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Miscommunication in the age of communication: A crowdsourcing framework for symptom surveillance at the time of pandemics

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ABSTRACT

Objective: There was a significant delay in compiling a complete list of the symptoms of COVID-19 during the 2020 outbreak of the disease. When there is little information about the symptoms of a novel disease, interventions to contain the spread of the disease would be suboptimal because people experiencing symptoms that are not yet known to be related to the disease may not limit their social activities. Our goal was to understand whether users' social media postings about the symptoms of novel diseases could be used to develop a complete list of the disease symptoms in a shorter time.
Materials and Methods: We used the Twitter API to download tweets that contained 'coronavirus', 'COVID-19', and 'symptom'. After data cleaning, the resulting dataset consisted of over 95,000 unique, English tweets posted between January 17, 2020 and March 15, 2020 that contained references to the symptoms of COVID-19. We analyzed this data using network and time series methods.
Results: We found that a complete list of the symptoms of COVID-19 could have been compiled by mid-March 2020, before most states in the U.S. announced a lockdown and about 75 days earlier than the list was completed on CDC's website.
Discussion & Conclusion: We conclude that national and international health agencies should use the crowd-sourced intelligence obtained from social media to develop effective symptom surveillance systems in the early stages of pandemics. We propose a high-level framework that facilitates the collection, analysis, and dissemination of information that are posted in various languages and on different social media platforms about the symptoms of novel diseases.

1. Introduction

Pandemics happen when a new virus, to which people have little or no pre-existing immunity, emerges and infects people sustainably all over the world. As an outbreak evolves, communication about it must also evolve [1,2], using a mix of media outreach, partner and stakeholder outreach, and social media engagement [2,3]. The use of these communication strategies is backed by the evidence suggesting that between 40–60 percent of US residents receive their news from online sources or through social media channels [4].

Following these guidelines, and as the extent of the recent COVID-19 outbreak began to unfold, WHO and national health agencies, such as the Centers for Disease Control and Prevention (CDC) in the US, advised people to stay at home to slow down the spread of the disease, especially if they had signs and symptoms of the disease. However, the communications on what constituted those signs and symptoms were not well-timed, contributing to the further spread of the disease by those who had signs that were not yet included in the official list of symptoms. For instance, as shown in Table 1, fever, cough, and shortness of breath were the only symptoms that were announced for the month between March 15, 2020 and April 15, 2020. Several emergency warning signs, such as bluish lips or face, pain in the chest, or new confusion, were also reported for this period on CDC's website. However, some of these symptoms and signs, such as shortness of breath, are not early signs of COVID-19 and usually appear over the course of a week after the other symptoms start [5]. What is interesting during this period (i.e., March 15

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Table 1
Chronological list of COVID-19 symptoms as announced on CDC's website (The list of symptoms on CDC's website is shown in the Appendix).

Date	Symptoms	Other Possible Symptoms or Emergency Warning Signs
March 15, 2020	Fever, Cough, Shortness of breath	Difficulty breathing or shortness of breath, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
April 1, 2020	Fever, Cough, Shortness of breath	Trouble breathing, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
April 15, 2020	Fever, Cough, Shortness of breath	Trouble breathing, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
April 19, 2020	Cough, Shortness of breath or difficulty breathing, Fever, Chills, Muscle pain, Sore throat, New loss of taste or smell	Gastrointestinal symptoms like nausea, vomiting, and diarrhea
April 22, 2020	Fever, Cough, Shortness of breath or difficulty breathing, Chills, Repeated shaking with chills, muscle pain, Headache, sore throat, New loss of taste or smell	Trouble breathing, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
April 29, 2020	Cough, Shortness of breath or difficulty breathing, Fever, Chills, Repeated shaking with chills, Muscle pain, Headache, Sore throat, New loss of taste or smell	Trouble breathing, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
May 5, 2020	Cough, Shortness of breath or difficulty breathing, Fever, Chills, Repeated shaking with chills, Muscle pain, Headache, Sore throat, New loss of taste or smell	Trouble breathing, Persistent pain or pressure in the chest, New confusion or inability to arouse, bluish lips or face
May 9–13, 2020	Cough, Shortness of breath or difficulty breathing, Fever, Chills, Muscle pain, Sore throat, New loss of taste or smell	Gastrointestinal symptoms like nausea, vomiting, and diarrhea Trouble breathing, Persistent pain or pressure in the chest, New confusion, Inability wake or stay awake, bluish lips or face
May 22, 2020	Cough, Shortness of breath or difficulty breathing, Fever, Chills, Muscle pain, Sore throat, New loss of taste or smell	Gastrointestinal symptoms like nausea, vomiting, and diarrhea Trouble breathing, Persistent pain or pressure in the chest, New confusion, Inability wake or stay awake, bluish lips or face
May 31, 2020	Fever or chills, Cough, Shortness of breath or difficulty breathing, Fatigue, Muscle or body aches, Headache, New loss of taste or smell, Sore throat, congestion or runny nose, Nausea or vomiting, Diarrhea	Trouble breathing, Persistent pain or pressure in the chest, New confusion, Inability wake or stay awake, bluish lips or face

