Original Article

Why Some Patients Died at Home Due to COVID-19 in a Rural, Tribal Area of India?

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Abstract

Introduction: We conducted this study to understand the proportion of deaths that occurred at home and the factors associated with home deaths in a tribal rural area of Gujarat, India. **Materials and Methods:** We collected a list of all deaths that occurred during the study period from local authorities and triangulated the data. Data collectors (DCs) visited the houses of the deceased person and interviewed the relatives as well as local health-care providers. The DCs categorized each death as COVID-19 or non-COVID-19 death based on the World Health Organization standard definition. For each COVID-19 death, we filled pretested questionnaire (local language) to know the care-seeking behavior of deceased persons. Subsequently, we conducted in-depth interviews of relatives whose family members died of COVID-19 at home (or within 48 hr of admission to a health-care facility) to find reasons for not seeking care at a health-care facility. **Results:** The risk of home deaths was high among the scheduled tribe population, laborers, below poverty line cardholders, those who did not seek care from private practitioners, those who did not test for COVID-19, those who did not seek care from qualified care providers, and those seeking care to nonqualified care providers. Shortage of health-care facilities, cost of care, and stigma/fear of hospitals were the major factors associated with the care-seeking behavior of patients. **Conclusion:** The unavailability of critical care, testing facilities, lack of knowledge, high cost of care, and lack of trust in hospitals were the major causes of home deaths among COVID-19 patients.

Keywords: COVID-19, death, tribal area

Introduction

Early in December 2019, an unknown acute respiratory disease, now called COVID-19, appeared in Wuhan City, Hubei Province, China. A new coronavirus has been named severe acute respiratory syndrome coronavirus 2 and the World Health Organization (WHO) has defined this pneumonia as a global pandemic.[1] COVID-19 surge occurred in urban areas in the first half of the year 2020.[2] Although after July–August 2020, COVID-19 cases started appearing in rural areas of India,[3] the caseload was higher in rural areas as compared to urban areas for the year 2021.[4] Another side, there is a surge in unreported deaths in rural India.[5] In addition, there is a high possibility of the COVID-19 pandemic continuing as endemic.[6] We conducted a study to understand the proportion of deaths that occurred at home and factors associated with home deaths in a tribal rural area of Gujarat, India.

Material and Methods

Objective

Among COVID-19-related deaths in the tribal area of Gujarat, we want

1. Out of all COVID-19-related deaths, the proportion of deaths occurred at home
2. Reasons for patients not seeking care at a health-care facility.

Study design

The study design of the study was a cross-section mixed-method study.

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Study area and population

This study was conducted by a voluntary organization, SEWA Rural, situated in the tribal, rural town of Jhagadia of the Bharuch district situated in Gujarat, India. We included all COVID-19 suspected and confirmed deaths from 21 villages (population of 36,850) within 15 km of Jhagadia town, and that occurred between January 1, 2021, and June 30, 2021, during the second COVID-19 wave.

Data collection

We collected a list of all deaths that occurred during the study period from local community health workers, key informants, block administrative offices, and panchayats. We triangulated data so that we do not miss any deaths.

Data collectors (DCs) visited the houses of the deceased person and interviewed the relatives as well as local health-care providers. The DCs categorized each death as COVID-19 or non-COVID-19 death based on WHO standard definitions.[7] For each COVID-19 death, we filled out a pretested questionnaire (local language) to know the care-seeking behavior of deceased persons. Subsequently, we conducted a few in-depth interviews of relatives whose family members died of COVID-19 at home (or within 48 h of admission to a health-care facility) to find reasons for not seeking care at a health-care facility.

Data analysis

We analyzed quantitative data using SPSS 20 (IBM, Chicago, IL, USA). We used the Chi-square test and Student's *t*-test for categorical and continuous variables, respectively, to find the difference between various groups. Qualitative data were analyzed using weft QDA software. Thematic analysis was performed.

Ethical consideration

Ethical approval was taken from the SEWA Rural institutional ethical committee. Written consent was taken before interviewing the participants.

Results

As shown in Figure 1, out of the total of 409 deaths, 136 people died due to COVID-19 during the study period. Out of 136 deaths, 58 died at home, on the way, or within 48 h of admission at the health-care facility. Among all deaths, a total of 92 (68%) were male and 100 (74%) were more than 45 years old. A total of 22 (16%) were illiterate, 93 (68.4%) were labor workers, 44 (32%) people were scheduled tribe, 68 (50%) were below poverty line (BPL), 59 (43%) had comorbidity, and 17 (13%) received at least one dose of COVID-19 vaccine. Among them, fever, cough, breathlessness, tiredness, and body aches were common symptoms. The average duration of death from symptoms appearance was 12.2 days.

