospitalizations and absence from work have a low socioeconomic position, which has hampered their access to healthcare (19). Additionally, Qods et al. (2017) demonstrated a substantial correlation between improved economic position and life happiness in asthmatic individuals (20). By looking at the financial outcomes of these patients’ hospitalization in the respiratory special care department, Griffiths et al. (2013) concluded that frequent and protracted hospitalizations had a detrimental impact on employment and the inability to earn money, leading to anxiety and depression in patients afterdischarge.

Another significant class identified during the qualitative portion of the study was “disturbance in estimating fundamental requirements,” which includes five subclasses: “sleep disorder,” “sexual activity disorder,” “excretory difficulties,” “disorder in sexual activities,” nutritional,” and “health concerns.”

One of the most frequent issues that individuals with chronic respiratory failure deal with are sleep disruption. The majority of the participants in this study had sleep disorders as a result of nocturnal breathlessness, anxiety brought on by breathlessness while sleeping, stretching and repositioning oxygen therapy connections, drug effects, and positioning in sitting or semi-sitting positions to lessen breathlessness. These individuals experience daytime drowsiness as a result of low quality sleep at night, which has negative effects on their health state, physical performance, mood, and daily productivity. According to Luyster (2020), who conducted a study that is consistent with the findings of the current study, sleep disorders are among the most common complaints of chronic patients with respiratory failure. He notes that most patients report regular sleep disturbances, poor sleep quality, difficulty falling asleep, and early morning awakenings.21
The majority of patients with chronic respiratory failure also felt that sexual activity disturbances were an issue. These patients claimed that physical factors (such as heart palpitations, shortness of breath, severe sweating), psychological factors (such as anxiety, fear, and stress), physical factors (such as physical restraints such as oxygen cannula and mask), and factors related to treatment (such as drugs) and physical factors (such as physical restraints such as oxygen cannula and mask) were among the causes of disruption in the sexual relations of the patients, which led to the abandonment of the relationship. In line with the findings of the current study, Holmes (2019) referred to the theme of “sexual problems” in his qualitative study and claims that he suffers from extreme fatigue, shortness of breath, drug side effects, fear of losing his sexual partner, and disturbances in his mental image as a result of side effects, corticosteroids, physical restrictions, weight gain, and an inability to use cosmetics due to shortness of breath. He also uses respiratory aids like oxygen and a nebulizer.

Constipation, flatulence, persistent pains during feces, a sense of incomplete emptying, a need to use laxatives frequently, urinary incontinence during disease attacks, and the unpleasant experience of using a urinary catheter were among the excretory problems that most of the study participants mentioned. Excretion issues, interference with sleep and rest habits, exercise, and deteriorating shortness of breath have all contributed to a number of issues for these individuals. In accordance with the aforementioned findings, Gloeckl (2018), in his study, also makes reference to the concurrent manifestations of chronic respiratory failure and intestinal-urinary issues and claims that patients’ respiratory problems are negatively impacted by their excretory disorders and that patients who have more excretory disorders also have more respiratory problems.

The phrase “nutritional disorder” refers to a broad spectrum of nutritional problems that are typically present in patients, particularly those who have persistent respiratory failure. Disorder in dietary activities was one of the subcategories derived from participant interactions in this study and was mentioned by the majority of patients. In this situation, some patients complained of weight gain as a result of the disease’s immobility, while others had muscle wasting and weight loss as a result of the heavy use of their respiratory muscles and respiratory support. Additionally, the majority of these patients distinguish limits and bans regarding the use of particular flavors and diets, and they explain that eating less than what the body actually requires while being hungry to a fear of becoming breathless. According to Shalit (2016), shortness of breath, weariness, lack of appetite, economic situation, emotional state, and swelling issues are the variables impacting nutritional abnormalities in patients with chronic respiratory failure, which is consistent with the findings of the current study.

The majority of patients with chronic respiratory failure faced health issues and were unable to complete basic health tasks, which was one of the issues they faced. Primary health issues are crucial in avoiding illnesses and improving people’s health. These patients claimed that their dependency on performing these tasks was a major issue for them since they were unable to undertake them owing to weakness and shortness of breath. Overall, the findings of the present study, based on the experiences shared by the research participants, testify to the numerous challenges that these patients feel. Among the study’s advantages, we may point out the qualitative methodology, which allowed for deep interviews with individuals who represented the widest range of chronic respiratory failure types. One of the study’s weaknesses was the coincidence of the disease COVID-19 with the study, which was eliminated by keeping a close eye on the interviewees’ and interviewer’s health and maximal social distance from each other.

CONCLUSION

The results of this study revealed that patients with chronic respiratory failure experience financial issues such as unstable treatment costs, unemployment and insufficient income, and an inability to cover bills. It appears that it is required to identify and monitor the patients, provide justifications for supporting them, and implement practical actions. This, in a manner, demonstrates the need for additional assistance for these patients from policymakers and management. Through job searching, financial assistance, and working in part-time centers in accordance with the patient’s conditions, policymakers and lower-level authorities can assist in improving the health and reducing the issues of these patients. Additionally, by gaining a better understanding of the living situations and inability of these patients to predict their basic needs, these findings assist the health system as well as welfare and social organizations in taking steps to facilitate and strengthen the services provided to these patients.

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