Illness Behavior in the Face of COVID-19 Infection: A Qualitative Study on Homecare in Afghanistan

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Abstract

Background: Illness behavior refers to the ways of perceiving, assessing, and managing specific symptoms by an individual.

Objectives: The present study aims to investigate illness behavior during the COVID-19 outbreak among Afghan people.

Methods: The study is a thematic analysis conducted between May and September 2020. Data were collected purposefully through semi-structured telephone interviews with 17 infected people from the cities of Kabul, Bamian, and Balkh in Afghanistan.

Results: As the participants believed, the COVID-19 outbreak in their country was a socio-political rather than a medical phenomenon. In this situation, the health system is unable to meet medical needs, and patients creatively take care of themselves at home with exercise, local soups, and oxygen therapy if needed. There were four themes explored, including de-hospitalization, healthcare-seeking behavior, social stigma, and the role of media.

Conclusions: The illness behavior regarding disease outbreaks is a social rather than a clinical phenomenon. It includes de-pharmaceuticalization perceptions and activities. Therefore, healthcare systems are recommended to pay attention to the socio-political dimensions of illness behavior during such outbreaks.

Keywords: COVID-19, Illness Behavior, De-pharmaceuticalization, Sick Role

1. Background

Illness behavior refers to any activity or response of an individual who feels unwell to characterize his or her health conditions and physically or emotionally alleviate the perceived or real ailment (1). Regarding this concept, Henry Sigerist conducted a study on the 'special position of the sick' in 1929, and Talcott Parsons conceptualized the 'sick role' in 1951 (2). According to Parsons' paternalistic view, the sick role represents the behavior of a patient who accepts the symptomatology and diagnosis of the medical care system and attempts to meet its expectations.

The COVID-19 epidemic is a global crisis in healthcare systems (3). It started in China and spread to all countries. Nowadays, governments seek to somehow manage the crisis by prevention and treatment. The crisis management includes preventive measures such as quarantine, social distancing, training citizens for hygienic practices, and hand washing. The final step is treatment at the advanced levels of the disease (4).

The therapeutic approach in many countries is implemented in two ways. In less advanced cases, a prescription is given to the patient, and home quarantine is recom-

mended (5). Regarding home quarantine, special dietary instructions are given, and recommendations are made for daily exercises (6). However, in the advanced cases of the disease, the patient is hospitalized, and special treatment is performed (7).

There seems to be some kind of inequality in the world in the face of COVID-19 (8). The economic problems of countries are the most important reason for this inequality (9). Home quarantine and social distancing have caused the most severe economic damage to many countries, especially in developing countries (10). Developing and underdeveloped countries are involved in the devastating economic consequences of the epidemic, on the one hand, and fail to adequately provide health or medical services to their citizens, on the other hand. The fundamental question is: 'What strategies do people use in these countries for prevention and treatment?' Surely, when the health system of a country is poor, people have to take creative methods to save themselves and their lives. They try to survive and sustain their families in any possible way. However, the duality of economy and life is a problematic issue in these countries.

Afghanistan, located at the crossroads of central and south Asia, is one of the least developed countries in the world. On February 24, 2020, the Afghan Ministry of Public Health reported the first individual with confirmed COVID-19 symptoms in Herat province, western Afghanistan (11). The number of patients in this country has been gradually increasing, similar to many other countries. The question of the present study is: 'What perceptions and experiences have the affected Afghan citizens had when dealing with COVID-19?'

2. Objectives

Accordingly, the present study aimed to explore the illness behavior of the infected people during this epidemic.

3. Methods

The present research, as a qualitative study, was conducted in Kabul, Bamyan, and Balkh provinces in Afghanistan, between December and September 2020. The participants were 17 Afghan citizens infected with COVID-19; it means; their tests were positive. These participants had experienced a difficult period of illness and were recovering. They also preferred home quarantine to hospitalization. According to their perceptions and experiences, they felt capable of overcoming the disease with home treatment.

The selection of participants was performed purposefully and through snowball sampling. The data were gathered through telephone interviews. This type of interview is less attractive than the face-to-face one (12), but it has recently been welcomed by many researchers. For example, it has been employed in nursing care (13). Ward et al. (14) revealed that this form of data collection could be used in grounded theory studies and that participants had a positive view of it. Lechuga (15) indicated that this type of interview could even be used in cultural studies. During the COVID-19 outbreak, the technique can help researchers gather the data from a distance. In addition, many participants in qualitative studies prefer physical distancing under these conditions. In the present study, the identified participants were telephoned and talked to before each interview. Once they agreed to do the interview, a time was set, and the interview was conducted. The interviews were semi-structured, and each one lasted about 35 to 45 minutes. There were three main questions to ask as follows:

- 1- Please tell us about your experience regarding COVID-19.
- 2- What did you do after you found out you were infected with COVID-19?

