Improving TeleDiagnosis: A Call to Action

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Conversations with Patients

Problem

Over time, with the advent of institutions like PCORI, patients have played an increasing role in the design of the healthcare systems and modalities that serve them. With that shift in mind, it is interesting to consider how patients and families view the current situation in which, thanks to the COVID-19 pandemic, in-person appointments with primary care providers have been replaced by telehealth. Although patients are the ultimate consumers of telehealth, they have had virtually no input into how it works so far, or how it is used. What do they think of this new approach? In this brief we will examine the patients' perspective on the use of telehealth for diagnosis. Yes, it provides safety from COVID-19 transmission, but what else? Do they like it? Is it easy to use? Does it meet their needs? How is it impacting the quality and safety of their health care? And what would they change, if they had the chance?

In this series of 'Conversations" we are seeking to learn how all of the different stakeholders involved view this new modality of healthcare delivery as it applies to diagnosis. Telehealth changes almost every single aspect of the diagnostic process, and the effect these changes impart on diagnostic outcomes is not known. (1) We have previously considered telediagnosis from the perspectives of hospitals, health systems, and clinical practices (2), clinicians (3), and telehealth vendors and companies (4). In this fourth *Conversation* brief, we report on the experiences and concerns of patients using telehealth for diagnosis in ambulatory care settings. Findings from the recent literature, and interviews with patients are presented, again using the RE-AIM framework (**R**each, **E**ffectiveness, **A**doption, **I**mplementation, and **M**aintenance and future prospects) to organize discussion topics.(2)

Reach

> ***"How many lives could be saved – for those with any type of hard-to-diagnose, stigmatized, or rare condition–through the use of telediagnosis?"***

Key findings from the literature: The COVID-19 pandemic of 2020 set the stage for an explosion of telehealth utilization throughout the United States. Over a period of just a few months, virtually every healthcare organization expanded their telehealth offerings, and hundreds of millions of patients made their first telehealth visit.

Telehealth has been a staple for certain rural patients for many years, but the reach of telehealth in 2020 expanded dramatically to include not only savvy young urban patients, but a much broader spectrum of patients nationally, including the elderly and low-and-middle income patients. In a report subtitled "From Safety Net to Solid Ground" the Robert Wood Johnson Foundation reported that one in three Americans used telehealth in the first six months of 2020, and even among the elderly, uptake was rigorous; nearly half of patients on Medicare or Medicaid had used telehealth.(3) Similarly, a poll from the University of Michigan found that a third of elderly patients had participated in a telehealth visit as of mid-2020, compared to 4% in 2019. (4)

"These are populations that traditionally we don't think of as having the fanciest technology access, but they all had access to smartphones" .(5) Another clinician noted that:

"Historically, we had to deal with older folks who may not be able to drive and older folks who would have difficulty finding a parking space. If the weather was bad, some older folks did not want to go to a doctor appointment. But now with telehealth, that situation has been resolved."(6) Another novel finding was that many younger patients were using telehealth for mental health counseling, a population that hadn't used health services of any sort pre-pandemic.(3)

Many other reports took the 'glass is half empty' perspective, acknowledging the broad uptake of telehealth, but noting that disparities have become particularly evident.(7) Proportionately, the elderly, children, and individuals in low-income counties and rural areas have been less likely to be telehealth users. In one example, a detailed study of telehealth users of the University of Pennsylvania Health System found that elderly and non-English-speaking patients were less likely to have had a telehealth visit of any sort, and that older, female, black, LatinX, and poorer patients were less likely to have had a video visit.(8)

Suboptimal use by the elderly has received the most attention. It is not just their limited digital literacy that explains this; other factors include a lack of internet access or 'smart phone' technology, and physical limitations including hearing impairment or cognitive issues.(9)

Finances may impose an additional constraint, because video visits come with a cost in terms of chewing up data-plan allowances. Roughly one third of elderly patients are left out the virtual healthcare world. "As long as clinics remain virtual, older patients can't get in. It's like having a clinic up a flight of stairs with no ramp or elevator."(10)

What we heard: Almost all the patients we spoke with were very comfortable accessing telehealth services however, many of them referenced family and friends who had significant challenges in participating in such appointments. Most of the examples provided were individuals who were older and did not have a lot of experience working with technology. Even though many of them had smartphones, they did not understand how to utilize the technology. One of the patients we spoke with suggested that patients should be provided with training on how to utilize the telehealth options within their health system or practice. This echoed sentiments from previous conversations with clinicians, who noted that training on the use of technology needs to meet the end-user where they are.

