

SURVIVING COVID-19: AN ILLNESS NARRATIVE OF PATIENTS IN PAKISTAN

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ABSTRACT

Objective: To explore the perspective of survivors with regards to their experience with COVID-19, in order to provide health care professionals a better insight to the disease and its management.

Study Design: Mix method study.

Place and Duration of Study: The study was carried out in COVID declared Pak-Emirates Military Hospital Rawalpindi, from Apr to Jun 2020.

Methodology: Forty two patients admitted to PEMH Rawalpindi who were Polymerase Chain Reaction (PCR) positive for SARS COV-2 were included in the study. Non-probability purposive sampling was used. Face to face in depth semi structured interviews were carried out by two doctors in which the detailed narrative of each patient was obtained. The findings of the interviews were discussed in front of the panel of research team members and the main recurring themes were sought.

Results: Out of the 42 patients interviewed 41 (97.1%) were satisfied with treatment received at PEMH Rawalpindi. Sixty nine percent of the patients believed the fear associated with COVID was most distressing than the disease itself. All of the participants believed that mask and social distancing helped in prevention of disease and 85.7% were in favor of lockdown. 17.17% patients acquired their awareness of COVID through unreliable means like social media. Natural remedies were used by 78.8% of the participants out of which the use of Senna leaves was the greatest (42.86%).

Conclusion: Most patients received their information through the media and social media which created superfluous fear among the patients. Patients turned to alternative therapies which need to be evaluated with a scientific approach. The medical care being provided by PEMH is appreciated by the patients, however bed bound patients require attendants for better care.

Keywords: COVID-19 pandemic, Fear, Pandemic, Interview, Narrative medicine

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INTRODUCTION

On 31st December 2019 an epidemic of pneumonia emerged in Wuhan, China¹. On January 2020, a virus was isolated named SARS-CoV-2 the causative agent of COVID-19. On 27 February 2020, WHO reported the first two cases of COVID-19 in Pakistan².

By March 2020 the world health organization (WHO) declared the outbreak of pandemic with the current number of cases as of 10th June 2020 reaching 7 145 539 and 408 025 deaths globally³. This global pandemic is different from the Spanish flu and SARS-MERS in this century due to its rapid spread because of easy intercon-

tinental travel and secondly the spread of information and fear via media.

In Pakistan, a developing country, the lockdown policies implemented though strict initially gradually lost their momentum and adhesiveness. The public was not also not compliant as a result the number of cases in Pakistan have escalated to 113 702 as of 10th June 2020 with the number of deaths being 2255³.

In COVID-19 person-to-person transmission occurs primarily via direct contact or through droplets spread by coughing or sneezing from an infected individual. This infection led to the isolation of patients the main stay for prevention of transmission, frequent hand sanitization, use of mask and use of PPE helped restrict spread⁴. At present, there are no specific antiviral drugs or

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Received: 15 Jun 2020; revised received: 14 Jul 2020; accepted: 22 Jul 2020

vaccine against COVID-19 infection for potential therapy of humans. Currently Vitamin-C, zinc and Vitamin-D are being given to patients of COVID-19. Remdesivir and hydroxy chloroquine are highly effective and use is under therapeutic trial⁵. LMWH, loprin, convalescent plasma and plasma exchange therapy are also being used and proving efficacious⁶.

This pandemic has caused an increase in the anxiety and stress level of the general population particularly among persons having the disease⁷. As this is a novel disease our medical knowledge regarding it is insufficient and continuously evolving, the result of which is that the patients suffering from COVID-19 are faced with an unusual predicament of having a disease in which health care professionals cannot answer all their queries and cannot provide a definitive cure. Although a large number of studies on this topic have been conducted⁸ since the emergence of this virus a very few of these have explored the patient's perception and standpoint of this illness. Patients' narratives of their experience with COVID-19 is essential for doctors, nurses, paramedic staff and others to view the disease from a compassionate perspective rather than just a factual angle. "Patient perspective" is the patient's experience of going through the disease and its impact on him/her and caregivers, including symptomatic, intellectual, psychosocial, spiritual and goal-oriented dimensions of the disease and its treatment⁹. Our goal in this study was to analyze the disease from the patients' perspective to help us to fill in the gaps towards approach in the management to improve patient's recovery and quality of life, allay anxiety and increase chances of survival. Assessment of patients' understandings and expectations toward disease, treatment and care provided can help in finding issues which later can be incorporated into patient care¹⁰.

