

Primary Care Physicians' and Patients' Perspectives on Equity and Health Security of Infectious Disease Digital Surveillance

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ABSTRACT

PURPOSE The coronavirus disease 2019 (COVID-19) pandemic facilitated the rapid development of digital detection surveillance (DDS) for outbreaks. This qualitative study examined how DDS for infectious diseases (ID) was perceived and experienced by primary care physicians and patients in order to highlight ethical considerations for promoting patients' autonomy and health care rights.

METHODS In-depth interviews were conducted with a purposefully selected group of 16 primary care physicians and 24 of their patients. The group was reflective of a range of ages, educational attainment, and clinical experiences from urban areas in northern and southern China. Interviews were audio recorded, transcribed, and translated. Two researchers coded data and organized it into themes. A third researcher reviewed 15% of the data and discussed findings with the other researchers to assure accuracy.

RESULTS Five themes were identified: ambiguity around the need for informed consent with usage of DDS; importance of autonomous decision making; potential for discrimination against vulnerable users of DDS for ID; risk of social inequity and disparate care outcomes; and authoritarian institutions' responsibility for maintaining health data security. The adoption of DDS meant some patients would be reluctant to go to the hospital for fear of either being discriminated against or forced into quarantine. Certain groups (older people and children) were thought to be vulnerable to DDS misappropriation.

CONCLUSIONS These findings indicate the paramount importance of establishing national and international ethical frameworks for DDS implementation. Frameworks should guide all aspects of ID surveillance, addressing privacy protection and health security, and underscored by principles of social equity and accountability.

Ann Fam Med 2023;21:33-39. <https://doi.org/10.1370/afm.2895>

Annals "Online First" article

INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic re-exposed the weaknesses of the conventional infectious diseases (ID) reporting approach observed with Severe Acute Respiratory Syndrome.¹ Multiple levels of reporting and incomplete responses drove the rapid development of digital detection surveillance (DDS) systems to quickly collect, interpret, and respond to outbreaks in countries like China.² The World Health Organization (WHO) has prioritized health security in responses to public health threats, while strengthening the capacity for public health surveillance and response, to minimize the impact on people's health across geographical regions and international boundaries.^{3,4} Digital detection surveillance refers to a range of tools, that include: clinical decision-making support systems designed to detect suspected ID cases; contact-tracing mobile applications to facilitate epidemiological investigations (eg, the traffic-light health code system used for risk stratification of contracting COVID-19 by tracking geo-locative movements on a mobile application); and outbreak monitoring tools that utilize informal data sources and search engines made available with novel technologies (eg, big data, artificial intelligence, and cloud computing).^{5,6}

The Chinese government introduced national medical insurance reforms committed to re-establishing primary health care in 2009⁷ which aimed to address service gaps and mistrust between institutions providing health care and the general



Conflicts of interest: authors report none.

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public.⁷ By 2021, a network of 35,000 primary health care facilities employing over 416,000 health care workers were established.⁸ The newly developed DDS (a response to the COVID-19 pandemic) was anticipated to provide a primary care network to benefit both primary care physicians and patients during public health efforts to prevent the spread of disease.⁸ Nevertheless, a recent systematic review on the ethical integrity of DDS for ID showed that little attention was paid to the potential for breaches of privacy and confidentiality, human and civil rights, and governance structures.⁹ Digital detection surveillance engagement studies with primary care physicians have highlighted concerns about the consistency of the information.¹⁰ Patients (end users) have reported a lack of knowledge and limited autonomy in decision making,¹¹ and there are recent reports that DDS has widened existing health care disparities for certain patient groups.^{12,13}

Under China's National ID Report Management System, all health care institutions are now required to report new ID cases to the local Center of Disease Prevention within 2 hours of diagnosis.⁷ Within this system, a series of preventive and surveillance measures were implemented to combat the COVID-19 pandemic.¹⁴ These included extensive testing, strict quarantines, mandatory border control, social distancing, mass mobility control through scanning health codes, and isolation in *fancang* (field) hospitals.¹⁴ Local governments and commercial organizations have applied a traffic-light health code system within this context to determine citizens' access to transportation, public spaces, and shops.¹⁵ See [Supplemental Appendix 1](#) for traffic light description used in China. So far, there is no reliable regulatory and ethical rights protection framework to inform personal data collection and analytics when engaging with these contact-tracing applications.³ There are increasing calls, globally, for the establishment of a universal ethical framework for ID surveillance that provides governance and protection of private health information when engaging with DDS.¹⁶⁻¹⁸

It is crucial to have insights from both primary care physicians and patients on their unique experiences, perceptions, and ethical concerns when using DDS for ID management in China in order to effectively integrate an ethical framework into DDS. This study aimed to identify the ethical imperatives that need to be addressed to ensure patients' autonomy, protect their health care rights, and optimize responsive public health outcomes for DDS use in ID management.

