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Viewpoint

Visibility Versus Privacy of Physicians in the Age of Social Media

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Abstract

As access to the internet has grown over the years, social media has become an important resource in the health care sector. Third-party physician-rating websites in particular have gained popularity. However, there are ethical implications of such websites. These websites provide a platform for patients to evaluate and review physicians and likewise increase visibility and advertisement of physicians, but they also violate the rights to privacy that these doctors should have. This paper aims to study and assess the ethical implications of these websites on the visibility and privacy of physicians. After presenting the ethical dilemma associated with such websites, it provides guidelines that can be incorporated by both physicians and third-party sites to help maintain physician privacy while providing public service in the form of advertisement and visibility.

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KEYWORDS

social media; privacy; internet

Introduction

Social media websites have become the new norm throughout our society. Readily available, these sites allow users to contribute, retrieve, and explore content. In the medical world, patients are increasingly relying on the internet to search for health information and inquire about health care providers [1]. Physician-rating websites in particular have grown over the years in the United States, providing patients with an avenue to influence the quality of care provided by physicians and their services. These websites come in a variety of forms and are often found in the United States as separate, third-party rating sites exclusively reviewing physicians or as hospital staff directory websites with health care-related surveys and reviews addressing patient experiences with their physicians. Many hospital systems and clinics utilize their own sources like Press-Ganey studies as internal tools [2,3], but third-party physician-rating websites have recently gained a large online presence and are the primary concern of this article. There are currently >60 third-party physician-rating websites, of which Google, Healthgrades, Vitals, Rate MD, and Yelp were noted to be among the most frequently visited [4-9]. Yelp and Healthgrades appear to be the most popular [9]. In 2010, Lagu

et al [7] conducted a study in which they found that 88% of Americans used the internet to search for health-related information, out of which approximately half searched for their physicians. Over 90% of physicians are also noted to have their professional information available online, much of which is found on these websites [10]. These websites function to not only provide basic information regarding individual physicians but also enable users to enter and view reviews for specific physicians. Physician details such as personal demographic information (ie, name, address, phone, specialty, education, links to practices and professional affiliations, licenses or board certifications, insurance coverages) along with structured review questions involving care, accessibility, communication, professionalism, and billing are often provided [11]. With the growth of the internet, consumerism, and social media in recent years, further utilization of such sites has already occurred and will inevitably continue to expand [4]. Emmert et al [5] looked at the impact physician-rating websites have upon selecting a certain physician. Their study found that 65.4% and 52.2% of survey participants selected and rejected, respectively, a particular physician based on ratings shown on physician-rating websites. Similar findings of these websites swaying public opinion in regard to physician experiences were corroborated in a later investigation by Emmert et al [12] as well. In another

study, physicians themselves were asked about their thoughts regarding the effect of publicizing patient opinions; 78% of surveyed physicians acknowledged that posting patient experience data publicly would negatively affect their job-related stress [13]. Suffice to say, social media has the power to shape a physician's professional identity and experience. With the rise of online reviews and their consequences, it is pressing to understand the implications that these websites have upon physicians. While they provide a platform for advertisement and branding that can help many physicians expand their market and share their practice, there are ethical concerns regarding the privacy and visibility that such sites afford.

Yet, what exactly defines these terms: privacy and visibility? In medicine, most references to privacy deal with patient confidentiality and the Health Insurance Portability and Accountability Act of 1996. However, privacy is a convoluted term with a multitude of definitions that reference all individuals, patients, and physicians alike. In this article, privacy refers to one's control over his or her own personal information and having the ability to limit access where he or she deems appropriate. It is an individual's fundamental right to decide for himself or herself to what extent he or she would like to share personal details for public observation and discussion [14]. Visibility in turn is simpler to understand than privacy and refers to the attention or self-promotion one receives for advertising personal information. It primarily highlights how an individual is marketed to the public.

Discussion

Current Situation

Information regarding a physician is available to patients on state medical licensure websites and is provided as a service to the public by the government. Part of such information can be considered accurate and verifiable as it comes directly from state medical boards, the United States Medical Licensing Examination, and other validated sources. Given the value we as a society place on the assessment of quality of care and patient satisfaction, it is an appropriate service to the public who have a right to know about their providers. While physician-rating websites may utilize and advertise physician information, they have an inherent moral obligation to ensure that the information regarding providers listed on their websites is accurate. An ethical issue, however, arises when third-party sites aggregate information related to provider practices that may be outdated and potentially misleading to patients. Some physicians may be inaccurately classified, while others may have transitioned from their previous practice resulting in different addresses, telephone numbers, and coverage information. A simple perusal through the Better Business Bureau for complaints against third-party physician-rating websites has shown that multiple instances exist where physicians have requested that companies like Healthgrades and Vitals.com remove their personal information from their website and database for a variety of reasons, ranging from incorrect, misleading information that affects their patient population to a personal wish to no longer be publicly visible [15,16]. Even though some providers wish not to have their

information publicly available or be removed from such sites, these companies and their policies require physicians to update such information themselves through their portal regardless of their opinions. However, is it an ethically acceptable practice for a company to require a physician to update his or her information when they themselves have not given consent for its dissemination? Since this information is utilized by these websites, it should be their responsibility to provide accurate information if they wish to use it and post it in a public domain. The standard argument by these companies is that the information posted on their websites is publicly available from other sources, and hence, individual consent is not required. The responsibility of accuracy of this information is sidestepped since this service is claimed to be pro bono publico. It should also be acknowledged that vetting the accuracy of the information for each provider would be an extraordinarily onerous task. In such situations, the public expects that a reasonable amount of time and effort should have been committed to ensuring that attempts have been made to preserve accuracy of the information as much as possible. Some level of accountability should be established.

Additional Ethical Issues

Another major ethical issue is the solicitation of reviews by third-party websites. It is an acceptable practice to invite public opinion on newsworthy issues to increase awareness and broaden the scope of discussion. But is a physician's practice by itself newsworthy enough to solicit reviews? If this is done without the consent of the physician, then this principle could be extended to any individual whose profession deals with interaction with the public such as a cobbler, grocer, or butcher. For example, one could solicit reviews about a store at the corner of a residential block and claim it to be of public service. If the store is no more extraordinary than any other store in the neighborhood and the owners of the store have not given their consent for a third party to solicit reviews, what constitutes appropriate legal grounds to move forward to solicit reviews but not take responsibility for the accuracy of the reviews? Can such a third-party entity be held legally liable in a situation where slander and libelous material are posted online and cause subsequent damage? This issue is addressed by some websites that rate services by ensuring that the customers are indeed genuine and that their details are verifiable. Patients who decide their health care based on online reviews of health care entities should feel assured that the information being provided to them is reasonably accurate. Moreover, physicians should have the right to decide whether to allow or authorize third-party websites to broadcast their professional image and solicit reviews and evaluations on their behalf. Every individual has a reasonable expectation of privacy, and physicians are no exception. Physicians have a fundamental ethical obligation to maintaining patient confidentiality and privacy for the welfare of their patients; it becomes onerous to defend an accusation in public while strictly maintaining confidentiality. This asymmetric playing field can be addressed if patients give up their right to confidentiality should their feedback be challenged by the physician in a public forum. On one hand, broadcasting a physician's personal information may be seen as an act of public service that empowers consumers with the opportunity to find