The purpose of our study was: to provide the patients suffering from COVID-19 a voice that can reach out to health care workers and health related policy makers, so that they can understand what the patient is going through and

recognize any shortcomings in the current management practice of preventing and treating COVID-19.

METHODOLOGY

A mix-method study carried out in Pak-Emirates Military Hospital (PEMH) Rawalpindi which was declared a COVID hospital in March 2020. Our study spanned from April 14th to the 10th of June.

Non-probability purposive sampling was used to select participants. A total of 42 participants were included in the study aged 13 to 71. Males and females were eligible for the study if they: 1) had tested positive for SARS COV-2 through nasopharyngeal or oropharyngeal swabs 2) were admitted for at least 1 day in PEMH Rawalpindi 3) were willing to be a part of the study. Patients who were too ill to talk for the interview and those who could not survive the disease were excluded from the study.

The Study was approved by the ethical committee of PEMH Rawalpindi ERC number A/28/EC/144/22. Data was obtained by conducting in Depth face to face interviews based on a semi-structured questionnaire. The objectives of the research were first made clear to the participants and then verbal consent was taken. Any of the participants not willing to reveal their identity were assured that their response would remain anonymous. Interviews were carried out in the hospital either on the bedside of the patient or the counselling room depending upon the patient's preference by two doctors (the first and second authors). The interviewers remained in full personal protective equipment and maintained a distance of 6 feet throughout. Each interview lasted on average of forty minutes. We included patients admitted to a variety of wards which included asymptomatic ward, High dependency Unit HDU, Gynae COVID ward, family medical ward and Intensive Care Unit.

The interview was broadly divided into 3 parts. In the first portion demographic details were taken and basic medical history was covered which included any comorbid conditions,

previous hospital admissions or known allergies. These were noted on the questionnaire. The second part consisted of details concerning the COVID status of the patient.

After this the most extensive part began in which asked the patient to describe in detail their narrative during the course of their illness. Open ended questions were asked to get information about patient's emotional state at the time of being diagnosed, coping strategies, family support and insight into the disease. The patient's opinions regarding the nature of this disease, the hospital and medical staff's management, government's response to the crisis and the role of social media during this pandemic was also taken. The personal cell phone numbers of the participants were taken and they were followed after they were discharged from the hospital. After their recovery they were asked to describe their life post COVID through telephone calls. In the end of the interview they were asked if they wanted to add anything to their narrative.

The first and second author were the interviewers. The findings of the interviews were discussed in front of the panel of research team members and the main recurring themes were sought. The themes of experiences were identified through several reading of the experiences and final thematic categories were derived through discussions among the research team. The quantitative data from the questionnaire, for example number of days of admission were entered in SPSS version² and frequencies of the computable information were calculated.

RESULTS

Our study comprised of a total of 42 participants aged 13 to 71 years with a mean age of 39.71 ± 17.43 years out of which 16 participants currently resided in Rawalpindi-Islamabad. Thirty seven patients (88.09%) were categorized as COVID Mild Category A or B, 5 patients had moderate disease and 3 had severe COVID pneumonia out of which 2 patients remained on ventilatory support during their course of treatment. We also included participants of

various ethnicities to know their view as well. The remaining characteristics are described in table-I.

The reason most patients had got tested for SARS-CoV-2 was because they had symptoms of COVID (n=15) the most common of which was fever. Part of Hospital policy at the time of admission although they didn't not have any symptoms related to COVID was the next most common reason quoted for getting tested (n=14).

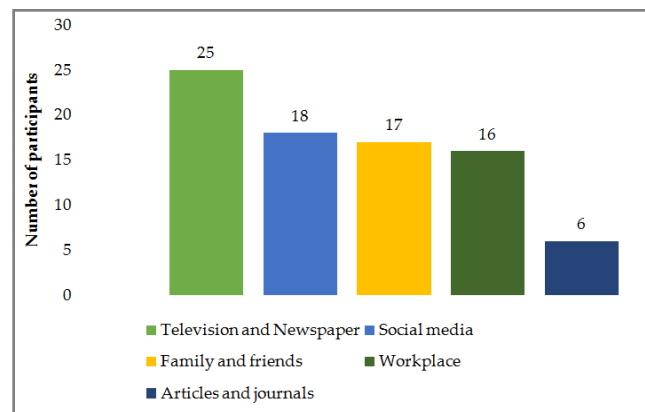


Figure-1: Patients sources of information on COVID-19.

The other reasons were history of contact with COVID positive person (n=13), as a job requirement (n=3) and 3 patients got tested on self-basis just to make sure they hadn't acquired it.