METHODS

We conducted semistructured interviews, individually, with primary care physicians and patients. The domains of the Consolidated Criteria for Reporting Qualitative Studies (COREQ) were used in reporting the methods and results of this study.¹⁹ Ethical approval was granted by the Institution Review Board of the University of Hong Kong-Shenzhen Hospital in China (HKUSZH2021019).

Recruitment and Data Collection

We recruited primary care physicians from March through June 2021 via mass WeChat groups of national professional organizations such as China General Practice Teachers' Association and the Medical Prevention Society General Practice section, which link hundreds of primary care physicians across the country. A research team member advertised the study through the WeChat groups, answered queries, and referred potential participants to the study team. The research team consisted of academics focused on ID, sexual minorities, and aging. Most are registered primary care physicians and nurses, as well as experts in artificial intelligence and information technology. Primary care physicians were recruited purposively across sex, age group (aged ≤ 45 or >45 years), and region (northern or southern China), to provide a diversity of views.²⁰ Each primary care physician nominated at least 2 adult patients for inclusion in the study. If the patient met the study inclusion criteria (adult and able to communicate in Chinese), they were sampled across sex, age, educational attainment, and occupation. WeChat was the main means of communication with primary care physicians and patients. Video conferencing software, such as Zoom (Zoom Video Communications) and Dingtalk (Alibaba Group), were used to conduct the interviews. Informed verbal consent was obtained and confidentiality was assured to all participants before the interviews, which were audio recorded. Incentives (gift cards equivalent to US \$28) for participation were provided and documented.

Semistructured interview guides were developed separately for primary care physicians and patients based on the systematic literature review conducted by the research team ([Supplemental Appendix 2](#)).⁹ Pilot interviews were conducted with 7 participants (4 primary care physicians, 3 patients) and refinements were made to the guides before the data collection. All interviews were conducted in Putonghua, each lasted 45-60 minutes. All audio recordings were stored with access restricted to the study team. The research team met regularly to review the interview codes and themes until no new topics were emerging, indicating data saturation was achieved.²¹

Data Analysis

The digitally recorded interviews were transcribed verbatim by an independent research assistant. The post-analysis translation method was utilized for retaining explicit and implicit meanings embedded in the language for culturally specific expressions and concepts.²² Thematic analysis followed Braun and Clarke's guidelines.²³ Two researchers independently studied the data, reading, rereading, assigning codes, then sorting, grouping, and merging approximately 390 codes. These were further categorized into patterns or themes.²³ An audit of 15% of the coded segments was conducted by a third researcher (W.C.W.W.) who discussed findings with both I.Y.Z. and Y.X.M. to ensure inter-rater agreement. Disparities were discussed until agreement was reached.

RESULTS

Summary of Demographic Data

A total of 16 primary care physicians (8 of each sex) aged 29 to 65 years completed the interviews. Of these, 11 had additional training in general medicine (most physicians in China start in general medicine then become primary care physicians via on-the-job training). Thirteen of the physicians had more than 10 years of professional experience and concurrently held titles of Associate Chief Physician or above.

A total of 24 patients (13 females, 11 males) aged 21 to 70 years completed the interviews. Patients had a variety of occupations and levels of educational attainment (Table 1). Five key themes and exemplar quotes from primary care physicians and patients are summarized in Table 2.

