Experiences of Patients With COVID-19 Admitted to the Intensive Care Units: A Qualitative Study

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Abstract

This study aimed to describe the experiences of patients with COVID-19 admitted to the intensive care units (ICU). The data were analyzed by content analysis on 16 ICU patients with COVID-19. Data were collected by semi-structured interviews. Three categories were identified: (a) captured by a challenging incident with subcategories: perceived sudden and challenging death, fear of carelessness in overcrowding, worry about the family, and frustration with stigmatizing; (b) the flourishing of life with subcategories: spiritual-awakening, resilience in the face of life challenges, promoting health behaviors, and striving for recovery; and (c) honoring the blessings with subcategories: understanding the importance of nurses, realizing the value of family, and realizing the value of altruism. COVID-19 survivors experienced both positive and negative experiences. The results of this study could help health care providers identify the needs of ICU patients with COVID-19, including psychological, social, and spiritual support and design care models.

Keywords

content analysis, COVID-19, patient, intensive care units

Introduction

On March 11, 2020, the World Health Organization declared COVID-19 a global pandemic (1) COVID-19 is the cause of a dangerous illness with the absence of a specific treatment or vaccine and widespread human-to-human transmission that affects people's lives (2,3). Patients with COVID-19 experience mild-to-severe respiratory and nonrespiratory symptom (4). Symptoms of the viral infection vary from mild to extremely severe. The signs of the infection include fatigue, fever, coughing, and difficulty breathing (5). Considering the high risk of disease transmission, these patients need isolation that could lead to severe mental distress (6). The COVID-19 pandemic, like the severe acute respiratory syndrome (SARS) and MERS pandemic, has caused severe physical and psychological crisis in these patients even after discharge (7).

From the beginning of the COVID-19 pandemic, studies have focused on the clinical aspects of the disease, experiences, and psychological status (6,8,9). These patients experience more health problems during outbreaks than other

patients, so that even after discharge from hospitals, they may have long-term health issues (10). Sahoo et al conducted narrative research on 3 patients with COVID-19 and

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2 Journal of Patient Experience

Table I. Demographic Characteristics.

Participant number	Gender	Age (years)	ICU stays (days)	Severity of disease	Therapeutic interventions	Educational level	Employment status	Ethnicity	Religious preference	Comorbidities
I	Male	37	10	Both lungs	NIMV	ES	Employed	Persian	Muslim; Shia	None
2	Male	33	8	Both lungs	NIMV	University	Employed	Persian	Muslim; Shia	None
3	Female	48	5	One of the lungs	ORBM	Diploma [*]	Housekeeper	Persian	Muslim; Shia	Diabetic
4	Male	39	4	One of the lungs	NIMV	Diploma	Unemployed	Persian	Muslim; Sunnite	None
5	Male	34	7	Both lungs	ORBM	ES [']	Unemployed	Persian	Muslim; Sunnite	None
6	Male	27	4	One of the lungs	NIMV	University	Student	Persian	Muslim; Shia	None
7	Female	52	5	One of the lungs	NIMV	ES	Housekeeper	Persian	Muslim; Shia	Diabetic
8	Female	24	8	One of the lungs	NIMV	University	Student	Persian	Muslim; Shia	None
9	Female	38	8	Both lungs	ORBM	University	Employed	Persian	Muslim; Shia	None
10	Female	47	9	One of the lungs	NIMV	ES	Housekeeper	Persian	Muslim; Shia	Hypertension
11	Male	44	10	Both lungs	ORBM	Diploma	Employed	Persian	Muslim; Sunnite	None
12	Male	26	12	Both lungs	ORBM	Diploma	Employed	Persian	Muslim; Shia	None
13	Female	40	9	Both lungs	ORBM	ES [']	Housekeeper	Persian	Muslim; Shia	None
14	Male	21	5	· ·	NIMV	University	Student	Persian	Muslim; Shia	Asthmatic
15	Female	28	5	One of the lungs	NIMV	University	Employed	Persian	Muslim; Shia	None
16	Male	47	13	Both lungs	ORBM	ES	Employed	Persian	Muslim; Shia	None

Abbreviations: ES, elementary school; ICU, intensive care unit; NIMV, noninvasive mechanical ventilation; ORBM, oxygen reservoir bag mask.

showed that these patients experience anger, guilt, and shame (11). Rahmatinejad et al showed patients with COVID-19 experience anxiety, stigma, and ambiguity during their disease (12).

