Introduction

World Health organization (WHO) declared COVID-19 pandemic on 11th March 2020. By this time COVID-19 was reported in 114 countries with 4292 deaths all over the world.\(^1\) Since the appearance of first case of COVID-19 on 30th Dec 2019 in Wuhan, China, over 28 million cases and 9 lakh deaths have been reported globally.\(^2\) With these figures in the background for last 6 months, still the medical community worldwide is struggling to complete the natural history of disease of COVID-19, its clinical course, treatment and vaccination.

India reported its first confirmed case on 30th January, 2020 in Kerala and first death due to COVID-19 in a patient with positive travel history on 13th March 2020 in Karnataka.\(^3\) Over 51 lakhs cases and 83,000 deaths have been reported in India.\(^4\) In terms of morbidity and mortality, the course of epidemic is showing.

ABSTRACT

Context: The spread of COVID-19 pandemic poses a great challenge to health care organizations and unprecedented need for information. This study aims to identify possible factors causing delay and losing precious time during diagnosis and treatment of COVID-19 at home and health facility level. It also aims to highlight perceptions and experiences of family members of deceased regarding diagnosis and treatment of COVID-19 infection in hospital. Methods: A retrospective study was done to review COVID-19 deaths from 18th March to 5th June 2020 in Punjab, India. A total of 48 laboratory confirmed (RT-PCR) COVID-19 deaths were reported during this period. Socio demographic profile, sequence of events including clinical symptoms, medical aid taken, time of confirmation of diagnosis and treatment before death were noted from the records on a predesigned proforma. Family members of deceased were also interviewed and asked open-ended questions regarding their experiences at various health facilities. Descriptive statistics was presented in percentages, mean, and median. \(^{Results:}\) Mean age of subjects was 56.3 ± 18.3 years. Majority (82.2%) had three or more than three comorbidities. Median time from appearance of first symptom to first medical contact and confirmation of diagnosis was 1 and 5 days, respectively. On the basis of interview with deceased’s relative, various themes like delay in diagnosis and treatment, dissatisfied with hospital system and lack of communication between relative and patient were generated. \(^{Conclusion:}\) Presence of comorbidities was the most important risk factor. Health seeking behavior of patients immediately after appearance of symptoms was found to be satisfactory.

Keywords: COVID-19, deaths, delay, experiences of relatives
variation not only in India in comparison to the rest of the world but also in different states within India. Mortality in COVID-19 is affected by demography of the population and efficiency of health care in dealing with the epidemic.

A lot of efforts are going on worldwide to reduce morbidity and mortality due to COVID-19 by various preventive strategies and treatment options. With limited knowledge available regarding COVID-19 infection, understanding the determinants, delays in treatment seeking, diagnosis and disease management can help us to decrease mortality. This can be done by analysing deaths due to COVID-19. Punjab reported 2461 COVID-19 positive cases with 48 deaths till 5th June, 2020.[5] Therefore, this retrospective study was done in state of Punjab to identify possible factors causing delay and losing precious time during diagnosis and treatment of COVID-19 at home and at health facility level. Knowledge of these factors can help in preventing deaths due to COVID-19. Besides the visible damage, this pandemic is silently causing a lot of mental stress to health care providers, COVID-19 infected patients and their relatives. It is the need of the hour to address these mental stress-related problems in different strata of society. Qualitative studies enable us to get an insight into experiences of those who suffer during this pandemic in some or other way. Few qualitative studies have been published on the experiences of health care providers and general public during COVID-19 crisis.[6] None of the published qualitative studies to our knowledge have tried to get insight into experiences of family members of deceased because of COVID-19 infection. Thus, this study also aims to highlight perceptions and experiences of family members of deceased regarding diagnosis and treatment of COVID-19 infection in hospital.

**Methodology**

A retrospective study was done to review COVID-19 deaths from 18th March to 5th June 2020 in the state of Punjab, India. A total of 48 laboratory confirmed (RT-PCR) COVID-19 deaths were reported during the study period. Medical Records of deceased subjects were obtained with prior permission of Directorate Health Services (DHS), Punjab. Out of 48 deceased subjects, 3 cases were excluded because of incomplete records. Socio demographic profile, sequence of events including clinical symptoms, medical aid taken, time of confirmation of diagnosis and treatment before death were noted from the records on a predesigned proforma. Out of 45 listed deceased relatives, 42 could be interviewed as three could not be contacted because of incorrect phone number or refusal to talk on the issue [Flow chart 1]. Verbal consent was taken before commencement of interview, followed by informing them about the purpose of the interview.