Potential Impacts on Trust and Informed Consent

Chinese primary care physicians and patients were aware of health codes being used as a form of DDS and contact tracing in response to the COVID-19 pandemic. Many of the primary care physicians and patients credited the Chinese government's efficient response and success with COVID-19 pandemic control to China's centralized administrative system. While primary care physicians generally held positive views on DDS, they had considerable reservations. Some primary care physicians believed that the clinical decision support system that allowed use of telehealth and an automated diagnosis program helped address a workforce shortage and

offered timely warnings of ID outbreaks, yet it fell short of replacing in-person medical assessments. Primary care physicians were also concerned that the implementation of DDS might adversely impact their patient relationships. Some suggested a lack of transparency about use of patients' data could potentially disrupt the already fragile trust-based doctor-patient relationship in China.

During health care reform, patients were led to believe that all information provided to the hospital would be kept confidential, but there are exceptions. Medical confidentiality is subordinate to active public health threats. An option to opt out of DDS would defeat its purpose. Some primary care physicians were under the impression that it was their responsibility to seek the patients' consent. This was at odds with mandatory ID reporting that does not allow for sufficient consumer understanding of the implications of engagement with DDS. Some physicians felt this could cause future doctor-patient conflict.

Need for Autonomous Decision Making

Digital detection surveillance negatively impacted both primary care physicians' and patients' sense of autonomy in decision making. Primary care physicians expressed a sense of diminished autonomy in their decision making. Some patients expressed concern that clinical decision support systems could de-skill physicians despite DDS being intended as an auxiliary clinical tool. Patients also stated that their engagement with DDS meant they had no ability to ensure personal privacy and no formal channels to express their concerns. Several primary care physicians and many patients agreed that national institutions in China hold considerable power, and as a result local governments and primary institutions apply strict control strategies. The fear of interfacing with DDS during clinical consultations meant some patients were reluctant to go to hospitals when they had symptoms of potential IDs because they feared compulsory quarantine. Others admitted to lying about their symptoms, such as fever or cough, in order to obtain a green health code.

Potential Discrimination Associated With ID

The DDS was seen as forcing citizens to adopt the traffic-light health code system based on infection risk. Of note, a few primary care physicians described how their communities discriminated against them after they had been in contact with COVID-19 patients. Patients also outlined fears

Table 1. Demographic Summary of Participants (N = 40)

Characteristic	No.	Characteristic	No.	Characteristic	No.
Primary Care Physicians (n = 16)					
Age, y		Postgraduate training		Qualification	
29-39	3	General Medicine	11	Assistant Physician	1
40-49	10	Infectious Diseases	1	Resident	2
50-59	2	Ophthalmology	1	Associate Chief Physician	7
61	1	Health Management	1	Chief Physician	6
Sex		Chinese Medicine	1	Length of employment, y	
Female	8	Surgery	1	1-10	3
Male	8	Region		11-20	6
		Northern China	8	21-30	4
		Southern China	8	31-40	3
Patients (n = 24)					
Age, y		Occupation		Educational level attained	
21-29	5	Professionals	4	Bachelor's degree and above	10
30-39	2	Managers	2	Vocational school	7
40-49	9	Semi-skilled labor	5	Senior high school	4
50-59	3	Self-employed	3	Junior high school	3
60-69	4	Student	3	Marital status	
70	1	Retired	7	Married	18
Sex		Region		Single	6
Female	13	Northern China	14		
Male	11	Southern China	10		

about the risk of ID disclosure, being identified as yellow or red code holders, and being treated differently in the community. Some patients questioned the accuracy of the coding within DDS (eg, coincidental fever, or not including a district with known COVID-19 cases) which could lead to unnecessary quarantine and significant stress on families. Both primary care physicians and patients recommended public

awareness education on the integrity of ID and DDS as being a useful solution to reduce public discrimination and fear.

Risk of Inequity and Divided Care

Certain groups (ethnic or sexual minorities) were regarded as being vulnerable to ID disclosure and resultant shame or exploitation. Older people and young children, who might

