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“It feels like I’m the dirtiest person in the world.” Exploring the experiences of healthcare providers who survived MERS-CoV in Saudi Arabia



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ABSTRACT

In summer 2015, a Saudi 1000-bed tertiary care hospital experienced a serious outbreak among patients of Middle Eastern Respiratory Syndrome (MERS); during which, some healthcare providers contracted the virus, but none died. The outbreak provoked not only fear and stress; but also professional, emotional, ethical, and social conflicts and tension among healthcare providers and patients alike. Therefore, this study aims to explore what healthcare providers, who survived coronavirus infection, have experienced as a MERS patient and how the infection affected their relationship with their colleagues. Semi-structured, face-to-face interviews were conducted individually with seven survivors (healthcare providers). Each interview lasted up to 90 min, and the data were analyzed using the thematic analysis technique. Within the participants' rich and illuminating experiences, four themes were identified: caring for others in the defining moments, perceived prejudice behaviours and stigmatization, lived moments of traumatic fear and despair, and denial and underestimation of the seriousness of the disease at the individual and organizational levels. Survivors still suffered as a result of their traumatic experiences, which might negatively influence their performance. As these survivors are vulnerable, it is their organization's responsibility to provide a system that embraces HCPs during and after disastrous events.

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Background

The Middle Eastern Respiratory Syndrome (MERS) is caused by an emerging zoonotic virus that was identified for the first time in September 2012 [1]. It quickly became a virus of international public health significance due to the high mortality rate (around 35% of infected people) and its ability to spread rapidly in hospitals. Over 80% of reported cases have occurred in the Arabian peninsula, with the largest reported outbreak occurring in a tertiary hospital

in Jeddah in 2014 [2], and led to major political ramifications on the healthcare system in the Kingdom of Saudi Arabia [3].

MERS-CoV affects the respiratory system and leads to respiratory failure, especially in older people, immunocompromised individuals, and those suffering from cardiopulmonary illnesses [4]. MERS-CoV belongs to the lineage of the C beta-coronaviruses first identified in bats [5] and is transmitted to humans through an intermediate animal, such as the dromedary camel [6,7]. However, most MERS-CoV infections are spread from human to human through direct or indirect contact with infected people, for example through droplets from coughing or sneezing, from shaking hands or from touching contaminated surfaces [8]. These infections can be transmitted among close family members, in the community and in healthcare facilities from patients to healthcare providers.

Since its emergence, MERS has been diagnosed in patients in 25 other countries, including: Jordan, Kuwait, Oman, Qatar, Yemen, Tunisia, the United Arab Emirates (UAE), Egypt, Iran,

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Lebanon, Turkey, the United Kingdom, Germany, France, Italy, Algeria, Austria, Greece, the Netherlands, the United States, Malaysia, China, the Philippines, the Republic of Korea and Thailand. The highest number of cases was reported in Saudi Arabia (1470) [9], the second highest in the Republic of Korea (165 cases) and the third highest in the UAE (74 cases) [10]. More than 9 hospital based outbreaks have been reported by Saudi Ministry of health authorities [9].

So preparation for a potential MERS outbreak at King Abdulaziz Medical City in Riyadh (KAMC-R), the hospital based “Outbreak Committee”, assisted by the infection prevention and control department, prepared a staged response to MERS that was based on the number of MERS cases clustering together at any given time. This was known as the Infectious Disease Epidemic Plan (IDEP) [3,11]. For this particular outbreak the index case was identified on June 21, 2015, and as the number of cases were increased the IDEP was activated. With the widespread of MERS in the emergency room, level three, which is the highest level for the plan, called for the closure of the hospital and evacuated wards were being reassigned to cohort confirmed, exposed and non infected/none exposed patients. This eventually led to the successful control of the outbreak, which was declared over, on October 12, 2015.

Research has identified that such outbreaks do not just have organizational implications: outbreaks of severe viruses such as SARS-CoV and MERS-CoV can provoke fear emotional, ethical and cultural conflicts and tensions for healthcare providers in workplaces and those providing direct patient care to infected patients or those who have survived infection [12,13]. In such instances, healthcare workers have refused to provide patient care [14].

