

Anxiety, Knowledge and Lived Experiences of Families with COVID-19 Patients: A Mixed-Method Multi-Center Study in Iran

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What's Known

- During community-wide outbreaks, patients and their families may suffer from anxiety after making behavioral changes. Assessment of anxiety levels in the families of COVID-19 patients and understanding their experiences during the pandemic may contribute to the prevention of the disease.

What's New

- Anxiety was relatively high in families with COVID patients during the pandemic, and it was associated with age, sex, income, and familial relationships. The level of knowledge existing on the COVID-19 disease in families was moderate. Therefore, relevant psychosocial interventions and raising people's awareness are recommended.

Abstract

Background: During community-wide outbreaks, patients and their families may suffer from anxiety after making behavioral changes. This study aimed to investigate the anxiety, knowledge, and lived experiences of families with COVID-19 patients admitted to medical centers.

Methods: The present multi-center study was conducted by a mixed method using convenient sampling in hospitalized COVID-19 patients in Firoozgar and Rajaie Hospitals between May and July 2020. Anxiety was measured using a short form of the State-Trait Anxiety Inventory. The participants' knowledge level was examined by an online questionnaire. The lived experiences of the families were explained through semi-structured interviews. Data were analyzed by Chi square, ANOVA, independent-samples *t* test, Kruskal Wallis, and Mann-Whitney tests in SPSS 16. P values ≤ 0.05 were considered statistically significant.

Results: The mean age of the 324 family members participated in the study was 45.1 ± 13.3 years. The mean anxiety score of the subjects was 13.5 ± 4.1 , and 63.6% of the participants had moderate to severe anxiety. The subjects' mean score for knowledge on COVID-19 was 7.15 ± 1.32 . The highest mean percentage of data received by the subjects on COVID-19 (42.7%) was obtained through radio and television broadcasting. A total of 251 important phrases were obtained from interview analysis and code extraction, out of which five main themes and 17 sub-themes were extracted.

Conclusion: Our findings showed that anxiety was relatively high in families with COVID patients during the pandemic, and it was associated with age, sex, income, and familial relationships. The level of knowledge on the COVID-19 disease in families was moderate. Therefore, relevant interventions and raising people's awareness are recommended.

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Keywords • Anxiety • Knowledge • Family • COVID-19

Introduction

In December 2019, patients with pneumonia of an unknown source with an increasing daily growth were detected in Wuhan, China, which led to the identification of a new human coronavirus.

The number of patients and the mortality rate in this city increased sharply during July and resulted in the virus being introduced as a disease of global significance and concern to the World Health Organization (WHO).^{1,2} The virus has been detected in various countries in Asia and Europe. A number of studies have hitherto investigated the characteristics of this virus,³ which is known as SARS-CoV-2 and causes Coronavirus Disease 2019 (COVID-19). The patients complain of symptoms such as fever, coughing, fatigue, and dyspnea. Changes in the microbiome after viral respiratory infections make them more susceptible to bacterial respiratory infections after recovery.⁴ Thus, these patients and their families receive the necessary training on the isolation and disinfection of the patients and their caregivers.

Naturally, during pandemics and community-wide outbreaks, patients and their families may suffer from anxiety after making behavioral changes.⁵ Anxiety is a mental and physical disorder accompanied by the prediction of an unpleasant event. It may be normal or abnormal. Normal anxiety refers to an acceptable level of anxiety that people seek to overcome, and they succeed in doing so. However, abnormal anxiety refers to an excessive level of anxiety that people strive to overcome, but cannot cope with.⁶ A number of studies have shown that the level of anxiety in patients' family caregivers in developed countries varies from 11% to 45%. Patients' family caregivers undergo significant levels of psychological consequences, such as stress, anxiety, and depression.⁷ The variety and intensity of care roles lead to psychological problems in patients' family caregivers. Moreover, caregivers' lives are overshadowed by several factors, such as time constraints, loss of emotional well-being, social disruption, feelings of losing control over personal life, and suffering from physical and emotional burdens (anxiety, stress, and depression), as well as different types of acute and chronic diseases.⁸

Phenomenology is a type of qualitative research that describes people's experiences as they happened. In other words, it is the process of learning and creating meaning for the experience by talking to people with the same experiences. It aims to reveal the meaning of the experience as it happened to the subjects. According to the paradigm of naturalism in qualitative research, there are different interpretations of reality in the minds of different people. This type of research describes the dimensions of the diversity, importance, and meaning of phenomena.⁹

Since the family plays a major role in a patient's recovery and cooperation with the

medical team during the treatment procedures, it is vital to analyze the anxiety levels in the families of patients with COVID-19 admitted to medical centers and to understand and receive their lived experiences during the pandemic through a phenomenological approach. It may also contribute to the prevention of the disease, promotion of treatment conditions in society, and prevention of hospitalization of future patients. Hence, this study investigates the anxiety, knowledge, and lived experiences of families with COVID-19 patients admitted to a number of selected medical centers using a mixed-method.

