Journal of Community Genetics (2019) 10:375–383
https://doi.org/10.1007/s12687-018-0400-6

ORIGINAL ARTICLE

"Before Facebook and before social media…we did not know anybody else that had this": parent perspectives on internet and social media use during the pediatric clinical genetic testing process

Krysta S. Barton[1] · Andrew Wingerson[2] · Julie R. Barzilay[3] · Holly K. Tabor[4]

Received: 16 June 2018 / Accepted: 20 November 2018 / Published online: 19 December 2018

Abstract

Parents of children who undergo clinical genetic testing have significant informational and emotional support needs at different stages of the testing process. We analyzed parent views about use of both the internet and social media to help meet these needs. We interviewed 20 parents of children who underwent clinical genetic testing and analyzed transcripts to identify themes related to internet and social media use. Parents described using the internet to search for information at three stages of the genetic testing process: before testing, pending results return, and after results return. Each stage corresponded to different information vacuums and needs. Parents also described using condition-specific Facebook groups to learn more about their child's condition and to find support networks of families with similar experiences in ways that were challenging using non-social media approaches. Both the internet and social media play important roles in meeting informational and support needs in pediatric genetic testing, especially for rare conditions. Providers should consider engaging parents at different stages of the testing process about their use of the internet and social media, and consider directing them to vetted sites and groups as part of shared decision making and to improve satisfaction and outcomes.

Keywords Genetic testing · Internet · Social media · Diagnostic odyssey

Introduction

Parents of children who undergo diagnostic genetic testing have a variety of informational and support needs which traditional medical and social systems frequently fail to meet. These parents often report that the information given by health care providers about their child's condition, prognosis, and services frequently feels inadequate, hindering their ability to cope and manage their child's health. (Pelentsov et al. 2015; Lewis et al. 2010) Parents also experience social isolation after a genetic diagnosis, including a decrease in the number of friends they have after the birth of their affected child, limited interaction with similarly situated families, and challenges in accessing support groups, leaving them feeling "desperately lonely." (Rosenthal et al. 2001, Harmon 2007) Feelings of anxiety, fear, anger, frustration, isolation, and uncertainty are prevalent. (Yanes et al. 2016)

One way that parents can attempt to address informational and support needs is through use of the internet, and more specifically through the use of social media. These tools might be especially useful for rare genetic conditions, about which parents may know little and have challenges in connecting with other families with the same experiences. Only a few studies have examined use of the internet and social media by parents of children who undergo genetic testing. These studies examined parents with children: (1) in pediatric genetics clinics (Roche and Skinner 2009; Schaffer et al. 2008; Skinner and Schaffer 2006), (2) with a positive newborn screening test (DeLuca et al. 2012), and (3) with a rare genetic disorder. (Gunderson 2011; Jacobs et al. 2016; Nicholl et al. 2017) While all of the studies found that the vast majority of parents searched the internet about their child's condition,

✉ Holly K. Tabor
hktabor@stanford.edu

[1] Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute, Seattle, Washington, USA

[2] Keck School of Medicine of the University of Southern California, Los Angeles, CA, USA

[3] Stanford University School of Medicine, Stanford, CA, USA

[4] Stanford Center for Biomedical Ethics, Stanford University School of Medicine, 1215 Welch Road, Modular A, Room 69, Stanford, CA 9305-5417, USA

there were variations in use across demographic groups, diagnoses, and time since diagnosis. Parents varied in their responses to online information; some found it reassuring and empowering, while some found it anxiety provoking. One study found that providers did not routinely recommend websites to parents or discuss parents' internet searches. (DeLuca et al. 2012)

Social media use by parents was not evaluated in all but one of these studies (Jacobs et al. 2016). However, some parents reported joining "pre-social media" web-based forums and "chat groups" about their child's condition to address unmet emotional needs and to seek information about diagnosis, prognosis, treatment, and services. In one more recent study, the vast majority of parents reported sharing information about their child with online communities. (Nicholl et al. 2017)

