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COVID-19 deaths at home in south of Iran: A cross-sectional study

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ABSTRACT

Objective: To determine the causes of COVID-19 deaths at home.

Methods: This descriptive cross-sectional study was conducted on confirmed COVID-19 deaths, which were confirmed to occur at home using the “Electronic Death Registration System (EDRS)” database, from February 20, 2020, to September 23, 2021, in the Fars province, south of Iran. A semi-structured, face-to-face survey consisting of 29 items was filled by the family caregivers, and the information was confirmed based on medical records.

Results: One hundred and ninety-three deaths were included, with 60.1% male and 39.9% female. More than 75% of cases had at least one comorbid condition. Death was unexpected for 65.8% of the families and 45.1% of the deceased cases had been medically managed at home during the disease. According to the family caregivers’ opinion, the most frequent causes of death at home in their COVID-19 patients were early discharge/release from the hospital (28.5%), physician's reassurance to continue home quarantine/supportive care (14.5%), hopeless/oldest-old patient (11.9%), and family/relative recommendation to not to hospitalize their patient due to fears, myths, etc. (8.8%).

Conclusions: In family caregivers’ belief, deaths at home might be related to healthcare system preparedness, physicians’ knowledge, and public education and empowerment.

KEYWORDS: COVID-19; Death; Home care

Summary

Question: What are the causes of death from COVID-19 at home?

Findings: According to family caregivers, the most common causes of death at home among COVID-19 patients were, in order: early discharge or release from the hospital, physician reassurance to continue home quarantine and supportive care, hopelessness or advanced age of the patient, and family or relatives advising against hospitalization due to fears, myths, and other concerns.

Meaning: By identifying common factors contributing to COVID-19 deaths at home, we can improve hospital admission systems during epidemics. Family caregivers suggest that such deaths may be influenced by the healthcare system’s preparedness, physicians’ expertise, and the public’s education and empowerment.

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1. Introduction

As of April 13, 2024, there were around 7 million confirmed deaths due to COVID-19[1]. Iran was one of the first countries affected by this emerging pandemic[2], experiencing six incidence peaks, with 146 811 direct deaths attributed to COVID-19[3,4]. Notably, the Islamic Republic of Iran has the highest estimated excess deaths during this pandemic in the North Africa and Middle East region (MENA)[5]. Additionally, a study from Iran found that the all-cause excess deaths per 100 000 people were 178.86, while only 49.1% of these excess deaths could be attributed to COVID-19[6]. This suggests a substantial number of indirect deaths related to COVID-19. Indeed, one plausible cause may be improper or contraindicated home-care management for COVID-19 patients[7]. For example, during the pandemic, home deaths increased by 40% compared to the previous five years in England and Wales[8]. Therefore, it is important to determine the underlying reasons for COVID-19 deaths at home. In this descriptive cross-sectional study, we sought to explore the frequency and causes of deaths at home among COVID-19 patients in southern Iran.

2. Patients and methods

2.1. Study design and setting

This study focused on all COVID-19 deaths confirmed to have occurred at home in Fars province, South Iran, from the beginning of the COVID-19 pandemic on February 20, 2020, to September 23, 2021. The primary database was acquired from the

national “Electronic Death Registration System” (EDRS, <http://deathregistry.behdasht.gov.ir>), affiliated with the Deputy for Health of the Ministry of Health and Medical Education in Iran. This database encompassed all COVID-19 deaths that occurred at home, according to reports from the national “Registry Office,” “Forensic Medicine Office,” and “Cemetery Organization.” A total of 428 events on death at home were recorded in Fars province during the study period. To confirm at-home death and gather additional data, the Health Department of Shiraz University of Medical Sciences (SUMS) sent a list of cases, stratified by the covered cities, to the local sectors of the death registry system in each city. After excluding 235 events, 193 events were deemed eligible for data gathering (Figure 1). Notably, these cases were confirmed as COVID-19 diagnoses. A confirmed COVID-19 diagnosis was defined as an event with a positive RT-PCR test for SARS-CoV-2.

2.2. Data collection

The data gathering tool was a semi-structured, face-to-face survey developed at the Non-communicable Diseases Research Center (NCDRC) affiliated with SUMS. The survey consisted of 29 questions, which included sociodemographic characteristics of the COVID-19 cases (13 questions), clinical history of the COVID-19 cases (5 questions), and seeking behaviors and actions for receiving medical care related to their COVID-19 cases (11 questions). The survey took approximately 5-7 minutes to complete and was to be filled out by a family caregiver. Family caregivers were required to obtain written informed consent before the interview. All eligible cases' caregivers responded to the survey. After the interview, we re-examined the deceased's medical records, their medical history and the onset of symptoms, to ensure there were no inconsistencies.