Table 2. Summary of 5 Themes and Exemplar Quotes From Participants

Themes	Primary Care Physician Quotes (region of China, sex, age in y)	Patient Quotes (region of China, sex, age in y)
Potential impacts on trust and informed consent	<p>"Health QR codes used in mainland China during the epidemic period are good examples of making use of AI" (SC, male, 29)</p> <p>"Artificial Intelligence (clinical decision support system) can improve the issue of clinical manpower shortage by allowing telehealth and automated diagnosis program" (NC, female, 47; SC, female, 46)</p> <p>"DDS cannot deal with an issue flexibly and comprehensively, it is more about a process operation" (SC, female, 46; NC, female, 47)</p> <p>"It is difficult for DDS to analyze the psychological problems of a patient" (SC, female, 46)</p> <p>"Patients might worry about that I am using their data for a hidden income or something else, although they may not necessarily say it directly" (SC, male, 40)</p> <p>"Giving informed consent is troublesome, which would cause patients to have suspicion and confusion" (NC, female, 49)</p> <p>"Both primary care physicians' and patients' knowledge of DDS is insufficient. It is very difficult for me to do informed consent to patients. I think this is not reasonable either" (NC, female, 34)</p>	<p>"I support the health codes used by the government in COVID-19 pandemic, I don't think there is anything to worry about" (NC, male, 70; SC, female, 63; NC, male, 44)</p> <p>"In the hospital, it [DDS] may help with the detection of some infectious diseases, it brings convenience to us" (SC, female, 27)</p> <p>"Informed consent and a confidentiality agreement are necessary to protect patients' data. And the informed consent should be performed by primary care physicians" (NC, male, 58; NC, male, 46)</p>
Need for autonomous decision making	<p>"To meet hospital and state demands, primary care physicians had to encourage patients to use health code" (SC, male, 46)</p> <p>"But we still have a little doubt (the effectiveness of using health code for pandemic control) in our hearts" (NC, female, 34)</p> <p>"I understand the ID reporting strategies are for better control the pandemic. But I also want to know how the government will deal with our data. My own opinion is that I do not want our privacy to be disclosed. I hope government can do something to make a balance between ID control and our citizen rights" (NC, female, 34)</p> <p>"GPs will not absolutely dependent on DDS. We will follow a process of manual verification. Patients do not need to worry about this" (NC, female, 61)</p> <p>"To meet the ID control requirements of national institutions, local governments and primary institutions usually applied more strict control strategies than national instructions" (SC, male, 40)</p>	<p>"You are not allowed to go anywhere without showing the health code, and you cannot even get on the bus. What should you do? So, it's useless for you to think too much" (SC, female, 45)</p> <p>"If you say that you go to government departments to complain about your privacy disclosure, in fact, I think it is useless" (NC, male, 70)</p> <p>"The complaint process is not clear, there is no channel to complain about your privacy issue" (NC, male, 46)</p> <p>"Chinese value of filial piety requires citizen's obedience to leaders and the society" (SC, female, 63)</p> <p>"As long as you get a fever, no matter what kind of illness (infectious disease or common cold) you have, you must be quarantined first" (NC, female, 21)</p>
Potential discrimination associated with ID in China	<p>"People still fear and have discriminations on infectious diseases in China. The usage of DDS would increase the detection and identification of ID patients. Patients would afraid they would be exposed to the public" (NC, female, 61)</p> <p>"It is disgraceful to be infected with COVID-19. If people know that you had been in contact with COVID-19 patients, everyone will isolate you, fearing that you will spread virus to them. It will then affect your family. People will think that you have passed your virus to your family members. So, your family will be discriminated" (NC, male, 42)</p>	<p>"If you had a fever and you input your temperature into health code system, it would result in a yellow code. I had an appointment of CT, but they refused to let me access the hospital due to the yellow code. I was quite panic at the time" (NC, female, 21)</p> <p>"I don't know how to say it, but I can understand it anyway. People feel panic when they see your code is yellow" (NC, male, 43)</p> <p>"The government should provide some technical introductions to us about the DDS. The more detailed they explain, the less worry we may have" (NC, female, 45; SC, female, 45)</p>

continues

AI = artificial intelligence; CT = computed tomography; DDS = digital detection surveillance; GPs = general practitioners; ID = infectious disease; NC = northern China; QR = quick response; SC = southern China.