This is the first qualitative study to examine the perspectives of health professionals on an MERS outbreak. It contributes valuable and new insights into the unique challenges faced by health professionals caring for MERS during this 2015 outbreak at the KAMC-R. We believe our findings will provide specific insight into what is needed to enhance the preparation of institutions to support their HCWs in this very special scenario of a disaster.

Method

This study adopted a qualitative research approach. Qualitative inquiry is used to explore and describe a poorly understood phenomenon that is happening within a given context [15].

Data collection

Participants were selected using a purposive–non-probability–sampling strategy [16]. Participants were frontline healthcare providers who were MERS confirmed and were admitted to the hospital due to the infection during the 2015 outbreak, and who also met the following criteria: 1) they consent to participate in the study, and 2) they are fluent in English.

After obtaining ethical approval for this study, invitations to participate were sent to health professionals through the hospital's department of infectious disease, as they are responsible for the information concerning all MERS-CoV patients. Both volunteer and snowball sampling were used with seven participants agreeing to participate. Data were collected using face-to-face semi-structured interview approach with each participant [17]. The duration of each interview was approximately from 45 to 90 min.

Sample profile

The sample was composed of an almost equal number of male (N=3) and female (N=4) participants. They represent different age groups: four are from 28 to 29 years old, one is 51 years, and the last two are 61 and 66 years. Four participants are working as staff

nurses, and the other three are physicians. They have also worked at the study hospital for different lengths of time ranging from 2 to 17 years. Participants are from different countries: three from the Philippines, two from Saudi Arabia, one from the United States of America, and one from Korea.

Data analysis

The interview data were analyzed using the inductive approach to qualitative data analysis, in particular, the thematic analysis technique, which is a method of identifying and interpreting patterned meaning across the collected data. The analysis approach comprised six phases, including coding, searching, reviewing, defining, and naming themes and then weaving together the analytic narrative, data quotes, and discussion in light of the existing literature [18]. In this study, the data analysis was undertaken separately by the first and second authors of this study to strengthen the analysis process by supplementing and contesting each other's statements [19]. Collectively, these steps were intended to maintain the rigor of the study.

Ethical concerns

Every participant was given the choice to participate after receiving all the relevant information. The acceptance was recorded and documented by signing the informed consent.

The findings

The MERS outbreak in the hospital created widespread fear and panic among healthcare providers and other employees. They become suspicious of each other and continuously engaged in prejudice and stigmatization behaviours against those who worked in hospital units that received patients with coronavirus. Consequently, they were quarantined and unable to interact freely with their colleagues as before. For example, participants' traumatic experience is illustrated by the quote below:

“Neglect is pain. . . prejudice is there, it hurts, also. . . unbelievable human ignorance. There was one person who is in administration here, who was scared to call me because she might get Corona over the phone”

Such fear, anxiety, attitudes, neglecting behaviour, and rejection were cardinal findings manifested in the participants' reported experiences, as explained in the subsequent themes.

Theme 1: caring for others in the defining moments

Participants' reported emotions and involvement in care for MERS patients were diverse. Some participants expressed a high level of altruism associated with professionalism by always going the extra mile for their patients and exposing themselves to high levels of risk. Therefore, they believed they caught the virus as a result of prioritizing patient care over their own health, which consequently might have led them, either consciously or unconsciously, to exercise poor self-protection and precautions. The motives of feeling obligated to attend to the needs and best interests of those who were infected, as well as to maintaining their professionalism, were manifested in their reported intentional practice of providing the maximum level of care, even in a high risk situation. This was primarily how the participants reflected on how they caught the virus in the first place. For example, a participant explained as follows:

“In the ER. . . we had patients in the hallway. . . and we had patients positive with CORONA behind curtains. . . and I was examining

and seeing every single [patient with] CORONA in this hospital by myself. . . .and that's the price I paid. . . .”

“ . . .so the one [who] got positive virus I think was me [the survivor], I think I was too close to the patient . . . because I examine the patient more than the junior. . . .”

Another participant described his feelings about surviving the virus and considered his survival to be a reward from God for the hard work he was doing for patients during the outbreak:

“Let me tell you something, sometimes I feel that I survived this disease because God knows that I was doing the right thing. . . .”

