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ARTICLE

Rare disease narratives on social media: A content analysis

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ABSTRACT

Purpose: Social media provides an opportunity for the expression of people with rare conditions and may provide valuable insight into lived experiences to inform genomic care. Our objective was to describe the nature and content of rare disease video narratives on social media.

Methods: We reviewed content on a short-video-format social media website containing the tags of #raredisease, #raredisorder, or #raredisorders. Two authors independently coded videos for content matter and conducted thematic analysis using a mixed deductive-inductive approach. The demographic characteristics of the content and names of specific rare conditions were documented when available, as were the characteristics of the videos themselves.

Results: We reviewed 500 videos created by 299 unique users and identified 6 major themes: Spreading Awareness, Guidance for Others, Intimate View into Life, Interactions with Health care, Responses, and Requests for Support. The video narrators were typically family members or caregivers (50.2%) or the person affected (46.6%); a small percentage were health care professionals (2.2%). People with rare diseases in the video comprised both children (40.6%) and adults (52.6%). A total of 189 rare conditions were mentioned, the most common being Ehler-Danlos syndrome (7.8%), Sanfilippo syndrome (1.8%), and narcolepsy (1.8%).

Conclusion: Our data suggest that video-format social media allows community building among people affected by rare conditions. Insights from narratives expressed in this format may contribute to a better understanding of medical experiences in the context of daily life, both positive and negative, fostering empathy and leading to improvements in genomic medicine practice.

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Introduction

Rare diseases affect approximately 263 million 446 million people worldwide.[1] The National Institutes of Health defines rare diseases as conditions with an overall prevalence of <200,000 individuals in the United States.[2] Care for people with rare conditions may be limited by incomplete knowledge of the disease's pathogenesis, progression, and treatment because of the infrequency of diagnosis.[3,4] Furthermore, contributing to the already difficult journeys and feelings of isolation experienced by people with rare diseases is the fact that they also experience unique symptoms that affect daily life.[1] Although recent genomic advances have enabled the identification of the molecular underpinnings of many rare conditions and precision therapies are increasingly available, understanding of the lived experience of people with rare diseases remains limited. Because many people with rare conditions interface with genomic medicine in health care, this lack of insight presents a barrier to implementing optimal genomic medicine.

The rise of social media platforms has facilitated opportunities for information exchange and self-expression. In 2019, social media were used by approximately 75% of adults in the United States.[5] Of these, 75% reported daily use and nearly 50% reported that social media content had an impact on their approaches to managing health.[5] Usage has increased only over the last 5 years.[6] Social media have also catalyzed the speed and opportunities for health care interactions between patients, health organizations, and professionals.[7] In addition to serving as a tool for receiving and disseminating information regarding rare disease, it has the potential to help people feel empowered. Social media platforms have opened avenues for family-to-family communication among people with rare cancers and other rare diseases, allowing them to find support from peers throughout an otherwise isolating journey. However,[8,9] prior work has shown that physicians do not routinely discuss social media use with their patients.[1,10] Insights from social media interactions can eventually improve public health surveillance and offer insights into life experiences that providers can use to better tailor care according to patient needs.[1,11] It should be noted that those who are active on social media may not be representative of all individuals with rare diseases and that a potential risk to social media use is the stress associated with seeing others with more severe or advanced manifestations of a particular condition.[10,12] Nonetheless, social media show promise in facilitating increased social connections and education for those living with very rare conditions.

Thus, social media provides an opportunity for narrative expression for people with rare diseases and may provide valuable insights into genomic care. Although previous research has considered social media use in disseminating health information regarding rare diseases, an in-depth analysis of the content available on newer video-sharing applications has not been conducted.[1,11,12] Our goal was to understand the nature and content of narratives regarding lived experiences of rare diseases presented as brief videos on a social media platform.