optimal medical attention to their own personal liking. On the other hand, it can be considered an unreasonable invasion of privacy for a website to enlist a physician's details and information—especially if the physician submitted a request in writing to remove their details from the website. A glaring example of the misuse of public trust is providing a “Thank you for your review” reply comment by physicians on these websites. If the physician did not factually provide the reply comment, then there are legal grounds for impersonation since the website falsely represented the physician for the benefit of the website company. This information is made available to others without the consent of the subject and thus violates the physician's standards of privacy. It is ethically inconsiderate to accept unsolicited reviews on behalf of a physician who has not authorized the utilization of his or her professional information. Oftentimes, this occurs because many physicians are not even aware of their names being visible on such sites. For example, physicians of a certain area or medical group may be listed along with their phone numbers and other details gleaned through the internet. The allocation of this information can be claimed as public service but in fact, enlisting their names might invite unsolicited attention that individuals may not desire. While some physicians may feel the need to publicize and advertise their practice, others may not wish to have such attention and publicity. Privacy for these individuals serves as protection from public judgment and even more importantly, provides freedom from being consumed by constant visibility on social media—a necessary privilege that allows these individuals to control their outward appearance. That is a right that should be maintained and dictated by physicians themselves, not third-party websites unless express consent is obtained in each case.

Summary and Future Guidelines

As the internet becomes more integral to our lives and social media expands in the United States, the emerging role of physician-rating websites and their influence cannot be ignored. These websites provide an open forum for advertisement, transparency, and feedback that may help patients make informed decisions and also improve a health care provider's practice. However, as discussed, it presents many ethical challenges, such as the predicament of balancing the privacy and visibility of physicians. These websites encourage visibility and advertisement through self-promotion, but they also provide unsolicited attention that violates a physician's ethical right to privacy especially when information is utilized without consent. Our hope is to maintain ethical privacy for physicians while allowing websites to provide visibility in the field in order to

enhance patient and provider goals. The following list provides helpful guidelines and strategies to provide a practical solution to promoting appropriate behavior among physicians and third-party companies regarding visibility and privacy:

1. Construct the relationship between visibility and privacy as a symbiotic relationship. Create a platform or committee that focuses on creating direct, open collaboration among physicians and third-party websites to help illustrate the value of privacy and visibility. This mutual relationship may provide the foundation for more updated, claimed profiles with accurate information.
2. Educate third-party companies about the role that physician privacy and trust play in making their business reliable.
3. New residents or physicians should be contacted regarding potential advertisement of their own personal brands to ensure that their own rights of privacy as well as the accuracy of physician information are not violated. Follow-up should be designated annually to maintain validity. If the physician is unavailable to provide permission, it is appropriate to utilize information found on state-accredited sites, but a medium should be used to make physicians aware that information is being used. In such a case, public service to the community is provided without violating privacy rights as steps have been taken to communicate with physician.
4. Respect a request of privacy from a physician to remove details about their profile. It should be noted that such removal should not be selective to only negative reviews. Giving up presence on a website means giving up both good and bad reviews.
5. Third-party websites should take responsibility for any civil or criminal liability stemming from damages sustained by physicians due to false information on their websites. Even if the website only hosted the information, by providing a platform to disseminate unverified and false information, they have become an accomplice in a wrongdoing.

Both providers and third-party companies should take an active role in the development of quality physician-rating websites that ensure an appropriate level of visibility while maintaining a physician's ethical right to privacy. Joint collaboration will not only result in optimal quality and accuracy of updated information but also lead to a more satisfied population of providers and patients alike. If a physician requests privacy, it should be respected barring exceptional cases of newsworthiness.

Conflicts of Interest

None declared.

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Short Paper

COVID-19 #StayAtHome Restrictions and Deep Vein Thrombosis: Case Report

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Abstract

Background: The COVID-19 pandemic triggered countermeasures like #StayAtHome initiatives, which have changed the whole world. Despite the success of such initiatives in limiting the spread of COVID-19 to #FlattenTheCurve, physicians are now confronted with the adverse effects of the current restrictive pandemic management strategies and social distancing measures.

Objective: We aim to draw attention to the particular importance and magnitude of what may be the adverse effects of COVID-19–related policies.

Methods: We herein report a case of an otherwise healthy 84-year-old woman with deep vein thrombosis (DVT) due to COVID-19–related directives. #StayAtHome policies and consequential social isolation have diminished our patient’s social life and reduced her healthy movement behaviors. The patient spent long hours in a seated position while focusing on the intensive flow of media information regarding the pandemic.

Results: Reduced mobility due to preventive social isolation during the COVID-19 pandemic was the only identified cause of the DVT.

Conclusions: While evaluating the effect of the COVID-19 pandemic and governmentally implemented containment measures, including social isolation and mobility reduction, adverse events should be considered. Digital approaches might play a crucial role in supporting public health.

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KEYWORDS

thrombosis; public health; social distancing; physical inactivity; pandemic management; COVID-19; case study; vein; adverse effect; physical activity

Introduction

The COVID-19 pandemic has caused a global state of emergency since the end of January 2020. The spread of this virus has rapidly and strongly affected public, economic, and private life worldwide. Extensive governmental restriction policies were implemented and the media started encouraging social distancing. The catchy phrase #StayAtHome appeared all over the world, reaching everyone through social media,

television, banners, and newspapers. These strict measures in the fight against COVID-19 have led not only to social isolation, but also to enhanced restricted mobility in vulnerable groups [1,2]. This case report aims to highlight the importance of implementing preventive measures (eg, via digital approaches) to protect public health during this pandemic.

Methods

An otherwise completely healthy 84-year-old woman was admitted to the hospital due to deep vein thrombosis (DVT) in mid-April 2020. She had no pre-existing conditions, she was not taking any medication, and she did not have any cardiovascular risk factors apart from her age. Before the COVID-19 pandemic, the patient was very mobile for her age; she regularly went out for shopping and walks with her husband, and was active in her church group. The patient decided to reduce her social activities as a consequence of the increasing flow of alarming information on COVID-19 infections already being reported at the end of January 2020. The appearance of the slogan #StayAtHome and consequent social isolation, along with a later-implemented governmental contact ban, have extremely diminished her social life and everyday activities. Several hours each day were spent sitting in front of the television, extensively focusing on the overwhelming flow of media information concerning COVID-19, as well as new containment measures and the pandemic's effects on society and the economy. Due to her age and daily media information consumption, she developed anxiety about leaving her home and did not leave her apartment for 6 weeks prior to hospitalization.

Approximately 2-3 days prior to hospitalization, the patient had increasing pain and tenderness, as well as redness and swelling, in her left leg.