In contrast, such feelings of obligation and what arguably seems to be altruistic action were not always the case for many healthcare providers; other participants expressed how they were anxious about their safety and self-protection. Apparently, the seeming panic of colleagues, fear inducing stories that were told of infected patients, and perceived severity of clinical presentations of the virus contributed to their increased anxiety level, which consequently affected their work performance and willingness to work in such a risky environment. Despite these fears, participants perceived they had an ethical or employment related obligation to provide care:

“I was afraid, you know when I have patients that has fever I already get paranoid, so when I heard about the outbreak already I wanna go home, but there's nothing I can do I have a contract, and then I forced myself to stay”

“It's pretty scary but ah, as a healthcare provider we cannot say . . . I don't wanna work . . . because it's our job . . . that's the main reason how this virus got into my body . . .”

In instances in which health care providers were frightened of catching the virus to the extent, some decided to refuse to provide care to their patients.

Theme 2: prejudice and stigma

Participants described their own negative and painful experiences of being seen as carriers and survivors of MERS in the community, which were perceived to have affected them psychologically, emotionally, and cognitively. Apparently, people's desire to avoid the epidemic infection and remain healthy resulted in, either in a subtle or unsubtle way, behaviours of social rejection and neglect of those who survived the infection. Participants explained a variety of painful experiences of rejection and avoidance by their colleagues and neighbours even after recovery:

“I was standing by my window. Here, next to my house, there is a park, and a lot of people here walk to the bus stop, and in the park, there is a distance like maybe from here to you. I was standing here, looking to my window through the curtain, and one nurse who I talk to a lot called, and I was walking here, and I could see her but and I went back I didn't want her to see me. And she told, “Yeah, I'm at the hospital, and when I have the time I will come to see you.”. . . I said, “Okay, don't worry, yeah, I'm sorry.” It's basically very clearly implying that I don't want to be near you”

This stigma was perceived to arise from the public suspicion that the survivors still had the virus in their bodies. People's fear and anxiety resulted in intentionally ignoring and excluding survivors from their social life or signalling them for special questions:

“A lot of people knew about it. If I go near them, they will ask, “Are you negative? Were you the one who had Corona?” And then they will cover their nose. Yeah”

“I felt bad. . . it feels like I'm the dirtiest person in the world; that's why they have to avoid me. I can't approach them because they are terrified, you know. I felt bad . . .”

This conduct led to social isolation and appeared to reduce participants' self-esteem, sense of meaningful existence, and belonging, which resulted in social pain and distress. On the other hand, one participant described the opposite experience with a group of his Saudi colleagues during his illness. He explained the extent of caring and unconditional emotional support they provided when he was admitted into the hospital, and they did not exhibit any intimidation behaviours or rejection. The following quotes explain his sentiments:

“I was born Christian. . . I think the Islamic teaching of just brotherly love and compassion manifested in the way I was treated by A, B, and C, without question you know, and that was the first time I cried, and not because I was in pain but because of the showing of caring. It touched me so much. . . I didn't cry because I was in pain, no, but because of the genuine. . . I mean some people who fake it. It was genuine; it was real. . . .”

Theme 3: moments of traumatic fear and despair

The diagnoses of participants as MERS created intense feelings of fear and anxiety. Their infection was a traumatic and dreadful experience as they realized that their lives were at risk, and they could die at any time. Being in the hospital and receiving healthcare did not help. They reported feeling hopeless and helpless and frightened of the scenarios that could happen to them. Their despair about their futures was exacerbated by their medical knowledge and the fact that they had witnessed many patients die from this viral infection. For example, the following participant's quote revealed how they perceived the correlation between their infection and death:

“In the morning, they said I was positive of Corona, so my feeling that time was very terrible, and of course when I say Corona, all our patients died from Corona”

The participants' medical knowledge compounded their fear by adding additional stress. They started to imagine the scary and seemingly inevitable scenarios that could happen to them, including suffering the disease that would eventually lead to their death. For example:

“So, even I have this kind of thinking, “Oh my God, after few days I will die, after few days I will get intubated, or something like this like that.”. . . I was really scared if I will survive or if I will be gone that time. . . .”