Materials and Methods

To identify content related to rare disease, we searched a video-sharing application to identify 500 videos with the tags of #raredisease, #raredisorder, or #raredisorders. Users can film videos within the application or upload them to their profiles. This application provides tools that users can use to enhance their videos, such as filters, different effects, music, and text overlays. Users can tag videos and search for videos using hashtags. Users can like and leave comments on individual posts and engage in conversations by directly replying to the comments. Users can also mention or tag others in video captions or comments, allowing for public interaction between creators and their audiences or between fellow creators. Owing to the nature of the application, videos with evidence of high user engagement (eg, reflected in higher numbers of likes) receive more exposure from other users. Because the goal of this study was to present narratives from the viewpoint of affected individuals who perceived that they had a rare disease, we did not use exclusion criteria based on the prevalence (rarity) of specific conditions. One member of the study team (C.S.) reviewed the first 500 videos chronologically according to the order of the search results returned by the app's algorithm in July 2023. The hyperlink for each video, the username associated with the video, and the length of the video were recorded. The identities of the content creator(s) were extracted when available and were often explicitly stated in the video or caption. Identities and relationships were sometimes presumed based on the nature of the video; for example, if the narrator was bringing a child to an appointment or sharing insights into daily life at home, the narrator was categorized as a caregiver. People living with rare diseases featured in the videos were classified as either children or adults, informed by what was explicitly stated in the video or caption or estimated based on appearance and context, where possible. A second independent review of these videos for data accuracy was performed by another member of the study team (H.J.P.). Because this second review occurred 4 months after the initial review, the same search criteria were used to collect new videos to replace any of the original 500 videos that were no longer publicly available.

We excluded videos that were not in English. There were no duplicate videos. Videos from the same user regarding the same content were excluded if they were observed on the same day. Because hashtags are used at the discretion of creators, videos centered on mood disorders, such as anxiety or depression, are occasionally captured by the query terms. We excluded these videos given the frequency of these conditions in the general population.

Two investigators conducted thematic analysis of the video content using a mixed deductive-inductive approach (C.S. and H.J.P.). After the 2 investigators independently coded the videos, they met with a third member of the study team (M.H.W.) to develop and revise the themes and subthemes. All 500 videos were assigned to at least 1 theme and subtheme and were reviewed by all 3 investigators to establish a consensus. Data on the demographics of content creators (s) and themes and subthemes apparent in the videos were evaluated using descriptive statistics. This study was deemed a nonhuman subject research by the appropriate Institutional Review Board.

Results

A total of 299 unique usernames were represented in the 500 videos sampled for an average of 1.67 videos and a range of 1 to 8 videos per creator. The video narrators were typically family members, caregivers (50.2%), or the affected person (46.6%) (Table 1). A small percentage of narrators were health care professionals (2.2%). People with rare diseases that were present or mentioned in the videos included children (40.6%) and adults (52.6%), with some videos featuring both. In the other videos, there were no specific individuals with a rare disease that was mentioned or present (7.8%). The duration of the videos ranged from 4 seconds to 439 seconds (or 7:19 minutes), and the average duration of a singular video was 52.5 seconds (Of note, the duration of 57 of the 500 videos could not be identified. Fifty-one of these videos were no longer publicly available at the time of review for length, and 6 of these videos are in the format of a slideshow that viewers can click through themselves at their desired pace).

There were 189 rare diseases mentioned in the 500 videos reviewed (Supplemental Table 1). The most frequently mentioned conditions were Ehlers-Danlos syndrome (7.8%), unspecified chronic illness (2.4%), Sanfilippo syndrome (1.8%), and narcolepsy (1.8%). These diseases may have been mentioned in multiple videos created by the same user (Table 2).

We developed 6 major themes (Figure 1), each with subthemes, as shown in Table 3.

Table 1 Creator/narrator identity

Creator/Narrator	Frequency
Parent/family/caregiver	251
Person with disease	233
Health care worker	11
Other narrator[a]	9

[a]Includes people without a direct connection to the subject of the video (as self or parent/caregiver); for example, narrators describe rare conditions that they do not have.

Table 2 Rare diseases mentioned in videos

Type of Rare Disease	Number of Posts	# of Unique Users Who Mentioned
Ehlers-Danlos syndrome	39	26
"Chronic Illness"	12	9
San Filippo syndrome	9	4
Narcolepsy	9	5
Cancer (any type)	8	4
Spinal muscular atrophy	8	2
Giant congenital melanocytic nevus	8	1
Friedrich's ataxia	7	2
Monogenic condition or chromosomal disorder (not specified further)	7	5
Unable to determine	83	N/A

The 10 most frequently mentioned rare diseases are listed, with others listed in the Supplemental Table 1. The terms "chronic illness" and "monogenic condition" or "chromosomal disorder" were used without further specification and combined into a single group. "Cancer" includes both users who named a particular cancer or just the word "cancer" without further elaboration.