- 3- Tell us about your most important experiences during the quarantine and treatment.

In the case of any ambiguity, the researcher asked the participant to further explain by the phrase "Can you explain more?"

The data were analyzed using the thematic analysis method (16). In this study, the researchers closely examined the data in order to identify the common themes, including the topics, ideas, and patterns of expression that came up repeatedly. For the data analysis, six steps were taken based on Clark and Brown's approach, as described in the following:

- 1- Familiarization: At this step, the researchers controlled and re-read the data in order to become familiar with the details, paying specific attention to the patterns that occurred.

- 2- Coding: After the initial familiarity with the general concepts in the data, certain codes were used to mark where and how the patterns occurred.

- 3- Theme Generation: At this step, similar codes were combined into overarching themes accurately depicting the data. For this purpose, the researchers exactly described what the themes meant.

- 4- Reviewing the Themes: Attempts were made to explore how the themes supported the data and the overarching theoretical perspectives.

- 5- Defining and Naming the Themes: The researcher had to define what each theme was, which aspects of the data were captured, and what was interesting about each theme.

- 6- Writing up: A report was written, and decisions were made about the themes making meaningful contributions to the understanding of what was going on within the data.

Trustworthiness was practiced through 'member checking' for an accurate representation. Peer checks were also done. The researchers went back to the sample at hand to see if their description was an accurate representation. Through a reflective manner, the 'being fit' status of the codes and themes in the data was evaluated.

4. Results

All the participants believed that they were able to treat themselves creatively and away from the hospital environment. Being away from the hospital was not only a choice for them but also a social determination. Except for a small number of participants, most of them believed that medical facilities in the hospitals were insufficient and it would not be possible to communicate with family and friends there. They also pointed to the experience of stigma putting them under severe stress, so they

preferred to use the media to be aware of the medical procedures. Moreover, the media were considered as a space for leisure time during the quarantine. Home treatment, for them, was based on three activities such as exercising, going on a special diet, and using oxygen therapy.

Based on the analysis, four main themes were set for the present study, including de-hospitalization, healthcare-seeking behavior, social stigma, and the role of media.

4.1. De-hospitalization

According to the participants, since the beginning of the epidemic, most people have thought that informing about COVID-19 by the authorities is part of a political project to gain privileges and benefits. Therefore, political and social distrust has led to misperception of the hospital environment. This has not only caused the spread of the disease but also has created a reluctance to go to hospitals for diagnosis and treatment. In this case, one of the participants said:

"Hospitals did not provide many facilities for the people, and this made me receive home treatment. I even went to the pharmacy to diagnose my disease, not to the hospital, because I knew that the hospital was not a suitable place for diagnosis and treatment." (Participant no. 11)

Also, according to the participants, the lack of health facilities for the treatment of COVID-19 patients has made people disbelieve in political and medical systems. This is notable in the following quotation:

"I did not go to the hospital. I even forbade my friends because corruption is at its peak, and there is a commercial and political mafia in public health. There were many health facilities from foreign countries, but the patients referred to the authorities were not taken care of." (Participant no. 16)

This statement indicates that socio-political distrust leads to de-hospitalization. In other words, the hospital is not a treatment environment but a representation of social and political issues. Hence, people's view of the hospital is a mirror image of what they feel about politics, healthcare, and government. In addition to distrust, fear of the hospital was the second factor in the de-hospitalization process. The participants thought that staying in the hospital might delay recovery or be dangerous for other family members. Generally speaking, the word hospital conveys an impression of anxiety and fear during an outbreak. This anxiety, along with the view that a hospital is inefficient, leads to de-hospitalization. As a participant stated:

"The doctor said I was infected. After that, he gave me two pieces of advice: Home quarantine and hospitalization. My family members could not take care of me in the

hospital, and the hospitals were scary. Here, sick people are treated at home because there are so many of them and there is no sufficient medical equipment such as oxygen, etc., in the hospital." (Participant no. 1)

In this statement, the hospital is depicted as an infectious environment. This perception creates a fear leading to de-hospitalization.