Investigators interviewed the participants on a semi structured format focussing on sequence of events on appearance of symptoms, first medical contact, visits to various hospitals thereafter, availability of ambulance followed by collection of samples and diagnosis of COVID infection. They were also asked about their experiences, at various health facilities, regarding care and treatment given. Open ended questions such as “What were the initial symptoms and how it progressed”, “Were there any delays in seeking treatment”, “Were there any delays in arranging transport”, “Were there any delays at health facility level leading to death”, “What according to you could have been done to avert the corona deaths” were asked.

Mixed methods approach was used for analysis of the data. A mixed methods study comprises of research involving systematic integration/mixing of quantitative and qualitative data in a single investigation.[7] Due approval was taken from Institutional Ethics Committee, Dayanand Medical College and Hospital, Ludhiana wide IEC No. 2020-517. Data were compiled and results were analysed by using Epi Info TM 7 and Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.) Descriptive statistics was presented in percentages, mean plus standard deviation and median with inter quadrantile range.

**Results**

Out of total of 45 deceased subjects, about one third were in 40–60 and 60–80 years of age group, respectively. Mean age of subjects was 56.3 ± 18.3 years with range of 2.5 months to 91 years. Majority were males (73.3%). There were 46.7% of subjects who had hypertension followed by diabetes mellitus (40%), renal disease (20%) and heart disease (11.1%) as co-morbidities. Immunocompromised status (TB/HIV/ Malignancy) was found in 8.8% of subjects. Majority of the subjects (82.2%) had three or more than three comorbidities. Only 15.6% subjects had contact with confirmed case of COVID-19 and status was unknown in 42.2% subjects. There were 4 subjects who had history of International/National travel [Table 1]. Most of the deaths occurred at Medical Colleges (60%), followed by District Hospital (22.2%) and Private hospital (15.6%). Only one death occurred on way to tertiary care hospital. First death was reported on 18th March and maximum deaths (85.2%) occurred in month of April and May.

On further analysis, it was observed that median time from symptom onset to the first medical facility visited was 1 (0.5–2.75) days. Median time from appearance of first symptom to the sample taken and confirmation of diagnosis was 4 (1.25–7) days and 5 (3–8.75) days, respectively. Time interval between the sample sent and confirmation of diagnosis was within one day in majority (73.3%) of the subjects. Confirmation of diagnosis after first medical contact was done within 3 days in nearly 55% of subjects. Mean time between onset of first symptom to death was 8.1 ± 5.4 days [Table 2]. Mean duration of hospital stay was 4.9 ± 3.1 days. Majority of relatives of the deceased (76.2%) were of the view that there was no delay at home on their part for treatment seeking. However, 41% of the relatives complained about problems and delays at the facility level [Table 3].

Following themes were generated on the basis of interviews done with deceased relatives [Table 4].
This retrospective study was done to identify the factors associated with COVID-19 deaths and to identify key gap areas for prevention of mortality. The present study is probably the first attempt to highlight the experiences and perceptions of relatives of deceased regarding COVID-19 death. Punjab reported Case Fatality rate of 1.9% as compared to national average of 2.8%. [5,8]

The present study identified age, gender and comorbidity as the most important risk factors for COVID-19 deaths. Vulnerability with respect to age was not only found to be high in 60 to 80 years age group but also in 40–60 years age group. It was also observed that comorbidities were more prevalent in the same age groups (40–80 years). Similar findings were reported by Mumbai Metropolitan Region death audit report, which revealed maximum deaths in the 41–60 years age group (50.4%). [9] However, Li et al. in a retrospective review of COVID-19 deaths in Wuhan, China observed that the median age of deceased was 73 years. [10] In the United States, older patients (aged ≥ 65 years) accounted for 80% of deaths. [11] This may be due to different demographic profile of these populations. COVID-19 infection has predilection to serious patients and this study observed that the median age of deceased was 73 years. [10, 12] In a retrospective review of COVID-19 deaths in Wuhan, China [13], the median age of deceased was observed to be 73 years. In the United States, [10] older patients (aged ≥ 65 years) accounted for 80% of deaths. [11] This may be due to different demographic profile of these populations. COVID-19 infection has predilection to serious patients and this study observed that the median age of deceased was 73 years. [10, 12]

Discussion

This study attempted to highlight the experiences and perceptions of relatives of deceased regarding COVID-19 death.
The present study revealed that hypertension and diabetes mellitus were the most common comorbidities. Similar observations were reported within and outside India, wherein the most common comorbidity was hypertension followed by diabetes. Presence of other comorbidities such as chronic kidney disease and immune-suppressive diseases were also found to increase vulnerability to COVID-19 infection and deaths. Evidences also indicate that those with chronic kidney disease had an increased risk of infection. Awareness and sensitization of health care providers regarding these risk factors can help in efficient management of COVID-19 positive patients in hospital and therefore in prevention of mortality. Role of Primary Care Physician is the most important in this context in identification of high risk and vulnerable patients with comorbidities. Timely diagnosis and treatment will further reduce hospitalization and mortality. In current study 84.4% of subjects had no contact history with confirmed case and 91% of subjects had no travel history. Similarly, 84% deceased had no travel history or no known contact history as observed in a report.