Contrary to many participants' experiences, one of the survivors did not realize the serious and fatal consequences of MERS-CoV, even though he was admitted to the ICU. This could be because he was not physically too sick or he was in the denial phase. He only realized the seriousness of the condition when he witnessed deceased patients being taken from the ICU to the morgue. It was a shifting paradigm and life-changing moment.

Participants were traumatized to the point that they dreamt about their ordeals. Even after recovering, they still felt their recovery was not complete and suffered from the intensity of their experiences. The description below highlights one of the participants' feelings, which were echoed by others:

“I'm trying to avoid thinking about the incident. . . I still have dreams. Especially yesterday I dreamt about being in ICU seeing everything inserting all the tubes and needles. I saw, I think it will be a big part of my life already”

Theme 4: denial and underestimation of the seriousness of the disease

Denial and lack of understanding of the seriousness of the disease occurred in the early stages of the epidemic at two levels: the personal level, in which healthcare providers had different perceptions of the aggressiveness of the infection, and at the official level, in which the official responses to dealing with the situation and containing the virus could not cope with the nature of the infection. It is noteworthy that these findings only reflect the perceptions of those who were traumatized by their experience of surviving the virus in this environment, which may or may not reflect the complexity of the situation. Nevertheless, the perceived denial and underestimation might have contributed significantly to the outbreak of MERS in the hospital. For example, at a personal level, one participant reflected on his experience, which was similar to that of other participants, saying that he thought that the MERS outbreak was under control, and it did not occur to him that he would catch the virus. He explained:

“The thing that comes to mind is that life was going on as usual; you know that we had the outbreak in March, so we thought we were over it and Mafee Mushkelah [Arabic for ‘no problem’], and everything in life was going on. . .

Participants continued reflecting on their experiences and described how suspicious patients who eventually turned out to be MERS-CoV positive were scattered around the emergency department and in the hallway without applying proper infection control practices. Therefore, the official responses to the outbreak at the early stages were not congruent with the seriousness of the situation. One explanation of such a questionable infectious disease prevention response is official denial and underestimation of the outbreak. Such underestimation of the seriousness of the infection caused a delay in acknowledging the outbreak and then announcing it properly to everyone so they could exercise their highest level of vigilance. The participants' views on this matter were critical. They described how they had to work under the high risk of infection without proper warning:

“Create a policy where you alert the staff as soon as you have one case or two cases in the ER; you [i.e. the decision makers] should have alerted all the staff”

Healthcare providers were seen to neglect hand hygiene practice and other infection prevention measures as they believe it will slow down their practice. Thus, from their perspective, if healthcare providers were well informed about the chances of getting the infection, they would prioritize strict infection control measures even if it would mean slower practice and that fewer patients could be seen in each clinic. The concerns about the lack of knowledge and proper education about the outbreak and related infection control measures were echoed by most of the participants.

Discussion and conclusion

From the participants' rich and illuminating experiences during the outbreak and of surviving MERS, four main themes were identified shaping their experiences. The first three themes mainly revolve around the extent of care that participants, as healthcare professionals, provided to patients during the epidemic outbreak, their painful experiences of social prejudice and stigmatization, and the moments of diagnosing participants as MERS-CoV positive, which provoked an intense feeling of fear, anxiety about their fate, and then despair about their future. The fourth theme refers to the underestimation of the seriousness of the disease as the healthcare providers had different understandings of the aggressiveness

of the MERS-CoV infection, which led them to perceive that the organizational responses were not congruent with the nature of the infection.

Regarding the extent of patient care during the outbreak, participants' experiences were not uniform. Some participants prioritized patient care over their own health, exposing themselves to risks. Such behaviours can be better explained through the theoretical lens of altruism, which is associated in this situation with a sense of professionalism. The notion of altruism, which was first coined by Auguste Comte in the 19th century, basically refers to an unselfish act that is undertaken voluntarily and intentionally to promote the welfare of others [20,21]. There are two types of altruism: normative and autonomous. The former refers to the usual acts of helpfulness regulated by social norms with low risk and low cost to the performer, whereas the latter refers to intentional acts that are undertaken primarily for the benefit of others and often associated with high risk and high cost [20]. Therefore, those participants who always went the extra mile for their patients believed that they caught the virus as a result of their altruism. It seems their eagerness to help their patients led them to either consciously or unconsciously practice poor self-protection and precautions. While fear of the infection, anxiety, panicky responses, and scary stories also negatively influenced the performance of some healthcare providers during the epidemic.