Table 2. Summary of 5 Themes and Exemplar Quotes From Participants (continued)

Themes	Primary Care Physician Quotes (region of China, sex, age in y)	Patient Quotes (region of China, sex, age in y)
Risk of inequity and disparate care	<p>"Older people and children may not have much knowledge about information security, so they will be easier cheated" (NC, female, 34)</p> <p>"It is unfriendly for some special groups of people. For example, some older people do not use smart phones or disabled people don't know how to use health code, etc" (NC, male, 42)</p> <p>"Patients in small places might be [sic] lack of ethical awareness to protect their rights" (NC, female, 34)</p> <p>"The number of patients is small due to the lower population density in small places. ID patients might have to be more cautious as they concerned they would be recognized more easily by other citizens" (NC, female, 47)</p> <p>"Artificial intelligence mistakes cannot be fully avoided" (SC, male, 29)</p> <p>"For example, if the information of ID patients did not be extracted, it will affect the algorithm of AI" (NC, male, 42)</p>	<p>"People in southern region are open-minded and accept new technologies. It may be easier to promote DDS. There will be more discrimination against infectious diseases in the north because of low acceptance" (NC, male, 58)</p> <p>"The exposure of travel trajectory has a great influence on people, especially for special groups (such as celebrities, sexual minorities, and sexual workers), which is unacceptable" (SC, male, 33)</p> <p>"Some older people's mobile phones cannot scan health codes" (NC, female, 22; SC, male, 69)</p> <p>"Ethnic minorities in China usually have lower education level, may be lack of knowledge of DDS and ethics" (SC, female, 63)</p>
Health data security: whose responsibility is it?	<p>"I think there still does not exist a leading organization, which can coordinate between countries, but at present it seems like our World Health Organization needs explore more in this area" (NC, male, 40)</p> <p>"Countries may tend to supervise each other, and accuse each other of loopholes in the prevention and control of infectious diseases" (NC, male, 40)</p> <p>"Data should be decrypted and the access must be restricted" (NC, female, 34)</p> <p>"Disease symptoms, sources of infection, transmission routes, and treatment records need to be extracted" (NC, female, 47)</p>	<p>"The country you shared data with may be quite different from our country. Different system, policy and culture. Your freedom may be restricted in that country if you shared your ID information to them. For example, international students, tourists, and expatriates, they have to pay for high cost of medical care without buying medical insurances" (NC, female, 45)</p> <p>"You only extract this patient's disease information rather than his name, home address, and contact information. Extracting purely pathological information and medication information is acceptable for me" (SC, male, 33)</p>

AI = artificial intelligence; CT = computed tomography; DDS = digital detection surveillance; GPs = general practitioners; ID = infectious disease; NC = northern China; QR = quick response; SC = southern China.

have difficulties in using smart phones or scanning health codes, were seen to be particularly at risk of falling victim to disparate care. This concern also applied to persons with lower literacy levels as they might not be aware of their data protection rights and could be more prone to online fraudsters. Some primary care physicians thought that the use of DDS in smaller towns could easily lead to the identification of ID patients. Some physicians also raised concerns about the accuracy of the predictions based on models using artificial intelligence, and felt most patients would not understand this implication.

Health Data Security: Whose Responsibility Is It?

While participants stressed that de-identified information from patients diagnosed with an ID should be shared globally for optimal public health outcomes, they felt the current lack of security and protection in the DDS system and regional variations in epidemic control could make information sharing a national security issue. Both primary care physicians and patients recommended that only disease-related information be extracted (not personal data), and that this information should be decrypted with restricted access. They worried that some countries would blame one another for

poor performance in the prevention and control of the ID, further imposing considerable security threats beyond the mandates of China's Center of Disease Prevention and WHO. Furthermore, there was widespread distrust in security of the transnational data, attributed to the loose state control of democracies and high cost of medical care for international students, tourists, and expatriates. Both primary care physicians and patients indicated that an independent international organization reporting to WHO should oversee the preparation and implementation of a universal ethical and legal governance framework. Primary care physicians suggested each country should establish a dedicated team to maintain personal privacy and prevent cyberattacks with inter-governmental agencies bearing the ultimate responsibility and legal regulation of the information.