Demographic trends about both internet and social media use have changed even in the last 5 years since most (71%) of these studies were published, with more Americans using the internet (87%) and owning smartphones (64%) than ever before. (Smith 2015) Almost two thirds of smartphone owners have used their phone to find health information (62%). (Smith 2015) These trends have been accompanied by the rising omnipresence of social media; 80% of online Americans are Facebook users, with 76% of users reporting using the site daily and 55% visiting several times a day. (Pew Research Center 2016)

Another important development has been the reported increase in social media groups created by patients that focus on specific medical conditions. This trend appears to be recent: one study found that the earliest groups for pediatric hydrocephalus were created in 2007, with a peak of group creation in 2011. (Elkarim et al. 2017) Several studies in the last 4 years have examined the prevalence, usage, and/or content of disease- and condition-specific Facebook groups including for breast cancer, (Bender et al. 2011) schizophrenia, (Athanasopoulou et al. 2017) hypertension, (Al Mamun et al. 2015) preterm infants, (Thoren et al. 2013) pediatric hydrocephalus, (Elkarim et al. 2017) and brain aneurysms and subarachnoid hemorrhage, (Alotaibi et al. 2017). Other studies have examined groups targeted to specific technologies or interventions, including diabetes foot care, (Abedin et al. 2017) hearing aid use, (Choudhury et al. 2017) and cochlear implants (Saxena et al. 2015).

Only two empirical papers described Facebook use for genetic conditions. One was a 2016 study of Facebook groups by parents for congenital anomalies that identified 54 groups. (Jacobs et al. 2016) A second study reviewed the use of social media by parents of children presenting for initial consultation about their child's congenital cleft anomaly, with 76% reporting using Facebook, including for information about their treatment team (43%) and where to receive care (26%). (Khouri et al., 2017) These two studies suggest that use of genetic condition-specific Facebook groups/social media may be broader than has been characterized to date.

More up-to-date characterization of how families undergoing pediatric clinical genetic testing use the internet and social media would help health care providers incorporate these resources into pre- and post-test counseling and care discussions and hopefully improve outcomes and care for this population. To begin exploring this issue, we examined parents' experiences of and attitudes towards potential uses of the internet and social media during different stages of the genetic testing process. These analyses were part of a larger qualitative interview study characterizing parents' experiences with pediatric clinical genetic testing.

Methods

Participants

The study team recruited parents whose children had undergone clinical genetic testing, or testing done by a physician as part of clinical care. Our goal was to identify children with a diverse range of genetic conditions. Parents were identified: (1) through advocacy organizations for pediatric genetic conditions (including moderator-approved use of social media sites or email lists), (2) through researchers with IRB-approved studies of genetic conditions at affiliated Seattle-based institutions, and (3) through snowball sampling. We employed these strategies for two reasons: (1) to optimize for recruitment from a diverse range of genetic conditions and (2) to identify families with rare genetic conditions who might be hard to identify through other recruitment approaches. All respondents were contacted by phone and provided with further details about the study. Parents were eligible to participate if they had at least one child who had undergone clinical genetic testing under the age of 18. A total of 21 families were enrolled and interviewed. One family was excluded from analyses because the interview clarified that the child's testing was conducted solely in a research study, rather than as part of clinical care.

Procedures

Because of the diverse locations and scheduling needs of participants, most interviews were conducted by phone ($n = 20$), with one conducted in person. Interviews with parents ranged in length from 22 to 120 min and were conducted by a member of the research team (KSB or HKT) between May and October 2015. The interview guide included questions about: (1) timing and experience of referral to a geneticist, (2) communication and return of clinical genetic testing results, (3) clinical translation and implications of results, (4) personal meaning of results, and (5) sharing of results with other health

care providers and family members. There were no specific structured questions about either participant internet use or social media use, so all responses reported here arose spontaneously from the participants during the interview and emerged from the coding process. All interviews were audio-recorded and transcribed by a member of the research team, removing any identifiers. A second researcher then reviewed and verified the transcription for accuracy. This study was approved by Seattle Children's Hospital Institutional Review Board.

