Research Article

'Surviving COVID-19': Illness Narratives of Patients and Family Members in Pakistan

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Abstract

Objective: To explore the emic perspective of survivors and their family members with regards to their lived experience with COVID-19

Study Design: Cross sectional qualitative research using phenomenological approach with a constructivist paradigm

Place and duration of study: Telephonic interviews of patients from Punjab and KP for 2 weeks during May 2020, as approved by the ethical review committee of Fauji Foundation Hospital, Rawalpindi

Methods: Non-probability maximum variation purposive sampling technique was employed to conduct semi structured interviews with 22 individuals; including those who had tested positive for COVID-19 on PCR test and recovered after minimum 2 weeks of isolation, along with their family members. Braun and Clarke's thematic analysis was done concurrently with data collection and management.

Results: 5 data-driven themes with 21 subthemes were; "Perceived Susceptibility": symptoms, risk factors, causes/origin, modes of transmission, "Knowledge and Experience with Precautionary Behaviors": use of masks, hygiene practices, social distancing, religiosity, "Treatment seeking behavior: Perceived costs and benefits": experience with test, complementary home remedies, medical treatment, mistrust for quarantine facilities, interaction with health care practitioners, less priority to other diseases, "Psycho-social dimensions of COVID-19": guilt and fear, caregiver burden, family quarantined, renewed spiritual connections, "Barriers to Care": health care workers: dichotomy of praise and stigma, media: dramatic and traumatic, stigma-behavior of others.

Conclusion: This study revealed the lived experiences of COVID-19 survivors and their family members, detailing their conceptualization with regards to disease vulnerability and associated precautionary behaviors. It mainly showed how survivors and family members navigate through biomedical systems, complementary healing practices, resilience and stigma.

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Introduction

The outbreak of the Novel Coronavirus (COVID-19) has progressed within a few months from a cluster of 44 cases reported in Wuhan, China on 31st Dec 2019, to a global pandemic status as declared by the World Health Organization on 11th March 2010. Pandemics are large-scale outbreaks of infectious disease with a significant impact on the morbidity and mortality over a wide geographic area[1]. Pakistan is a neighbor

to China, where the first cases infected with the Novel Coronavirus were reported. Following the first local case being identified in Pakistan in Feb 2020, thousands of people have tested positive for COVID-19 which highlights the magnitude of this public health issue.[2] While the initial focus has understandably been on the lifesaving and biomedical aspects, COVID-19 has rapidly established itself as an illness that negatively impacts the psychosocial health of all affected individuals.[3] Public health experts around the world are calling attention to the need to study the behavioural aspects during this pandemic, and the wide ranging psychosocial effects that can be expected to arise as a result of the public health response to the novel coronavirus outbreak.[4] Being an unprecedented and evolving public health crisis, the uncertainty surrounding the disease and treatment along with socially isolating and stigmatising community preventive measures may be some factors that cause distress to the affected cases and their families.[5] Recent studies have highlighted a variety of emotional responses in healthcare providers of COVID-19 cases; the initial fatigue, anxiety and fears gradually led the way towards growth under pressure.[6]

Limited work has been published so far focusing on the initial reactions and perception of various factors related to COVID-19 among the patients and their families who have survived this illness in Pakistan. Keeping this in mind, it appears intuitive to employ a qualitative approach to explore the direct perspectives of COVID-19 patients and their caregivers. We conceptualized our study to provide a valuable insight into the illness narratives of people faced with this novel disease, thus bringing to our attention the holistic impact of this COVID-19.

Methods

This is a cross sectional qualitative research using phenomenological approach with a constructivist paradigm. Institutional ethical review was taken from ethical review committee of Fauji Foundation Hospital, Rawalpindi on 14th May 2020 (Ref no. FFH/2020/Psy-3). An interview guide with probing questions based on literature review and expert opinion was formulated. The face validity of the protocol was carried out using committee approach of experts which included health care practitioners in the field. Pilot of the instrument was done, looking at the sequence and terminology used in the protocol. The questions were related to knowledge of COVID-19, sources of information, initial discovery of symptom and reaction, time spent in quarantine, physical, psychological, social health and the coping mechanisms. After explaining the objectives and scope of our study, verbal consent was taken from each participant before the interview; and the name or any other specific identifying information for each individual was not recorded on the interview sheet to guarantee anonymity and confidentiality. Non-probability maximum variation purposive sampling technique was employed to conduct telephonic interviews with 22 individuals, aged 20 years to 70 years, who had tested positive for COVID-19 on PCR test and recovered after minimum 2 weeks of isolation, along with their family members. We excluded cases who reported current or past history of psychiatric illness to avoid undue negative coloring of the patient accounts; we also did not include those cases who had severe cognitive impairment and could not engage fully in the interview.