These issues highlight the need to develop knowledge of the health dimensions of patients with COVID-19 (13). One of the ways to achieve the above goal is to know the perceived experiences of these patients (14). Explaining and understanding the health problems of patients with COVID-19 throughout and after the disease crisis could be very effective in expanding knowledge on how to better deal with possible future outbreaks and improve our preparation for similar outbreaks (15). Therefore, this study aimed to describe the experiences of intensive care unit (ICU) patients with COVID-19.

Methodology

Design

Qualitative content analysis approach was used to explain the patient's experiences. Content analysis is useful to direct extraction of participants' messages without imposing a researcher's opinion (16).

Setting and Participants

This study was conducted in Qom public hospitals as the main center of the COVID-19 outbreak in Iran (17). Setting was all patients admitted to ICU department of 3 public hospitals, Qom city, Iran. These 3 hospitals have dedicated ICUs for patients with COVID-19 without room quarantine. Inclusion criteria were history of ICU admission due to COVID-19, ability to speak Persian, negative serologic test after quarantine and no complications of COVID-19 (weakness, shortness of breath, and cough), and willingness to participate in the study. Exclusion criteria were being under mechanical ventilation and use of sedative drugs during the

stay in the ICU. Participants were 16 patients with COVID-19 with a history of hospitalization in the ICU. The participants were those who had completed a 2-week quarantine period after discharge from the hospital. Interviews were conducted immediately after the end of the quarantine period. Participants were given a home care training package for patients with COVID-19 and a package containing disinfectants and masks. Eight patients refused to participate in the study due to general weakness and cough. The maximum variance sampling was considered (18) for gender, age, ICU stay, and severity of disease, therapeutic interventions, educational levels, employment status, ethnicity, religious preference, and comorbidities (Table 1).

Data Collection

Data were generated by in-depth semi-structured face-toface interviews and field notes. The interviews were conducted from March to May 2020. The first author conducted the interviews in the Persian language in a comfortable environment where the patients did not feel restricted or uncomfortable. The interviewer performed all prevention protocols according to the guidelines of the National COVID-19 Committee. The first author conducted the interviews after introducing himself and the objectives of the study. Interviews were conducted at the request of the participants at the participants' homes. One of the possible confounding variables was the presence of the family with the patient at the time of the interview. Therefore, the interviewer informed the patient's family that they should be as quiet as possible or engage in their own activities during the interview due to the prevention of the patient's distraction. Each interview lasted for 30 to 50 minutes. Questions were (a) "Would you please tell me about your illness?" (b) "What happened when you were hospitalized?" and (c) "What experiences have you had with COVID-19?" Probing questions were also used to elicit further details or clarification during the interviews (19).

Interview guide questions were developed by counseling with nursing experts in qualitative studies and were revised after several pilot interviews. All interviews were audiotaped and were transcribed verbatim on the same day.

Data Analysis

An inductive content analysis was used because of the limited theories and literature in the experiences of participants with COVID-19. Data analysis was performed manually simultaneously and continuously with data collection. After transcription of each interview, backward translation was conducted by a native Persian-speaking person from research team, and then each translation was translated to English again by an English language educator. First and second English translation was compared and rechecked. Finally, to ensure the accuracy of the translation, the translated content was reviewed and approved by an external reviewer who was fluent in Persian and English and with experience in qualitative research. The text of each interview was read several times word-by-word, sentence-tosentence, and paragraph-to-paragraph. Initially, several interviews were conducted, coding was done, and the extracted codes were then initially classified. Transcript and coding were done by the first and second authors. To verify the accuracy of the extracted data, interviews, coding process, and classified data were reviewed by an external reviewer specializing in qualitative studies. After confirming the accuracy of the data extracted by an external reviewer, the interviews and coding continued until saturation of the data. The categories seemed saturated regarding their properties and dimensions after the 14th interview. However, 2 additional interviews were conducted to ensure that no new data emerged and no new conceptual code was emerged. The decision about achieved data saturation was made by the research team and the external reviewer by continuous review along with data collection. In the last step after reaching data saturation, the extracted codes were reviewed by the research team, duplicate codes were removed, and the categories and subcategories were extracted from the initial raw data inductively. At this stage, in order to check the accuracy of the data, the external reviewer examined the classified data, and the data were modified based on their opinions.