As far the patients' knowledge on COVID-19 preventive measures, mechanism of disease production, treatment options were concerned most patients got their information from the media. Figure-1 shows the various sources of information the patients had.

Themes

Recurring themes in the interviews can be placed into the following categories as shown in table-II.

Coping with the Diagnosis

Most of the participants (n=36) were distraught when the diagnosis was made. They felt upset and worried about what would happen next, where they would they be admitted and how long they will remain isolated. In contrast to this the remaining participants were quite self-

assured, they said they knew many people would be affected by this pandemic. One patient describes his diagnosis "I was not at all worried, why would I be? What ever is written in my fate I cannot escape it. It is all in the hands of God." Most of the patients turned towards religious

Table-I: Characteristics of participants in the study.

Characteristics	Frequency	Percentage
Gender		
Male	22	52.38
Female	20	47.62
Ethnicity		
Punjabi	29	69.04
Pathan	5	11.90
Sindhi	4	9.52
Gilgit-Baltistan	2	4.76
Kashmiri	2	4.76
Occupation		
Health care workers	12	28.57
Retired army personnel	9	21.42
Housewife	8	19.04
Serving army personnel	7	16.66
Students	2	4.76
Others	4	9.52
Co-Morbid Conditions or Any Other Medical Condition		
None	25	59.52
Hypertension and Diabetes Mellitus	4	9.52
Pregnancy	3	7.14
Ischemic heart disease	3	7.14
Hypertension only	2	4.76
Diabetes mellitus only	2	4.76
Asthma	1	2.38
Brucellosis	1	2.38
Road traffic accident	1	2.38

practices during their hospital stay, many stating that they got closer to God after they were diagnosed. Namaz (prayers), zikr, darood sharif, reciting the Quran and charity were the most commonly mentioned ways of releasing stress and passing time during the admission. Companionship of the neighboring patients in the ward or isolation room was another frequently described source of comfort for the patents. Before being shifted to the COVID wards the patients were afraid and felt isolated and social

outcast constantly being reminded of how contagious they were. But after coming to a COVID designated hospital they felt at ease as all the patients here had the same disease. They could easily talk among themselves, narrating to each other the success stories of those COVID patents

Table-II: Showing main themes encountered during the interviews.

Themes
Coping with the Diagnosis
Fear and anxiety
Attitude towards the hospital management
Feeling of Regret
Use of Alternative medicine
Views on lockdown, isolation and preventive measures

who were previously admitted here but have now recovered and discharged. All of the participants said their family had been very helpful in mentally coping with the disease. Although attendants were mostly not allowed to visit the

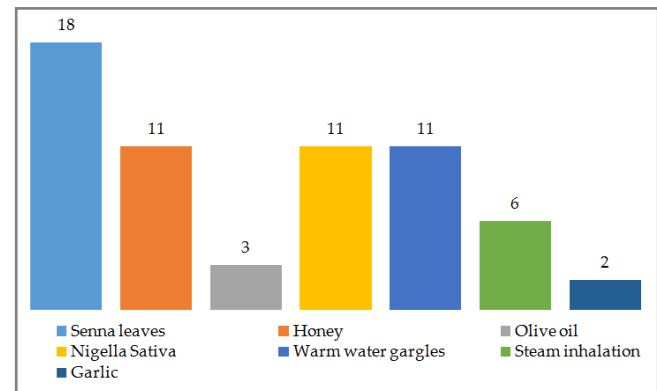


Figure-2: Use of natural remedies in survivors of COVID-19.

patients during admission due to the contagious nature of the disease, they talked regularly over the phone and sent them whatever they needed through the ward boys.

Fear and Anxiety

This was a feature of almost all the participants' narrative. More upsetting than the symptoms or the isolation was the fear: The fear of dying due to COVID, the fear of transmitting it to other family members, the fear of pregnant mothers that it could be transmitted to the fetus,

the fear that if one died of corona virus their body would not be handed over to the family. Pregnant women interviewed had a genuine concern for the pregnancy outcome and whether their baby would also contract the virus. Most young mothers with small children at home worried about spreading the disease to them.

Twenty nine (69%) of the participants believed the fear to be more distressing than the disease itself. They said that the symptoms were not that discomfoting, as most of them (93%) had only symptoms of cough, myalgia and flu like symptoms, but the dread associated with having "corona" made every mild symptom seem as if it would lead to death because of all the panic present among the populations. Some patients blamed media and social media for spreading horror among the populations. One patient said "there things on the internet that some injections are given to corona patients which kills them instantly. These things made me very scared at the beginning but after staying here (at the hospital) I realized those were lies." 6 other participants were troubled about what happened to the dead body of a COVID positive patient as they had heard stories that their bodies "disappear" from the hospital and the families are only given an empty coffin.