The average duration of each interview was 30 to 45 minutes. Bracketing[7] was used as a method to avoid any bias due to any preconceptions. Data was collected till 'sufficiency'[8] whereby data gathered yielded sufficient understanding against emerging thematic categories. A master code sheet along with memo was shared among the research team members to account for inter-coder reliability. Thematic analysis[9] framework was concurrently used during data collection, management and analysis to become familiarized

Table 1: *Socio-demographics of Research Participants N=22*

Variable		Survivor n=12	Family Member n=10	Total Research Participants N= 22
Gender	Male	9	3	12
	Female	3	7	10
Marital Status	Unmarried	0	2	2
	Married	12	8	20
Residence	Rural	4	4	8
	Urban	8	6	14
Age	20-45	5	6	11
	46 and above	7	4	11
Educational Level	Undergraduates	5	3	8
	Graduation and above	7	7	14

with transcribed data and notes, develop initial codes (a-priori through literature review and in-vivo from the data) and generate overarching themes to explain large section of data. Manually, initial line by line coding was done followed by focused color coding emergent themes. An independent reviewer compared results for validity purposes.

Findings

Table 2: *Clinical characteristics of Research Participants (Survivors) n=12*

1	Symptomatic	**Yes**	**9**	**Moderate**	**3**
				Mild	3
				Severe	6
		No	3		
2	Co-morbid illness	Yes	5		
		No	7		
3	Place of isolation	Home	3		
		Hospital	9		

The study explored the health related beliefs of survivors and their family members, looking at their experiences during and after the disease. Five major data-driven themes that emerged were; Perceived Susceptibility, Knowledge and Experience with Precautionary Behaviors, Treatment seeking behavior: Perceived costs and benefits, Psycho-social dimensions of COVID-19, Barriers to Care. The themes along with their subthemes and selected verbatim are being presented in table 3.

Theme 1: Perceived susceptibility: The participants talked about fever, cough, and shortness of breath as some of the major symptoms of COVID-19, along with highlighting vulnerable groups like elderly or those with low immunity or co-morbidities. The modes of transmission were reported to be through droplet via cough or sneeze. Majority believed that it was a viral infection caused by new coronavirus, some suggesting how the origin may be traced to China.

Theme 2: Knowledge and Experience of Precautionary Behaviors: All participants acknowledged the significance of masks and in some cases gloves as a precaution for the disease, but majority shared the difficulty with the use of mask in public owing to its symbolism with lack of faith in religion, its connotation with sick people, breathing issues particularly in hot weather and also its ineffective usage. Along with practice of regular handwashing and the use of hand sanitizer, majority mentioned how they keep outside clothes and shoes separate or change clothes after coming from outside and wash them with Dettol water. Most participants shared their belief that a religious understanding of the pandemic in these testing times would protect people from the negative impact of this disease.

Theme 3: Treatment seeking behavior: Perceived costs and benefits: The test was reported to be painful or uncomfortable, and the waiting time of 2 days or sometimes more to receive the test result was stressful. The most frequently used home remedies included regular use of kalwanji, hot water and green tea, steam, haldi gargles with warm water, hot lemon water, multi vitamins, cough syrup, use of honey and neem pattay. Majority shared how currently there are no approved medicines for COVID and all treatment is on experimental basis only. With regards to vaccine, it was shared that it may take years and it may not be safe, accessible or affordable for us. Majority of the participants expressed their fear and mistrust for the hospitals especially corona wards, saying how they might be initially COVID-negative and could have actually caught the disease from the quarantine facility. They acknowledged that having someone from the medical field in the family facilitated testing, understanding the reports and treatment options. They appreciated how donning the heavy kits, doctors used to come for daily rounds. Majority of the participants shared their worry about other illnesses being ignored due to the targeted focus on corona cases in every hospital.

