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Patients as diagnostic collaborators: sharing visit notes to promote accuracy and safety

<https://doi.org/10.1515/dx-2018-0106>

Received December 14, 2018; accepted April 8, 2019

Abstract: Error resulting from missed, delayed, or wrong diagnoses is estimated to occur in 10–15% of ambulatory and inpatient encounters, leading to serious harm in around half of such cases. When it comes to conceptualizing diagnostic error, most research has focused on factors pertaining to: (a) physician cognition and (b) ergonomic or systems factors related to the physician’s working environment. A third factor – the role of patients in diagnostic processes – remains relatively under-investigated. Yet, as a growing number of researchers acknowledge, patients hold unique knowledge about themselves and their healthcare experience, and may be the most underutilized resource for mitigating diagnostic error. This opinion article examines recent findings from patient surveys about sharing visit notes with patients online. Drawing on these survey results, we suggest three ways in which sharing visit notes with patients might enhance diagnostic processes: (1) avoid delays and missed diagnoses by enhancing timely follow up of recommended tests, results, and referrals; (2) identify documentation errors that may undermine diagnostic accuracy; and (3) strengthen patient-clinician relationships thereby creating stronger bidirectional diagnostic partnerships. We also consider the potential pitfalls or unintended consequences of note transparency, and highlight areas in need of further research.

Keywords: delayed diagnoses; diagnostic error; Open Notes; patient engagement; patient-generated data.

Introduction

Theoretical accounts of diagnostic error, including proposed interventions, emphasize a tripartite division of

factors: [1] physician cognition; [2] ergonomic or “systems factors” pertinent to the physician’s work environment such as weaknesses in communication practice, poor coordination of care, and inadequacies of electronic medical records; and [3] patient-related factors such as adherence or the quality of patient symptom reporting [1, 2]. Historically, research in the field of diagnosis has overwhelmingly focused on the first two factors with the role of patients marginalized [3, 4]. Recently, however, there are signs that this is changing.

In 2015, the National Academy of Medicine’s (NAM) report “*Improving Diagnosis in Health Care*” prompted a deeper discussion about the role of patients in diagnostic processes, defining diagnostic error as, “the failure to (a) establish an accurate and timely explanation of the patient’s health problem(s) or (b) communicate that explanation to the patient” [5]. Notably, part b signals an important shift in diagnostic excellence, highlighting the patient perspective. Although there is a general consensus that engaging patients in diagnosis is a good idea, specific mechanisms to do so have been relatively lacking.

Sharing ambulatory visit notes with patients through the patient portal

The innovative idea that inviting patients to read their visit notes may improve patient care [6, 7] prompted a major study in 2010. Involving 20,000 patients, located at three U.S. healthcare centers, the study aimed to examine the effects of inviting patients to read their primary care visit notes online through the patient portal, and investigated both patient and doctor reports of the experience after 1 year [8]. Patients reported several benefits including feeling more in control of their care, better remembering care plans, and improvement in taking medications as prescribed. Initial worries among physicians about worsening workload were largely not borne out, with the majority reporting no changes to their practice and data demonstrating no change in messaging volume [8]. Since this initial study, the practice of sharing visit notes has today grown into an international movement with over 38 million patient-users in the U.S. and additional activity worldwide [9].

In 2015, the NAM cited patient access to visit notes online (“Open Notes”) as a mechanism for improving

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Box 1: Summary of 4 out of the 8 relevant goals from National Academic of Medicine Goals for Improving Diagnosis in Health Care (2016) relevant to patients as diagnostic collaborators.^a

Goal 1: Facilitate more effective teamwork in the diagnostic process among healthcare professionals, patients, and their families.

Goal 3: Ensure that health information technologies support patients and healthcare professionals in the diagnostic process.

Goal 4: Develop and deploy approaches to identify, learn from, and reduce diagnostic errors and near misses in clinical practice.

Goal 5: Establish a work system and culture that supports the diagnostic process and improvements in diagnostic performance.