4.2. Healthcare-Seeking Behavior

In an atmosphere of social fear and anxiety and with a feeling of distrust regarding hospitals, the desire to survive pushes people toward creative measures to save their lives. Those in such a situation try to save themselves from a deadly disease in any possible way. The most important feature of home treatment by the participants was non-medical therapy. Their illness behavior was care rather than treatment. Two participants took antibiotics, four used paracetamol injections, four took vitamins, and two used zinc. All of them believed that home treatment with exercises and local soups could give them a good mood and lead them to recovery without medication; medication would just control their pain. A common behavior of the participants in these conditions was exercising. They all prioritized exercising as a way to get rid of the disease. As participant 3 said: "I rested for an hour, and it was a little comfortable as usual. Then, I did exercise slowly, not intense exercises."

Another healthcare-seeking behavior at home was consuming local diets. In this regard, participants took creative actions through consulting their friends and doctors or using the solutions provided in cyberspace. The home remedies were, indeed, a combination of different diet interventions. Fruits and vegetables were part of this care. According to a participant: "The thing that helped a lot was homecare; that is, I used onions, vegetables, apples, and wheat. They helped a lot. I boiled onions in water and inhaled the steam. I also used stuff such as malt, apple, and garlic, which seemed to be very helpful to me". (Participant no. 4)

In addition, eating local soups together with honey and hot spices was a priority for the participants. Note the following statement:

"During COVID-19, my first function was gargling salt-water. I always used fruits, breathed in the steam of salt-water, and ate a mixture of sesame. I also sunbathed for 45 minutes because the sun in Afghanistan is hot. My lunch was always soup and potage. I did not drink cold water during the day, but I drank tea and lukewarm water instead." (Participant no. 8)

The final approach of some participants was oxygen therapy. They obtained oxygen cylinders in every possi-

ble way and used them when they were severely short of breath.

4.3. Social Stigma

A bitter experience of the participants was “social stigma”. Besides the distrust, social stigma was the main reason for not going to the hospital. The stigma would cause two major crises for the individual, including social rejection and fear of death. It discouraged some patients from going to the hospital. As participant 6 said: “I did not go to the COVID-19 hospital because most people would not disclose their disease. They were ashamed of it and had a fear of death.”

Social stigma causes the worst form of social exclusion. It even keeps the patient’s closest friends away from him/her. This experience leads to severe emotional problems for the patient. Mustafa, 33, experienced unpleasant social behaviors even after his test was declared negative:

“Many of my friends avoided me and were afraid of me. Despite my negative test result, people were still afraid of me and even did not treat me humanely. For example, my friends did not even say hello to me and used bad words. This gave me a bad mood and turned my sadness into isolation.”

Therefore, detection of an infection or the news of quarantine can make friends and relatives stay away from the infected individual. This puts a lot of stress on the individual, especially when a vague or deadly disease is involved. In other words, when a person has serious emotional needs, social exclusion not only fails to meet the needs but also exacerbates the emotional and psychological pressures. One participant (no. 4), who had experienced such exclusion, tried to have the least possible support from those around him. He stated:

“I experienced this social exclusion, and it negatively affected my behavior toward my family, and others. I was even worried that I would upset my friends and family members. I tried to behave in such a way that they would not stay away from me.”

4.4. The Role of Media

In the context of home quarantine, due to fear of death and social exclusion, the media were the most important companions of the participants. Despite a 40-year-old participant who claimed that “I did not spend much time in cyberspace because the news was terrible and it demoralized me”, other participants used the media. As they reported, the media played two important roles: A medical counselor and a hobby for leisure time. Given the limited access to doctors, nurses, and health consultants under quarantine conditions, the most convenient way to access medical advice seems to be social media. Social media function

as a platform for learning the ways and means of treating COVID-19. The participants acquired most of their knowledge of the disease from the mass media and cyberspace. Here is what participant 2 reported:

“I did not find out about my infection through the doctors, but I did through the media and advertisements. In addition, I learned about my infection with the coronavirus based on my relatives’ experiences.”

A similar experience was presented by some other participants. For example, Khodadad, 29, said the following:

“When I was afflicted, I followed the media, got information about the coronavirus, and compared my symptoms with those I had noticed in the media. Then, I realized that I was infected.”