Theme 4: Psycho-Social dimensions to COVID-19: All the participants highlighted the element of guilt during and after disease, especially of making their family members worried or isolated; or bringing the infection home to them. Survivors who had severe symptoms talked about panic attacks and post traumatic flashbacks after recovery. Participants also shared how the uncertainty of this new disease was one of the most disturbing aspects. Where the survivors worried about the additional duties their family members were doing for them, the caregivers also discussed feeling overwhelmed with uncertainty and new responsibilities. The significance of religion and faith as a coping mechanism during quarantine period was highlighted by all participants, and most

mentioned the renewal of their faith as a new realization post recovery.

Theme 5: Barriers to Care: Some of the participants or their family members who were affiliated with health care professions expressed their dismay at how people appreciated the role of doctors and nurses particularly on media; however when it came to their personal contact with healthcare workers they criticized the profession for being source of infection spread in the community. They mentioned how media's negative portrayal along with uncertainty and disputes over government corona policies failed to provide relevant information and led to a rise in anxiety. All participants shared how the behavior of friends, family members, work colleagues or neighbors had changed towards them after coming out as COVID-19 positive. Few participants shared how they felt stigmatized by government policies where they had posted a caution on their gate of the house, banner on street and police guard outside the house.

Table 3:

Theme 1: Perceived Susceptibility		
	Sub-themes	Verbatim
a.	**Symptoms**	"…dry constant cough, fever and shortness of breath" "I got severe myalgia, couldn't lift arm, hard to get out of bed…body aches…" "…sore throat, difficulty breathing and especially loss of sense of smell and taste"
b.	**Risk Factors**	"Already sick people are at more risk…" "…elderly are at risk, more than 50 years of age…but children are said to be safe from virus…" "…people with high exposure and contact with patients, especially doctors who may have inadequate protective gear…" "…people with low immunity or diseases like diabetes, cancer and especially respiratory infections etc"
c.	**Causes/Origin**	"…viral infection…caused by a new form of coronavirus family…" "…new virus, maybe China has made it in its own labs " It is the same old flu but maybe they are testing it now…" "…new disease…it's a trial from Allah and we should rectify our deeds"
d.	**Modes of transmission**	"…spreads via droplets through coughing and sneezing…" "…sharing food and handshakes…"
Theme 2: Knowledge and Experience with Precautionary Behaviors		
a.	**Use of Masks**	"…use masks in public spaces but does not feel comfortable wearing them as people ask me if I am still sick, because they said masks are for people who have the disease" "…use masks, gloves…people use masks incorrectly, even doctors, where the nose is uncovered, exposed and there are chances of cross-contamination." "…when I wear mask, people say I am afraid of corona" "Masks are suffocating in this hot weather..."
b.	**Hygiene Practices**	"…change clothes after coming from outside, wash from dettol water….keep outside shoes and clothes separate…" "…regular handwashing and use of sanitizer, but also ablution 5 times a day cleanses you"
c.	**Social Distancing**	"…take food from store early in the morning to avoid crowd, do not allow friends and family to visit…" "there are some family pressures like attending funerals or wedding where one cannot stay away from family and relatives" "6 feet distancing from confirmed or suspected cases is possible….but there are asymptomatic cases also so distancing is actually needed from all in general…it is practically difficult".
d.	**Religiosity**	"We are Muslims, Allah will not put us in this hell… if *Momin* (true Muslim) has a weak faith, and then the devil keeps putting mistrust in him…If you have a strong faith in Allah then what is the need for these gloves and masks…"
Theme 3: Treatment seeking behavior: Perceived costs and benefits		
a.	**Experience with test**	"Nasal swab was so painful, it even hurt to blow nose for 2 days". "When my test was being done and they put a swab in my throat, I gagged so I think the test was not conducted well"
b.	**Complementary home remedies**	"…use *kalwanji*, green tea, *haldi* gargles with warm water," "… fruits and juices are important and a good diet also to build immunity" "…*sena makki* tea which you can easily get from a *pinsaar*" "If there's a virus in the body, drinking hot fluids will burn it...virus stays in throat for four days…so if you drink warm fluids it will not reach chest area"