^aFrom National Academies of Sciences and Medicine: Improving Diagnosis in Health Care (National Academies Press, 2016), pp. 7–18.

diagnostic accuracy [5]. Since then, national experts have issued a progress report describing open notes as a “transforming concept” in patient safety [10], and other leaders have also advocated a role for open notes in reducing diagnostic error and improving medication adherence in expert commentaries and systematic evidence reviews [11, 12]. We suggest that patients’ access to visit notes might also play a role in helping to address four of the eight goals put forth by the NAM to improve diagnostic accuracy [5] (see Box 1). In support of these claims, in this opinion paper, building on previous foundational work on building patient-clinician partnerships [3, 4, 13–15], we identify three ways in which sharing notes with patients might augment diagnostic processes. We also consider potential downsides of note-sharing and highlight research gaps in need of greater attention.

Avoid delays and missed diagnoses

Delays and outright missed diagnoses related to lack of timely follow-up and tracking of diagnostic information such as recommended tests, results, and referrals are now considered a major source of medical error. A recently published analysis of 190 diagnostic errors in primary care settings concluded that the failure to track and follow-up diagnostic information arose in 14.7% (28/190) of incidents [16]. In outpatient centers, around 7% (79/1163) of critical imaging notifications and automated abnormal laboratory results did not prompt timely follow-up [17, 18]. These findings are supported by survey research that around a third of primary care physicians admit to missing test results that lead to delays in patient care [19].

Despite a variety of recommendations to overcome delays associated with missed test results and referral follow-up [20–22], there are few readily available, practical solutions proposed in the literature. Solutions for alert

fatigue, clinical workflow, and explicit roles regarding test result management are imperative, but such approaches are ultimately dependent on technological resources which may risk further constraining physicians’ time and attention. Alongside improving physician workflow to ease the burdens and pitfalls of the diagnostic process, patients and their friends and families may also play a role in helping with test result tracking and prevention of diagnostic delay.

How access to visit notes helps: remembering and following up on next steps, including tests and referrals

Experts estimate that between 40% and 80% of information from healthcare encounters is misremembered or forgotten by patients [23]. Patients often report how difficult it is to remember what was said during the visit, especially if they are receiving unexpected or difficult news. Access to medical notes can serve as an extension to the clinical encounter. Returning to clinicians’ notes at a later time and in a more relaxed setting than the office visit can facilitate patient recall about next steps, and help to close the gap on missed tests; as one patient attested, “*Weeks after my visit, I thought: Wasn’t I supposed to look into something? I went online immediately. Good thing! It was a precancerous skin lesion my doctor wanted removed (I did)*” [24]. Making clinicians’ thought processes visible to patients not only helps with adherence to recommended tests and treatments, it can also prompt patients to follow up on test results [25]. In a survey of over 10,000 patients and family members, approximately 75% of respondents who had actual tests (4896/6622) and referrals (2294/2998) reported that reading their notes helped them to understand the rationale for tests and referrals; around half reported that reading notes helped them to get tests done (2949/6624) and remember to go for a referral appointment (1642/2998); and 75% (5166/6621) added that they were more likely to check test results after reading notes [26].

Improved access to records

Despite state and federal regulations, >80 leading healthcare organizations fall short in providing patients with reasonable and timely access to their records [27]. Lack of access to pertinent records by specialists or clinicians at different organizations is also a recognized challenge that can lead to duplication, inefficiency, unnecessary costs, and diagnostic delay. For example, in one study, 41% (1095/2644) of patients were discharged from hospital with

pending test results, yet about a third (31/105) of in-patient and primary care physicians were unaware that tests had been ordered [28]. This raises the thorny issue of who is responsible for following up on test results. Although the responsibility for informing patients about pending test results ultimately belongs to clinicians, advising patients about pending studies at the time of discharge, ways to check results on the portal, and whom to follow up with, may potentially help to prevent missed results among those patients willing and able to participate in result surveillance.

Patients who access their health information can also help clinicians in other ways. Estimates suggest that specialists lack access to patient notes in around 25% of referrals in the U.S. [29]. Ultimately, system-level interoperability solutions are needed to address these problems, though they are likely to be expensive and protracted. In the meantime, it might be valuable to advise patients who have access to their notes to share them with healthcare providers who may not be able to access their records. Paired with education and clinician encouragement, patients' access to notes may similarly help to close the gap on test results and "incidentalomas" otherwise lost to follow-up [30]. A new law in Pennsylvania requiring patient notification of abnormal imaging results resonates with this approach, **although balancing a patient's right to know and his/her potential role in safety with preventing harm from alarming findings need careful attention** [31]. While not every patient may wish to serve as the "hub" for their notes or results among various healthcare providers, online portals facilitate retrieval for those who do wish to participate in these processes.