– April 15) is that although COVID-19 was officially reported to WHO at the end of 2019 and had been infecting people in several other countries such as China, Iran, and Italy prior to surfacing in the US, CDC still referred to the symptoms and incubation period of the Middle Eastern Respiratory Syndrome (MERS) of 2012 as the basis of the symptoms it announced on its website.

There are at least four reasons why public health agencies did not provide an accurate picture of the symptoms of COVID-19 in a timely manner. First, the cause of the disease was a novel coronavirus, and as a result, the information about the possible signs and symptoms of the disease was accumulated as the virus infected more and more people. Second, the variation in geographical presentation of diseases [6] and the ease of traveling from one corner of the world to another created challenges for the identification of a complete list of symptoms. Third, a lack of international cooperation[1] hindered the dissemination of experiences and sharing of knowledge among the global and national agencies. Fourth, the global and national agencies did not fully utilize the power of social media platforms in obtaining and spreading information about the symptoms of the new disease.

Because another pandemic is inevitable and unpredictable ([7], p. 142), it is important that we learn from this experience to prepare for the future. We draw upon the utility of social media, especially Twitter, in public health surveillance to develop a symptom surveillance system (SSS) that can be used for more effective identification of the symptoms of novel diseases. We believe a social media-based SSS does not only help in obtaining a timely and accurate list of the symptoms of novel diseases, but also can mitigate the detrimental effects of the blame game between countries. Therefore, by focusing on "time" as a central and pivotal aspect of pandemics and examining its role on the effectiveness of the interventions implemented by governments [8], we determine how the global response to future pandemics can be improved with the use of crowd-sourced information.

The remainder of the manuscript is structured as follows. In the subsequent section, we review the literature on people's use of social media for sharing health-related information. Next, we develop and evaluate the proposed SSS using COVID-19-related postings on Twitter. At the end, we conclude the paper with a summary of the study and discuss how it can guide us in unwelcomed, but probable, future pandemics. Specifically, we use our findings to propose a framework that uses the information shared on social media to enable more effective communication and knowledge sharing between the international and national agencies during pandemics.

2. Materials and methods

Prior research shows that people discuss their health-related issues with their peers on social media long before such information is available to the healthcare authorities through other surveillance channels [9]. Therefore, social media are important platforms for risk communication during public health crises [10,11]. The utility of these platforms, however, extends beyond states of emergency to allow for public health surveillance [12,13] and the exchange of health information [11, 14–17], including information about illnesses and associated treatments [18].

In previous studies on the use of social media for sharing health-related information, Twitter has broadly been considered as an essential channel both by individuals and healthcare organizations [11,15,16, 19–22]. We follow the previous studies and use postings on Twitter to develop and evaluate a SSS based on users' information exchange about the symptoms of COVID-19 during the 2020 pandemic. Fig. 1 depicts the methodology we employed.

2.1. Data acquisition

Using Twitter API, we downloaded tweets that contained 'coronavirus', 'COVID-19′, and 'symptom'. The initial dataset consisted of over 14 million tweets in English that were posted by unique accounts between January 17, 2020 and March 15, 2020. After discarding retweets, duplicate tweets, and tweets posted by news agencies, public organizations, or those that had external URLs to news reports, 95,863 records remained that contained references to the symptoms of COVID-19. The full text of the tweets and any meta data associated with them, such as username, time stamp, URL, location, and hashtags were captured and stored in our database.

[1] https://www.nationalacademies.org/news/2020/04/the-critical-need-for-international-cooperation-during-covid-19-pandemic.