On the day of hospitalization, the patient called her primary care physician, who advised her not to come to his medical practice but to start immediate oral anticoagulation therapy with

Dabigatran since the patient's husband was already on this medication for atrial fibrillation. Furthermore, he referred her to the emergency department.

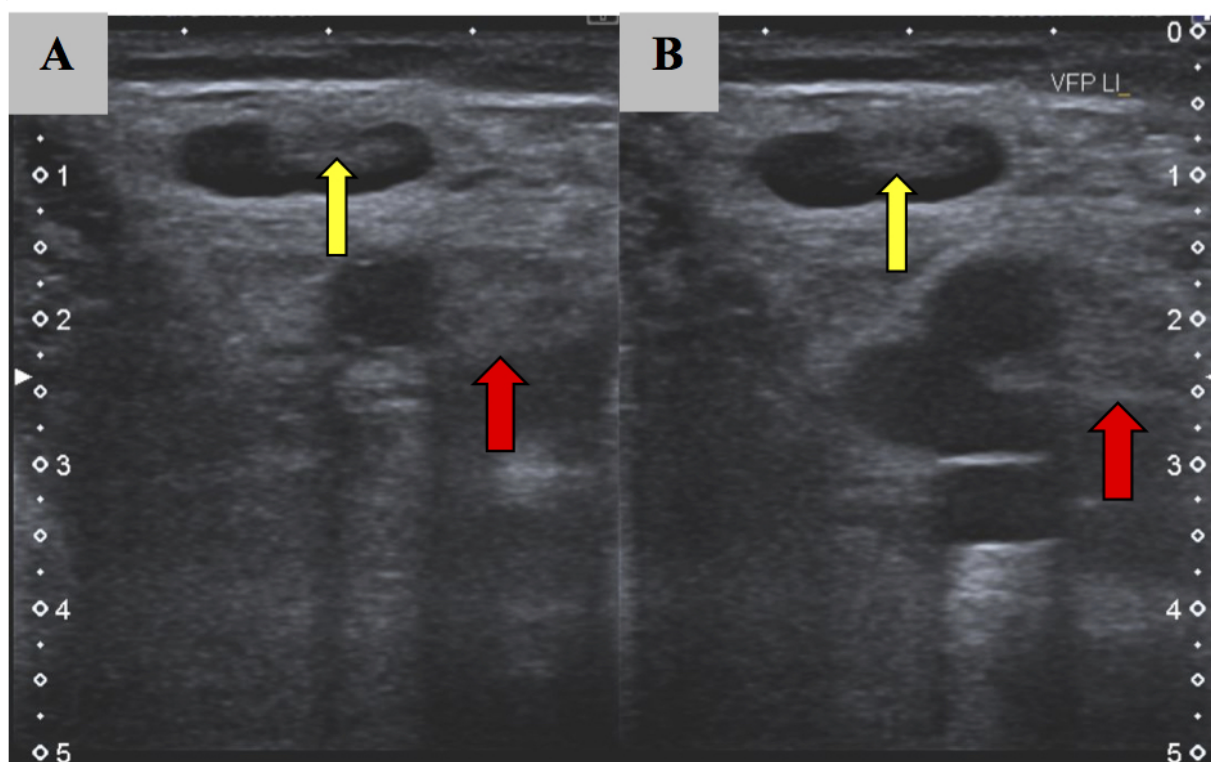
Results

On admission, the patient presented with redness, increasing calf temperature, and positive thrombosis signs (Wells score of 4 points). No injury or exceptional muscle use in the days before the initial pain were reported. There was no clinical evidence for hemodynamic instability or pulmonary embolism, and the patient had no history of prior thromboembolic events. Anamnestic, clinical, and diagnostical evaluation of the etiology of the DVT took place and showed no evidence of any other cause than reduced mobility due to preventive COVID-19 isolation.

Blood tests revealed leukocytosis ($12.94 \times 10^9/L$), increased C-reactive protein (13.3 mg/L), and abnormal D-Dimer concentrations (2.38 mg/L). Doppler sonography showed a long-distance thrombosis in the small saphenous vein and posterior tibial veins in her left leg (Figure 1).

The patient was diagnosed with provoked DVT, and it was recommended that she continue the anticoagulation treatment with Dabigatran for 3 months. A 2-week hospitalization became necessary as the patient's mobility was impaired by the DVT. Physical rehabilitation was initiated and following physiotherapeutic treatment, the patient's mobility markedly improved. The patient was informed about the most likely cause of her condition and instructed to maintain her physical activity at home by using the stairs on a daily basis and taking walks in the neighborhood while adhering to protection rules.

Figure 1. Ultrasound of the left lower extremity showing noncompression of the left saphenous vein (red arrows) and left posterior tibial vein (yellow arrows), as well as a visible thrombus in the lumen. Panel A and Panel B show a well-formed Thrombus in two different locations.



Discussion

To our knowledge, we herein report for the first time a case of DVT as a result of #StayAtHome directives and preventive social isolation during the COVID-19 pandemic in octogenarians. No other cause than the reduction of physical mobility due to preventive social isolation was identified.

Restrictive policies including social distancing have been implemented by the government, with the aim of reducing the transmission of COVID-19 and keeping the mortality rate low [3]. However, since this is the first larger worldwide pandemic in the last 100 years [4,5], it is crucial to take into consideration that #StayAtHome directives themselves can have adverse effects, such as a reduction in physical activity and the accompanying consequences. These include not only physical issues (eg, an increased risk of cardiovascular diseases and thromboembolism), but also psychological effects and the impairment of public well-being [6-8].

As illustrated by this case, adverse patient outcomes like DVT can be traced directly to the effects of #StayAtHome directives [9]. Next to seated immobility in relation to travel, work, or computer gaming, a sedentary lifestyle due to COVID-19 restrictions could present as another cause of seated immobility thromboembolism (SIT) [9,10]. Therefore, effective prevention and protection concepts are indispensable during the COVID-19 pandemic, especially for vulnerable and older patients [11-13].

The COVID-19 pandemic has already lasted for several months, adverse effects have already been discussed in scientific forums,

and nonpublic institutions have implemented prevention programs (eg, home workout instructions), which have shown that adequate prevention programs are possible while adhering to transmission reduction rules. Nevertheless, governmental policies still lack sufficient consideration of how to integrate measures for adopting positive health-related behaviors into the pandemic management strategy [14]. New strategies including population-wide thrombosis prophylaxis performed at home (such as practicable mobility programs on public television or the enhanced use of digital preventive medicine) should be developed, with special attention paid to the older adult population. Teleworking and teleschooling are already playing a crucial role in this pandemic situation, while integration of telehealth into public health management is, generally speaking, overdue [15,16]. Digital health apps could play an essential role for both psychological issues and physical conditioning [17]. In addition, quality social interactions using telecommunication should be supported since they are negatively associated with the deterioration of physical and psychological health [18]. Moreover, it is important to develop simple and safe solutions (eg, via public television, radio, telephone, newspapers, or flyers) for older people who are not confident using new digital technologies [11].