Informing family and friend caregivers and supporting vulnerable patients

An estimated 40 million Americans serve as family and friend caregivers for vulnerable patients including the elderly, chronically ill, and those with multiple comorbidities; this number is expected to grow to 117 million by 2020 [32]. Such patients are at increased risk for inappropriate prescribing, preventable readmissions, and diagnostic errors [33–35]. Against these challenges, studies show that many patients are willing to share their medical notes with select individuals. For example, in a survey of over 18,000 veterans, 80% (14,546/18,471) expressed a desire to share their medical information with family, friends, or health providers outside their own care system [36]. Providing patients with access to their visit notes can help to accommodate these preferences.

Better access to notes also uniquely benefits family and friend caregivers by informing them about changes to a patient's medications, diagnostic findings, and any follow-up appointments – especially when they cannot accompany patients to appointments [37]. Among family and friend caregivers who reported that the patient had a note relating to a test in the previous year, 80% (96/120) reported that reading the notes improved their understanding about the rationale for tests; around half of these respondents reported that the notes reminded them to get the patient's tests done (66/120) [37]. Accessible information about specialist referrals also yielded similar outcomes: 92.3% (48/52) of family and friend caregivers of patients with referrals in the previous year reported that they better understood the need for the referral after reading the patient's notes, with nearly 70% (36/52) agreeing that the note helped them to remember the patient's appointment [37].

New research also hints that reading visit notes may benefit those who are most at risk of harm from diagnostic error [38]. For example, in one study of approximately 7000 patients in one healthcare center, nonwhite or less-educated patients were more likely than white or better-educated patients to favor note sharing. Compared to their counterparts, these patients were two to three times more likely to report that access to notes is "extremely important" to engage in their care. The majority of nonwhite or less-educated patients reported that reading their notes helps them to remember their care plan, as well as to better understand the provider's thought process [38]. But data regarding the impact of shared notes on traditionally more vulnerable populations are scant. Portal registration rates are lower for such patients, and more research is needed to better understand their experiences, preferences, and needs.

Identify documentation errors

Traditionally, human errors in record-keeping include omissions, oversights, and inaccuracies. Nowadays, electronic health records (EHRs) have given rise to a new breed of vulnerability via the propagation of "cut/copy/clone" documentation errors [39]. Although EHRs were intended to improve safety, some contend that they may contribute to errors such as faulty medication updates and prescriptions, mistakes related to test ordering, or erroneous data migration upon EHR vendor changes [40]. A recent survey reported that a quarter of primary care physicians anticipated that, if given access to their notes, patients

would find significant errors in them [41]. While some mistakes in documentation are unlikely to harm patients, others, such as wrong side documentation, inaccurate family history, wrong test results, faulty test ordering, or notes entered about the wrong patient have the potential to significantly impact care and increase the likelihood of missed or delayed diagnoses. More problematically, even if clinicians had the time to double check every patient's record, they could miss mistakes that a patient could catch because the patient holds unique knowledge about their symptoms and the course of their illness, and patients are unlikely to confuse their own history with that of another patient.

How access to visit notes helps: “more eyes on the charts”

Patient access to their notes has the potential to improve the accuracy of records because it allows each individual to review one chart (his or her own), rather than relying on a clinician to review thousands of charts. While not all patients may be receptive to what is contained in their notes – for example, some patients may disagree with the reporting of their symptoms or even their diagnoses – data suggest that among patients who access their visit notes, a substantial proportion are willing to engage with their medical notes with the explicit goal of safety advocacy. For example, of 4500 survey respondents who read at least one medical note during a 12-month period, around one third reported the reason for reading their notes was specifically to check for accuracy [41]. Among the 7% (331/4592) of patients who reported contacting their physician's office about a note, over a quarter perceived an error, and 85% (231/331) reported satisfaction with how the matter was resolved [41]. As one patient described it, “*Reading my notes allows me to see how well I'm communicating my issues, which leads to how well my doctors are hearing and documenting my issues. It also allows me to catch errors*” [25].