Data analysis

Content and thematic network analysis was applied to the transcripts. (Hsieh and Shannon 2005; Attride-Stirling 2001) First, three investigators (KSB, AW, HKT) read and discussed all transcripts to define codes and establish the code book through an iterative process. Two investigators (KSB, AW) then coded the transcripts using the Atlas.ti software and reviewed transcripts during joint meetings to reach agreement about any divergent coding through discussion. Code summaries were written to identify and organize emerging themes, which were discussed with the research team for refinement and resolution through discussion of any disagreement. The coded data were then subjected to thematic network analysis to identify the main themes and interrelationships by two of the investigators (KSB, HKT). (Hseih and Shannon 2005) The analyses reported here derived from three codes from the larger study (previous genetic knowledge, experience of receiving results, experience with advocacy organizations and other families).

Results

The study population (Table 1) was predominantly mothers (90%), Caucasian (85%), married (90%), and highly educated (100% with a minimum of a bachelor's degree). Most reported they had more genetic knowledge than others and had more than one child. The children had a wide range of pediatric genetic conditions (Table 2), and four did not have a diagnosis. Seven (35%) spontaneously mentioned use of the internet or social media before the structured question in the interview guide about web-based return of genetic test results. The qualitative results are presented in four themes: (1) genetic knowledge prior to testing, (2) use of the internet, (3) use of social media specifically, and (4) barriers to the use of internet and/or social media.

Genetic knowledge prior to testing

Many parents stated they had little knowledge of genetic testing or conditions prior to their child undergoing genetic diagnostic testing. One parent described her lack of knowledge, saying, "I am sure maybe I read one chapter in high school biology or something, really had zero information or knowledge." (P6) Several cited being confused about genetic testing in general: "I don't think I really comprehended what we're doing, what we were searching for. We're just looking at our child, things weren't quite right," (P12) and "I really didn't understand this and to some extent I still don't understand how this works." (P5) A minority ($n = 2$) spontaneously mentioned having medical or scientific background or expertise that helped them, at least in part, understand genetic testing and any results that were returned.

Five parents said their previous knowledge of genetic conditions and testing was restricted to Down Syndrome. As one parent explained, "I mean, I feel like I have learned so much, but walking into genetic testing for the first time, I didn't really have a grasp of the idea that there were other disorders out there besides Down Syndrome." (P2). A parent of a child with 22q deletion syndrome said, "when I thought about genetics, I thought about, you know, the big ones like Down Syndrome or Fragile X, and I didn't know all the subtleties to, genetic, what the genetic testing could show." (P21)

Table 1 Study population demographics

	Categories	
Gender	Female 90% (18)	Male 10% (2)
Race	White 85% (17)	Other 15% (3)
Marital status	Married 90% (18)	Single/divorced 10% (2)
Education	Bachelors 40% (8)	Advanced degree 60% (12)
Genetic knowledge	More or much more than others 75% (15)	As much as others 25% (5)
Number of children	One	15% (3)
	Two	30% (6)
	Three	50% (10)
	Four	5% (1)

Table 2 Diagnoses for children of participants and self-reported wait time for genetic results

Number	Diagnosis	Wait time for results
P1	Hearing loss (Connexin 26)	2 months
P2	Williams syndrome	1 week
P3	Undiagnosed (developmental)	Ongoing
P4	Branchio Oto renal syndrome	6 months
P5	Undiagnosed	Ongoing
P6	Chromosome 3p deletion	7 months
P7	Achondroplasia	10 days (prenatal)
P8	Facioscapulohumeral muscular dystrophy (FSHD)	2 weeks
P9	Sickle cell anemia	< 1 month
P10	Usher syndrome	1–2 months
P11	Suspected primarily ciliary dyskineseia (PCD)	Ongoing
P12	Pyruvate dehydrogenase complex deficiency	2 years
P13	Suspected dystonia	Ongoing
P14	Usher syndrome	2–3 months
P15	CHARGE syndrome	2.5 years
P16	(Removed from study because of ineligibility)	–
P17	DYT1 dystonia	2.5 weeks
P18	22q Deletion (DiGeorge) syndrome	< 2 weeks
P19	Tuberous sclerosis	6 months
P20	Dravet syndrome	1.5 months
P21	Chromosome 22q deletion	3–4 weeks