The risk of home death among laborers, ST population, and BPL cardholders was 2.1 (confidence interval, *P* value) (1.004–4.7, 0.035) times, 3.1 (1.5–6.6, 0.002) times, and 3.4 (1.7–7.1, <0.001) times higher than salaried/farmers, non-ST population and non-BPL cardholders, respectively [Table 1].

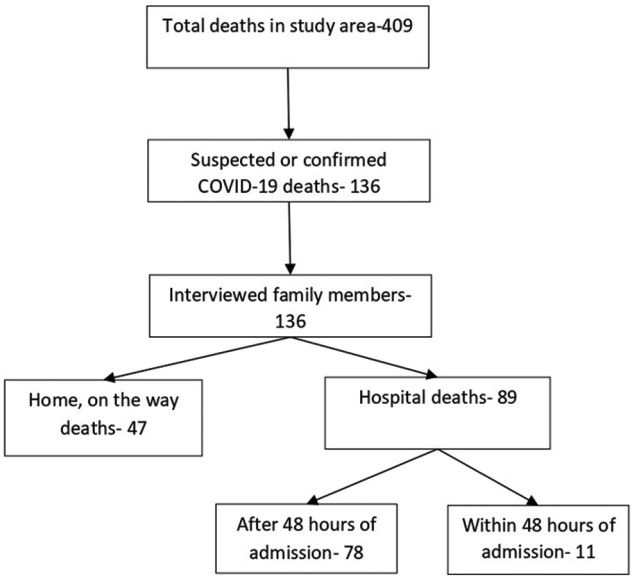

Figure 1: Flow chart of the study

The risk of home death among those who have tested for COVID-19 and sought care from private practitioners was 0.03 (0.007–0.135, <0.001) times and 0.25 (0.1–0.6, 0.001) times lower than those who have not tested and those who did not seek care to private practitioners. The risk of death among those who sought care from qualified care providers was significantly ($P = 0.005$) low compared to those who did not seek care from qualified care providers. Those who sought care from nonqualified caregivers have a 5.9 (1.5–22.0; 0.005) times higher risk of home deaths compared to those who did not seek care from nonqualified caregivers [Table 1].

Qualitative

Following are the key themes that played an important role in the typical care-seeking behavior of the study population for COVID-19.

Shortage of health-care facility

The relatives mentioned the shortage of COVID-19 care facilities, including hospital beds, oxygen, and COVID-19 testing in rural areas as an important reason for not seeking care at a health-care facility. "Testing facility was less, No beds available in hospitals, in a nearby city, government and private, we went all places. No beds, lastly, my wife's oxygen level was down from 80 to 20. Oxygen was also not available. I spent Rs. 40,000–60,000 to get oxygen. She died at home and I was helpless."

High cost of care

COVID-19 cost of care was high in private sector facilities and was out of reach for the rural tribal people. "We spent Rs. 35,000/day for the care at a private hospital. On the last day, they took Rs. 100 thousand from us. We are under debt of Rs. 400–500 thousand. We don't have any insurance card."

Table 1: Risk of home deaths according to sociodemographic and care-seeking behavior among COVID-19 deaths in the tribal area of western India 2021 (*n*=136)

	Total deaths (%)	Death at home£, *n* (proportion %)	Death at hospital£, *n* (proportion %)	OR (95% CI)	*P*
Gender					
Male	92 (67.6)	41 (44.6)	51 (55.4)	1	0.32
Female	44 (32.4)	17 (38.6)	27 (61.4)	0.8 (0.4–1.6)	
Age (years)					
0–44	36 (26.5)	18 (50.0)	18 (50.0)	1	0.199
45 and above	100 (73.5)	40 (40.0)	60 (60.0)	0.7 (0.3–1.4)	
Education					
Literate	114 (83.8)	46 (40.4)	68 (59.6)	1	0.159
Illiterate	22 (16.2)	12 (54.5)	10 (45.5)	1.7 (0.7–4.4)	
Occupation					
Job/farming	43 (31.6)	13 (30.2)	30 (69.8)	1	0.035
Not working/labor work	93 (68.4)	45 (48.4)	48 (51.4)	2.1 (1.004–4.7)	
Caste					
Scheduled tribe	44 (32.4)	27 (61.4)	17 (38.6)	3.1 (1.5–6.6)	0.002
Other	92 (67.6)	61 (66.3)	31 (33.7)	1	
BPL card					
Yes	68 (50.0)	39 (57.4)	29 (42.6)	3.4 (1.7–7.1)	<0.001
No	68 (50.0)	19 (27.9)	49 (72.1)	1	
Comorbidities					
Yes	59 (43.4)	27 (45.8)	32 (54.2)	1.3 (0.6–2.5)	0.320
No	77 (56.6)	31 (40.8)	46 (59.1)	1	
COVID-19 test*					
Yes	107 (78.7)	31 (29)	76 (71)	0.03 (0.007–0.135)	<0.001
No	29 (21.3)	27 (93)	2 (6.9)	1	
Sought care					
Yes	130 (95.6)	52 (40)	78 (60)	-	0.005
No	6 (4.4)	6 (100)	0	-	
Sought care from government					
Yes	58 (42.6)	25 (43.1)	33 (56.9)	1.03 (0.5–2.1)	1.0
No	78 (57.4)	33 (42.3)	45 (57.7)	1	
Sought care from private					
Yes	102 (75.0)	35 (34.4)	67 (65.7)	0.25 (0.1–0.6)	0.001
No	34 (25.0)	23 (67.6)	11 (32.4)	1	
Sought care from nonqualified					
Yes	14 (10.3)	11 (78.6)	3 (21.4)	5.9 (1.5–22.0)	0.005
No	122 (89.7)	47 (38.5)	75 (61.5)	1	