Although accessing technology was challenging, all the patients felt that appointments were more convenient since many of the barriers to care were overcome, such as lack of transportation, and the time spent in traffic or in the waiting room. And it is not just the convenience – patients also like the efficiency and the comfort of virtual video visits, not to mention the cost saving if they don't have to pay for parking and gas.(11) One patient noted the increased family and caregiver support engendered by telemedicine. During COVID, in-person visits were typically limited to just the patient, without a care partner. However, with the use of telemedicine, care partners were able to be present during the appointment and actively engaged in discussion with the physician.

Effectiveness

Key findings from the literature: Studies on health outcomes of telehealth users have yet to be published, but a growing literature points to very high levels of satisfaction among most users. Obviously,

a key factor during the COVID pandemic was the safety factor – a virtual visit obviated the need to take public transportation, sit in a waiting room with other people, and be exposed to potential infection from every contact. But beyond safety, patients liked it – especially the convenience and the time savings.(12) A Press-Ganey survey of over 1.2 million patients found that patients appreciated both the convenience and the intimacy of telehealth encounters.(13)

Satisfaction was high even among the elderly; in one study of telehealth users in an emergency-department setting, a third were elderly and their satisfaction and quality assessment scores were similar to that of younger patients.(14) Another study of elderly patients said that the time they spent with their virtual providers was comparable to in-person care, but they were concerned about quality: two-thirds felt that the quality of care was better in-person.(4)

An interesting paradox noted by Zulman and Verghese was that the technology that enabled telehealth provided a pathway for patients and providers to stay connected during the isolation of the COVID-19 pandemic. Beyond that, the intimacy provided by eye-to-eye contact and seeing the patient in their home setting acted to enhance the connection between patients and their clinical providers.(15) This was in stark contrast to the impact of the technology represented by the electronic medical record over the past decades; the EMR was perceived to be a barrier, or least a distraction, to effective patient connection.

Patients also expressed dissatisfaction with telehealth. At least one patient openly admitted she missed the familiar surroundings of the physical waiting room – it just wasn't the same on a video platform.(16) A more important concern was that the quality of care was not the same; one study found that two-thirds of users felt that the quality of care was better in-person.(4) Many patients have also voiced concerns about privacy, challenges using the technology, and the limitations on care imposed by not being able to conduct a full physical examination. (Figure 1)

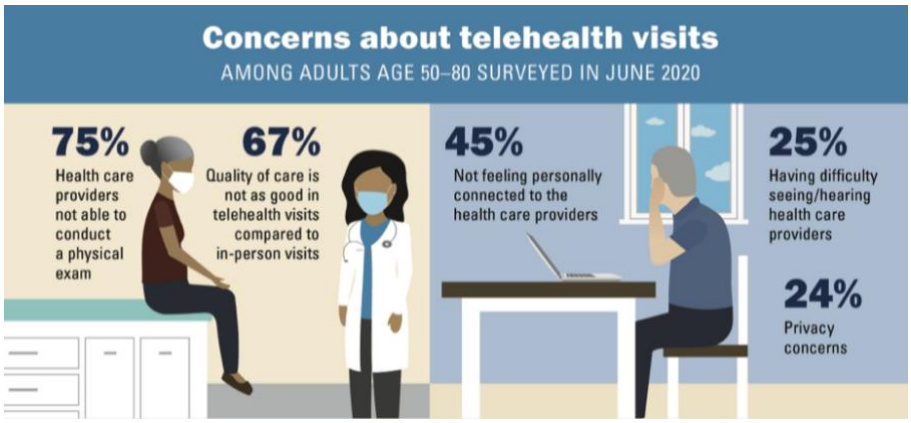

Figure 1: From Malani et al. 2020. Telehealth Use Among Older Adults Before and During COVID-19(4)

What we heard: Our discussions with patients echoed what was found in the literature. Most felt that the effectiveness of the appointment and subsequent diagnosis was contingent upon the symptom or condition. They all agreed that many times, certain conditions simply couldn't be adequately assessed without a physical examination. There were other times when additional blood work or imaging was required to allow for a more accurate diagnosis, in which case several patients preferred to just move

forward with an in-person visit—wondering why they should "bother" with a virtual visit first. All of them patients felt more confident in the effectiveness of the appointment when they had an existing relationship with the provider.