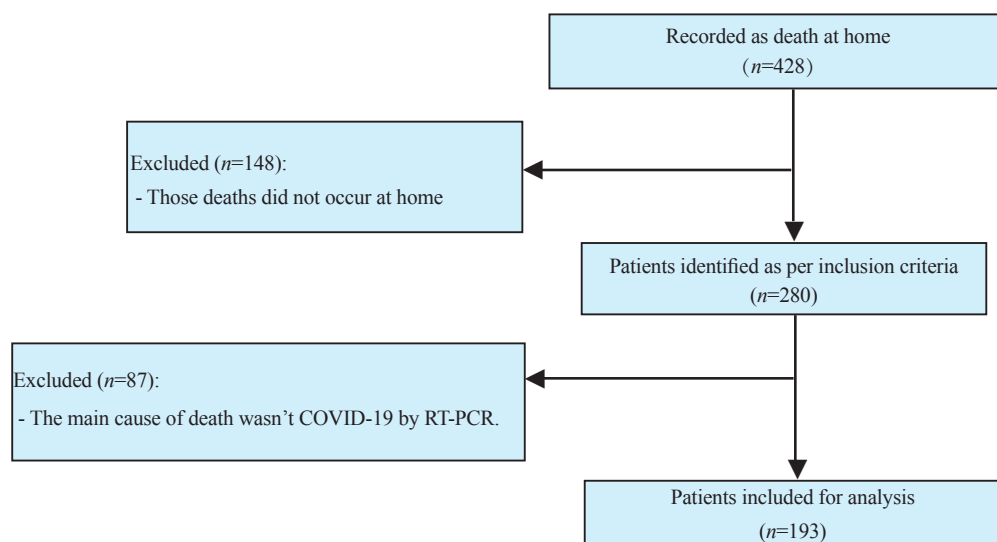


Figure 1. The study flowchart. RT-PCR: Reverse transcription polymerase chain reaction.

2.3. Statistical analysis

For descriptive analysis, R programming language (version 4.0.4 for MacOS) was used. Descriptive data was reported by frequency (percent) and median \pm interquartile range (Q1-Q3). Microsoft® Excel (version 16.43 for MacOS) was used for data visualization.

2.4. Ethical statement

This study was approved by the local Ethics Committee of Shiraz University of Medical Sciences (Approval No. IR.SUMS.REC.1399.1165).

3. Results

3.1. Sociodemographic characteristics

From the beginning of the COVID-19 pandemic in Iran until September 23, 2021, 193 deaths [60.1% male and 39.9% female, median (Q1-Q3) age of 80 (67-88) years] were confirmed to have occurred at home due to COVID-19 in Fars province. Two hundred thirty-five hospital mortalities were excluded as mentioned in flowchart (Figure 1). Most of the cases lived in urban areas (65.8%), were married or widowed (92.2%), were illiterate or had education only up to early childhood/primary levels (84.5%), had a monthly income of less than \$200 (89.6%), and had health insurance (92.2%). The detailed sociodemographic characteristics of the cases are shown in Table 1.

3.2. Clinical history of COVID-19 cases

More than 75% of cases had at least one comorbid condition, with hypertension (58.5%), cardiovascular diseases (34.6%), and diabetes (25.8%) being the most common comorbidities. Most cases (83.9%) had positive COVID-19 molecular diagnostic tests and/or HRCT findings supportive of COVID-19 pneumonia; additionally, 71.0% of the remaining cases were symptomatic. Furthermore, about half of the cases reported having at least one family member with COVID-19 concurrently (Table 2).

3.3. Medical care in COVID-19 cases

A majority of the cases had been visited by a physician for COVID-19 (90.2%), and approximately half of them required admission to a hospital or an OPAT center. On the day of death, about half of the cases exhibited severe COVID-19 symptoms, while 32 cases (16.6%) had a normal general health appearance.

Table 1. Sociodemographic characteristics of COVID-19 cases who died at home.