Subjects and Methods

This was an applied study carried out with a quantitative-qualitative (mixed) method.

Subjects

The study population included first-degree family members of hospitalized patients with Covid-19 diagnosis admitted to Firoozgar Hospital and Rajaie Cardiovascular, Medical and Research Center of Tehran between May and July 2020. During the course of three months, one person from each family was continuously enrolled in the study using the convenience sampling method. After explaining the goals and obtaining written informed consent from the participants, a link to the online questionnaires was sent to their phone numbers.

Inclusion criteria were: age of over 18 years for a family member of the patient hospitalized with a COVID-19 diagnosis, willingness to participate in the study, and the ability to complete the anxiety and knowledge questionnaires. Exclusion criteria were: family's unwillingness to continue participating in the study, previous anxiety or depression diagnosis or history of using related medications, and the event of the patient's death.

After receiving the ethical code (IR.RHC.REC.1399.002) from the Research Committee of Rajaie Cardiovascular, Medical and Research Center, obtaining the necessary permits from the research centers, and explaining the objectives to them, anxiety and knowledge levels associated with COVID-19 were assessed via the completion of an online questionnaire by the families of patients with the disease.

Measures

The Spielberger State-Trait Anxiety Inventory (STAI) – short form was used to measure the family members' anxiety levels. The validity and reliability of this questionnaire have been proven in previous studies.¹⁰⁻¹² In our study, the

content validity of this tool was verified using expert panel opinions. The translation process was performed by the forward-backward method. Initially, the original version of the questionnaire was translated into Persian by two translators. Then, the final Persian version, which was based on the two translations, was reviewed and modified by the research team. The approved Persian version was given to two other translators, who independently translated it into English. The reliability of this questionnaire was 0.79 measured by Cronbach's alpha. The questionnaire consisted of six items scored based on a Likert scale rated from one (almost never) to four (almost always). When scoring the instrument, items three, five, and six were reversely scored. The sum of the scores determined the anxiety score, 6 being the minimum and 24 the maximum scores. Scores of 6-11, 12-17 and 18-24 indicate mild, moderate and severe anxiety, respectively.

In order to measure the family members' knowledge on COVID-19, a questionnaire was utilized that was used in a previous study with confirmed validity and reliability.¹³ A content validation by expert reviewers was performed on this scale in the present study using the forward-backward method as described earlier. The Cronbach's alpha coefficient of the knowledge questionnaire was 0.71. The questionnaire consisted of 12 items to measure the level of knowledge on COVID-19. Items 1-4, 5-7, and 8-12 measured the knowledge of the clinical presentations, transmission routes, and prevention and control, respectively. Items were answered as true, false, or "I do not know". Each correct answer was scored one, and incorrect/ unknown answers were scored zero. Finally, the correct scores were added together to arrive at the overall knowledge score, which varied from zero to 12. Higher scores indicated a higher level of knowledge on COVID-19. The maximum scores on the knowledge of clinical presentations, transmission routes, and prevention and control were four, three, and five, respectively.

The first part of the questionnaire consisted of demographics, including age, sex, marital status, education, occupation, economic status, and the length of hospitalization of the patients.

Qualitative Study

In the qualitative portion of the study, the researcher conducted interviews with a first-degree family member, who had come to the hospital to visit the patient. Qualitative research method and descriptive phenomenology were used to explain the lived experiences of

the families with COVID-19 patients. These participants were selected by convenience and purposive sampling with maximum variation. Semi-structured interviews were employed for data collection. Then, the participants completed a questionnaire with six items related to anxiety and 12 items pertaining to knowledge on COVID-19. As soon as each interview was ended, the contents were transcribed word by word on paper. The codes were then extracted from the transcription of each interview. Then, according to similarities, the codes were placed in sub-themes. Next, the sub-themes were combined, and the main themes were extracted.