There was also a slight fear of being labeled as having "corona" for this reason 26 of our participants hadn't informed their neighborhood that they were admitted due to COVID-19. An interesting finding was that 3 out of the 42 participants did not even tell their family members that they had "corona" as they didn't want them to worry. All three of these participants were serving army soldiers living away from their families.

Attitude Towards The Hospital Management

An overwhelming majority of the patients showed extreme gratitude to the hospital staff. Saying that each and every one of the staff from the sanitary workers to the paramedics, nurses, doctors and consultants, all were very cooperative and compassionate. They acknowledged that

these were dangerous times yet the medical staff risks a lot to provide care for the patients. Along with this they were also very appreciative of the hospital facilities and of the military for looking after them and providing them free medical treatment. A point was raised by 4 of the participants that the patients suffering from COVID who were unable to walk or talk and were bed bound should be allowed to have attendants in the hospital ward. The said the young and fit patients have to provide help for the dependent patients like giving them water when they ask. 61.9% of the participants thought that they were better managed at the hospital then they would be at home, while 14% said it didn't really matter if they were admitted or not as they were asymptomatic or with mild symptoms and the disease cured itself. There was a contrast in the opinions of the duration of hospital stay among those patients who were asymptomatic or had very mild symptoms and those who had troublesome symptoms. The asymptomatic patients found it very frustrating to be admitted in the hospital for more than a week they used terms like "sometimes I just felt like running away". They thought that they could easily be managed in their homes in an isolated room. But the patients who had symptoms believed that they couldn't be managed well at all at their homes.

Feeling of Regret

Eight participants felt regret that in spite of taking all recommended precautions they still contracted the virus. This sentiment was mostly observed in the well-off participants and mostly among women. One retired military officer described his efforts to avoid getting the disease, "we took all the preventive measures; we did not go outside, we wore mask, used hand sanitizers, we even used to get our house sprayed (with antiseptic spray) after every few days, but I still got it." This brought them to the conclusion that no matter how many precautions one takes "the ones who have to get it will get it." A number of the patients could describe exactly when, where and from whom they believed to have contracted the virus. One man recalled the guest who came

to his house right before he got sick, "I shook hands with him. He didn't have any symptoms but he spread it to me."

Use of Alternative Medicine

Thirty one participants (73.80%) turned to alternative medicine along with taking the prescribed medical treatment from the hospital. They said that as there is no scientifically proven cure of the corona virus, they felt that trying herbal remedies might provide a cure. The most used and recommended herbal treatment revealed in the interviews was Senna leaves. In One ward a patient bought a large amount of Senna leaves and distributed it among all the other patients, they would then boil the leaves and drink it. They said it soothed their throats and relieved the myalgia. Other patients used black seeds (*Nigella sativa*), honey, steam inhalation and warm water gargles. Figure-2 shows the frequencies of various alternative remedies used by the participants

Views on Lockdown, Isolation and Preventive Measures

Out of the 42 participants only 6 of them did not think the lockdown policy by the government to be beneficial. All of the remaining 36 participants were in favor of lockdown, however many of them said that it would be more beneficial if the lockdown continued for a longer duration of time and remained till after the Eid holidays. The 6 participants not agreeing to the lockdown policies also presented a reason, that the laborers and others belonging to lower socioeconomic group could not earn their livings and hence they would starve if the lockdown continued.

All 42 participants (100%) agreed that mask and social distancing was key in preventing and controlling the disease. Once elderly gentleman emphasizing the importance of isolation by saying, "I'll stay at home for two whole months if they tell me to. No problem, as long as it helps stop the disease."

DISCUSSION

"Listen to the patient: he or she is telling you the diagnosis". This is an oft repeated phrase we

have all heard at medical school and during our residency and in turn have passed it on to our next generation of medical professionals. Narratives of illness provide a medium for the education of both patients and health professionals and may also expand and enrich the research agenda¹¹.

Experts argue on importance of patient perspective evaluations and their effectiveness in shaping medical practice. Many evidences in favor of such evaluations have suggested that such measures are robust and useful indicators of quality health services¹². Assessment of patients' understandings and expectations toward disease, treatment and care provided can help in finding issues which later can be incorporated into patient care¹³.