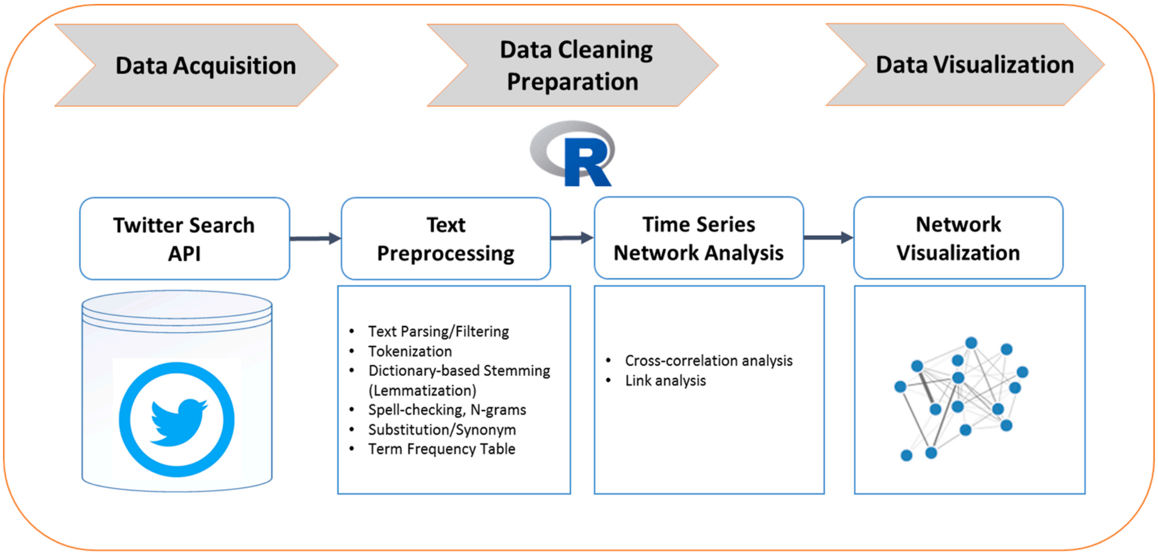

Fig. 1. SSS implementation methodology.

2.2. Data cleaning and preparation

We used a combination of text mining algorithms to process the collected Twitter data and to convert them into a structured format. This process included techniques such as tokenization, transformation (e.g., punctuations and numbers removal, stop words filtering, spell-checking), and normalization (e.g., lower case conversion, lemmatization, stemming and synonyms). We searched for *n*-grams ($n = 2, 3$) to capture multiword terms or meaningful phrases that represented COVID-19 symptoms (e.g., 'shortness of breath' and 'loss of taste'). Next, we created a term-frequency matrix for the corpus of Twitter data to represent the number of times a term (i.e., symptom) appeared in a given day. We filtered the term-frequency matrix to retain the most commonly mentioned symptoms of COVID-19. Finally, using the R package 'ICD', we compared the extracted COVID-19 symptoms with the symptoms of infectious diseases and retained most frequent symptoms (based on their network centrality metrics as explained next) for further analysis.

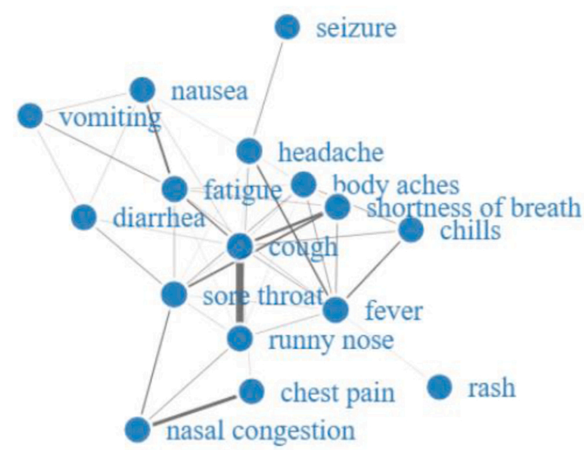

Fig. 2. Symptom graph of COVID-19.

2.3. Data visualization

We used the *networkD3*[2] package in R to visualize COVID-19 symptoms as a weighted graph (network). Nodes in this graph represent the symptoms of COVID-19 and edges denote the concurrent appearance of two symptoms in the same tweet. To illustrate the weight (i.e., intensity) of an edge, we counted the number of tweets that mentioned both of the symptoms of that edge and adjusted the thickness of the edge accordingly. Fig. 2 shows the weighted graph of COVID-19 symptoms.