During this crisis, the implementation of digital approaches to protect public health and avoid an increased mortality rate due to pandemic-related measures is of particular importance [19,20]. We suggest that instead of #StayAtHome, the message could be #StayHomeKeepMoving.

Authors' Contributions

All authors contributed significantly to this article and read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

DVT: deep vein thrombosis

SIT: seated immobility thromboembolism

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Letter to the Editor

Patient Empowerment and the Exclusion of Dietary Intervention Studies. Comment on “Diet and Multiple Sclerosis: Scoping Review of Web-Based Recommendations”

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KEYWORDS

multiple sclerosis; dietary interventions; clinical evidence

Beckett et al [1] performed a scoping review of online dietary recommendations for multiple sclerosis (MS) from nonscientific, internet-based webpages, available as of November 2016. The authors found 32 internet articles detailing four diets—low-fat high-fiber, low saturated fat, modified Paleolithic, and an elimination diet—and provided scientific literature for the basis of each diet. We would like to thank the authors for performing this necessary work because many people with MS seek nonconventional treatments to improve their disease outcomes. It is imperative that researchers and health care professionals understand the dietary strategies that are popular among people with MS.

However, we are concerned that the authors excluded all scientific articles regarding the outcomes of human trials using the proposed dietary strategies due to fees for obtaining these articles and the assumed lack of ability of people with MS to interpret these types of articles. In our experience, people with MS who desire to incorporate diet into their personal treatment plans are often highly informed of the scientific literature regarding dietary strategies for MS. In addition, scientific journals often are open access and/or provide lay language summaries of the article; for these reasons, we disagree with the authors' justification for excluding these articles.

Furthermore, the authors conclude that online dietary advice is often the result of an individual's experiences and has not been scientifically evaluated. However, at the time of the internet search (November 2016) performed by Beckett et al [1], the case study of Dr Terry Wahls' personal experience [2] and results from a single-arm trial indicating that a modified Paleolithic diet is feasible [3] and associated with positive outcomes [4] had been published. Prior to the publication of the article by Beckett et al [1] in January 2019, secondary outcomes from the trial demonstrated additional improvements in progressive MS patients [5,6], and a supporting randomized controlled trial [7] was published. This is only in regard to the diet promoted by Dr Wahls and does not include the many scientific publications supporting the low-fat diet promoted by Dr Roy Swank. Finally, several online websites provide links to research articles supporting the promoted dietary strategy; thus, it is important to mention that some websites provide information on diets for MS along with relevant scientific evidence.

We agree with Beckett et al [1] that the online dietary advice for people with MS is confusing and contradictory, and that it is the responsibility of health care professionals to interpret evidence for and against online dietary advice. However, we

are concerned that by excluding dietary intervention studies and not updating their search prior to publication, the authors arrived at an erroneous conclusion. Some people with MS are eager to adopt dietary changes as part of their personal treatment plan due to the limitations of conventional treatment. For this reason, we agree with the authors that the scientific community needs to rigorously evaluate dietary interventions promoted for MS such as the Swank and Wahls diets. In fact, we hope that our on-going study comparing the Wahls and Swank diets among people with relapsing-remitting MS [8] will provide some of these answers.

We would like to thank the journal editors for allowing us to reply to Beckett et al [1], who conducted an important and relevant review of the online dietary advice for people with MS. Our goal in this response is to point out that currently available scientific evidence of the clinical outcomes, limited as it may be, supports the use of dietary interventions for MS. Because people with MS often incorporate diet into their personalized treatment plans, this distinction is important to facilitate future research and support for dietary intervention studies for MS.

Editorial Notice

The corresponding author of “Diet and Multiple Sclerosis: Scoping Review of Web-Based Recommendations” declined our invitation to reply to this commentary.

Conflicts of Interest

TW has published the Wahls Protocol and the Wahls Protocol Cooking for Life, has trademarked the Wahls Diet and the Wahls Protocol, and owns the website www.terrywahls.com.

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Abbreviations

MS: multiple sclerosis

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Letter to the Editor

Addressing Disciplinary Misconceptions: Mentorship Programs and Student-Led Surgical Societies. Comment on “Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study”

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medical education; plastic surgery; students

We would like to thank Mortada et al [1] for their recent article, highlighting the misconceptions of plastic surgery among medical students. Upon reading the article, we were surprised by the lack of awareness reported among both female and male students.

As the authors highlighted, medical students generally possess a poor understanding of what plastic surgery entails. These results are not unique to Saudi Arabia, with analysis of medical schools in both the United Kingdom and Canada indicating that students are unaware of the full breadth of operations plastic surgeons perform, including the management of pressure ulcers, cleft palate, and carpal tunnel syndrome [2,3]. Given the competitive nature of plastic surgery globally, it is important that students begin to construct competitive portfolios early [4]. However, if students are unaware of the full range and utility of plastic surgery, it is questionable how they may be expected to do so. Moreover, only 26% of qualified doctors would refer neuronal injuries of the hand to plastic surgeons [5]. This highlights a fundamental gap in the understanding of plastic surgery among both students and qualified practitioners.

We recognize that many students engage with medical television programs and agree that accurate multimedia representation of plastic surgery is important. However, we disagree that television represents a viable tool to promote student awareness of the full range, complexity, and utility of plastic surgery. In

fact, there is evidence that television representation of plastic surgery may actively contribute to a skewed understanding of the specialty among medical students [3]. Similarly, content on social media is likely to reinforce existing misconceptions around the work of plastic surgeons, with research suggesting that surgeons with a cosmetic focus to their practice are more likely to utilize social media [6]. Furthermore, content on social media platforms is unregulated, and the reliability of information cannot be guaranteed.

We propose that there are more effective strategies to promote student understanding of plastic surgery. Exposure to plastic surgery during medical school has been shown to increase matriculation into the specialty; yet only 29.4% of students report such exposure [2,7]. One method shown to effectively overcome this gap in the formal curriculum is extracurricular mentorship programs. Within these programs, students can shadow plastic surgeons in their clinical environment, gaining insights into the realities of the specialty [8]. In addition, there is a clear role to be played by proactive interaction with student-led surgical societies. Student-organized career sessions allow trainees to deliver accurate information on the variety, demands, and rewards of a career in plastic surgery. Mentorship programs and society-organized careers sessions both enable students to develop a realistic understanding of plastic surgery

and offer the opportunity for students to develop competitive portfolios.

Overall, we agree with Mortada et al [1] that students possess an inadequate understanding of plastic surgery. However, we

propose that more effective strategies to overcome this would include mentorship programs and student-led surgical societies, rather than potentially skewed representations of the specialty on television and social media.

Editorial Notice

The corresponding author of “Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study” did not respond to our invitation to reply to this commentary.

Conflicts of Interest

None declared.