The findings of this study helps understand the in-depth perception of the COVID-19 patients their fears, anxieties and possible relieving factors and remedies of this novel disease which understanding and management is still in its infancy. The participants further suggested the attitude of doctors and health care providers greatly influenced their outlook, acceptance and willpower to combat the disease process and often have associated physicians, nurses and paramedical staff synonymous with "custodians and guardians" during this novel pandemic. However, despite this, patients had general opinion that patients with mild disease should be managed at home, this not only preserves medical resources and staff employment but also state economy. Patients often felt the media played its part in disseminating information but in many instances created undue fear and glamorizing a morbid disease process. Social media often helped spread rumors and misinformation leaving the Public mind in total disarray and disbelief often not knowing whom to trust in this period of isolation. The government should curb the spread of harmful content by media.

This insight can also facilitate healthcare decision-making, providing important information for developing future person-centered health care at government and public level¹⁴. It shows

the central role of the family, traditional beliefs, and concerns about social boycott and taboos. It is imperative that the public be educated about importance of lockdown and isolation and violation in many instances led to regret. Home deliveries of groceries, medicines and other vital product can facilitate the lock down process as in the West¹⁵.

In our study Some patient revealed how they did not receive information about exercise and diet from the doctor, so they relied on alternative sources such as media and traditional apothecary to fill in the gaps and give them more detailed information. This suggests dissemination of health care pamphlets with authentic advice from professionals would educate the general public about various aspects of the disease such as spread, origin, pathogenesis, symptomatology, treatment and precautions.

Our study showed supportive role by relatives also enhanced recovery and early discharge from hospital although most attendants are restricted from ward but in a few select cases where patients are moribund attendants can be allowed in full PPE to facilitate their patients. Physicians, nurses and paramedics served the role of councilors, supporters and even as a bridge to family members. Many relatives would take the numbers of healthcare providers to know the progress of patients and even say 'you are the guardian of our patient.' Patients once understanding the nature and course of the disease and the reality of COVID-19 survivors were much better equipped to deal with ailment whether symptomatic or asymptomatic.

From the findings of our study we would suggest that further research should be done on the herbal remedies being used by the patients, so that doctors can clearly know whether these remedies are actually beneficial or not. There are a few studies supporting our findings in which Senna leaves have had a beneficial effect on health¹⁶⁻¹⁸. but no research has been done in its role in COVID-19.

A study very similar to ours was conducted in Italy titled "COVID-19 and the fear of senior citizens"¹⁹. Their study concluded that Forced isolation, loneliness, and fear of contracting the disease are tough challenges for all people, especially for frail, elderly people. Promoting self-help and positive coping and reducing isolation also through technology appear imperative. Our study's conclusion was not wholly similar because it did not focus primarily on older people and because our participants were admitted patients in hospitals rather than from old age shelter homes. But both our studies did conclude that the fear associated with the disease is causing psychological trauma to the patents.

One study on the perspective of a healthcare worker and her challenges during COVID-19 has been conducted in May 2020 and numerous similar studies have shown the narratives and encounters of healthcare workers dealing with COVID patients and the impact on their mental wellbeing²⁰⁻²² but there is a lack of researches on patient's narrative on COVID-19.

LIMITATION OF STUDY

As with all qualitative studies, this was an in-depth study with few informants and restricted to one teaching hospital, and this cannot be considered representative of the population of all COVID-19 patients. It might also be that the patients who were willing to talk about their experiences might have differed from those who chose not to participate especially their social milieu and severity of disease. Both quantitative and qualitative studies in future research are needed.

ACKNOWLEDGMENT

We would like to express our gratitude to all of the patients who shared their esteemed experiences and journey of COVID-19 with us for this study.

CONCLUSION

All patients in our study followed and relied on medical advice given but in addition some also used alternatives like herbal medication,

diet and meditation. The practices and usage of alternative medication and support were profoundly influenced by Pakistani traditions, culture and beliefs as an adjuvant to medical treatment advised. Most of our participants got their information on this disease from media and social media. Misinformation by media and other sources greatly enhanced the anxiety and fear levels in the masses further this led to the use of alternative products which may be harmful. Health care and information pamphlets by responsible experts are essential in spread of information. Overall patients were satisfied with the care they received at the hospital however bed bound patients suggested they required permission for attendants to be allowed in the ward for better care. Providing person-centered health care and taking patients' desires into account are necessary. It is important for nurses and doctors to optimize patient's participation in treatment of this novel virus as various beliefs and remedies enhanced patient's optimism combating disease and survival ability.

CONFLICT OF INTEREST

There is no conflict of interest to be declared by any author.

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