Participants in this study were traumatized by their experiences as patients with and survivors of MERS-CoV infection. Those, who survived the infection and were happily looking forward to life, reflected on their painful experiences of rejection and neglect by their colleagues and neighbours. Such findings were not surprising because the fear of the disease and the desire to remain healthy pushed people either consciously or unconsciously to engage in prejudice behaviours against those who were victims of the virus. Many studies conducted in different settings and with different groups of people, such as those with hepatitis C virus infection and those with Ebola, indicated how patients suffered from social isolation and rejection [22–25].

Significantly, research indicated that social rejection and neglect, even when experienced in lesser forms, have painful and distressing negative impacts on individuals [26,27]. These effects of social injury may last longer than physical injury and affect individuals psychologically, affectively, and cognitively [27]. The findings also revealed that the social injury (isolation and rejection) experienced by the survivors threatened their fundamental human needs such as self-esteem, confidence, self-worth, and sense of belonging. Many researchers have argued that being socially valued, liked, appreciated, and included lead to the enhancement of well-being and self-esteem, whereas opposite experiences will evoke negative emotions and consequently may lead, in some situations, to antisocial reactions such as aggression or withdrawal [28–30]. They may also lead to impairment of individuals' self-monitoring and self-regulatory processes, which could result in negative behaviours, such as unhealthy eating, which might be detrimental for some people [31].

The findings revealed the magnitude of survivors' traumatic experiences, including near-death experiences, feelings of alienation and rejection, and social stigmatization, which affected them psychologically and emotionally. These survivors, as well as the healthcare providers who were working in the environment where MERS-CoV broke out, are still vulnerable because of their terrifying experiences of constantly anticipating frightening scenarios and the possibility of death. Therefore, they need support and help at the organizational level. In order to reduce their fear and anxiety, an educational campaign must be launched immediately after diagnosing the first case in the hospital. It should focus on the signs and symptoms, transmissibility, personal hygiene and protection, precautionary practices, and help-seeking behaviour. Educating and

increasing healthcare providers' awareness will help reduce the incidents of rejection and stigmatization of colleagues who are in contact with MERS-CoV positive patients. It is important that hospitals remain vigilant and proactive when it comes to infection control measures and exhibit a high level of transparency about the nature of the infection with employees.

It is noteworthy that this organization developed the 'Infectious Diseases Epidemiological Plan' (IDEP) prior to the outbreak. It was based on recommendations and guidelines from the World Health Organization (WHO) and Center for Disease Control and Prevention (CDC), and was activated during the outbreak [3,32]. Unfortunately, despite these guidelines and plans, the outbreak still occurred due to a failure to adhere to the infection control measures. Therefore, healthcare providers should remain vigilant and take emails, educational material and warnings about MERS-CoV more seriously, and hospital management should ensure that the healthcare providers abide by all infection control plans/measures.

Despite the fact that participants survived the infection, they still suffer from its complications. Therefore, it is important that the hospital dedicate special clinics to helping survivors and their families receive support in the form of psychotherapy geared toward addressing the psychological and emotional effects of the infection and its social consequences. Such a measure will help survivors overcome their challenges and increase their resilience in order to maintain fairly stable lives.

In this study, we struggled to recruit participants due to the sensitivity of the topic. Although this qualitative study explored the experiences of only a limited number of survivors, it produced rich, reliable, and trustworthy insights. Further studies will be useful to investigate the public's perceptions of the nature of the MERS-CoV infection and their views of and reactions to the survivors. Another longitudinal study is recommended to investigate the development of survivors' resilience over time.

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Competing interests

None declared.

Ethical approval

Ethical approval and clearance was obtained from the institutional review board at Ministry of National Guard-Health Affairs.

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