EXPLAINING COVID-19 PATIENTS' EXPERIENCES OF THE DISEASE: A QUALITATIVE STUDY

Mahbobeh Sajadi[1] , **Aida Arjloo[2]** , **Mohamad Golitaleb[1]**

[1]Department of Nursing, School of Nursing, Arak University of Medical Sciences, Arak, Iran
[2]Medical Student, Islamic Azad University Najafabad Branch, Najafabad, Iran

To the Editor,
the coronavirus disease 2019 (COVID-19) claims the title for the deadliest pandemic in the recent century [1]. The novel coronavirus is responsible for an emerging infectious disease with high morbidity and mortality, leading to a great deal of mental distress in people [2, 3]. Patients' extensive care needs and family members' lack of awareness on how to provide care to the patient can cause anxiety, as well as difficulty in adaptation with the care providing role, which ultimately increases the care burden [3]. Despite the widespread propagation of COVID-19 around the globe, there is a paucity of qualitative studies on the psychological, emotional, mental, and social consequences of the disease [4, 5]. Nonetheless, none of these studies have investigated COVID-19 patients' perspectives and experiences of the disease. So, we conducted this qualitative study to explain COVID-19 patients' experiences of this disease. Participants in this study included the COVID-19 patients referring to the hospitals affiliated with the Arak University of Medical Sciences, who were recruited by purposeful sampling and based on inclusion criteria. Inclusion criteria were consciousness, ability to communicate verbally, and willingness to participate in the study. The subjects were chosen purposefully and according to the study objectives. After a primary agreement and consent, the participants were interviewed by either phone or video call (via WhatsApp) [6].The data were collected using semi-structured interviews that continued until data saturation. All interviews were audio-recorded, then transcribed verbatim. The data were analyzed and coded based on the Granheim & Ludman conventional content analysis method. In this method, the researcher started the interview by asking a general question, such as "Would you please explain about your illness?", and then based on the explanations, perspectives, and experiences expressed, guided the interview. The researcher also asked probing questions when necessary. The guiding questions mainly included open-ended queries as follows:

1. What was the attitude of your family, spouse, and friends towards the disease?
2. How did you compromise with the disease?
3. What strategies did you use against this disease? [7].

In this study, 14 patients with COVID-19 and three of their family members participated in semi--structured in-depth interviews. A total of 21 in-depth individual interviews were held. Most participants were urban residents (82.4%). The age of the participants ranged from 24 to 68 years, with a mean age of 47.6 ± 3.4 years. The participants' experiences in this study are presented under the following five concepts: denial and disbelief, fear of disease, stigmatization, entrapping into a cycle of agony and striving to survive.

DENIAL AND DISBELIEF

This category covered the participants' feelings about facing symptoms and a positive test result for the COVID-19 Disease and included two subcategories:

1. The initial shock facing the diagnosis

All the participants denoted an initial shock and feeling of losing everything, as well as negative feelings, attitudes, and thoughts after being informed of the diagnosis, especially in early hours, causing debilitation in decision-making.

2. Disbelief

The data showed that the participants sometimes could not believe that they had the disease. They thought that it must have been a mistake in the test result.

FEAR OF THE DISEASE

This category consisted of three subcategories:

1. Intense fear of the disease

This category reflects that many of the participants thought that the COVID-19 disease was an incurable, mysterious, and fatal disease.

2. Fear of death due to the disease

Many of the participants stated that they experienced fear of death after being diagnosed with the COVID-19 Disease. They felt that everything was over for them and contracting the disease for many of them was equated to death.

3. Fear of transmitting the disease to family members

All the patients and family members participating in the study stated that one of their biggest fears was to transmit the disease to other family members, imposing a great deal of stress on patients and their family members.

STIGMATIZATION

Many of the participants expressed that they were disturbed by the social stigma of having the disease.

BEING ENTRAPPED INTO A CYCLE OF AGONY

Most of the participants addressed their painful experiences. This category consisted of two subcategories:

1. Suffering due to the disease nature

The disease symptoms, including body aches, frequent coughs, dyspnea, constant thinking about the prognosis and outcome, the possibility of death, aggravation of the clinical condition, and lung involvement, brought unpleasant moments for patients.

2. Suffering due to others' behaviors

The participants noted the inappropriate behaviors of some of their friends or family members. For example, they were calling the patients and saying words that would upset them.

STRIVING TO SURVIVE

The participants in the study acknowledged that they were seeking ways to save themselves from the disease, improvising many ways in their minds to cope with this problem. In this research, we divulged the positive and negative experiences of Covid-19 patients, including their worries and concerns. Our findings can help nurses and medical staff identify the needs of these patients and accordingly design an appropriate care model for them.

Institutional review board statement

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the COVID-19 Research Center (3710) and the Research Ethics Committee (IR.ARAKMU.REC.1399.278) of Arak University of Medical Sciences.

Authors' contributions

All authors contributed equally. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare no conflict of interest.

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