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Review

Barriers and Facilitators to Genetic Service Delivery Models: Scoping Review

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Abstract

Background: Advances in diagnostics testing and treatment of genetic conditions have led to increased demand for genetic services in the United States. At the same time, there is a shortage of genetic services professionals. Thus, understanding the models of service delivery currently in use can help increase access and improve outcomes for individuals identified with genetic conditions.

Objective: This review aims to provide an overview of barriers and facilitators to genetic service delivery models to inform future service delivery.

Methods: We conducted a scoping literature review of the evidence to more fully understand barriers and facilitators around the provision of genetic services.

Results: There were a number of challenges identified, including the limited number of genetics specialists, wait time for appointments, delivery of services by nongenetics providers, reimbursement, and licensure. The ways to address these challenges include the use of health information technology such as telehealth, group genetic counseling, provider-to-provider education, partnership models, and training; expanding genetic provider types; and embedding genetic counselors in clinical settings.

Conclusions: The literature review highlighted the need to expand access to genetic services. Ways to expand services include telehealth, technical assistance, and changing staffing models. In addition, using technology to improve knowledge among related professionals can help expand access.

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genetics; telehealth; genetic services; rare diseases

Introduction

Advances in diagnostic testing and treatment options for genetic conditions have led to increased demand for genetic services in the United States. The gateway to genetic services is through multiple paths. For example, newborn screening programs test all infants shortly after birth for a variety of genetic conditions. Other avenues include clinical diagnosis from a broad array of specialists, such as neurologists, oncologists, and geneticists. We sought to understand how genetic services are provided and identify the most cost-effective methods of meeting growing needs for services. Understanding the current delivery models being used can help strengthen the long-term follow-up of

individuals identified with genetic conditions and, ultimately, improve outcomes for patients and families.

The goal of this study is to identify evidence from the literature regarding the challenges and potential solutions to improve service delivery models. We sought to understand the following research questions: (1) What are the current practice methods and models for genetic services? (2) What are the barriers or challenges presently being encountered that impede the provision of timely genetic services? and (3) What are the best practices, lessons learned, and service offerings that can inform future efforts?

Methods

We conducted a series of 3 iterative literature searches with increasing specificity of search terms. The searches enabled the research team to amass a broad base of literature related to genetic service models spanning from genetic services delivered in early infancy, as part of newborn screening, to services delivered in adulthood, with the onset of health conditions such as cancer. This was intended to explore models that may have been implemented successfully in other health areas or populations that could potentially be of interest for application or adoption in the United States. Search parameters were

consistent in all 3 searches ([Textbox 1](#)), and search terms were altered for each search ([Textbox 2](#)).

In total, 2 researchers reviewed all search results for initial inclusion. Researchers independently reviewed each abstract and made notations related to reported challenges and potential solutions regarding the delivery of genetic services. These notations guided inclusion and exclusion decisions. Researchers reviewed each other's notations, discussed any areas of disagreement, and ultimately came to a consensus on whether the article should be obtained and included in the review. Full-text articles were obtained for all search results that met these initial criteria; each article was reviewed, and themes were extracted.

Textbox 1. Search parameters of the scoping review.

<p>Language</p> <ul style="list-style-type: none"> English <p>Period</p> <ul style="list-style-type: none"> 2010-2020 <p>Geographic population</p> <ul style="list-style-type: none"> United States and international <p>Databases</p> <ul style="list-style-type: none"> PubMed Embase PsycINFO Web of Science (includes Science Citation Index Expanded, Social Sciences Citation Index, Conference Proceedings Citation Index-Science, and Conference Proceedings Citation Index-Social Science and Humanities)

Textbox 2. Search terms of the scoping review.

<p>Search 1</p> <ul style="list-style-type: none"> Genetics AND service delivery OR model <p>Search 2</p> <ul style="list-style-type: none"> Genetic(s) service(s) provision OR genetic(s) service(s) delivery OR genetic(s) service(s) delivery model(s) OR genetic health care service(s) delivery OR genetic(s) support delivery OR genetic(s) support model(s) OR genetic(s) service(s) delivery structure OR genetic(s) services delivery system OR genetic(s) delivery of health care OR genetic counseling services OR genetic diagnostic services <p>Search 3</p> <ul style="list-style-type: none"> Pediatric genetic counseling OR newborn screening follow-up AND genetic(s) service(s) provision OR genetic(s) service(s) delivery OR genetic(s) service(s) delivery model(s) OR genetic health care service(s) delivery OR genetic(s) support delivery OR genetic(s) support model(s) OR genetic(s) service(s) delivery structure OR genetic(s) services delivery system OR genetic(s) delivery of health care OR genetic counseling services OR genetic diagnostic services

Results

The search yielded 187 unique abstracts or references ([Table 1](#)). Of these, 112 articles were reviewed.

After an initial review, 93 articles related to genetic service models from across the 3 searches were selected for a full-text review. Three researchers categorized the articles by theme together and carried out full-text reviews. [Table 2](#) outlines the articles included across the 3 major themes that were incorporated into the final review.

Table 1. Number of articles selected to be reviewed from search results.

Search	References in search results (n=187), n (%)	Mention of challenges in abstract/title (n=8), n (%)	Mention of solutions in abstract/title (n=85), n (%)	Mention of challenges and solutions in abstract/title (n=19), n (%)	Number of articles retrieved for full-text review (n=112), n (%)
Search 1: broad	90 (48)	2 (25)	44 (52)	14 (74)	60 (54)
Search 2: genetic services specified	67 (36)	3 (38)	31 (37)	5 (26)	39 (35)
Search 3: pediatric	30 (16)	3 (38)	10 (12)	0 (0)	13 (12)

Table 2. Number of articles by theme.

Category	Number of articles reviewed for solutions		
	Telegenetics (n=37), n (%)	Training, education, and awareness (n=34), n (%)	Infrastructure/workflow (n=36), n (%)
Search 1: broad	23 (62)	18 (53)	15 (42)
Search 2: genetic services specified	2 (5)	5 (15)	7 (19)
Search 3: pediatric	12 (32)	11 (32)	14 (39)

Challenges and Barriers Identified in the Literature

Limited Number of Genetics Specialists

The shortage of genetics professionals coupled with a rapidly growing need has been described as one of the biggest challenges facing the field [1]. There is approximately 1 genetics professional per 300,000 individuals in the United States [2]. Radford et al [3] reported similar deficits in staffing, noting that 2500 certified genetic counselors practice in the United States, equating to 8.1 genetic counselors per 1 million population. Rural areas and certain states experience these shortages more profoundly [3,4]. Increased demand for genetics professionals is based on a few factors, including the growing number of conditions that can now be identified as having a genetic cause, affordability of testing technologies, and demand for genetic counselors in more diverse clinical settings [3,5].

In a survey of state newborn screening coordinators within the Southeast Regional Newborn Screening and Genetics Collaborative, close to half of the respondents indicated that the adequacy of the number of genetic counselors, dietitians, and medical or biochemical geneticists was minimal to insufficient [6]. One study related to newborn hearing loss reported that the deficit in the workforce has resulted in poor follow-up of patients. Al-Mulki and Todd [7] sought to explore staffing and loss to follow-up in newborns who did not pass hearing screening. The authors found that follow-up rates were higher when a full-time navigator position was filled [7].