Family and friends too can help identify documentation errors, perhaps with the potential to offset harm, considering the high stakes of inaccurate medications, delayed diagnoses, and costly preventable admissions, among vulnerable patients [37]. One family caregiver commented, “*We are grateful to receive ‘notes’ to be able to review the visit and procedures (if any) performed. [Notes are] especially helpful for older patients who may have hearing and/or cognitive [or] memory loss*” [25]. Patients also express the benefits of sharing notes; for example: “*It really is much easier to show my family, who are also*

my caregivers, the information in the notes than to try and explain myself. I find the notes more accurate than my recollections” [24]. In one small survey, nearly one third of surveyed family and friend caregivers perceived at least one possible mistake. These included inaccurately documented symptoms, medications, and accounts of the patient's family history [37].

Encourage patient and friend/family caregiver feedback: a “learning EHR”

A pilot quality improvement initiative using a patient reporting tool which specifically requested patients to provide feedback on possible mistakes in their notes found that 21% (55/260) of patient reports included possible mistakes (such as perceived medication errors, missing information, and inaccuracies in personal history or family medical history) [42]. Upon clinician review, 64% (38/59) of these reported concerns were classified as either “definite” or “possible safety concerns” with over half (57%) (29/51) directly resulting in amendments to patients' medical records or their care [42]. Anecdotal reports from physicians support these experiences with “more eyes on the charts” identified as one of the “best things” about patients' access to their medical notes: “*[I] felt like my care was safer, as I knew that patients would be able to update me if I didn't get it right*” [24].

Combined, these findings resonate with other studies demonstrating that patients and their caregivers can identify documentation errors – including mistakes that are imperceptible to clinicians [43–45]. The need to harness patient, family, and caregiver feedback is an essential step to “close the loop” in a “learning EHR” – one in which mistakes can be identified and corrected; such feedback may also facilitate clinician recalibration about diagnostic decisions [46]. Notwithstanding these encouraging results, we also flag up the potential danger of physicians depending on patients to check the accuracy of medical records [47]. While we think it unlikely that physicians might become careless as a consequence of relying on patients to check for mistakes in their notes, we emphasize that the responsibility for accuracy still lies with the clinician, and the long-term effects of sharing visit notes on the quality of physician reporting will require future analysis. We also uphold expert views highlighting “differences between *relying* on patients to check on the delivery of their healthcare to ensure their safety and *involving* patients in their care while efforts are made to improve their safety [48].”

Strengthen the patient-clinician relationship

Sharing visit notes not only presents a tangible step toward transparency, it may also promote trusting relationships between patients and clinicians [26]. Promotion of trust is especially important to empower patients as members of their own healthcare team who can provide valuable feedback on their care. Although patients are not always the foremost experts on interpreting their own symptoms, many, especially those with chronic illness, have unique knowledge related to their clinical course. In addition, patients' first-person experiences of their health mean that they are well placed to help clinicians judge the accuracy of diagnoses and the success of recommended treatment plans. However, finding tangible ways to empower patients as a means to promote such feedback has remained a longstanding, elusive goal of medicine.

To date, proposed strategies have tended to focus on patient self-advocacy, such as a checklist of questions to ask clinicians, or directives to improve communication style (e.g. "Tell your story well", "Be a good historian") [49, 50]. But training campaigns that target patient self-advocacy may unfairly shift the burden of responsibility, particularly for individuals from already disempowered, demographic groups [51–54]. Even among empowered patients, a rushed office visit can make it difficult to ask questions, remember the details of the visit, and ensure that one's story is correctly heard.

How access to visit notes helps: "extending the visit" and unburdening patients

Reading visit notes may help to strengthen face-to-face interactions by relieving performance anxieties within time-pressured consultations. Patients are no longer burdened with memorizing visit information or taking notes. As one patient said in an interview, "...*It allows me to be more present, ...to ask more thoughtful questions ...because I know that note is coming*" [55]. Patients can digest the clinician's thought process at their own pace and leisure [37, 38, 41]. This subtly but importantly shifts the focus from educating patients to *tell their story well*, to assessing whether the clinician heard them correctly and *captured their story well*. However, this process is not always straightforward. Patients and clinicians may disagree about what was said (by either party) or how they remember the visit. Indeed, it may also be the case that physicians capture accurately what is communicated to

them at the visit but upon reading their notes, patients recognize that they themselves have omitted or failed to fully describe some details about their health. In such cases, while the discrepancy does not reflect an error per se, patient follow-up may be helpful to provide a more accurate medical record.