3. Results

3.1. Network analysis

To better understand the symptoms associated with the COVID-19 disease, we used degree, closeness, and betweenness centrality metrics to rank the symptoms in the network according to their relevance to the COVID-19 pandemic. We hypothesized that the symptoms that are central in the constructed network of symptom are more likely to be associated with COVID-19. Centrality of a node defines how important a node is within a network. There are several metrics that are often used to measure centrality: The *degree centrality* is the number of edges that are connected to a node; the *closeness centrality* of a node measures how close it is to other nodes in the network; and the *betweenness centrality* of a node measures the number of times a node appears on the shortest paths between other nodes.

We calculated the closeness centrality of each node by inverting the sum of the distances from that node to all other nodes in the symptom network. We computed the betweenness centrality of each node by taking the number of the shortest paths that passed through the given node and divided that number by the total number of shortest paths within the network. A node is considered central if it is *closer* to all other nodes in the graph, or in other words, it appears on many shortest within the network.

Table 2 contains centrality values of each node (i.e., symptom) in our symptom network. The top ranked symptoms as suggested by these three approaches nearly identical. In particular, the degree, closeness, and betweenness centrality metrics revealed the same top five core symptoms, including cough, fever, sore throat, fatigue, and runny nose. As we discussed earlier, some of the better known symptoms of COVID-19, such as shortness of breath, develop later as more severe complications of the disease and, as a result, do not surface among the most frequent symptoms (we believe this is expected because patients with shortness of breath are more likely to seek help than tweeting about their condition). Additionally, Table 2 shows that tweets from the early

[2] https://cran.r-project.org/web/packages/networkD3/networkD3.pdf.

Table 2
Centrality metrics of COVID-19 symptoms.

Symptom	Degree	Closeness	Betweenness
Cough	12	0.0625	27
Fever	9	0.0525	7
Sore throat	9	0.0525	10
Fatigue	8	0.05	9.5
Runny nose	7	0.0475	4
Body aches	6	0.045	1.5
Headache	6	0.045	3
Nausea	5	0.042	3
Diarrhea	4	0.042	2
Shortness of breath	4	0.042	0
Chills	3	0.037	0
Difficulty breathing	3	0.037	0
Nasal congestion	3	0.0345	1
Vomiting	3	0.0345	0.25
Chest pain	2	0.037	0.75
Seizure	2	0.03	0
Rash	2	0.03	0

stages of the pandemic (i.e., between January and mid-March) could have been used to put together a more complete list of symptoms before nationwide lockdowns in many countries around the globe as well as several states in the US.

Social media-based intelligence can also be used to detect some of the rare symptoms of novel diseases in early stages of a pandemic. As the last row of Table 2 demonstrates, in the early stages of the pandemic, rash was not among the most common (or most commonly known) symptoms of COVID-19 but could have been monitored more closely as an early sign of the disease, especially if it was later accompanied by a few other symptoms. A study that was published about a year after the beginning of COVID-19 pandemic finds that skin rashes are the first presentation of the disease among 17 % of patients [23]. Similarly, the Twitter data points to neurological manifestations of COVID-19 such as seizure, particularly among those with a history of the condition [24–26]. It deserves to mention that even until the end of May 2020 neither of these two conditions were included as potential symptoms or effects of the disease on CDC's website.

3.2. Time series analysis

We derived time series data for each symptom from the daily data within the term-frequency matrix and used them in a cross-correlation analysis at different time lags. In time series analysis, cross-correlation is a measure of similarity of two time series as a function of the lag of one relative to the other. This approach allowed us to examine the lag or lead relationship between the *initial* symptoms of COVID-19 (i.e., the three symptoms *fever*, *cough*, and *shortness of breath* that were identified by CDC during the first weeks of the pandemic) and those identified from the Twitter data. We observed that the cross-correlation metric reaches its maximum value at a lag of zero, indicating that the initial symptoms of COVID-19 and those identified from the Twitter postings followed the same pattern but with different frequencies. Our correlation analysis showed that there is a reasonably strong correlation (mean Pearson $r = 0.94$, range: 0.81 to 0.98) between the initial symptoms of COVID-19 and the ones identified from Twitter. Interestingly, almost all of the *eventual* symptoms of COVID-19 (i.e., those announced later by CDC) start to surface among the Twitter postings from the last week of February and continue their upward trend into the second week of March. Table 3 lists the daily counts of COVID-19 symptoms in user tweets and presents the results of the zero-lag cross-correlation analysis.