However, as the need for these professionals continues to grow, the number of clinical geneticists entering the field is decreasing, with approximately 50% of medical genetics residency positions unfilled each year [1]. In some areas, genetic counseling positions have been difficult to fill [8].

Wait Time for and Length of Genetics Appointments

Two of the main challenges related to the delivery of genetic services were the time intensiveness of providing genetic counseling and wait times for appointments. Despite the fact

that genetic service delivery models have changed over the years and fewer visits per patient are common, this is not the case for all areas of genetic counseling; genetic counseling continues to be a time- and resource-intensive process [1]. In a survey of cancer genetic counselors, 92% were spending fewer than 75 min for initial counseling, although recommendations suggest up to 3 hours [9]. Genetic counseling sessions have been reported to take longer when conducted by a genetics professional compared with another specialist [10]. Time was also mentioned in a study by Brierley et al [11], where nongenetics professionals required more time than they had available to perform genetic counseling and testing. In addition to the length of genetics appointments, several studies have discussed wait time as a significant barrier to accessing services, which is often linked to limitations in the workforce and geography [1,4,12].

Delivery of Services by Nongenetics Providers

Several studies have explored the delivery of genetic services by nongenetics professionals and the resulting challenges and impacts on patients [1,4,11,13-15].

Although primary care providers are well positioned to recognize whether genetic tests or referral to genetic counseling is appropriate, there are still gaps in identifying the need for genetic services [1]. In addition, nongenetics professionals do not always follow guidelines. This was indicated in one survey conducted in Florida that focused on pretest genetic counseling services for hereditary breast and ovarian cancer [15]. Another study reviewed 200 patients with breast or ovarian cancer who met the criteria for genetic testing. Lacking a referral from the attending oncologist was cited as the biggest barrier for 30% of the patients who did not receive adequate testing or counseling [16].

Patients can experience adverse outcomes from delivery of services by nongenetics providers. A web-based survey and structured telephone interview with genetic counselors revealed patients' negative outcomes on receiving genetic services from nongenetics professionals in Minnesota. These outcomes

included adverse psychosocial effects, medical mismanagement, inadequate counseling, negative shifts in attitudes toward medical providers, and unnecessary use of resources [13]. Another study invited genetic counselors from the National Society of Genetic Counselors (NSGC) Cancer Special Interest Group to submit cases of adverse outcomes of genetic counseling and testing performed by nongenetics professionals. The list included incorrect genetic tests ordered, misinterpretation of results, inadequate genetic counseling, unnecessary testing and surgery, distress, and false reassurance [11].

Reimbursement and Licensure

There are inherent challenges related to difficulties in implementing, sustaining, and scaling alternative delivery models [1,5]. Some of these challenges are because of logistical issues, including billing, reimbursement, required equipment and setup, and the inability to see the patient (ie, in the case of telephone counseling) [17]. Nonuniform delivery of services may be because of the varying state-level laws and license requirements for genetic counselors [2]. Others have described that alternative models have not been widely tested, and given the increasing role of technology, new approaches to training counselors will also need to be developed [6].

Models to Address Barriers Identified in the Literature

Provider-to-Patient Telegenetics

The use of telehealth practices in the field of genetics, often referred to as telegenetics, has increased steadily in the past decade. Most often, this is through the use of video-based technology, although phone-based delivery of services to patients has also been used. A landscape review article by Terry et al [12] found that many clinics in the Mid-Atlantic region had started using telegenetics to deliver services to patients. Clinics that had used telegenetics were often located in academic or other medical institutions with a focus on prenatal and cancer services. However, in-person counseling is still a prevalent method of genetic counseling delivery. In a web-based survey of members of the NSGC Familial Cancer Special Interest Group, the face-to-face pretest and posttest model was reported as the most commonly used (92.2%) [18].

Those who have used telegenetics to deliver services to patients indicate that it allows providers to see more patients, reduces wait time, and improves costs [8,19-21]. In addition, patient satisfaction is high, with many studies citing benefits such as reduced travel time and increased convenience [22-28]. Most patients report being comfortable with using technology [22], although some still prefer in-person care, given possible technical problems or reduction in the quality of the interaction [24]. Those who are less in favor of telegenetics are often older patients [26].

A mini-review by Buchanan et al [23] identified models that use telephone genetic counseling at different points of care. This included pretest telephone counseling, posttest telephone counseling, and a model developed by a Dutch group, called *DNA-direct*, with a telephone pretest counseling model accompanied by mailed educational materials, followed by an in-person posttest consultation. Rayes et al [29] described the

protocol for MAGENTA (MAKING GENetic Testing Accessible), a national randomized controlled trial that will compare web-based genetic education and telephone genetic counseling for hereditary cancer genetic testing.

Outcomes reported through telegenetics are fairly well documented, with most focusing on the delivery of telegenetic counseling. When compared with baseline scores or in-person genetic service delivery, most patients reported reduced anxiety and high levels of knowledge [22]. Telephone counseling has also reported positive outcomes [30], although one study found better outcomes for video- versus phone-based genetic counseling [31].

Group Genetic Counseling

Another possible option for improving the efficiency of genetic services is the delivery of genetic counseling services through a group model. Two studies compared group counseling with individual counseling [32,33]. In both the studies, participants in each group reported high levels of satisfaction. Although participants in both the group and individual genetic counseling encounters reported significantly decreased patient anxiety, increased perceived personal control, decreased decisional conflict, and increased knowledge, those in the individual session reported a greater reduction in anxiety than those in the group session [32]. Woodson et al [34] described a group counseling model for an underserved population in Texas focused on women receiving counseling for hereditary breast and ovarian cancer [34]. Group genetic counseling was also reported to increase efficiency by decreasing the time spent per patient [23]. When asked to rate their preference for individual versus group counseling, however, most ranked individual counseling higher [35].

Provider-to-Provider Telegenetic Consultation

In this model, primary care providers have access to specialty providers to gain knowledge regarding care and monitoring of patients with special health care needs. Much of this work has been patterned after the Extension for Community Healthcare Outcomes model. This approach is gaining traction in the field of genetics [36].

Partnership Models Between Genetics and Nongenetics Providers

In addition to telegenetics, the use of a team-based or collaborative approach has been suggested as an alternative genetic service delivery model [37]. Kubendran et al [38] described the implementation of pediatric telegenetic services by a team comprising a geneticist, a pediatrician, and a genetic counselor. Patients reported high satisfaction with this team-based approach. A similar multidisciplinary approach was used in a pediatric metabolic practice for patients with inborn errors of metabolism [39]. This team consisted of metabolic geneticists, pediatric dietitians, clinical pharmacists, social workers, metabolic nurses, and genetic counselors who provide care and frequent follow-up to patients. An important feature that was highlighted as part of this model was the ability of the genetic counselor to build a long-term relationship with the patients and families because of the frequency of management visits. Other benefits of the multidisciplinary model include

reducing the burden of frequent visits to the hospital for the patient and family to see each care provider separately and reducing the financial burden for frequent visits to the hospital because many patients travel from longer distances to access tertiary care.