Analyses and results were presented to the participants and approved using the method of controlling and supervising the members to ensure the accuracy and validity of the study. The researcher was immersed in the data and completely involved, as another method to validate the findings. For the measurement of reliability, all interviews were analyzed by colleagues, and the correlation coefficient of the themes obtained from the two coding procedures performed by the two researchers was 0.78. Moreover, the samples had maximum diversity in order to increase the transferability of the findings.

Statistical Analysis

The quantitative data were analyzed using descriptive and inferential statistical methods. Mean±SD was used to describe the quantitative variables, and frequency and percentage were used to describe the qualitative variables. Comparisons were performed by a Chi square test for categorical variables, ANOVA or independent-samples *t* test for normally distributed variables, and Kruskal Wallis or Mann–Whitney tests for non-normally distributed variables. All statistical analyses were performed using SPSS Statistics 16.0 for Windows (SPSS, Chicago, IL, USA). P values≤0.05 were considered statistically significant.

Results

The statistical population consisted of 324 family members of patients with COVID-19. The mean age was 45.1±13.3 years, and the median and quartile range of age was 43 (35-54). The minimum age was 18 years, and the maximum age was 90 years. Table 1 reports the frequency distribution of the socio-demographic variables of the participants.

The mean anxiety score of the participants was 13.5±4.1, and the median and interquartile range was 14 (11-17). Their minimum anxiety

Table 1: Frequency distribution of sociodemographic variables of the study population

Variable		N (%) n=324*
Sex	Male	203 (64.60)
	Female	111 (35.40)
Marital status	Married	242 (77.10)
	Single	62 (19.70)
	Divorced/ Widowed	10 (3.20)
Occupation	Employed	116 (37.50)
	Retired/ Housekeeper	112 (36.30)
	Self-employed with sufficient income	81 (26.20)
Income	Inefficient	101 (35.60)
	Efficient	175 (61.60)
	Excellent	8 (2.80)
Education	Under diploma	43 (13.60)
	Diploma	117 (37.00)
	Academic degree	156 (49.40)
Familial relationship with the patient	Sibling	26 (9.00)
	Spouse	129 (44.50)
	Parent	44 (15.10)
	Child	91 (31.40)

*If the sum of the numbers does not equal 324, it is related to missing data

Table 2: Relationship between anxiety and quantitative and qualitative variables

Variable	Anxiety			P value	
	Mild	Moderate	Severe		
Age (year), Mean±SD	42.3±11.20	46.8±14.18	46.5±13.96	0.028*	
Length of stay (day), Mean±SD	9.64±8.21	11.1±8.47	12.1±9.75	0.103*	
Knowledge, Mean±SD	7.31±1.43	7.06±1.32	7.09±1.10	0.295**	
Sex N (%)	Male	85 (76.60)	87 (62.10)	31 (49.20)	0.001***
	Female	26 (23.40)	53 (37.90)	32 (50.80)	
Marital status N (%)	Married	79 (70.50)	113 (80.70)	50 (80.60)	0.222***
	Single	27 (24.10)	25 (17.90)	10 (16.10)	
	Divorced/ Widowed	6 (5.40)	2 (1.40)	2 (3.20)	
Occupation	Employed/ Retired	40 (36.00)	57 (42.20)	19 (30.20)	0.392***
	Housekeeper	38 (34.20)	46 (34.10)	28 (44.40)	
	Self-employed with sufficient income	33 (29.70)	32 (23.70)	16 (25.40)	
Income	Inefficient	23 (23.00)	51 (40.50)	27 (46.40)	<0.001***
	Efficient	69 (69.00)	75 (59.50)	31 (53.40)	
	Excellent	8 (8.00)	0 (0.00)	0 (0.00)	
Education	Under diploma	10 (8.90)	25 (17.90)	8 (12.50)	0.226***
	Diploma	41 (36.60)	54 (38.60)	22 (34.40)	
	Academic	61 (54.50)	61 (43.60)	34 (53.10)	
Familial relationship with the patient	Sibling	9 (8.60)	17 (13.90)	0 (0.00)	0.009***
	Spouse	41 (39.00)	58 (47.50)	30 (47.60)	
	Parent	17 (16.20)	20 (16.40)	7 (11.10)	
	Child	38 (36.20)	27 (22.20)	26 (41.30)	

P values≤0.05 were considered statistically significant. *Kruskal-Wallis, **ANOVA, ***Chi-square test

score was six, and the maximum score was 22. A total of 118 patients (36.4%) with mild anxiety, 141 patients (43.5%) with moderate anxiety, and 65 patients (20.1%) with severe anxiety were identified. The mean length of hospitalization was 10.8±8.67 days, and the median and its quartile range was 10 (4-14).