c.	**Medical treatment**	" …no effective treatments, only experimental basis and symptomatic" "…no vaccine yet, may take more than a year…even then it will not be accessible or affordable for all of us." "use panadol or paracetamol for fever and cough syrup or antibiotics for throat…Doctors also give HCQ but it has side effects, it is heavy"
d.	**Mistrust for Quarantine facilities**	**"**I was symptom free initially, then after 'ward stay' for 2 days, I developed cough….I think I got infected from this corona ward" "There was a lock outside the ward….I was all the time fearful that the doctors or nurses mig ht give me wrong medicine and count me as a dead body….maybe the international NGOS give them funds which go into their pockets…we all patients here pray that we get free from this prison"
e.	**Interaction with health care practitioners**	"Nursing staff helped in feeding as I couldn't even hold spoon…upon discharge, hospital celebrated like I was hero but they are true heroes" "I got more fearful after seeing the PPE of doctors and nurses…it seemed as if they were some aliens or astronauts… when nursing staff used to come inside, they used to stay at a distance even with safety gear and their voices were inaudible due to heavy masks" "I am a former nurse so thought to get my brother tested for COVID as he was showing symptoms… brother couldn't gather courage to get report himself so I went on his behalf."
f.	**Less priority to other diseases:**	"…No one did my ECG although I was a heart patient…missed medicines also…have this complaint from doctors…they should also focus on other diseases along with corona…" "Everyday, millions of people die because of hunger then why are we only focusing on corona?..."
Theme 4: Psycho-social dimensions of COVID-19		
a.	**Guilt and fear**	"Only I go outside of home for office duty…so some guilt as wife had to manage grocery and care for son after I got unwell…sad that my wife is a housewife and she got this disease because of me" "Fear that I was wrongly counted as patients of a big disease "Even after negative test, I have health anxiety and keep monitoring symptoms, keep imagining worst case scenarios that tomorrow I will be in ICU undergoing intubation "I am confused about the changing stance over precautionary guidance and most agonizing pain was no effective vaccine or treatment being available "
b.	**Caregiver Burden**	"Decision to put on vent was hard…I faced extreme hopelessness…I was fearful how I will raise kids if something happens to wife…Uncertainty was worst…felt like family was ripped from my hands…I had insomnia, poor appetite. "One of my sister -in-laws who was staying at our home to help with new born baby and kids was tested and her own 9-month baby came out positive…felt guilty that they both also had to be isolated at hospital because of me"
c.	**Family quarantined**	"I haven't hugged my daughter and also restricted father from visiting me" "…only after 10th day, I opened my bedroom door and chatted with wife in lounge more than 10 feet away…asked wife to leave food outside door and knock…would wash my own dishes to avoid spread…had to lie to my son that I am out of city for some office work…it made me sad" "Our conversations were intentionally kept to topics other than COVID unless necessary…time seemed still…but religion helped…5 times prayers
d.	**Renewed spiritual connections:**	"Belief in God (*tawwakul*) got me through the worst days.. now I feel as if I have been given a new life … we should not take life for granted.. have inclined towards Allah (LAU laga li) as it gives relief"". "I now feel the pain of the patients…am more compassionate to others now especially patients"
Theme 5: Barriers to Care		
a.	**Health Care Workers: Dichotomy of Praise and Stigma**	"We are doing a high risk job…. neighbors avoided us even before we were COVID positive saying we go to the hospital so we can spread the infection.. they said that it is the downside of having doctors in the apartment building…Doctors don't need applause and songs, they need genuine appreciation and support as they take all the risk for well-being of others"
b.	**Media: dramatic and traumatic**	"I saw a ne ws item in which a funeral was being conducted with four people wearing PPE…Its everyone's worst nightmare to die alone…media projected the disease as very lethal" "There were many messages on social media about a doctor who had died of COVID… I kept having flashbacks of that image with my husbands' face over the deceased doctor's picture "
c.	**Stigma- Behavior of others:**	"When my COVID test came out positive, hospital instantly discharged me saying they don't have any facilities for corona patients…my husband and son had to physically lift me up and take me back home…doctors and staff didn't even come to my room…and informed me of discharge procedure on phone even though I was still in pain" "No one wanted to pair up with me for on -call duty, when I needed an imaging procedure, my appointment was scheduled close to midnight.. long after routine working hours.. reason being, they wanted me to avoid large group of people…and staff and seniors were hesitant to see me". "People on the street labelled our home as corona home" "I felt that workers (daily maids, guards, shopkeepers who would deliver groceries were very afraid that they will get infected even if we just look at them and they kept a very good distance from us and even our house."

