

Original Article

Lived In Experiences of Covid-19 Survivors

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Abstract

Background: COVID-19 pandemic has emerged as a disaster for the human beings. Worldwide all the Governments, have been preparing to deal with this medical emergency, which is known to be associated with mortality in about 5% of the sufferers. Gradually, it is seen that, many patients with COVID-19 infection have mild symptoms or are asymptomatic. Due to the risk of infecting others, persons with COVID-19 infection are kept in isolation wards. this isolation made restricted access to health care workers and visitors, resulting in varied levels of positive and negative impact among the survivors.

Aims: To explore lived-in experiences of COVID-19 survivors.

Settings and Design: Covid-19 survivors who were home quarantined within the country and out side. A cross sectional phenomenological research approach

Methods and Material: For the study, a cross sectional phenomenological research approach was used. Selection of the samples was done by using Purposive sampling technique. Semi-structured interview was used to collect the data from 23 COVID-19 survivors who were admitted and home quarantined for COVID-19 treatment in different hospitals of the world from 5th July 2020 to 30th October 2020.

Statistical analysis used: Thematic analysis is used to analyze the data

Results: The lived-in experiences of COVID-19 survivor's are summarized under four themes. These were fear of family quarantine, family support, patient safety and financial burden versus Govt. scheme.

Conclusions: The study revealed new meanings and new experiences of survivors while sailing through the illness-wellness continuum and their efforts for resilience.

Keywords: Covid19 survivors, Lived in experiences, Patient safety, Quarantine.

Introduction

WHO declared the outbreak of a new corona-virus disease (COVID-19) is a Public Health Emergency of International Concern and in March 2020, it made the assessment that COVID-19 can be characterized as a pandemic.^{1,13} The COVID-19 pandemic has taught the entire human fraternity a big lesson, as it has affected millions of people across the world. Corona-virus disease is associated with a very

high rate of infectivity causing high level of fear and anxiety among people because of getting infected. Resultantly, the pandemic has led to severe restrictions on the free movements of human beings and the lockdown of almost all countries across the World. The literature on laboratory testing, preventive measures, management protocols to tackle a highly infective virus and data related to the mental health issues among front line warriors/ health care workers is well-documented but the real-life experiences of patients admitted in the COVID wards and their well-being in the COVID-19 era is largely neglected. There are few blogs/you tube videos of the recovered patients/ Corona survivors on their experience during their hospital stay, yet no descriptive data is available.² Consequently this study was undertaken to know the lived-in experiences of COVID-19 survivors.

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Conflict of Interest: None

Financial Aid: Nil

Vijayalakshmi and Radha. Lived In Experiences of Covid-19 Survivors.

Literature

We searched Google Scholar, Pub Med, and Science Direct for studies describing the Lived-in experiences of COVID-19 survivors, using the search terms "lived-in experiences of patients with COVID 19" or "experiences of patients with COVID 19" or "patients with COVID 19". We found several news paper articles on perception of patients and psychological experience of patients with covid-19. There were very few research articles on life-experiences of COVID-19 survivors.

A study was conducted to know the COVID-19-related discussions and experiences using tweets posted by Twitter. For the study analysed 4 million Twitter messages related to the COVID-19 pandemic using a list of 20 hashtags (eg, "coronavirus," "COVID-19," "quarantine") and identified 13 discussion topics and identifies 5 themes such as public health measures to reduce the spread of COVID-19, issues related to social stigma associated with COVID-19, media information related to COVID-19 cases, and deaths, COVID-19 in U.S and rest of the world.³

A qualitative design with phenomenological approach was conducted to explore the emic perspective of COVID-19 experiences of survivors and their family members. Interviews were conducted by using semi-structured questionnaire through Telephone with 22 individuals who 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. The study mainly showed how survivors and family members navigate through biomedical systems, complementary healing practices, resilience and stigma.⁴

Material and Methods

The design adopted for the study was Phenomenological research design. Obtained Ethical clearance from the Institutional ethics committee. Based on objectives of the study, literature review and expert opinion a semi-structured interview questionnaire was prepared on lived in experiences of COVID-19 survivors.⁵ The questions were related to initial discovery of symptom and reaction, time spent in quarantine, type of care received, and expenditure for the treatment. Ethical clearance was obtained from Institutional ethics committee.

Setting and Participants

Researchers referred the admission and discharge registers of a selected hospital and identified the survivors who were discharged without any complications. Twenty three participants were contacted through their mobile numbers obtained from discharge register and

recruited by using purposive sampling technique (whose PCR test showed negative and recovered from COVID-19). After explaining the purpose of our study, oral consent was obtained from the participants, then a telephonic interview was conducted which was lasted for 20 to 30 minutes with each participant. The interview was recorded on the interview sheet. Confidentiality was maintained by giving numbers to the participants.

Data analysis

Data analysis was done by content verification while reading line by line and paragraph by paragraph, looking for significant statements and codes according to the topics addressed.

The researcher used three levels of coding. In level one coding, researcher examined the data line by line and making codes which were taken from the language of the subjects. In level two coding, comparing of coded data with other data and creation of categories were done. In level three coding, the categories that seem to cluster together were formed as themes. Then the documents were submitted to two assessors for validation. This action provided an opportunity to determine the reliability of the coding.