Table 2 shows the relationship between anxiety and quantitative and qualitative variables. There was a significant relationship

between anxiety severity and the variables of age, sex, income, and family's relationship with the patient. The mean age of patients with mild anxiety was lower than those with moderate or severe anxiety (P=0.028). The severity of the anxiety was higher in women (P=0.001) and low-income individuals (P<0.001). Severe anxiety was also higher in the spouses of patients with COVID-19 than in other family members (P=0.009) (table 2).

The mean score of participants' knowledge on COVID-19 was 7.15±1.32. The minimum score of knowledge was three, and the maximum score 10. The mean score of knowledge on clinical presentations, transmission routes, and prevention and control were 1.83±0.67, 1.65±0.74, and 3.68±0.67, respectively.

The relationship between knowledge score and socio-demographic variables is shown in table 3. The mean knowledge score of employees, families with sufficient income, participants with higher education, and spouses of patients with COVID-19 was higher compared with other groups (table 3).

There was a significant inverse correlation between knowledge score and age (P=0.003, r=-0.163). There was no significant correlation between the families' knowledge score and their anxiety score or the length of stay of their patients.

According to the participants' self-reports, the mean percentage of information received from radio and television broadcasting, virtual networks, the internet, articles, and from surrounding people and friends were 42.7, 0.36, 30.4, 20.4, and 24.6, respectively.

There was a positive and significant correlation between the knowledge score and the percentage of information received by radio and television broadcasting (P=0.015, r=0.135), as well as the information received through articles (P=0.004, r=0.161).

The family members participating in the qualitative portion of the research included 11 women and nine men. A total of 251 important phrases were obtained from the interview analysis and code extraction, out of which, five main themes and 17 sub-themes were extracted (table 4).

Information Needs

The information needs of the family members with COVID-19 patients was considered as one of the main concepts and themes, covering the sub-themes of clinical manifestations of the disease, prevention methods, treatment routes, and techniques for coping with stress. Although the families had little information on the symptoms and clinical manifestations of the disease and followed few tips, they still did not know whether the methods of disease prevention and treatment were definitive or not,

Table 3: Relationship between knowledge score and participants' socio-demographic variables

Variable		Knowledge Mean±SD	P value
Sex	Male	7.09±1.45	0.195*
	Female	7.28±1.05	
Marital status	Married	7.12±1.39	0.845**
	Single	7.23±1.11	
	Divorced/Widowed	7.20±0.42	
Occupation	Employed/Retired	7.36±1.11	0.019**
	Housekeeper	7.21±1.15	
	Self-employed with sufficient income	6.83±1.74	
Income	Inefficient	6.91±1.40	<0.001**
	Efficient	7.34±1.15	
	Excellent	5.75±2.96	
Education	Under diploma	6.70±1.93	0.039**
	Diploma	7.16±1.33	
	Academic	7.28±1.06	
Family relationship with the patient	Sibling	7.35±1.09	<0.001**
	Spouse	7.44±1.20	
	Parent	6.11±1.71	
	Child	7.38±0.96	

P values≤0.05 were considered statistically significant. *Independent-samples t test, **ANOVA

Table 4: Main themes and sub-themes of the lived experiences of the families of COVID-19 patients

Main theme	Subtheme
Information needs	Clinical manifestations of the disease, methods of prevention, treatment routes, techniques of coping with stress
Anxiety	The patient's death, loneliness, lack of patient visits, disease unknowns
Fear	Being labeled, being infected and transmitting the infection to family members, family breakups
Worry	Being cut off from family relationships, method of patient's burial
Health-related behaviors	Mask use, social distancing, hand washing, washing purchased products

and whether there was the risk of re-infection. They were not aware of other tips that should be observed in the hospital to prevent the infection of other family members. They did not know how to cope with the stress and desired to receive counseling services.

Anxiety

This theme included anxiety related to the patient's death, loneliness, lack of patient visits, and disease unknowns. The complex, ambiguous, and unknown nature of the disease led to anxiety in the families. Lack of families' knowledge about the length of their patient's hospital stay, recovery time, and discharge time, and in general, lack of information on the patient's conditions was one of the unknowns, which increased their anxiety.

Fear

This theme covered the fear of being labeled, infecting oneself and other family members, and a family breakup. Therefore, this theme included the egregious status of patients with COVID-19, distancing of family members with the patient, patient's fear of family members labeling each other for not having observed the required tips, unwillingness to go to the hospital due to the fear of getting infected and transmitting the infection to family members, and consequently, family breakups.