N/A, not applicable.

Spreading awareness

Spreading awareness was the second most frequent theme in the reviewed videos (48.6%). Within the theme of Spreading Awareness, informative (1.1) videos that shared general information about a disease were most prevalent (28.8%). Informative (1.1) content was present in nearly all videos in which health care providers were the narrators or creators (9 of 11 videos). Opportunities for spreading misinformation related to disease pathogenesis or symptomatology are uncommon because most videos focus on personal experiences. Rather than attempting to diagnose viewers or provide medical advice, many contained general statistics pertaining to rare diseases and photos or video clips of symptoms, such as rashes or seizures.

Creators also often shared their diagnostic odyssey (1.2) (9.4%), which refers to insights into the process of finding a diagnosis, including the testing performed, treatments undergone, and misdiagnoses made before reaching a final diagnosis (if at all). They used the platform as a space to express their frustrations about how they were treated as patients or family members of people living with rare diseases.

Guidance for others

The creators used a platform to build and support rare disease communities. Creators provided guidance to others (12.0%) through inspirational messages (2.2) (6.0%) and promoting advocacy (2.3) for themselves and the rare disease community (3.8%).

Intimate view into life

An intimate view into life with rare disease was the most frequently identified (52.6%). Within this theme, updates on

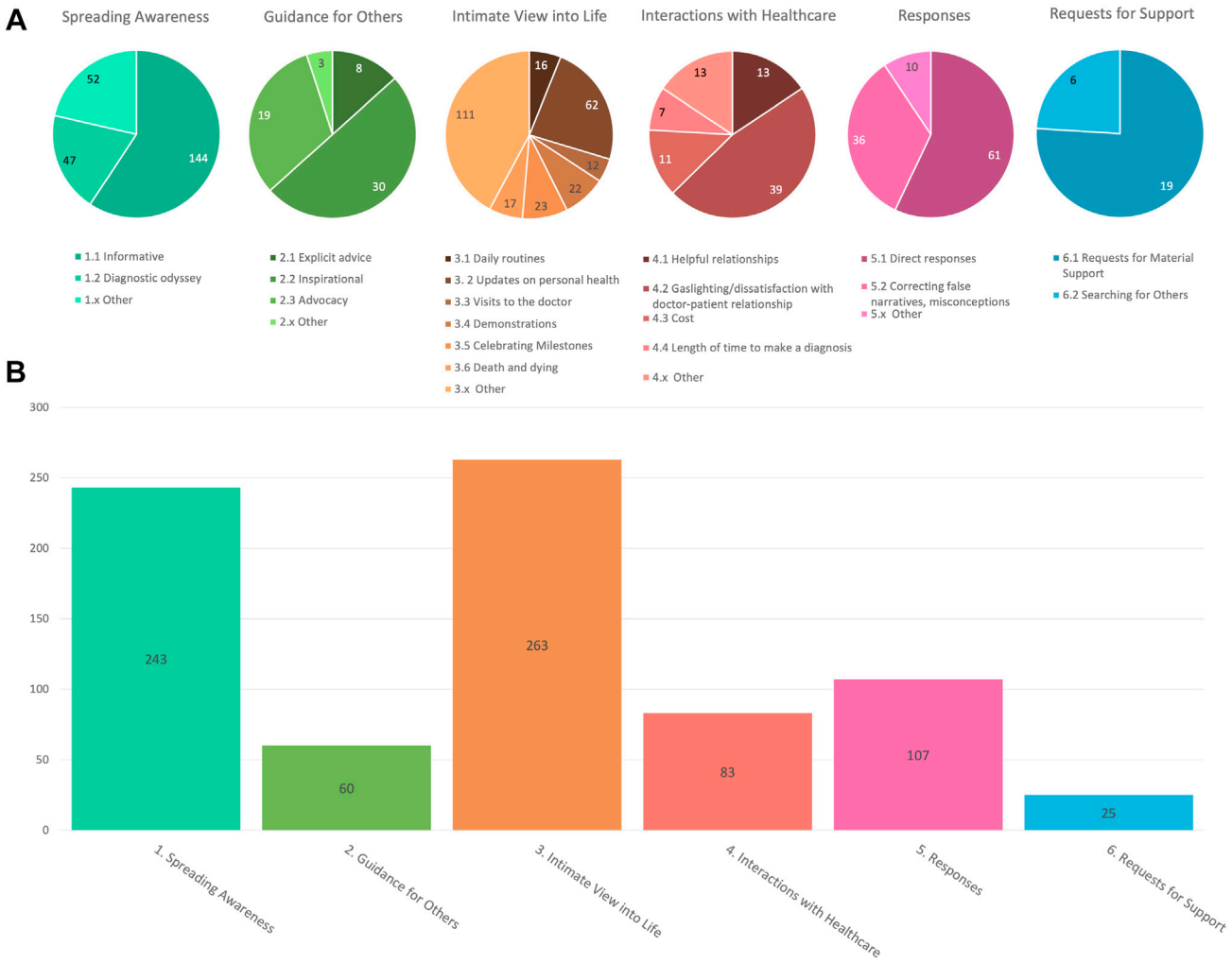

Figure 1 Frequency of themes and subthemes for videos tagged with #raredisease, #raredisorder, and #raredisorders. A. Pie charts depict frequency of subthemes within a theme. B. Bar graph depicts frequency of themes across 500 videos.

personal health (3.2) (12.4%) and other (3.x) that gave viewers a look into life with rare diseases (22.4%) were most frequently addressed.

Interactions with health care

Of the videos that discussed interactions with health care (16.6%), many referred to instances of being gaslighted by doctors or expressed dissatisfaction with doctor-patient relationships (4.2) (7.8%), in which gaslighting refers to the act of manipulating someone into feelings of confusion or insecurity, perhaps even questioning their own reality or judgment, using actions or words.[13] More than 1 creator referred to a metaphor used in health care to describe an approach to diagnosing diseases. Creators explained that doctors are taught "when you hear hoofbeats, think of horses, not zebras." In other words, they were instructed to think about more common diagnoses than rarer ones. Many creators, being so-called "zebras," discussed how this approach can negatively affect patient care for those with rare diseases and often lengthens their diagnostic odysseys. Creators also expressed frustration regarding the cost (4.3) of health care (2.2%) and the length of time to make a diagnosis (4.4) (1.4%). Nonetheless, some videos acknowledged helpful relationships in health care (4.1) (2.6%).