Variable	Frequency (n=193)
Sex, n, %	
Male	116 (60.1)
Female	77 (39.9)
Age, years, median, Q1, Q3	80 (67-88)
Habitat, n, %	
Urban	127 (65.8)
Rural	66 (34.2)
Marital status, n, %	
Single	13 (6.8)
Married	118 (61.1)
Divorced	2 (1.0)
Widow/Widower	60 (31.1)
Family size, n, median, Q1, Q3	3 (2-5)
Occupation, n, %	
Freelancer	42 (21.8)
Civil service employee or retired	37 (19.2)
Private sector employee	0
Student	0
Housewife/Housekeeping	60 (31.1)
Unemployed	39 (20.2)
Other	14 (7.8)
Breadwinner, n, %	
Yes	100 (51.8)
No	93 (48.2)
Household monthly income †	
<\$80	90 (46.6)
\$80-\$200	83 (43.0)
\$200-\$400	19 (9.9)
>\$400	1 (0.5)
Health worker's opinion on the family economic status, median, Q1, Q3 ‡	2 (1-4)
Education level, n, %	
Illiterate	104 (53.8)
Early childhood/primary	59 (30.6)
Lower secondary	15 (7.8)
Upper secondary	5 (2.6)
Post-secondary non-tertiary	5 (2.6)
Short-cycle tertiary	1 (0.5)
Bachelor	4 (2.1)
Master and higher levels	0
Health insurance holder, n, %	
Yes	178 (92.2)
No	15 (7.8)

† The Iranian Rial was converted to USD at time of study.

‡ Scored based on the 0-10 Likert scale.

The event was unexpected for 65.8% of the families. Furthermore, 45.1% of caregivers reported that their patients were entirely managed at home during the disease, while 54.9% of patients were initially treated in tertiary care centers (Table 3).

3.4. Barriers led to death at home

According to family caregivers, the most common barriers that prevented their COVID-19 patients from being hospitalized on the day of death were early discharge from the hospital (28.5%),

Table 2. Clinical history of COVID-19 cases who died at home, *n*, %.

Variable	Frequency (<i>n</i> =193)
Smoking history	
Cigarette	16 (8.3)
Water pipe	7 (3.6)
Opium	10 (5.2)
Other	1 (0.5)
Comorbidity	
Diabetes	38 (25.8)
Hypertension	86 (58.5)
Cardiovascular diseases	51 (34.6)
Chronic kidney diseases	16 (10.8)
Cancer	8 (5.4)
Other	53 (36.0)
COVID-19 RT-PCR/rapid test and/or HRCT in favor of COVID-19	
Yes	162 (83.9)
No	31 (16.1)
Symptom(s) in favor of COVID-19 †	
Yes	22 (71.0)
No	9 (29.0)
Simultaneous COVID-19 amongst other family members	
Yes	102 (52.8)
No	91 (47.1)

† Amongst those with negative COVID-19 RT-PCR as well as HRCT against COVID-19 pneumonia diagnosis (*n*=31). HRCT: high-resolution computed tomography.

Table 3. Seeking for or received medical care in COVID-19 cases who died at home, *n*, %.

Variable	Frequency (<i>n</i> =193)
Visited by physician	
Yes	174 (90.2)
No	19 (9.8)
Allocated medical interventions	
Home quarantine	60 (31.1)
Hospitalization/OPAT requested	96 (49.7)
Home hospitalization	18 (9.3)
Prescribed medication	120 (62.2)
HRCT requested	54 (28.0)
Death being expected by the family caregiver	
Yes	66 (34.2)
No	127 (65.8)
General appearance of patient at death day	
Normal	32 (16.6)
Symptomatic and stable	62 (32.1)
Symptomatic and unstable	95 (49.2)
Unknown	4 (2.1)
Medical plan	
At home entirely	87 (45.1)
At home after discharge/release from hospital/OPAT center	106 (54.9)
Cause of death in death certificate	
COVID-19	177 (91.7)
Other	16 (8.3)

OPAT: outpatient parenteral antibiotic therapy.

Table 4. Frequency of the barriers led to death at home in COVID-19 subjects, *n*, %.

Barriers led to death at home	Frequency (<i>n</i> =193)
Lived alone	1 (0.1)
Lack of health insurance	2 (1.0)
Challenges in access to healthcare (<i>eg. geographic, shortage, etc.</i>)	2 (1.0)
Trust of the traditional medicine	5 (2.6)
Unable to afford to pay hospital bills	5 (2.6)
Hospital bed available	7 (3.6)
Distrust of the healthcare system	7 (3.6)
Recommended by family/relative to not to hospitalize (fears, myths, <i>etc.</i>)	17 (8.8)
Hopeless/oldest-old patient	23 (11.9)
Physician's reassurance to continue home quarantine/supportive care	28 (14.5)
Early discharge/release from hospital	55 (28.5)
Other	41 (21.2)

physician reassurance to continue home quarantine/supportive care (14.5%), the hopelessness of the oldest-old patients (11.9%), and recommendations from family or relatives against hospitalization due to fears and myths (8.8%) (Table 4).