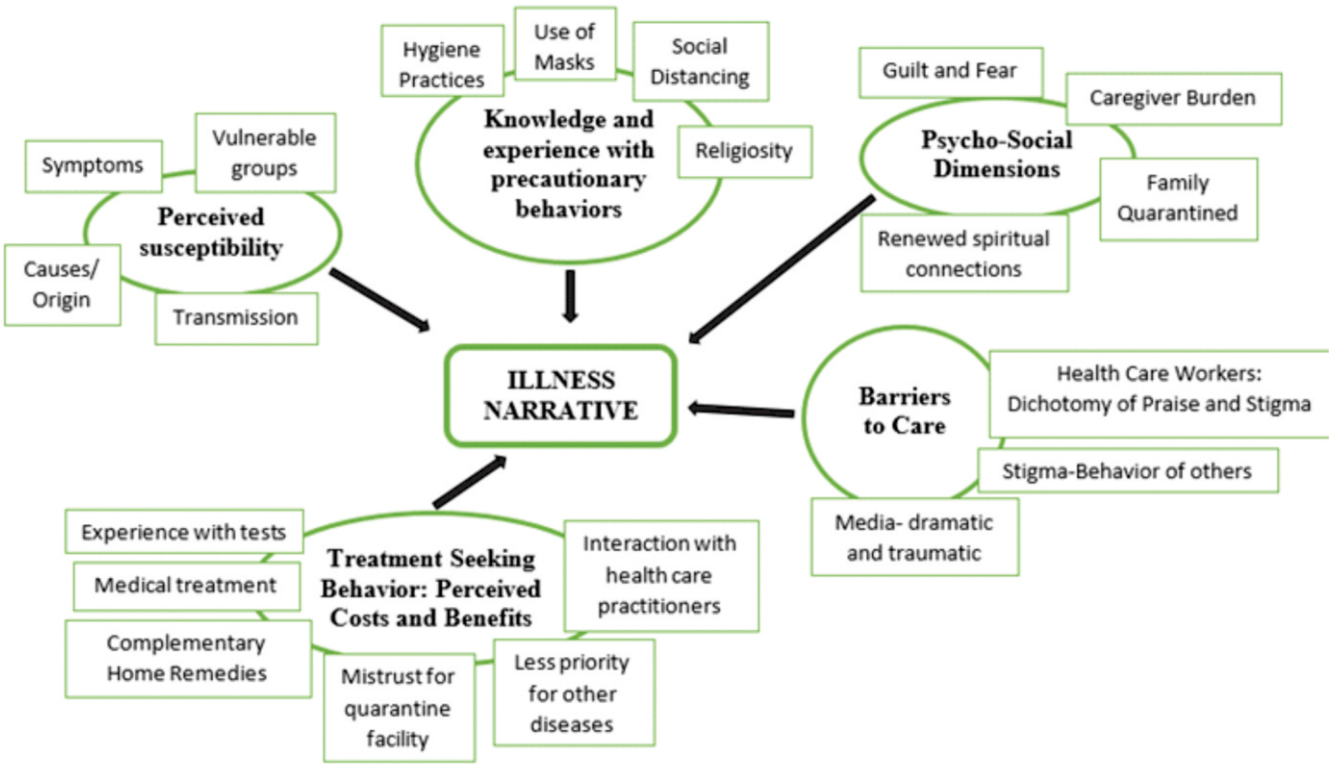

Figure 1: *Thematic Map of Illness Narrative of COVID-19 Survivors*

Discussion:

This study explored the illness narratives of COVID-19 survivors and their families. While most participants appeared to be aware of the general information about the disease as disseminated by the local health authorities, the majority of cases opted to focus on traditional home remedies as part of prophylactic or symptomatic treatment of COVID-19. This may be explained by our cultural context and limited formal healthcare resources, thus traditional health practices are expected to form a major part of the pathway to health care during pandemics.[10]

Common precautions reported in our study were the use of masks, hygiene practices and social distancing, these are consistent with the findings of another study on population affected by the Middle Eastern Respiratory virus (MERS) requiring community protective measures MERS.[11] Similar to other studies[12,13], our participants found it difficult to avoid close family members while practicing social distancing. Most were however able to limit their outings to essential trips for work or groceries, and there was a general disruption of community activities.

The majority of our participants reported the significant role of family support and their renewed spiritual connections as an integral component of effective stress coping. This matches the reports of a study on Ebola survivors who talked about the presence of a religious leader, gathering patients to pray and sing together, was perceived by respondents as very supportive during the time they were admitted inside the facility[14]. The family members in our study highlighted being overwhelmed with additional responsibilities along with concerns for their own and family's health. Similar results were stated in studies on caregivers of patients with MERS who talk about caregiver burden, feeling extreme physical fatigue, intense workload and psychological helplessness.[6]

Our study revealed a significant incongruence between the biomedical health system and the health belief model of the general public, as reflected in themes on mistrust of quarantine facilities and less priority given to other diseases. A research on history of past pandemics like cholera and plague talk about the "…fear of discrimination, mandatory quarantine and isolation" due to outbreaks which bring about issues of prejudice and intolerance and there arises need to gain public trust.[15] Similar to our results, a study on Ebola showed how participants described shifting perceptions of the healthcare system , sharing how "some HCWs were afraid to physically interact

with patients and distanced themselves to prevent possible infection"[13]. Studies acknowledge dichotomy of physician and patient perspective of disease and illness16 and show that there is social resistance to disease control efforts due to mistrust of governments[17]; this may be interpreted as a misunderstanding among community members with regards to infection prevention and control (IPC) measures taken by HCW and this "convergence of fear, avoidance and misunderstanding has been shown to contribute to community mistrust in healthcare systems".[18] A study on Ebola survivors stated that "… during the time of the pandemic , healthcare providers refused to provide Ebola survivors with care (especially those who disclose their status) because of the fear of being infected".[10] In concordance with our research findings, various studies on past epidemics like MERS and EBOLA have shown that even after full recovery, survivors and family members report experiencing rejection and avoidance by neighbors and colleagues[19] by health care workers[14] and also by community as reported by recent Iranian study on COVID-19.[5] As reported in our study, some patients' homes were labeled as "corona homes' by neighbours; similarly "Ebola survivor" used as a pejorative term has been reported earlier.[14]

Some of the COVID-19 positive cases in our study with co-morbid conditions like heart disease or pregnancy talked about limited access to health care facilities during the national focus on COVID-19 as the priority disorder. This is consistent with the findings of a study on patients with rheumatic diseases in early days of COVID-19 pandemic, who reported issues with access to health care, medicine, medical appointments being cancelled or switching to telephonic or video consultations.[12] Another study on knowledge of pregnant women surrounding Zika concluded that achieving high uptake and compliance with protective measures can be challenging.[20]

A prominent theme in our study was the uncertainty of life and health, traumatic fears and being distressed by imagining worst case scenarios and negative outcomes of illness. This was also reported by a Saudi Arabian study related to MERS 19 and a study on Ebola survivors talking about images of corpses as flashbacks.[14] Our survivors felt guilty for infecting family members, an Iranian study reports the same.[5] PTSD, as a longer term secondary effect of the pandemic, is also reported by scholars. [21,22,23,24]

Conclusion:

This study revealed the lived experiences of COVID-19 survivors and their family members, detailing their conceptualization with regards to disease vulnerability and associated precautionary behaviors. It mainly showed how survivors and family members navigate through biomedical systems, complementary healing practices, resilience and stigma.

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