Overall, the patients felt as if virtual visits functioned well in terms of receiving an appropriate diagnosis and treatment plan. One minor exception was a sense of surprise and disappointment when some of their virtual appointments with a physician ended abruptly, with no other office staff coming on to the call. Patients were accustomed to a different experience with their in-person visits; after seeing the physician they would interact with a nurse and the office staff to arrange follow-up arrangements.

Only a few of the patients we spoke with had received a survey after their telehealth encounter. Of the ones that were asked for feedback, they all agreed that the questions were not specific enough to truly evaluate the effectiveness of the telehealth appointment. Many patients had concerns about how we will ultimately know if telemedicine "works" for diagnosis. Some articulated a clear sense of knowing which symptoms would automatically trigger an in-person visit, but they also admitted that for many other symptoms or presentations they weren't sure whether in-person evaluation would be important.

One limitation of this project is that we only spoke with telehealth users; none of our interviews involved non-users, who likely would have presented very different impressions about telehealth as a replacement for in-person care. Of major concern are the many patients who just 'dropped out' of the healthcare system entirely during the COVID pandemic. According to data from the Rand Organization, in-person care in outpatient settings declined by over 50% during the COVID-19 pandemic, only two-thirds of which was replaced by virtual visits.(17) It will be important moving forward to understand who telehealth is "missing" and why, and how to best architect the system—with patient input—to be most receptive and responsive to patient needs.

Adoption

Key findings from the literature: Implementing telehealth services was an enormous, costly, and challenging endeavor for healthcare providers nationally; some had dabbled in it previously, but for most, enabling telehealth visits was a novel undertaking, especially at the grand scale that was ultimately needed. In contrast, implementation on the patient side was either black or white. Engaging in telehealth was largely painless for most of those with smart phones or digital access, or impossible for those without, the 'digital divide'.

In isolated cases, it was the healthcare organization, not the patient, that was late-to-the-table.(18) In June of the COVID-19 year, less than 1% of telehealth engagements by Cambridge Health Alliance in Boston were conducted using video, and a large predominance of audio-only visits were also noted by New York Health and Hospitals, the largest safety net system in the country.(18)

What we heard: The patients echoed that successful implementation seemed to be dependent on how well the health system or practice had been previously using telehealth. The systems and practices that had already been utilizing telehealth, even if only to a small extent, were able to more quickly scale-up the usage. Although implementation was sometimes rocky over the first few months, by mid-year most patients felt that their telehealth encounters went smoothly. Many patients felt like providers were more polite and more focused on the discussion through telehealth, and as mentioned above, more engaged and 'connected'.

Patients also noted frustration with telehealth on occasion, especially when the technology was balky, or the physician was interrupted or seemed distracted during the encounter. Some commented that their virtual visits discouraged their connections to other members of their healthcare team. Interactions with nurses, nutritionists, social workers, or other members of the clinical care team that they were accustomed to having with in-person visits were conspicuously absent in the virtual environment. On the plus side, however, patients appreciated that the absence of the usual team also meant that they didn't have to repeat telling their story to three different people during the same visit. One patient did express how frustrating it was when the doctor was not focused on the patient, due to interruptions taking place in the environment in which they were working. This depending largely on whether the clinician was working from a clinical office or hospital environment versus at home. Patients

More than one patient commented that a virtual visit was sometimes more complicated than an in-person encounter because of the extra steps that were required post-visit, like going somewhere else for an Xray or blood tests, or for an in-person evaluation. In contrast, in-person appointments had value to the extent that they allowed 'one-stop-shopping', where all of these could be accomplished in the one setting. As a consequence, one patient with a chronic condition found herself not attending appointments as diligently as she previously had.