Worry

This theme included concerns about getting cut off from social relationships with friends and relatives in the future, the burial of the patient in case of death, not holding a funeral, lack of a formal ceremony, and the absence of relatives at the funeral.

Health-related Behaviors

This theme included mask use, social distancing, hand washing, and washing purchased products. Analysis of the interviews indicated that the families found themselves in an unbearably difficult situation, due to the increased amount of health-related behaviors and other emotions, such as fear, anxiety, and worry, despite observing health-related behaviors, as they believed there was a lot of unknowns about this disease.

disease was about 7 out of 10. Anxiety, fear, and worry were the dominant feelings. Mask use, social distancing, hand washing, and washing purchased products were among the reported health-related behaviors that they had adopted.

Goodarzi and colleagues indicated that anxiety is common in family caregivers of patients with dementia, and that behavioral control and economic and health status are predictors of the caregivers' anxiety. The results of the present study showed a significant relationship between anxiety and household income.⁸ James Holland and colleagues found that after an initial increase in anxiety, its levels decreased as people's perception of the virus increased. In summary, they concluded that emotional states control behavioral responses. This anxiety resulted from high exposure to social networks.¹⁴ Bults and colleagues reported that the level of knowledge on swine flu increased at the outset of the H1N1 flu epidemic. Although precautionary measures were reduced, people's anxiety gradually decreased. Preventive measures were associated with not having children at home, high anxiety, and extreme attention to the media on H1N1 influenza.¹⁵

Taylor-Robinson and colleagues conducted a qualitative study and showed that if transparent information is not disseminated by the official sources, the spread of rumors will lead to confusion and anxiety during the outbreak. In general, it was concluded that accurate information during this period is useful for relieving potential anxiety. Most participants in the study reported that they were sufficiently aware of the status quo before receiving official announcements, and that the information provided by health care institutions was generally useful, but they received them too late.¹⁶

The qualitative information in the present study also showed that the families received most of their information about the disease from radio and television broadcasting. Their information needs were about the clinical manifestations of the disease, methods of prevention, treatment routes, and techniques for coping with stress.

Research has shown that in life-threatening illnesses and end-of-life situations, the role of social support, including family members, becomes more important, and the presence of family members next to the patients would reduce their death anxiety.¹⁷ However, this study showed that patients were unable to visit their family members, friends, and relatives at the time of hospitalization, a factor, which itself, increased death anxiety in these patients.

Various studies have demonstrated that the fear of stigma leads to the delayed reporting of

Discussion

The results showed that nearly 44% of the participants experienced moderate anxiety, and nearly 20% experienced severe anxiety. The average score of their general knowledge of the

symptoms and increased feelings of confusion,¹⁸ guilt, and depression.¹⁹ In the present study, the egregious status of the COVID-19 patients, distancing of family members with the patient, and the patient's fear of family members labeling each other for not having observed the required tips were among the items extracted from the interviews.

Rahmatinejad and colleagues reported that a great concern about the future of family members and relatives was dominant. On the other hand, the patients constantly fostered a mental image of funeral ceremonies without the presence of their family and relatives.²⁰ These results were consistent with those of the present study.

Mask use, social distancing, hand washing, and washing purchased products were among the health-related behaviors in the current study. Rubin and colleagues showed that about 38% of the participants reported implementing all the recommended behavioral changes after four days of swine flu. About 5% performed all avoidance behaviors. They also stated that controlling the anxiety and implementing the recommended changes increased their perception of swine flu.⁵ Concerning the research limitations in the qualitative portion of the study, the inherent limitations of the qualitative content analysis approach, such as lack of generalizability or limitations in the reliability of data and results, should be taken into account. Another limitation was the mental status of families, which can affect the quality of their responses. Of course, they could complete the questionnaires, when they were in good mental health. Lack of a control group of families without COVID-19 patients was also another limitation in this study.

Conclusion

In this study, anxiety was relatively high in families with COVID patients during the pandemic. The severity of anxiety was associated with age, sex, income, and familial relationships. The level of knowledge on COVID-19 was moderate in the families and was associated with age, occupation, income, education, and being the spouse of a COVID-19 patient. According to the participants' self-reports, the largest proportion of their information was received from radio and television broadcasting. In the qualitative portion of this study, the emotional experiences of the participants included fear, anxiety, and worry. Therefore, raising people's awareness and predicting the potential problems facing families, as well as the designing of relevant psychosocial interventions by governments, would be ethical and helpful.

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