These statements illustrate the fact that the media are the major source of information about COVID-19 diagnosis and self-treatment. Another important function of the media, as reported by the participants in this study, was to fill their leisure time during home quarantine. The pains and pressures of being away from friends and family, social exclusion, and many other issues were found to decrease via social media. The participants interacted with friends and relatives through media as well. The following statements are worth considering:

“During my treatment process, I was busy with cyberspace because others said positive conditions would effectively reduce the virus impacts. I kept myself busy with Facebook and the Internet in order not to feel too much pain and to be in a good mood.” (Participant no. 17)

“During my illness, I spent more time with the media, cyberspace, etc. Of course, the media broadcast bad news that affected me. Yet, I had to keep myself busy to forget the pain.” (Participant no. 9)

5. Discussion

The present study demonstrated that the illness behavior in the COVID-19 outbreak is a social phenomenon. The participants understood and interpreted health system activities in a socio-political context. In this respect, one can refer to de-hospitalization as a social behavior as well as a socio-political phenomenon. The participants initially interpreted the epidemic as a political product, and they were pessimistic about hospitals as service providers on the part of the government. This negative view of hospitals was based on their pessimism about the socio-political conditions. This means that, during an epidemic, people evaluate all the components of a health system and its function based on their judgments and attitudes towards the government. Undoubtedly, the health system in Afghanistan has made every effort to control the epidemic

and treat the patients. However, the people judge these attempts based on their view of the government. In other words, trust in government can play a pivotal role in the illness behavior of people during an outbreak. Zarei et al. (17) showed that the Iranian citizens expected their government to better control the disease during the COVID-19 pandemic. This expectation is directly related to their trust in the government. Therefore, public trust in the government's ability to deal with the pandemic is significant as it supports the public perspectives and practices for wellbeing at an unstable time (18).

As another theme in this research, healthcare-seeking behavior was explored concerning the non-medical approach adopted by the participants. In this case, de-hospitalization was found to be more a matter of care than of treatment. The participants did exercises, went on local soup diets, and used oxygen therapy when needed. In the absence of medication, non-medication care helped them use their body power to survive. This, indeed, means the de-pharmaceuticalization of COVID-19. Abraham (19) believes that de-pharmaceuticalization is due to a significant amount of growth in pharmaceuticalization which is inconsistent with the scientific evidence. As he argues, due to drug innovations, offering significant therapeutic services declines across the public health sector, especially when a major health problem comes up. The authors of the present paper believe that the lack of scientific evidence about the effect of medication on COVID-19 and the problematic access to medical treatment are the main reasons for de-pharmaceuticalization in Afghanistan. Although the COVID-19 outbreak has generally medicalized society, it seems to be de-medicalized and especially de-pharmaceuticalized in some therapeutic sub-fields. As a matter of fact, in a health crisis, medicalization often expands across the life in society (20), as COVID-19 protocols have medicalized the world nowadays. However, the expansion becomes limited in certain aspects. Conducting proper theoretical studies and providing evidence in this field are recommended.

Social stigma is another factor to be explored in this outbreak. As most World Health Organization policymakers have pointed out from the outset, the issue of social stigma is of paramount importance in this epidemic. Stigma has been reported against nurses (4), healthcare workers (21), and patients who have survived COVID-19 (22). It seems that the experience of stigma in the current epidemic differs from what it has been so far. The participants reported their social exclusion imposed by their closest relatives, putting a lot of emotional and psychological pressure on them. In a previous study by Srivastava (23), it was shown that COVID-19 stigma was associated with selfishness, preventing any kind of intimacy with patients. The

researcher, therefore, proposed a solution based on thinking in terms of the reversal of roles and the ethos of empathy.

Finally, the present study showed that media, in general, and social media, in particular, are the main tools of informatics for those infected with COVID-19. Social media play two major roles: Promoting the knowledge about the disease and serving as a context of spending leisure time during the period when no one is willing to communicate with the infected person. Views on media are different during this epidemic. On the one hand, there are criticisms that social media spread wrong information and cause misunderstanding (24). They are also said to be a cause of social anxiety and mental health problems in society (25). On the other hand, it has been shown that media promote risk perceptions when epidemics occur (26). The findings of the present study are in line with the second perspective. In addition, media have been found as a context for spending one's leisure time during home quarantine.

5.1. Conclusions

The present study showed that illness behavior among the people infected with COVID-19 was a socio-political phenomenon. The participants in the study managed their behavior based on their attitude towards the hospital performance and the accessibility of medication. Therefore, they started a healthcare-seeking behavior creatively through de-pharmaceuticalization, which involved doing exercise, going on local diets, and using oxygen therapy if necessary. They believed that they could overcome the disease by taking these measures. The study also indicated that the participants were influenced by social stigma and the media. It is suggested that health policymakers pay attention to the findings of this research and focus on the negative socio-political aspects of the epidemic, thus promoting social and political trust. In addition, paying attention to the de-pharmaceuticalization phenomenon and social stigma is recommended.

Footnotes

Authors' Contribution: Study design, statistical analysis, and drafting of the manuscript: A.K.S; Acquisition of data, data analysis, and first drafting of the manuscript: K.M.

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Informed Consent: The participants were informed that they could request the deletion of their interview records.

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