As health information transparency grows, patients will need a clear system and clinician encouragement to report potential errors in their records and their diagnostic pathways, especially when they arise in the space between visits, and health systems will need to find ways to respond meaningfully to these reports while avoiding further clinician burden, to improve individual patient care. Aggregate patient reports also represent an important opportunity for organizational learning and safety improvements [56]. Forging effective safety partnerships with patients and families will require concerted efforts including broad outreach, education, and mechanisms to adjudicate disagreements.

Relational benefits: trust, teamwork, and goal alignment

Despite clinician concerns about disagreements, evidence suggests that sharing notes has an overall positive impact on the relational aspects of care, and may especially benefit vulnerable patients [37, 38]. Many who read their clinicians' notes feel listened to, validated, and understood; they express appreciation for the provider, noting the time spent on writing detailed notes and "knowing them" so well [25, 41]. A major patient survey at three U.S. sites found that 37% (1699/4592) of patients felt better about their doctor after reading their notes [with 62% (2847/4592) expressing no difference]; among older, male, nonwhite, less-educated, or those with poorer self-reported health, reports of positive feelings were higher, at 42–44% [41]. Sharing notes that reflect patients' values and priorities and foster patients' sense of "belonging to the team" may help build positive relationships. Sharing notes also appears to enhance patient trust in physicians [41] – a factor which, a recent meta-analysis shows, is correlated with improved health outcomes [57].

By strengthening the patient-provider relationship, alongside greater patient understanding of their health conditions and how the clinician thinks, access to visit notes may provide a mechanism for patients to provide diagnostically valuable feedback to clinicians [42]. In a survey of over 10,000 patients and families, 97% (8645/8879) reported that trust in the provider, alignment of goals, and teamwork were better or the same after

reading one or more notes [26]. Notably, caregivers who found possible errors in patients' notes, reported little or no negative impact on their trust or level of teamwork relationship with the clinician [37]. Nonetheless, while misinterpretation of visit notes does not appear to be prevalent among survey respondents, we caution that even minimal risk of confusion among patients accessing their medical notes cannot be ruled out and must not substitute for careful collaboration and effective communication by physicians in clinical encounters [58].

Limitations, additional potential drawbacks, and research priorities

While evidence suggests some promise in enhancing diagnostic partnerships between patients and physicians, and in reducing diagnostic errors via provision of access to visit notes (Table 1), limitations with prior survey research and its synthesis in this article are worth emphasizing.

So far, published research into patient access to notes has been conducted at a limited number of hospitals or medical centers, restricting the generalizability of the findings. As with all self-administered surveys, the results

are dependent on self-report, and biased by individuals who were activated to use the portals, as this is the platform through which notes are available. Therefore, to strengthen the findings, more research is needed to investigate the effect of sharing visit notes on diagnostic processes among broader patient populations.

We propose the following four steps: First, greater clarity, organizational structure, and educational support are required to establish pathways for the follow-up of test results and feedback on potential documentation errors when patients have access to their notes. Well-advertised, user-designed systems should invite but not rely on patient feedback about perceived errors, avoid overwhelming already over-stretched and over-burdened clinicians, and ensure patients are not frustrated by lack of ineffective organizational responses to those they report.

Second, further research is needed to optimize the benefits of shared notes for more vulnerable populations, such as effective mechanisms to drive portal registration and use. This will require a better understanding of the relationship between patient demographics, health literacy, language of choice, mental health, privacy concerns, the barriers to providing feedback, and the solutions to overcome them [59–61]. For example, it is conceivable that some patients, perhaps especially those from vulnerable demographic groups, may have different experiences with or interest in note sharing. Others may prefer a phone call, or even another face-to-face visit. Indeed, the goal of sharing visit notes would be to extend the visit, not replace it, and lost face-to-face time would be an unintended negative consequence. Further research might usefully identify those patients who feel less comfortable accessing their medical notes, and the reasons for it. In addition, characterizing patient and provider attitudes about patient contributions to diagnostic accuracy may also help uncover unrecognized barriers, and inform strategies to (a) support patients speaking up about mistakes as well as undiagnosed symptoms, and (b) enable clinicians to respond effectively when they do so. In the interim, we suggest that alongside educational outreach and end-user portal redesign, a strong message from providers encouraging portal registration and welcoming patient feedback might go some way to mitigating any such reticence [26, 62–64].