Responses

Many creators use the platform to create responses to the general public (21.4%). Some of these videos involved direct responses (5.1) to comments made by other users on previous videos (12.2%). This type of content was used to answer viewers' questions about rare diseases, express gratitude for viewers' supportive messages, and address hurtful comments. Other videos corrected false narratives/misconceptions (5.2) (7.2%), serving as a general response to experiences a creator may have had as part of living with rare disease. For example, one mother whose son has Beckwith-Wiedemann Syndrome (BWS) created a video

Table 3 Themes and subthemes for videos tagged with #raredisease, #raredisorder, and #raredisorders

Themes	Subthemes	Examples
1. Spreading awareness		
Communicating information about a rare disease	1.1 Informative	Symptoms, statistics.
	1.2 Diagnostic Odyssey	Describing process of testing, waiting for results.
	1.x Other	
2. Guidance for others		
Suggestions and empowering messages	2.1 Explicit Advice	Demonstrating how to use wigs.
	2.2 Inspirational	"Don't give up!"
	2.3 Advocacy	Encouragement to "keep searching."
	2.x Other	
3. Intimate view into life		
Window into living with a rare disease	3.1 Daily Routines	Narrator describing what she eats in a day.
	3.2 Updates on Personal Health	Countdown of days until surgery.
	3.3 Visits to the Doctor	Parent taking child to see a specialist.
	3.4 Demonstrations	Mother putting on her son's leg braces.
	3.5 Celebrating Milestones	Sharing a child's first steps.
	3.6 Death and Dying	Photo montages from grieving parents.
	3.x Other	
4. Interactions with health care		
Experiences with the medical community and industry	4.1 Helpful Relationships	Creation of goodie-baskets for narrator's child's health care providers.
	4.2 Gaslighting/Dissatisfaction with Doctor-Patient Relationship	"None of my doctors believed…"
	4.3 Cost	Expressing shock at the high cost of a child's medication.
	4.4 Length of Time to Make a Diagnosis	Describing time from symptom onset to diagnosis.
	4.x Other	
5. Responses		
Sharing a message or reacting to specific people, users, or a general audience	5.1 Direct Responses	Content creator responds to negative comment telling her to get over herself
	5.2 Correcting False Narratives, Misconceptions	"Things not to say…"
	5.x Other	
6. Requests for support		
Asking for viewer engagement	6.1 Requests for Material Support	Asking for viewers to donate to a fund or to like or comment on a video.
	6.2 Searching for Others	Creators sharing symptoms and experiences in the hope of finding others with similar experiences.