In present study, the patients reported to health facility within one to two days after becoming symptomatic as compared to 2.8 days reported by Tian et al. in Beijing, China. The reason for less time taken for seeking treatment can be attributed to increase sensitization of people regarding COVID-19 by that point of time in India. Confirmation of diagnosis is most important milestone for isolation and treatment of patient. In present study, it took 4.6 days to confirm the diagnosis since first medical contact and mean time period increased proportionately with increase in number of health facilities visited by the patients (p = 0.09). Therefore, it took longer to confirm the diagnosis from first medical contact due to multiple visits or referrals of patients. Mean duration from 1st medical contact to sample taken in month of March, April and May was 3.8, 4.5 and 2.5 days respectively. Time duration decreased in month of May due to increase in testing facilities. However, report could be obtained within 1.3 days of sample sent as the authorized labs were available at Medical College and district level only. Hence, confirmation of diagnosis could be done within one day of sample sent.

In the present study, median time between onset of first symptom to death was 8 (4-11.5) days. Li et al. reported median course of the disease as nine days. However, Brihanmumbai Municipal Corporation (BMC) report found that average time between the onset of COVID-19 symptoms in a person and death was 6.4 days. Majority of deaths occurred at Medical Colleges (60%) followed by District Hospital. One death was reported on the way to tertiary care hospital before getting test report of COVID-19.

On interviewing deceased relatives, the description of their experiences ranged from disbelief to acceptance of death of their relative. It also highlighted their difficulties in reaching health facilities and getting diagnosis and treatment for COVID-19 infection. Finally, they also described an unforeseen consequence of isolation of patients in form of lack of communication between them, patient and health care providers. The overwhelming conditions due to COVID-19 pandemic prevalent globally provided much needed time for preparation before their actual arrival in India in form of prior sensitization of health care providers and general public. However, there were many preparations and conditions which were unforeseen and their management evolved eventually with time. Besides the visible damage, this pandemic is silently causing a lot of mental stress to health care providers, COVID-19 infected patients and their relatives.

Relatives of deceased could not accept the fact that their patient died because of COVID infection because majority of family members (87.1%) were found to be negative on subsequent testing. In 6.6% of cases, they could not get the report and therefore, could not believe on the results. Many (20.9%) complained regarding delay in diagnosis and treatment. During month of March and April delay in sending sample and getting report was observed due to lack of suspicion on atypical presentation of cases on part of health care providers.

Few of relatives (9.36%) suspected that their relative got infected in hospital itself as their patient never had any symptoms of COVID infection before getting admitted to hospital and 23.2% were not satisfied with care given in isolation ward of the hospital. They complained about few visits of doctor and nurses to the patient, as they expected multiple visits. However, as the situation gradually improved in health facilities with better understanding of the disease, increasing availability of labs for diagnosis and increasing availability of full personal protective equipment's (PPE) kits, the complaints of relatives regarding this issue decreased over time in late April and May. One fifth of relatives of the deceased expressed their satisfaction on...
treatment and care given in hospital. Few relatives complained about nil communication with doctor and health care workers. They also complained about lack of communication with patient while admitted in isolation ward. Relatives could not see and talk to their patient admitted in isolation ward except for few who could contact their patient with their mobile phones. Nicoti et al. in their study also documented similar observations regarding communications of patients with their loved ones via mobile phones or electronic tablets and recommended that physicians and nurses who are overwhelmed by the emergency can provide support to patients to maintain humanity at the end of life. In current study, relatives regretted not getting a glimpse of their deceased family member when their loved one was struggling to survive from the infection. Few of relatives (11.6%), refused to discuss this matter on the pretext that there was no reason to talk as they lost their relative. As the pandemic is evolving over time this study gives an early experience of COVID-19 deaths in state of Punjab. The results can guide us towards further improving the health services in treatment of COVID-19 patients and prevention of mortality. However, the results cannot be extrapolated among general population and further research is needed according to the current state of epidemic.

Conclusion

This study highlights age, gender, and comorbidities as important factors contributing to COVID19 mortality. Analysis of timeliness matrix reveals satisfactory treatment seeking behavior. However, some delay was observed in diagnosis and initiation of treatment at tertiary level. Therefore, present study underscores need for prior identification of risk factors, early diagnosis and initiation of treatment at primary level. Based on experiences of relatives of deceased subjects, it was observed that they undergo a lot of emotional stress. Therefore, it is recommended that sensitization of relatives should be done on admission of patient in isolation ward at tertiary level.

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Conflicts of interest

There are no conflicts of interest.

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