Trustworthiness

According to Lincoln and Guba, the credibility was established through allocating enough time for each interview, prolonged engagement, and member check (20). For confirmability, 2 members of the school of nursing who were skilled in qualitative studies checked the quality of interviews, coding, and categories to reach a consensus. For dependability, all stages of the study were reported in detail. Finally, transferability was established through maximum variation sampling (20,21).

Ethical Consideration

This study was approved by the National Committee for Ethics in Biomedical Research and the Ethics Committee of Qom University of Medical Sciences, Qom, Iran (approval code: IR.MUQ.REC.1399.005). Participants were informed about the study aim, the voluntary participation, and the right to withdraw from the study, and then, verbal informed consent was obtained verbally from each of them.

Results

In total, 512 initial codes were extracted. After combining codes with similar meanings, 224 codes remained. Then, the initial codes were classified into subcategories and categories based on meaning and conceptual similarity. Data analysis led to the extraction of 11 subcategories and 3 main categories. The main categories were "captured by a challenging incident," "The flourishing of life," and "Honoring the blessings" which were conceptualized as "Journey to peace" (Table 2).

Captured by a Challenging Incident

Participants with COVID-19 had severe fears and anxieties due to the severity of their condition, their family situation, and social consequences after recovery from the disease. This category consists of: "perceived sudden and challenging death," "fear of carelessness in overcrowding," "worry about the family," and "frustration with stigmatization."

Perceived sudden and challenging death. Participants were afraid of sudden death. They considered death as an unpleasant and unexpected event, but the main cause for their great fear of dying was a horrible and painful death because of their severe clinical condition. They were also worried that they would die without visiting and the presence of their families and not having an Islamic funeral.

Many times, I saw my death with my own eyes. I thought death was one step away from me. I was always afraid of a terrible death. In those days, I wished for a quit death (p2).

When I saw the death of other patients, I was very scared of dying like this...I am young and I did not want to die at this young age and under these difficult conditions (p6).

Most participants reported exhausting shortness of breath, body aches, general weakness, loss of taste, and smell. They stated that enduring these symptoms were very exhausting and tedious.

It was so hard to bear the pain and breathlessness; that I was willing to die to get rid of it as soon as possible (p5).

These symptoms were so severe that participants feared the symptoms would return. It was tough to bear the body's pain, cough, and chest pain. It was difficult for some

Table 2. The Process of Abstracting Data.

Initial codes	Subcategory	Category	Theme
Fear of a painful death	Perceived sudden and challenging	Captured by a challenging	Journey to
Fear of difficult death	death	incident	Peace
Fear of death followed by severe shortness of breath			
Difficulty enduring body aches and shortness of breath			
Intolerable symptoms			
Suffering from enduring pain and shortness of breath			
Annoying tolerance of weakness and lethargy			
Painful and tearful tolerance of symptoms			
Fear of overcrowding in the hospital	Fear of carelessness in overcrowding		
Fear of overcrowding of patients			
Fear of shortage of nurses			
Fear of failure to perform timely diagnosis and			
treatment			
Worry about the condition of the family after the death	Worry about the family		
Worry of infecting other family members			
Worry about being unaware of the family			
Discomfort caused by fear and avoidance of people	Frustration with stigmatizing		
The discomfort of stigma in the workplace			
Understanding God's mercy	Spiritual-awakening	The flourishing of life	
Understanding the impact of spirituality on health	Resilience in the face of life challenges		
Increasing self-care behaviors	Promoting health behaviors		
Putting aside unhealthy behaviors	-		
Increasing adherence to hygiene			
Increasing health information			
Using maximum physical strength for recovery	Striving for recovery		
Resistance to disease goes beyond the individual ability			
Gaining new insights into the nursing profession	Understanding the importance of	Honoring the blessings	
Understanding the abilities of nurses	nurses		
Understanding the precious blessings of the family	Realizing the value of family		
Understand the invigorating effects of family support			
Happiness appreciation of the kindly presence of volunteers Not feeling lonely and helpless with volunteers	Realizing the value of altruism		

participants to describe this situation, and these symptoms were one of the worst experiences of their lives.