Third, although the function of medical records has evolved throughout medical history to serve new purposes – for example, to inform other physicians and specialists about patients, and for supporting billing or legal procedures – the potential for patients to read their notes may engender subtle changes in physician reporting [8]. Some contend that a single note cannot reasonably serve so

Table 1: How sharing visit notes might reduce diagnostic errors.

Avoid delays and missed diagnoses
Improve patient understanding about the rationale for tests and referrals
Enhance recall of next steps, including tests and referrals
Enable information access for patients and clinicians; bridge EHR interoperability problems
Inform caregivers
Better support more vulnerable patients
Identify documentation errors
Enable patients and caregivers to check notes for documentation errors that may affect the diagnostic process, including reporting of symptoms, medications, past medical history, family history, and tests/referrals
Encourage patient and caregiver feedback to promote a “learning EHR”
Strengthen patient-clinician relationship
Unburden patients in the visit from trying to remember all the encounter details so they can be more “present” and interactive
Enhance patient trust, teamwork, and goal alignment with clinicians
Engage minority and less educated patients
Create a transparent environment supporting speaking up about concerns, mistakes, incomplete care plans, or undiagnosed symptoms

EHR, electronic health record.

many audiences, inviting reconsideration of its purposes and the regulations surrounding visit notes. Some physicians report a change of documentation practices when addressing sensitive issues such as weight; for example: replacing “obesity” with objective “body mass index” reporting [8]. Whether such subtle modifications in language influence patient behavior and clinical outcomes; interfere with the quality of record-keeping; or negatively affect clinician-to-clinician information sharing, has yet to be explored. Of course, as patients have a legal right to their records by the Health Insurance Portability and Accountability Act (HIPAA) of 1996, clinicians should already be writing notes mindfully. But the effect of broad, rapid, and easy access to notes on documentation behaviors and note quality (for better or worse) merits dedicated study.

Finally, establishing further data on the effect of sharing notes on outcomes such as delayed diagnoses, claims, and lawsuits may also create further organizational urgency for transparency, but will require development and application of consistent metrics for diagnostic error [65, 66].

Using open notes as a springboard for further engagement should be explored. Future research might include sharing in-patient notes [67] and even co-producing notes with patients and caregivers, potentially offsetting clinician documentation burdens and further expanding the horizon of patient and family engagement in diagnosis and care [60].

Conclusions

Patients, and their families or friend caregivers, are the biggest stakeholders in the accuracy of the diagnostic process. In light of the NAM definition of diagnostic error and its focus on the patient perspective, the involvement of patients and caregivers is crucial to tackle mistakes, gaps, and oversights in diagnostic reasoning. Sharing visit notes with patients provides a scalable way to extend the visit by enabling patients to access and reflect on information at a more leisurely pace. The invitation to read notes may empower patients and caregivers to become safety advocates by enabling test and referral adherence; facilitating identification and reporting of documentation errors, including mistakes which may be imperceptible to clinicians and can also affect the diagnostic process; and building stronger patient-clinician partnerships. Reaping the full potential of sharing access to visit notes on patient safety and diagnostic accuracy, however, will require

educational innovation and challenging age-old hierarchies in medicine to create a far more collaborative relationship between patients and their providers.

Acknowledgements: We thank Catherine DesRoches, Jan Walker, Tom Delbanco, and the clinicians and patients who shared their insights on sharing notes. We also thank the three reviewers and the editor for helpful feedback on an earlier draft of this paper.

Author contributions: All the authors have accepted responsibility for the entire content of this submitted manuscript and approved submission.

Research funding: CB was funded by the Irish Research Council-Marie Sklodowska Curie Global Fellowship, Grant Number: CLNE/2017/226. SKB was funded by: Robert Wood Johnson Foundation (Grant #73038); Gordon and Betty Moore (Grant #4926); Peterson Center on Health (Grant #16019); Cambia Health Foundation (Grant 28584).

Employment or leadership: None declared.

Honorarium: None declared.

Competing interests: The funding organization(s) played no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the report for publication.

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