DISCUSSION

Key Findings

This study reports, for the first time, qualitative data from primary care physicians and their patients on how they experienced DDS in primary care consultations and specific ethical concerns in China. The potential for DDS to disrupt

the essential but fragile trust in doctor-patient relationships in China was a primary concern, especially after hard-won gains based on updated medical training that emphasizes trust-based relationships.^{24,25} Other studies suggest that DDS introduced into primary care physician consultations without obtaining informed consent could reignite public fear and distrust of health care professionals.^{26,27} Trust is a foundation for medical consultations and highly relevant to predicting satisfactory patient outcomes.^{28,29}

Ambiguity about obtaining informed consent prior to DDS engagement in China has been highlighted.^{30,31} According to Article 13 of the “Personal Information Protection Law of the People’s Republic of China” passed in August 2021, personal information can be collected and processed without informed consent in response to public health emergencies, or for the sake of protecting citizens’ lives, health, and property.³² This is in contrast with the recent national policy changes in the hospital health care delivery system that reflect the increasing importance of engaging consumers in their own care.^{26,33} The process of seeking and obtaining fully informed consent for DDS has had vastly different outcomes globally.³⁴ Yet, the more often consent is withheld, the lower the accuracy of DDS. There is a need for a balance between an individual’s right to not give consent for DDS and public health-focused ID identification.³⁵

China’s current traffic light system of health coding, recommended by WHO for COVID-19 pandemic control, could discriminate against citizens with a yellow or red code. Engagement with DDS can contribute to social inequity by creating digital divides, particularly for some groups (eg, older people and children). The DDS accuracy is unavoidably influenced in the process of structuralizing the text data, coding the prescription data, and entering specific details of the presenting symptoms. Some cases of ID might be missed due to the limitations of artificial intelligence. This finding has also been noted in the use of digital health systems internationally, where contact tracing has exposed or exacerbated health inequities by failing to reach specific geographical areas and populations due to lack of internet access and smartphones.³⁵

Developing an Ethical and Regulatory Framework

An initial priority would be to unify data protection processes within China through regulations on data sourcing and shared responsibility for personal data by the use of strong encryption processes.³⁶ Citizens’ rights for autonomous decision making on the use of their personal information, data co-ownership, and participation in the oversight of their data must be respected.³⁷ Cloud-based data storage and sharing is the most frequently used technology to date, however a significant limitation is that patients’ rights are often ignored.³⁷ Next-generation data exchange solutions based on block chains have the potential to clarify access rights and ownership, protect data authenticity, and retain privacy. However, data processing rules such as those based on real-name authentication or facial recognition for data access must be

disclosed, and security protection measures adopted to safeguard public interests should not hinder normal personal and social lives.

Adopting patient-centered primary care models that carefully manage communication on the use of DDS³⁷ would further strengthen the doctor-patient relationship and establish transparent pathways from end users through to policymakers.⁷ Digital detection surveillance developers, data analysts, public health officials, and policymakers must also take responsibility for engaging collectively with certain groups to address the deep-rooted inequities in data set indigenization.³⁸ Furthermore, education on consumer rights, data security, and fraud detection needs to be prioritized within primary care physicians’ medical education and public awareness campaigns.

Limitations

This study has several limitations. First, involving allied stakeholders with DDS through co-design approaches could have enabled a more collective and real time development of an ethical framework than possible in the current approach. Second, some primary care physicians failed to recommend 2 patients due to high workload, thus response biases might exist which could have impacted data saturation. Third, although robust efforts have been applied to ensure translation quality, nuanced meanings in Chinese language interviews could be missed in the translation to English.

CONCLUSION

Findings of this qualitative study support the effective development and integration of an ethical framework into DDS for ID management in China. Furthermore, it is of paramount importance to establish an international ethical framework for DDS centered on patients’ rights, to steer all aspects of data collection, communication, and education. It must address privacy protection and health security and be based on principles of social equity and accountability. Public health systems in each country should work to increase the public awareness of infectious diseases and DDS for ID, and implement new technologies for ID surveillance in a more patient-centered and ethical manner.

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Key words: AI; artificial intelligence; disease outbreaks; disease surveillances; ethical issue

Submitted April 5, 2022; submitted, revised, September 26, 2022; accepted September 30, 2022.

Author contributions: W.C.W.W., E.H., A.M., and I.Y.Z conceived and designed the study. X.Q.L. helped recruitment. I.Y.Z. and Y.X.M. performed the data collection. I.Y.Z., Y.X.M., E.H., W.C.W.W., and A.M. analyzed data. All authors interpreted results. W.C.W.W., I.Y.Z., E.H., and A.M. prepared the manuscript. All authors had full access to all the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Data sharing statement: The full data set is available for review upon request to authors.

 [Supplemental materials](#)

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