Results

I. Socio-demographic data of COVID survivors

With regard to socio-demographic data of COVID survivors, it was observed that majority (48%) were in the age group of 45 to 55 years, most (52%) of them were males, majority (61%) were graduates and most (74%) of the survivors from India and the same is presented in table-1.

Table-1: Socio-demographic data of COVID-19 survivors. n=23

Variables	Percentage
Age	
26-35 years	18
36-45 years	17
45-55 years	48
56-65 years	17
Gender	
Males	52
Females	48
Qualification	
Professional	22
Graduate	61
Intermediate/diploma	09
Middle school	04
Primary school	04
Place of working	
India	74
Abroad	26

II. Lived in experiences of COVID-19 Survivors

From the analysis, four themes were identified. They are fear of transmission of infection and quarantine, family support, patient safety and financial burden versus Govt. Scheme.

1. Fear of transmission of infection and quarantine

Isolation and quarantine are key measures to prevent and control COVID pandemic. The findings of this study revealed that, almost all (100%) COVID survivors expressed that they were in shock, when they were diagnosed as COVID positive followed by guilt that they would have transmitted infection to the family members and whole family requires treatment and quarantine.

A. One survivor expressed that

"Soon after I was confirmed with COVID positive, I was shocked and worried about my small child and old parents at home."

B. Another survivor expressed that

The time my husband was diagnosed as COVID positive, as a primary contact I was helpless and started crying what can I do? Where can I go? To quarantine until my COVID result is out.

2. Family support

Family support is the support given by its members when any member/members of the family, are disabled.⁶

In the present study all survivors (100%) expressed that their family members were more worried on survivor's health condition as well as prognosis. Further they were also expressed that family members and friends were more supportive than the neighbours.

A. One survivor expressed that

Soon after knowing that I am positive my family supported me with strength, my friends ring me to give strength and my neighbours treated my family as untouchable.

B. Another survivor expressed that

Soon after diagnosing all our family as COVID positive, the treatment we got by public is like mental torture. Neighbours called municipality to place barricade around my house, instructed milk and vegetable vendors not to vend, municipality people insisting us to give photos.

3. Patient safety

Patient safety is a reduction of unnecessary harm associated with health care. In the present study, majority (91%) of survivors said that they were satisfied with the care received in the hospital as health care professionals treated them

as human beings when everybody were looking at them as untouchables. Few (09%) survivors expressed that, they found unsafe practice in the health care setting.⁷

A. One survivor expressed that

As a COVID patient, I was more fearful and anxious about my health but Doctors and nurses come daily once and later they never turn up.

B. Another survivor expressed that

When I was taking treatment in government hospital, my saturation level came down and I was referred to Private hospital where I used to get IV injection daily by unskilled health care personnel which was very painful and those 14 days I have seen a real hell.

4. Financial burden Versus Govt. Scheme

Health is wealth. Quality care matters more than money. In the present study survivors who opted better care chosen private health care centers. Few have spent lakhs on treatment. Around 26 % people taken treatment with free of cost, 9 % survivors taken treatment under government scheme but even paid amount for medicine which was not available in the beginning and 26 % survivors (abroad), treatment were taken care by employed institution.⁸

A. One survivor expressed that

When I was admitted at government hospital, there was no supply of Inj. Remdesivir, so I purchased and taken treatment. The cost of it for my full treatment was around Rs.60,000/-.

B. Another Survivor Said That

I got free treatment in government hospital with scheme where as in private hospital the bed charges itself costed Rs.2500/day.

Discussion

Study findings revealed that, with regard to socio-demographic data, majority (48%) were in the age group of 45 to 55 years, most (52%) of them were males and majority (61%) were graduates. With regard to lived-in experiences, most of them expressed fear and guilt of transmission of disease to their family members. Throughout their hospital stay, patients experienced a lot of fear and anxiety regarding the possibility of transmitting the disease and harming family members and others, to the extent that they were even scared to talk to their family members.^{9,10} Almost all participants have reported that family and friends were very supportive which led to a reduction in their distress and anxiety.¹

Furthermore the participants have experienced negative views and sympathy of neighbours which made them to feel isolated and rejected.^{10,11} Most of them were satisfied with the services received in the hospital but they were not satisfied with health care professionals as they were not frequently visited them. Further they also expressed that when they were experiencing fear and anxiety empathetic conversation in the form of awareness and counselling could have smoothened their problem during their isolation and quarantine period which was not found in the hospital setting. Similar findings were found in the studies on narrative experiences of COVID 19 survivors and experiences of COVID 19 survivors and their caregivers.^{4,5,12,13} Only few have expressed financial burden in order to get quality treatment and care in private sector, in spite of Government providing free treatment where they were not satisfied with the facilities.

Limitation

- The physical difficulties during and post COVID were not included in the study.
- Only fear, safety and support were addressed in the study.

Conclusion

This study revealed the lived in experiences of COVID-19 survivors detailing their experiences regarding their fear of transmitting the disease to the family members, psychological support received from the family members and rejections from others and quality of care they received and financial impact of the disease. It mainly showed how survivors struggled to sail through the illness-wellness continuum and their efforts for resilience. Understanding these aspects may be helpful in planning and implementing appropriate health care services to the COVID 19 patients.

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