When these symptoms started again after a little recovery, I cried for fear of the onset of body aches and painful shortness of breath (p8).

Fear of carelessness in overcrowding. Participants' fears were partly due to hospital overcrowding and the high number of patients with COVID-19. Many participants feared a shortage of medication and facilities, delays in starting treatment due to crowded hospital wards, and a shortage of nurses and physicians.

The crowded hospital was terrifying...I was terrified that the diagnosis and treatment of my disease would be delayed (p6).

Many participants were concerned that nurses would make medical errors due to fatigue and exhaustion or not provide adequate care. That is why I was constantly afraid that I would be mistreated because of the high volume of patients and that nurses and doctors cannot give me more attention (p11).

Worry about the family. In addition to the fears and anxieties of COVID-19, participants were worried about being unaware of their families, uncertain future, and lack of financial support and care for their family members in their possible death.

My family members could not come to see me...I was worried about how my wife could take care of the children alone (p14).

During the 10 days of hospitalization, I had no information about my family . . . I could not see them or even talk to them on the phone and this was very worrying for me (p12).

One of the important concerns of the patients was the fear of infecting other family members before hospitalization and after discharge.

Although I had isolated myself in a separated room, I was still worried about my children and my wife getting sick (p11).

Frustration with stigmatizing. Many participants said that even after complete recovery and quarantine, neighbors, relatives, and colleagues still considered them as carriers of the disease. The people's fear and avoidance were painful for patients who had fully recovered and made them feel lonely.

After recovery and quarantine, when I returned to work, my colleagues were terrified and walked away from me... These behaviors made me very sad (p13).

One of my concerns was what to do with the COVID-19 label and how people would feel about me and how I would endure the situation... It was very upsetting when you saw people disinfect themselves quickly and wear mask and do not talk to you (p16).

The Flourishing of Life

In addition to the horrific and distressing experiences of COVID-19, the participants also had experiences that made numerous changes in their lives. Their experiences included 4 subcategories: "spiritual-awakening," "resilience in the face of life challenges," "promoting health behaviors," and "striving for recovery."

Spiritual-awakening. Participants reported that they found peace only by remembering God. According to the participants, during the illness, they felt close to God and need more praying. They also stated that performing religious duties would help them to cope with the symptoms of the disease.

When I read the Quran, my shortness of breath decreased (p9). While suffering from COVID-19, I became aware of the effects of spirituality on my strength and staying healthy (p15).

Resilience in the face of life challenges. Participants expressed they should not allow that the stresses of life harm their health. These participants stated that financial issues were not as important to them as before the illness. This change of mind-set has led them to pay less attention to many of the issues that were once thought to be the challenges in their lives.

When I got sick, I found health was the important blessing of God (p9).

COVID-19 made me realizes that I have to be positive in life and always hope. Before I was a negative person and I had a negative view on life...This disease made me feel free from mental problems (p7).

Promoting health behaviors. Participants reported that COVID-19 increased their medical literacy and caused them to understand the importance of following the principles of health, such as hand washing, wearing a mask, and keeping a safe distance to maintain the health of oneself and others.

Before I got sick, I did not have much personal hygiene. After that, I realized the importance of hand washing (p5).

Through the education I received during my hospital days and by reading educational materials on social networks, I learned more about COVID-19 and realized that I must be more careful to maintain my health and the health of other (p12).

Striving for recovery. Some participants stated that having an incurable disease did not cause them to lose hope of recovery. They try to overcome the disease through full adherence to the health care providers' instructions, energizing themselves, pray and communicate with God, and complementary medicine such as relaxation.

I saw death in front of my eyes...I did not lose hope for recovery, and I did everything I could to be well...I prayed all the time...I knew relaxation, which was very good for me (p2).

I had severe shortness of breath when I was admitted to the ICU. I kept repeating that I have big goals in life and I have very valuable things like my spouse and children; I should do my best to recover as quickly (p5).

Honoring the Blessings

Honoring the blessings consist of 3 subcategories: understanding the importance of nurses, realizing the value of family, and realizing the value of altruism.

Understanding the importance of nurses. Most of the participants during hospitalization acquired perception about nurses' knowledge and competencies. Participants became more aware of the importance and necessity of nurses to recover from a deadly disease and their role as a patient advocate.