Other studies have discussed a partnership model between genetic counselors and physicians in oncology [40]. One study in an oncology clinical setting evaluated the differences between a model of cancer genetic counselors in traditional clinics combined with a medical geneticist compared with genetic counselor-only appointments [41]. The authors tracked the amount of time spent on patient interaction and outpatient-related care over 9 months and found that genetic counselors performed similar activities without the medical geneticist present and spent significantly less time in appointments when they worked alone as opposed to working with a medical geneticist, which may be attributed to redundancy in services.

One study in Hong Kong used a new model to provide clinical genetic services [42]. An institute located within a hospital provided genetic diagnostic and counseling clinics that were supported by an in-house laboratory, including cytogenetics, molecular genetics, and diagnostic laboratories. This model allowed the genetics team to work closely with a variety of other providers in the hospital setting.

Partnership models with other health professionals, such as social workers and psychologists, also emerged as potential models for patient-centered genetic care. Telfair argues that social work education should include the basics of genomics because social workers may play a large role in genetic counseling, noting their ability to ensure that clients have access to counseling and testing [43]. Other authors explore partnerships with psychologists to improve care for patients and families receiving genetic services. For example, the feasibility of offering a narrative group session offered by a genetic counselor and a clinical psychologist to individuals who tested negative for Huntington disease was assessed, and participants provided overwhelmingly positive feedback about this approach [44]. Another study assessed the level of satisfaction among Brazilian mothers of children with Down syndrome who received care from a multidisciplinary team consisting of 3 counselors, 3 psychologists, a social worker, 3 physicians, and 2 nurses. Satisfaction with the information received and psychological support was high among the mothers [45].

Training and Educational Resources

With genetics and nongenetics professionals alike, training and educational resources were indicated as needs [2,6,14,15]. Genetic counselor training programs face challenges related to the need to expand knowledge and to meet increasing demands within the context of the various roles that genetic counselors play in academia, clinical service, and industry [5]. Moreover, as genetic services continue to become more integrated into primary care or other specialties, roles, data and database sharing, and preparation of nongenetics professionals will need to be explored [46]. Stoll et al [1] discuss training and educational interventions as solutions to assist primary care providers in improving knowledge and helping to recognize

and triage patients for genetic testing and counseling services [1]. Others have noted that professionals can incur liability, and patients can experience negative outcomes as a result of inadequately trained providers [6].

Embedding Genetic Counselors Within Clinical Settings

Another approach to the delivery of genetic services is to embed genetic services or genetic counselors into nongenetic clinical practices. In 2012, Battista et al [46] carried out a literature review of genetic services in North America, Europe, and Australia, highlighting the advantages of integrating genetic services into primary care. For rare genetic conditions, the study's authors recommended the use of multidisciplinary specialist clinics or coordinated services with primary care providers. For other common genetic conditions, such as genetics-related cancers, interprofessional collaboration between geneticists and other medical providers seemed sufficient for coordinating care.

One study assessed the attitudes and barriers of incorporating a genetic counselor into a cystic fibrosis clinic in New York [47]. Among center directors and clinic coordinators who responded to the survey, 84% indicated that genetic counselors provide a valuable service in the clinic and 85% endorse this relationship (as indicated by a *recommend* or *strongly recommend* response).

This model has been translated into and tested in multiple clinical settings, including cancer care. In a gynecologic oncology clinic in Ohio, a higher number of patients were referred for genetic consultation after changing to a genetics-embedded model; referrals increased from 21% to 44% of patients [48]. In addition, time from referral to scheduling a genetics appointment was reduced. A similar finding was reported in a specialized gastrointestinal cancer center [49]. A 223% increase in the number of patients receiving genetic services occurred after integrating genetic counselors into the gastrointestinal cancer center. Pederson et al [50] conducted a retrospective review of patterns of genetics referrals, compliance, and testing over a 2-year period before and after a genetic counselor was embedded within a breast surgery clinic [50]. Not only did the likelihood of being referred to genetic services increase by 49%, but a greater number of patients were also more likely to go through with a genetic counseling appointment and take part in a genetic counseling session before surgery. Notably, the authors reported a 31% reduction in time to treatment between the 2 periods.

Use of Genetic Counseling Assistants

The use of genetic counseling assistants (GCAs) has also been explored as a solution to the shortage of genetic counselors. Pirzadeh-Miller et al [51] explored the use of GCAs from a survey distributed to certified genetic counselors, GCAs, and genetic counseling program directors [51]. Genetic counselors were able to see more patients when they had a GCA (58.5% more patients with a ratio of 3 genetic counselors to 1 GCA), and all genetic counselors surveyed reported an increase in efficiency in patient care or productive time utilization. GCA responsibilities endorsed by genetic counselors included entering data, shipping test kits, performing administrative tasks, and

ordering supplies. However, fewer than half of genetic counselors reported endorsing GCAs for calling patients with test results or formulating results letters for patients. Of the genetic counselor respondents, 90% reported that the GCA profession could lead to a genetic counseling career. GCA respondents reported similar duties, and most GCAs (86%) were interested in a genetic counseling career.

In a recent survey, members of the NSGC responded to a survey regarding the role of GCAs and the impact they may have on the genetic counseling profession [52]. Themes that arose for how GCAs could change their practice included increased time available for higher-level duties, higher patient volumes, and increased efficiency. There was consensus among respondents on what GCAs should be doing, but the scope and guidelines for the role of GCAs have not been clearly defined. Respondents who currently did not use GCAs had greater concerns about the role of, and burden of supervising, GCAs compared with respondents who were currently working with GCAs.

Use of Health Technologies and Patient Educational Tools

A handful of studies described various technologies that are being implemented to support the delivery of genetic services. Flannery [53] identified some of these technologies, including eConsult, an internet-based communication method between primary care physicians and specialists; chatbots, which use artificial intelligence (AI) to produce interactive conversations; and a web-based platform that integrates education on carrier results with personal test results. Moreover, 2 other studies endorse the use of chatbots [54,55]. Schmidlen et al [55] explored the use of chatbots for scaling up communication in genomics research, specifically for consenting to research, interacting with health care providers after receiving genomics results, and sharing genetic information with relatives.

Kearney et al [56] describe the current applications of AI in genomics and genetic counseling and the potential for continued and increased integration of AI in genetics. Medical genetic testing is one of the major applications of machine learning and deep learning in genomics. Another use of machine learning is

in the development of clinical decision support tools. Examples cited include tools that could search literature based on molecular profile, image recognition to identify a genetic diagnosis based on a patient's phenotype, or matching genetic diseases to the identified symptoms.