titled "Things Not to Say to a BWS Mom," in which she reenacted one of her son's appointments and expressed frustration toward doctors who commented on her son's health without looking at his medical chart.

Requests for support

Within this category are the following subthemes: requests for material support (6.1) and searching for others (6.2). Requests for material support (6.1) were videos in which creators used the platform to ask for financial or other support, such as asking viewers to donate funds, often to help pay for someone's health care, or to interact with the video by liking or commenting to elevate the video on the app's algorithm and increase the number of viewers the video will reach. When searching for others (6.2), creators shared their symptoms and experiences in the hope of finding others who had similar experiences. This theme highlights the ability of the platform to simultaneously serve as a means for creators to invite others to help them feel less alone, while also reassuring other creators that they are not alone.

Discussion

In this analysis of videos posted on social media about rare diseases, we identified themes such as Spreading Awareness, Guidance for Others, Intimate View into Life, Interactions with Health care, Responses, and Requests for Support, which involved direct requests for material or other types of support. Previous studies have noted the ability of

the internet to connect individuals to rare disease communities.[14] However, given the recent rise of short-form video-sharing social media sites, in which posts are often publicly available and meant for widespread sharing, our findings specifically relate to the use of this format as a platform for people living with rare diseases to spread awareness about their conditions and to give others insight into their lives. By contrast to studies conducted before the rise of short-form video sharing that focused on the function of social media and other Internet-based sources to address informational needs,[15,16] we found that short-form videos allowed for a more intimate view of the experiences of people with rare conditions and their families. Videos were frequently centered on the creators' personal experiences; although some videos educated viewers on certain diseases using symptoms and statistics, few seemed intended to diagnose viewers with disorders. We note that because of the short video format, users have cultivated unique methods of conveying and sharing information, such as utilizing sound effects and pictures. This format currently allows for a variety of video lengths, and our results highlight the multifaceted sharing potential of this social media format, in which a 4 second clip can include valuable information in terms of what narrators choose to share in that small amount of time. Prior studies, such as those that used comments from conversations in 2 Facebook groups to identify the most common sleep disturbances associated with Prader Willi Syndrome, have also demonstrated the potential of social media platforms to deepen our understanding of medical disorders and, in turn, aid in better targeted care.[17] Similarly, video-sharing social media platforms provide the public and health care providers with the opportunity to learn how to best support rare disease communities through positive social and health care interactions.

Thus, our study offers unique insights into rare disease content on social media as presented in a short-form video-sharing app. Similar studies have conducted thematic analyses of video-sharing app content pertaining to topics such as sex education, ophthalmology, and other medical topics.[18-20] In sex education studies, researchers have found that these video-sharing apps provide an opportunity to fill the gaps in sex education curricula that are currently provided in schools, homes, and doctors' offices.[18] Because of the lack of general knowledge on rare diseases, even from health care providers, many people with rare diseases and their families also experience gaps and thus seek health information on their own,[21] particularly as it relates to daily experiences. This video-sharing platform thus presents a potential avenue through which people with rare diseases and their families can attempt to learn in various ways from others with the same or similar conditions.