When I saw their ability, effort, and commitment to care for critically ill patients, I realized that society's view of nurses is very superficial...I realized the importance of nurses for the health of society (p12).

After I was discharged from the hospital, I constantly watched the nurses' activities on TV. Nurses are really brave, strong and self-sacrificing persons. Their existence is necessary for society like the water for a plant (p8).

Realizing the value of family. During the quarantine period, participants were aware of the role and support of the family in recovery from COVID-19 disease and overcoming the disease. According to the participants, although families were not physically present with them during hospitalization and quarantine, the support of family members, such as nutritional, emotional, and religious support, was very effective in helping them recover and have easy coping.

If my family did not support me, and they did not give me hope, maybe I would not get well soon (p6).

During the peak days of my illness, I thought about important things, and one of the things I realized I missed was my good 6 Journal of Patient Experience

family. There I realized how valuable it is to have a good family and I should appreciate it. After recovering, my emotional relationship with my family became much stronger and more intimate (p9).

Realizing the value of altruism. Most participants stated that they witnessed the presence of volunteers at the hospital during their hospital stay. Participants stated that despite the risk of illness, volunteers were present to assist them with routine tasks such as eating, changing clothes, and bathing. Some of the volunteers, who were clerics, also provided religious care to patients. According to the participants, the presence of volunteers and the provision of altruistic assistance by them in the shortage of medical staff reduce the feeling of loneliness and anxiety of patients.

We felt lonely... The presence of volunteers who kindly helped us was very encouraging... The presence and services they provided are truly commendable (p7).

My mood was severely debilitated during the hard days of ICU and seeing the death and misery of patients. But the psychological support of the volunteers was very helpful (p2).

Discussion

The results of this study suggest that patients recovered from COVID-19 have a combination of negative and positive experiences; patients often see recovery from a serious illness as a turning point in honoring blessings and increasing spiritual awakening, resilience, or efforts to improve their health behaviors. These narratives tell the stories of the patient; moving from the dark spot of the disease, the challenges perceived during the hospitalization in the ICU to the bright horizon of life, which is reminiscent of a journey of peace in these patients.

Negative experiences in COVID-19 survivors are fears and worries. The results of this study showed that patients with COVID-19 experience fear and worry in several dimensions. Participants had a terrible fear of a difficult death. Participants express the fear of a difficult and painful death by observing the death of other patients, deterioration of clinical condition, awareness of the high death rate of patients with COVID-19 around the world on media, and being away from family members. In this regard, studies show any patients in the acute phase of the disease have a fear to death due to the deterioration of the clinical condition (22,23). Fear, as one of the important components of psychological trauma (24), is an adaptive response to a potentially threatening situation (25). Jesmi et al reported that one of the most important mental strain of patients with COVID-19 is fear of death and deterioration of the symptoms (26). Also, Moradi et al stated that patients with COVID-19 were always fear of imminent death, recurrence, and unpredictable complications (27). The severe psychological stress that these patients experience may increase the risk of psychological strain, including post-traumatic stress. Therefore, psychological support for these patients is very important to reduce the negative consequences of psychological strain.

In this study, the participants frighten of being neglected and mistreatment among the large number of patients with COVID-19. Similarly, an online survey on 439 patients with COVID-19 showed fear in social aspects, including intolerance of uncertainty, the anxiety of their health, and their loved ones (28). To manage the high number of patients in these conditions, health authorities should increase the primary health care centers and outpatient services, accelerate documentation and discharge process, preclinical services, increase the number of hospital beds, and monitoring units (29–32). Intolerable symptoms are of the experiences of participants with COVID-19. Even after recovery, thinking about the recurrence of symptoms, always frightened participants. These patients always have nervous, respiratory, gastrointestinal, and systemic manifestations (26). These patients are at risk for post-traumatic stress disorder, one of the reasons being the experience of severe clinical condition (33,34). Gysels and Higginson examined the lived experience of breathlessness in clinical conditions as a reminder of death, a self-inflicted symptom, gradual disability, a contributing factor, and as a life-threatening threat (35). Also, Castelino et al (2018) showed feeling incapacitated during breathing difficulty in patients with chronic obstructive pulmonary disease (36).