Maintenance

Key findings from the literature: Telehealth usage during the pandemic year looks like a mountain peak. According to Press Ganey data covering over 1.3 million patients, usage rose from near 0 usage in January to the peak of 37% in May, with a gradual fall-off over the last half of 2020 and leveling off in the mid-teens.(13)

The telehealth phenomenon has already sparked innovation in several areas. One example is how it has fostered patient engagement in co-creating the virtual visit note.(19) Another area seeing great interest is "m-Health", where health-related devices can be used at home to augment a virtual visit or replace elements of the physical examination. New products are appearing every week that will take your vital signs, look in your ears, or listen to your lungs.

What will become of many patients' affinity with telehealth in the future? A telling report from a mature telehealth system found that over a period of years interest faded, and users became more critical of the system's complexity and flaws.(20) The future of telehealth is likely to see services become more specialized or more sophisticated for certain clinical specialties. A need for special applications for women has been identified, as an example.(21)

It seems likely that in-person care will again become the norm as the COVID pandemic diminishes, but that telehealth will remain an important and desirable option for certain circumstances (eg triage, follow-up care), certain patients, or certain specialties. Even CMS has concluded that "the genie is out of the bottle", and there will be no turning back.(22)

What we heard: All of the patients we spoke with believed that they would continue to use telehealth in the future but planned to couple that with in-person visits.

One patient used a very helpful analogy; just like people have different learning styles (visual, tactile, audial), patients may want to select the type of care they prefer based on the same type of criteria.

One patient was clear that she felt a telehealth appointment for diagnosis was less effective because the best path to diagnosis is a physical exam. He lamented that someday, when we all have gizmos at home so you can do an ECG or listen to the lungs, it might be better. However, at the present time, he felt it is not a viable substitute for 'being there'. However, we did hear from several patients who were already using digital tools at home. They were doing blood pressure readings or measuring pulse ox numbers and sending information to their clinicians. One patient was utilizing a specific app to help monitor diabetes and hypertension.

Over the course of our conversations, we learned that there are a wide range of platforms being used to conduct telehealth visits. For example, the modalities many of us have begun to use for work or even personal virtual meetings are appearing in healthcare settings. Some of the platforms integrated effectively with the electronic medical record system, while others did not. For patients with complex medical needs and multiple providers, they were often forced to interact with multiple electronic records platforms and multiple virtual platforms which created additional burden and frustration for the patient.

At the current time, none of the patients we spoke with expressed any specific challenges related to insurance coverage of telehealth appointments. They all just hoped that some form of virtual care would continue to be available into the future. One of the most vivid passages from the many patient conversations came from someone with cancer who helps other patients navigate diagnosis and treatment. She shared how often she meets people who were diagnosed "too late", often because of embarrassment about the type of screening required, or even not wanting to discuss the relevant symptoms at a clinic visit. She wondered how many lives could be saved—not only for people with this type of cancer, but for those with any type of hard-to-diagnose, stigmatized, or rare condition—through the use of telediagnosis. It could connect patients with specialists a world away and obviate some of the embarrassment of in-person discussions about intimate symptoms.

Conclusion

Understanding the barriers to and facilitators for rapid adoption of telehealth for diagnosis is key to promoting high quality diagnosis and ultimately, optimal patient outcomes. Through a series of conversations with providers from clinical practices, hospitals, and health systems, and an in-depth review of current literature, we were able to elucidate some early trends in **R**each, **E**ffectiveness, **A**doption, **I**mplementation, and **M**aintenance (including trends and future directions, using the RE-AIM framework. Future listening sessions with clinicians, representatives from telemedicine companies, and patients are planned for later this year.