The network and time series analyses presented in this section bear significance for two reasons. First, they illustrate that users were talking about the same symptoms of the novel coronavirus disease long before those symptoms were announced on the CDC website. Yet, these results were obtained only by analyzing English tweets. We believe the same results could have been obtained even earlier, and with more promising statistics, if a larger number of social media platforms were considered and when the disease stroke non-English speaking countries such as China, Italy, and Iran. Second, the results show that even without considering non-English tweets, responsible health organizations should have been able to compile a more complete list of the disease symptoms much earlier than they actually did. This is true because, according to our findings, the eventual symptoms were being mentioned on Twitter concurrently with the initial symptoms of the novel disease. Paying attention to the power of social media and the intelligence sourced from the crowd, therefore, is essential in fighting future pandemics.

4. Discussion & conclusion

Pandemics can catalyze enormous change by transforming the way people make sense of the world and by presenting a significant opportunity for digital technologies [27]. The global outbreak of COVID-19 in 2020 was the first worldwide pandemic since the establishment of most national and all international health organizations. A lack of experience with an emergency of this scale, as well as political reactions instead of a global cooperation to fight the disease, hindered an effective response to the emergency. One area in which we need better standards and coordinated actions in future pandemics, as we demonstrated in this paper, is the identification and announcement of new disease symptoms.

We reviewed how WHO and CDC used their websites and social media accounts to inform people about the symptoms of COVID-19. We made three important observations. First, there was a significant delay in making and updating a complete list of COVID-19 symptoms, which, as we discussed, can undermine the effectiveness of the interventions enforced to slow down the spread of novel, contagious diseases. Second, rather than joining forces to fight the disease as effectively as possible, the international community worked in isolation, resulting in suboptimal decisions and poor outcomes. For example, while there was anecdotal evidence on the effectiveness of hydroxychloroquine in treating some patients, WHO hastily halted trials of the drug based on the results of a single study [28] but soon after restarted the process when it was known that the study had validity problems [29]. This and other examples, such as recommending to not wear masks at the end of March [30] and then advising to wear them in public areas [31], suggest there is a lot of room for improvement in future pandemics. Third, despite the existing evidence on the utility of social media postings for disease surveillance, national and international health agencies did not make use of the crowd-sourced intelligence from these platforms to develop a more complete and accurate list of the disease symptoms.

As we demonstrated, social media activity (e.g., on Twitter) can be used to obtain useful information and learn from the experiences of others, especially from countries that are affected earlier by novel diseases. A similar approach has been in use, and is shown to be effective, in the recent decade in the drug safety surveillance area, where people's conversations on social media are used for the early detection of drug-drug interactions [32–35].

Our findings can be used to propose a high-level framework for more effective identification of the symptoms of novel diseases. Specifically, since users may post their symptoms in different languages and on various, sometimes regionally used social media platforms, a cooperation between local WHO offices, national health agencies, and the global offices of WHO would provide much better results. This high-level framework has two important benefits. First, it allows for a more effective and rapid compilation of novel disease symptoms, which can be updated and shared among all members of the international community during pandemics. Second, even when political issues between countries prohibit constructive collaboration, it enables more effective management of the disease compared with the situation in which each country fights the disease independently. This is true since WHO has local offices in all regions of the world, which oversee their operations in almost all members of the United Nations. One may argue that there needs to be

Table 3
Time series analysis of COVID-19 symptoms using Twitter data.