Implementation and Evaluation of Alternate Service Delivery Models

A few recent papers explored how to best implement or evaluate the use of alternate service delivery models. For example, Chou et al [57] developed a genetic services assessment tool consisting of 16 quality indicators for states to use to evaluate public health genetic services. The major domains identified include (1) structural metrics that are key components to quality genetic services: workforce, training and education, information systems, and types of programs provided; (2) clinical process metrics affecting quality genetic services: patient-provider interactions, care coordination and management, quality assurance and improvement mechanisms, and care provision and service delivery (metrics describe patient-provider interactions, continuity of care, quality programs, and performance tracking); and (3) outcome measures of quality genetic services: process-of-care outcomes (screenings and referrals rather than health outcomes). The authors suggest that this tool will help states identify key areas for improvement and quantify progress made.

Other quality improvement initiatives have underscored the potential for new and innovative frameworks or learning collaboratives to address existing shortcomings and challenges in genetic service delivery. Russ et al [58] described one such quality improvement approach that was used to reduce the significant loss to follow-up after newborn hearing screening. Before implementation, more than half of the children were lost to follow-up after a newborn hearing screening. However, after using this quality improvement approach, new strategies were adopted, and teams reported decreasing loss to follow-up rates.

[Textbox 3](#) presents an overview of the challenges and possible solutions outlined in the literature.

Textbox 3. Challenges and possible solutions.**Limited number of genetics specialists**

- Patient-to-provider telegenetics
- Group genetic counseling
- Use of genetic counseling assistants
- Use of health technologies and patient educational tools
- Implementation and evaluation of alternate service delivery models

Wait time for and length of genetics appointments

- Patient-to-provider telegenetics
- Use of health technologies and patient educational tools
- Implementation and evaluation of alternate service delivery models
- Embedding genetic counselors within clinical settings

Delivery of services by nongenetics providers

- Provider-to-provider telegenetic consultation
- Partnership models between genetics and nongenetics providers
- Training and educational resources
- Use of health technologies and patient educational tools
- Implementation and evaluation of alternate service delivery models

Reimbursement and licensure

- Use of genetic counseling assistants
- Implementation and evaluation of alternate service delivery models

Discussion

Expand Access to Genetic Services

The literature review pointed out several challenges that are currently facing the field of genetics. Those that cause the most concern for access to genetic services are the limited number of genetics specialists available to meet the growing demand for services and the long wait times needed to get appointments. However, several possible solutions highlighted in this literature review could be implemented to address these challenges.

The use of telehealth is one of the main ways to increase access to genetic services. On the basis of the literature review, there is ample evidence to support the use of telehealth. Several challenges can be addressed through the use of telehealth. First, because of the vastness of the United States and the dearth of genetic service providers, each of the genetic services centers serves a large catchment area. Thus, there are geographic barriers to access to care. Telehealth can help alleviate these barriers. Second, many states have a large Spanish-speaking population. However, there is a shortage of Spanish-speaking providers. Through telehealth, bilingual providers can expand their reach. In addition, telehealth can facilitate the use of remote translation services. Finally, there is a nationwide shortage of genetic service providers across the continuum. Telehealth expansion can help with workforce issues by obviating the need for staff to travel to multiple locations. In addition, telehealth can help with load-balancing staff across locations.

Increasing the use of telehealth services, however, may require additional assistance or planning. Other needs related to the expansion of telehealth may emerge. For example, providers may need access to training opportunities, to purchase equipment, or to feel prepared to implement telehealth. Support for training can come through existing resources, such as those provided by Telehealth Resource Centers [59]. Readiness assessment tools can assist with preparations to implement telehealth [60,61]. In addition, there are organizational factors associated with the implementation of telehealth. Providers need to develop a telehealth delivery plan that might include an outline for which types of visits will be used for telehealth (eg, only follow-up visits), which providers can implement telehealth (eg, dietitians and genetic counselors), and how to integrate the telehealth platform with the electronic health record. In addition, sharing ideas and recommendations on change management principles associated with telehealth, such as readiness, training, and workflow, can help the state manage implementations and save resources. Finally, it will be important to monitor the status of reimbursement for telehealth services. Although reimbursement for telehealth has expanded recently, mainly because of the COVID-19 pandemic, it remains unclear if some, all, or none of the recent changes will be permanent. Changes include the removal of geographic restrictions (including allowing telehealth from home), billing and reimbursement changes (eg, new reimbursement codes available and same fee-for-service rate as in-person visits), and the addition of phone-only service provision. Thus, coordinating with Medicaid,

as well as private payers, on reimbursement for telehealth services could facilitate uptake.

In addition to telehealth, there are a few possible solutions related to clinical workflow that may improve access to genetic services. The use of GCAs has been rated favorably in many of the studies included in the literature review. For high-volume clinics, another consideration to improve clinic flow could be the use of group genetic counseling for low-risk populations followed by an individual in-person or telephone session. Another possibility is the use of patient education tools to assist with the amount of time genetic counselors spend with patients individually.

Build Expertise and Improve Knowledge About Genetic Services Among Nongenetics Professionals

Given that fewer genetics professionals are entering the field and the current workforce issues, there is a need to build genetics knowledge and expertise among nongenetics professionals. This can be accomplished by using one or more possible approaches that were revealed during the literature review. Partnership models were used to expand access to genetic services in collaboration with nongenetics professionals, sometimes through telehealth. These solutions allow patients and families to access a genetics specialist and build relationships with nongenetics providers, which enhances their expertise. This could be accomplished through outreach to primary care settings of existing patients who see a genetics professional. Similarly, provider-to-provider telegenetic consultation is a strategy that can be employed to pair genetics providers with nongenetics providers. Through consultation with experts, nongenetics

professionals gain a better understanding of their patients and are better able to care for their unique needs. Both these approaches would also help to address the noted challenges of nongenetics providers delivering services without the support of a genetics specialist (eg, ordering the wrong genetic test or panel).

Another possible solution to improve the knowledge and expertise of nongenetics professionals is to embed genetics providers within primary care settings. Typically, genetic counselors are hired to be part of primary care settings to assist with referrals and provide long-term support to patients. This approach, though, may be more challenging to implement, given there is still an insufficient number of genetic counselors, although the field is growing. It may also be more difficult, given that the state does not have the authority to direct how primary care providers structure their office staff.

Conclusions

The literature review illuminated the challenges and identified possible solutions that could be implemented to improve the delivery of genetic services. Options that include telehealth applications may be the most straightforward and immediate option for genetic centers to pilot. However, a more long-term investment will be to complement telehealth models with the education of nongenetics professionals. Given the likely continued shortage of providers in the field of genetics, a transdisciplinary approach will be needed to build the expertise of primary care providers and other health care professionals to best serve the needs of patients and families.

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Authors' Contributions

MR and SH conceived the study design. All authors reviewed the search terms. RM and SH collected articles, and MR, RM, DT, and SH analyzed and interpreted the data. MR, RM, DT, and SH drafted, critically reviewed, and approved the submission of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence

GCA: genetic counseling assistant

NSGC: National Society of Genetic Counselors

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