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REFERENCES

1. Smith K, Singh H, Goeschel C, Graber M. Telediagnosis for Acute Care - Implications for the Quality and Safety of Diagnosis. 2020.
2. Glasgow R, Harden S, Gaglio B, Rabin B, Smith M, Porter G, et al. RE-AIM Planning and Evaluation Framework: Adapting to New Science and Practice with a 20-Year Review. Frontiers in Public Health. 2019;7:Article 64.
3. Smith L, Blavin F. One in Three Adults Used Telehealth during the First Six Months of the pandemic, but Unmet Needs for Care Persisted. Robert Wood Johnson Foundation; 2021.
4. Malani P, Kullgren J, Solway E, Buis L, Singer D, Kirch M. Telehealth Use Among Older Adults Before and During COVID-19. Ann Arbor, MI: HealthAging.Org; 2020.
5. Reuter E. For underserved patients, the promise of telemedicine still holds. 2021;Available at: https://medcitynews.com/2021/01/for-underserved-patients-the-promise-of-telemedicine-still-holds/.
6. Cheney C. Telemedicine with your older patients. Available at: https://wwwhealthleadersmediacom/clinical-care/how-use-telemedi. 2020.
7. Clancy C, Kirsh S. Virtual Care and the Pandemic: Are We Reaching All Patients? Ann Int Med. 2020;M20-5593.
8. Eberly L, Kallan M, Julien H, Haynes N, Khatana A, Nathan A, et al. Patient Characteristics Associated With Telemedicine Access for Primary and Specialty Ambulatory Care During the COVID-19 Pandemic. JAMA Netw Open. 2020;3(12):e2031640.
9. Lam K, Lu A, Shi Y, Covinsky K. Assessing Telemedicine Unreadiness Among Older Adults in the United States During the COVID-19 Pandemic. JAMA Intern Med. 2020;180:1389-90.
10. George J. Telehalth Boom Misses Older Adults. Medpage Today. 2020(August 4):Available at: https://www.medpagetoday.com/practicemanagement/telehealth/87901.
11. Powell R, Henstenburg J, Cooper G, Hollander J, Rising K. Patient Perceptions of Telehealth Primary Care Video Visits. Am Fam Med. 2017;15:255-9.
12. Powell RE, Stone D, Hollander JE. Patient and Health System Experience With Implementation of an Enterprise-Wide Telehealth Scheduled Video Visit Program: Mixed-Methods Study. JMIR Med Inform. 2018;6(1):e10.
13. Dudley J, Sung I. What patients like - and dislike - about telemedicine. 2020:Available at: https://hbr.org/2020/12/what-patients-like-and-dislike-about-telemedicine.
14. Greenwald P, Stern ME, Clark S, Sharma R. Older adults and technology: in telehealth, they may not be who you think they are. Int J Emerg Med. 2018;11(1):2.
15. Zulman D, Verghese A. Virtual care, telemedicine visits, and real connection in the era of COVID-19. JAMA Dermatol. 2021;325(5):437-8.
16. Scott-Vernaglia S. I Miss the Waiting Room. Medscape, Jan 23. 2021;Available at: https://bit.ly/2UE6hrx
17. Cantor J, McBain R, Pera M, Bravata D, Whaley C. Who is (and isn't) receiving telemedicine care during the COVID-19 pandemic. AJPM. 2021;doi.org/10.1016/j.amepre.2021.01.030.
18. Horn D. Telemedicine is booming during the pandemic. But it's leaving people behind. Washington Post. (July 9):Available at: https://www.washingtonpost.com/outlook/2020/07/09/telemedicine-is-booming-during-pandemic-its-leaving-people-behind/.
19. Kriegel G, Bell S, Delbanco T, Walker J. COVID-19 as innovation accelerator: Cogenerating telemedicine visit notes with patients. NEJM Catalyst. 2020;DOI: 10.1056/CAT.20.0154.
20. Lemon C, Liu N, Lane S, Sud A, Branley J, Khadra M, et al. Changes in User Perceptions of a Telemedicine System Over Time: From Initial Implementation to Everyday Use. Telemed J E Health. 2018;24(7):552-9.
21. Goldstein KM, Zullig LL, Dedert EA, Alishahi Tabriz A, Brearly TW, Raitz G, et al. Telehealth Interventions Designed for Women: an Evidence Map. J Gen Intern Med. 2018;33(12):2191-200.
22. Dyrda L. 'The genie's out of the bottle on this one': Seema Verma hints at the future of telehealth for CMS beneficiaries. 2021;Available at: https://www.beckershospitalreview.com/telehealth/the-genie-s-out-of-the-bottle-on-this-one-seema-verma-hints-at-the-future-of-telehealth-for-cms-beneficiaries.html.

Discussion Participants

The patient listening session participants came from an array of backgrounds, geographic locations, and experiences. Some individuals were caregivers to children or spouses, others had experience with chronic, serious conditions, and many had extensive experience navigating the healthcare system and supporting other patients in their diagnostic and care journeys. In addition to those listed below, two more patients participated but preferred to not be named. We are very grateful for all of our discussants' time and expertise!

Anne Richard

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