Our findings additionally highlight the platform's ability to bridge the physical gap between people living with rare diseases and facilitate connections that may reduce feelings of isolation. Research suggests that members of a rare disease community experience a lack of support and struggle to find realistic depictions of life after diagnosis. The rarity of these disorders makes it difficult for people to get confirmation that their symptoms are normal or to seek advice for everyday life.[21-23] The fact that most videos that we reviewed centered on people's personal experiences with rare diseases through advice, an exploration of their diagnostic odysseys, or an intimate view into their own lives or those of family members suggests that this video-sharing platform could provide people with insight into the lived experiences of rare disorders that they seek. Studies have shown that other social media platforms have revolutionized the ability of people with rare cancers to connect, provide, and receive emotional support.[1] The far-reaching nature of social media allows people with specific illnesses to congregate virtually to build communities and find solidarity among others without being confined by distance.[7,20]

Nonetheless, studies analyzing medical content on video-sharing platforms bring attention to the fact that not all content creators are experts in their field. Researchers have noted the presence of misinformation on the platform and recognized that the amount of content present on the app makes it nearly impossible for experts to respond to all the factually incorrect information.[18,19] The spread of medical and health-related misinformation has been investigated in previous studies involving multiple social media platforms.[24] Videos that were categorized as informative (eg, sharing information about symptoms or statistics pertaining to the disease) were most at risk of being factually incorrect and should be viewed with discretion. Future work is needed to factually characterize rare-disease narrative video content.

Social media also has the potential to help address the problem of delayed diagnoses or long diagnostic odyssey, which are common in many people with rare disorders. Social networks are being developed in an attempt to solve this problem by using artificial intelligence to match undiagnosed individuals with similar symptoms.[25] Similarly, video-sharing apps provide people with a means to connect with others who may have similar symptoms; however, it is important to note that social media is not a comprehensive diagnostic tool and that health care professionals should be consulted for diagnostic evaluation. Other social media platforms have been used to connect people to genetic counselors for genetic testing, which can sometimes reduce the time required for people to obtain a diagnosis.[22] Although only a small percentage of the narrators were health care professionals in the videos we reviewed, there are medical experts present in the video-sharing app who may present resources to lead people to appropriate medical diagnostic services.

Our study is limited by several factors. The videos analyzed were the results of multiple searches and were not confined to a single day. The search results are determined by the application's algorithm, which tailors the content based on user engagement. It is possible that earlier searches and activities on the application influenced the results of subsequent searches. In addition, the limited information presented in a video and its caption at times restricts our

ability to accurately record demographic information. Because presuming demographic information such as age and participant role (caretaker or health care provider) may introduce bias into the categorization of narrator identity and relationships, wherever possible, we attempted to include only information explicitly stated by the content creator, although bias in demographic distinctions may remain. Finally, many videos used songs or sounds, such as voice-overs, which were not original to the creator and had a particular meaning within the context of the app. Consequently, some of the messages conveyed through these sounds may be difficult to discern without a background knowledge of social media trends and how they are used.

In summary, our findings suggest that social media has extensive potential to disseminate information on rare diseases, foster connections and feelings of support, normalize experiences, and may promote advocacy that ultimately shortens the genetic diagnostic odyssey or assists in the journey after diagnosis. Given the pervasiveness of social media in the daily lives of people with (and without) rare conditions, it is important for clinical genetics providers to be aware of the available content and how it may affect people seeking genomic care.

Data Availability

Data are available from the corresponding author upon request.

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Author Contributions

Conceptualization: M.H.W.; Data Curation: M.H.W., H.J.P.; Formal Analysis: H.J.P., C.S.; Investigation: H.J.P., C.S.; Methodology: M.H.W., H.S.S.; Supervision: M.H.W., H.S.S.; Visualization: H.J.P.; Writing-original draft: H.J.P., C.S.; Writing-review and editing: M.H.W., H.J.P., C.S., H.S.S.

Ethics Declaration

The Boston Children's Hospital Institutional Review Board reviewed and approved this study as nonhuman subject research.

Conflict of Interest

Monica H. Wojcik reports consulting Illumina and Sanofi and has received speaking honoraria from Illumina and GeneDx unrelated to this work. Hadley Stevens Smith reports consulting income from Illumina that is unrelated to this study.

Additional Information

The online version of this article (https://doi.org/10.1016/j.gimo.2025.102844) contains supplemental material, which is available to authorized users.

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