	Initial Symptoms			Eventual Symptoms												
Date	Fever	Cough	Shortness of breath / difficulty breathing	Headache	Sore throat	Chills	Muscle pain/body aches	Fatigue	Loss of taste or smell	Gastrointestinal (nausea, vomiting, and diarrhea)	Pressure (pain) in the chest	Bluish lips or face	Inability to wake or stay awake	Congestion or runny nose	Rash	Seizure
1/17/2020–1/23/2020	2273	1738	242	236	109	80	6	7	49	0	69	0	0	149	0	0
1/24/2020–1/30/2020	9635	11365	845	1019	793	1010	14	57	311	147	261	0	0	914	0	0
1/31/2020–2/6/2020	6115	6557	258	166	362	421	15	27	213	425	619	0	0	252	0	33
2/7/2020–2/13/2020	3548	4200	90	24	193	284	0	35	142	263	143	5	0	91	0	0
2/14/2020–2/20/2020	2451	2292	69	4	105	121	7	17	0	4	99	6	0	34	0	0
2/21/2020–2/27/2020	4108	7448	378	274	320	829	20	255	197	73	629	92	6	412	0	0
2/28/2020–3/6/2020	11362	28435	1699	931	971	2566	111	353	783	794	2212	331	6	1883	31	0
3/7/2020–3/13/2020	39091	67917	5601	2195	2923	10106	790	1492	2152	5583	4655	876	34	6059	307	92
3/14/2020–3/15/2020[a]	12749	21374	1989	784	1157	3117	226	660	844	2229	2027	308	21	2098	97	27
Correlation between the *initial* and *eventual* symptoms of COVID-19 (*$p < 0.05$ for $N = 54$)				0.94*	0.98*	0.98*	0.85*	0.95*	0.97*	0.93*	0.95*	0.97*	0.81*	0.98*	0.91*	0.68*

[a] The last row contains data for only two days.

enough evidence to add any sign to the list of the symptoms of a novel disease. While this is generally true, we need to weigh what we gain versus what we lose: communicating about less common symptoms that manifest in a smaller proportion of patients or are even based on anecdotal evidence has little or no harm to the public, whereas ignoring them until there is "statistically significant" evidence to back their inclusion allows the novel virus to lurk among vulnerable individuals, claiming more lives that could be saved otherwise.

Our study was not without limitations. First, we were not able to retrieve non-English tweets about the symptoms of COVID-19 that were posted prior to March 15, 2020. Second, we only focused on user activity on Twitter to obtain the crowd-sourced intelligence, whereas such intelligence can be obtained from several social media platforms. Not only international health organizations, such as WHO, can easily overcome these limitations, but also launching a SSS based on our proposed framework is well within their responsibilities and capabilities. For instance, during the COVID-19 pandemic, WHO formed a social media monitoring team to stop the spread of rumors. Aleksandra Kuzmanovic, social media manager with WHO's department of communications told Lancet in an interview [36]:

> *"In my role, I am in touch with Facebook, Twitter, Tencent, Pinterest, TikTok, and also my colleagues in the China office who are working closely with Chinese social media platforms…So when we see some questions or rumors spreading, we write it down, we go back to our risk communications colleagues, and then they help us find evidence-based answers".*
>
> *"Another thing we are doing with social media platforms, and that is something we are putting our strongest efforts in, is to ensure no matter where people live….when they're on Facebook, Twitter, or Google, when they search for 'coronavirus' or 'COVID-19' or [a] related term, they have a box that…directs them to a reliable source: either to [the]WHO website to their ministry of health or public health institute or centre for disease control".*

If social media are being monitored to detect and stop the spread of rumors, they can also be used to detect and communicate about the symptoms of novel diseases in more effective and efficient ways. Future research can focus on the design and development of such social media-based SSS. Additionally, future research can determine what other social media platforms, besides Twitter, should be used in certain parts of the world to collect user generated intelligence on health-related outcomes.

As a final note, this study does not intend to make decisions for national and international health agencies or tell them how to make policies. Instead, it reflects our observations of the global and regional responses to the COVID-19 pandemic and presents what we think can improve their responses in future global health emergencies.

CRediT authorship contribution statement

Hamed M. Zolbanin: Conceptualization, Methodology, Validation, Investigation, Resources, Data curation, Writing - original draft. **Amir Hassan Zadeh:** Methodology, Software, Validation, Formal analysis, Data curation, Writing - original draft. **Behrooz Davazdahemami:** Investigation, Resources, Data curation, Writing - original draft.

Declaration of Competing Interest

All authors have participated in (a) conception and design, or analysis and interpretation of the data; (b) drafting the article or revising it critically for important intellectual content; and (c) approval of the final version.

This manuscript has not been submitted to, nor is under review at, another journal or other publishing venue.

The authors have no affiliation with any organization with a direct or indirect financial interest in the subject matter discussed in the manuscript

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.ijmedinf.2021.104486.

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