4. Discussion

From the beginning of the COVID-19 pandemic in Iran until September 23, 2021, 193 COVID-19 deaths at home were confirmed in Fars province. A majority of the cases (88.5%) were visited by a physician, primarily due to suspected COVID-19, and more than half required admission to a hospital or an OPAT center.

While only 34.2% of family caregivers expected death during home care, the most common barriers that led to COVID-19 deaths at home were early discharge from the hospital (28.5%) and the physician's reassurance to continue home quarantine/supportive care (14.5%). This may reflect the limited tertiary healthcare services in the region, particularly pronounced during peaks of COVID-19. Similarly, in Houston, Texas, the increase in home deaths during COVID-19 surges was associated with a shortage of hospital facilities (such as intensive care space and staff) and a reduced desire for hospitalization among patients with heart attacks, strokes, diabetes, and other conditions not directly related to the coronavirus.

In addition, fears, myths, and rumors surrounding hospital admissions, along with reluctance to visit health centers, were common causes of COVID-19-related home deaths. Generally, COVID-19 deaths can be viewed as a social process; the pandemic has imposed a massive psychological burden and instilled fear in

the population^[11]. Moreover, there has been a degree of public distrust regarding the healthcare system and COVID-19 itself^[12], coupled with low media literacy among the public and the influence of misconceptions and rumors about the virus. It is noteworthy that during the COVID-19 pandemic, the majority of home deaths reported in similar studies were caused by chronic and long-term conditions other than COVID-19, such as cancer, dementia, and lower respiratory diseases. This may be attributed to fears of contracting SARS-CoV-2 in hospitals or concerns about dying alone during hospitalization^[8].

We found that more than 75% of cases had at least one comorbid condition (e.g., hypertension, cardiovascular diseases, and diabetes). Notably, 65.8% of deaths were not anticipated by the family caregiver. Therefore, the disrupted management of comorbidities and their effects on the severity of COVID-19, as well as the early and late sequelae of this multi-organ disease, such as myocarditis, myocardial infarction, and exacerbated heart failure, may have contributed to the COVID-19 deaths occurring at home^[13-15].

It appears that two major reasons could explain this finding. First, the indirect health effects of COVID-19 (e.g., fear of COVID-19, lockdown, beliefs, shortages, etc.) may lead patients to ignore their symptoms and either refuse admission or be neglected. Second, cardiovascular events related to COVID-19, such as myocardial infarction and myocarditis, are plausible during the course of the disease or after recovery.

In our study, 11.9% of home deaths were related to family caregivers' preference not to hospitalize their patients due to perceiving them as hopeless old patients. There is a significant preference among older adults receiving palliative care to die at home instead of in a hospital setting^[16].

Last but not least, reliance on complementary and alternative medicine, specifically Unani medicine in Iran, was another cause of home deaths among COVID-19 patients, according to family caregivers' opinions. Complementary and alternative medicine can support health structures if used correctly; however, misuse can lead to fear, stress, anxiety, and risky behaviors^[17].

The most remarkable result of this study is the identification of common reasons leading to death in COVID-19 patients. By understanding these factors, it becomes possible to improve the patient admission system in hospitals during epidemics. A limitation of the present study is that it investigated barriers leading to COVID-19 deaths at home but did not explore the relationships between these factors and the deaths themselves. It is suggested that future studies be analytical and examine the potential relationships among these factors. In summary, we found that family caregivers believe the most frequent causes of COVID-19 deaths at home may be related to early hospital discharge, fear and misconceptions about COVID-19, and the patient's hopelessness or age. Also, data collected through caregiver interviews may suffer from

recall bias we re-examined the deceased's medical records, their medical history and the onset of symptoms, to ensure there were no inconsistencies.

Conflict of interest statement

All authors declare that they have no conflict of interests.

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Data availability statement

The data supporting the findings of this study are available from the corresponding authors upon request.

Authors' contributions

AM: conceptualized the study plan, designed the study, managed the data, and edited and reviewed the manuscript. AH: analyzed the data, interpreted the results. LK: wrote the manuscript. MJ: managed the data. AJ: conceptualized the study plan. AA: compiled and prepared the final data set for analysis and reviewed the analysis and final version of the manuscript. MJM: provided guidance in conducting the study and managed the data. AH: contributed to interpreting the findings and drafting the manuscript. All authors read and approved the final manuscript for publication.

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