Participants experience frustration of stigmatization. A study in India showed some patients were stigmatized due to COVID-19 (11). Stigmatization can be due to fear of the unknown of this disease (37). Patients with COVID-19 always had stigma due to feelings of rejection and negative view of public of the disease (27). The negative consequences of stigma on COVID-19 disease control include hiding the disease, avoid seeking treatment and adopting healthy behaviors immediately, and disrupt the identification and surveillance of patients (38,39). Therefore, in order to reduce the negative consequences of stigma, health care managers should have social support for these patients and increase public awareness of the disease. Also, participants express that COVID-19 impacts their mental, spiritual, and health behaviors. Shaban et al show that patients with COVID-19 after recovering from the disease make new behaviors, including healthy behaviors and changes in their lifestyle (40). On this subject, participants' spiritual awakening represents a kind of transcendence and God-centered spirituality which means finding the meaning of God as a source of power in their difficult situations. In line with our findings, Jesmi et al showed that patients with COVID-19 used religious mechanisms such as religious activities and beliefs to reduce their tensions and worries (26). Improving and training coping mechanisms according to patients' culture can have positive effects on these patients. Kimani et al showed that some heart failure patients in Kenya were optimistic about God's power to control illness and heal their illness (41). Striving for recovery suggests optimism and hope for the future in patients with COVID-19. Contrary to

this finding, Kar et al found that quarantined COVID-19 people feel a wide range of mental disorders such as boredom, loneliness, anger, depression, anxiety, denial, and despair (42). Liu et al found that progressive muscle relaxation and deep breathing in patients with COVID-19 can reduce their anxiety and improve sleep quality (43). Other mechanism used by patients with COVID-19 to recover as quickly as possible was the use of home remedies (44). In this study, participant's statements show that the emotional support and care provided by the family, health care provider, and volunteers had a significant impact on their recovery. McCabe found that the family presence accelerates recovery time, comfort, and decrease duration of hospital stay (45). Cabrini et al also declare that during the outbreak of COVID-19, health care providers were recognized as national heroes (46). In addition to the family and health care providers, participants also appreciate the altruistic of volunteers. Altruism is defined as acts of goodwill for the well-being of others, without any selfish intent (47). Studies suggest that patients recovering from COVID-19 perceived the family as the most important source of support (40,44). In relation to family support, Sun et al found that nurses also used the support of the patient's family to overcome the psychological damage caused by the COVID-19 (48). Also, Winnie et al introduce a model of perceived support by the family or care team to promote the mental health of SARS survivors (49). Therefore, the use of this model in epidemic diseases such as COVID-19 pandemic can also be effective on patients with COVID-19.

Limitations

The present study focuses on explaining the experiences of patients with COVID-19 with a history of ICU admission in one of the cities of Iran. In order to increase the generalizability of the findings, it is suggested that in future research, various centers for the treatment of COVID-19 be included.

Conclusion

The journey to peace as the final theme of this study is the movement of patients from unpleasant and painful experiences to flourishing life with understanding and appreciation of the blessings. The results of this study could help health care providers identify the needs of patients with COVID-19, including psychological, social, and spiritual support, and design care models. By understanding the negative experiences of patients with COVID-19, nurses will be able to plan appropriate preventive care. This is important because it can severely disrupt the patient or family psychologically and socially if the painful challenges of patients during ICU admission are not addressed. The fact that patients with COVID-19 show positive experiences, such as spiritual awakening, resilience to life changes, and appreciation of others, can be a source of hope and incentive for nurses to continue their care and strive to maintain and promote the patient's attitude and perception of illness and life.

Authors' Note

Bahman Aghaie and Mohammad Abbasinia contributed to design of the work, drafted the article, or revised it critically for important intellectual content. Mohammad Abbasinia, Zahra Tayebi, Ehsan Sharifipour, Alireza Koohpaei, and Bahman Aghaie contributed to data collecting and processing. Mohammad Abbasinia, Bahman Aghaie, Reza Norouzadeh, and Hossein Asgarpour contributed to writing the manuscript. The Ethics Committee of Qom University of Medical Sciences, Iran, approved this study (no: IR.MUQ.-REC.1399.005). Participants were informed about the study's aim, voluntary participation, and the right to withdraw from the study. Then, personal informed consent was obtained from each of them.

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8 Journal of Patient Experience

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