£Home deaths: Home deaths + on the way deaths + deaths at the hospital within 2 days of hospitalizations, Hospital deaths: Hospital deaths in which patient death occurred within 48 h of hospitalizations, *COVID-19 test - Either rapid or RT-PCR COVID-19 test or CT-scan. OR: Odds ratio, CI: Confidence interval, CT: Computed tomography, RT-PCR: Reverse transcription–polymerase chain reaction, BPL: Below poverty line

Stigma/fear of hospital

There was a fearful atmosphere everywhere. The families of COVID-19 patients were stigmatized. Due to news regarding the increasing number of deaths and lines in mortuaries in media, people were frightened and so due to a lack of trust in health facilities and uncertainty of outcome, people consulted multiple doctors.

"Mr. X, a factory worker, had a fever, but due to fear of coronavirus, he did not go to the hospital. His wife said that we sought care from three private clinics and three faith healers but no relief in breathing difficulties and severe headaches. From his factory, people suggested getting admitted to the hospital due to his worsened condition. However, he was frightened as his nephew died in a civil hospital, and from the hospital, the dead body was not given. He also thought if he went to the civil hospital he might not come back, so he had chosen to be at home and died at home."

A private practitioner in a rural area mentioned, "there was a fearful atmosphere everywhere. We supported patients despite putting ourselves in danger, but we are happy that we could help people."

Doctors shared that "we remained away from our families

for many days, worked for long hours and were available for patients." "It was good that when vaccination started government prioritized health staff, it was a very crucial step."

Discussion

There was a significant proportion of COVID-19 deaths that occurred at home, although most of the patients sought care from doctors in the private and public sectors. Patients from the tribal communities, poor families, and those who did not get tested were more likely to die at home. Local and private practitioners were the most frequent resource of care provision. The shortage of inpatient health-care facilities, high cost of care, and fear of hospitals were commonly reported reasons for not seeking care at a health-care facility.

Relatives could not see, and talk with admitted patients at hospitals, which led to dissatisfaction with the hospital system and decreased trust in hospitals. In addition, health workers have expressed their struggles, including working in a fearful environment, lacking personal protective instruments, and working for long hours. Punjab study also supports the role of primary care providers was crucial to identifying risk and timely referral although they found communication gaps between health-care providers and relatives of COVID-19 patients.[8] The health system needs to protect doctors and frontline workers with adequate provision of appropriate personal protection equipment.[9] There was a delay in the test results of COVID-19 in government and private laboratories due to the high load of cases and limited resources. Philippines study also highlights in difficulty in diagnosing COVID-19.[10]

Primary care-level screening, triaging, referral, emergency care of COVID-19 patients, and availability of beds, oxygen, and drugs in the backdrop of the current clinical understanding of the pandemic were very crucial. Laboratory capacity for testing, health-seeking behaviors, and testing strategies was inadequate and not accessible to the rural poor.[11] People dying at home, on the way, or immediately after admission to the hospital possible reasons could be a lack of timely access to health-care facilities, delayed seeking care, or an overwhelming health system with a sudden surge of cases.[12]

This might be the first study from India that presents the issues at the ground level among COVID-19 deaths among the ST population. We included only deaths, so we do not have information about who survived either at hospital facilities or at home. This might be a limitation of the study.

Conclusion

The unavailability of critical care, testing facilities, lack of knowledge, high cost of care, and lack of trust in hospitals were the major causes of home deaths among COVID-19 patients.

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Conflicts of interest

There are no conflicts of interest.

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