Use of the internet

Parents described using the internet prior to diagnosis, and before their child's first provider visit, to search for possible diagnoses or explanations for their child's symptoms or challenges (Fig. 1). These searches were described as open-ended and symptom-based, in an effort to find examples of phenotypically similar conditions that might explain their child's challenges. One parent said, "I combed the internet for possible diagnoses. You know and [husband] and I would look at them and say, 'Well, that, you know, ok like, two or three of the characteristics,' but it seems like she'd always be missing, like, most of the crucial ones, you know. Yeah, so I would do a lot of education on my own." (P3)

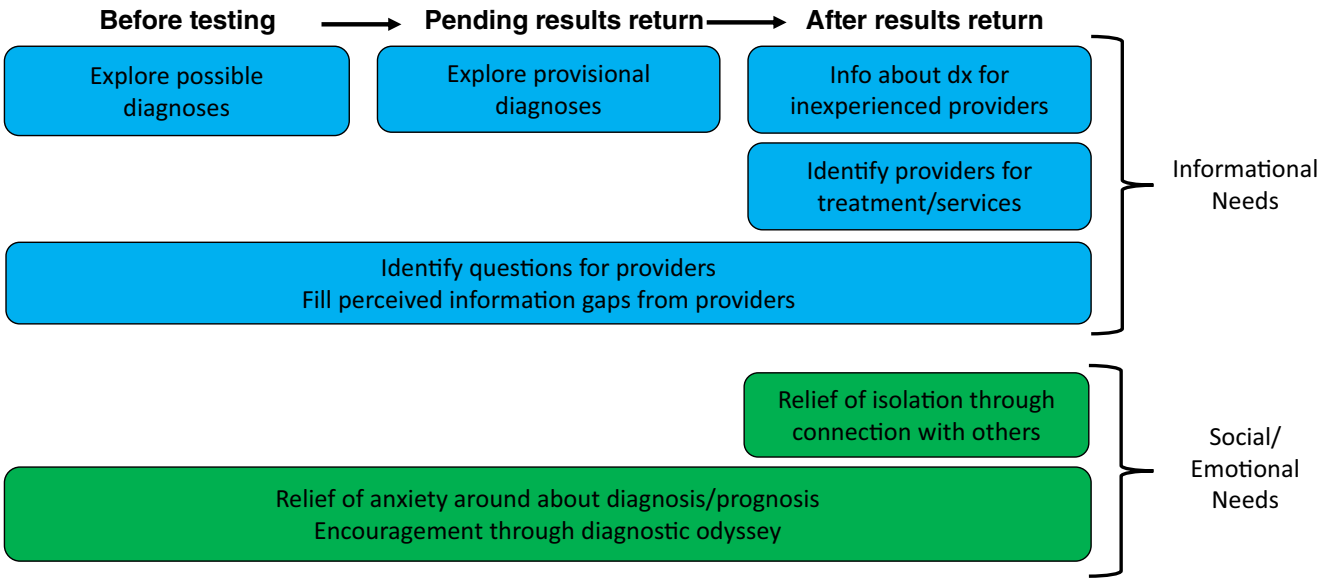

Fig. 1 Internet/social media uses at different stages of the genetic testing process

For some parents, this kind of informational internet-based searching continued after being given a provisional diagnosis, but before a confirmatory genetic testing result was returned (Fig. 1). One mother said that after her pediatrician gave a suspected diagnosis of Williams syndrome and referred her for genetic testing, "of course then we Googled it and we looked it up and realized a lot of these things are matching up." (P2)

While this kind of internet search frequently focused on gathering information, it was also connected to managing feelings of anxiety and ambiguity about the prognosis for their children (Fig. 1). A parent of a child with chromosome 22q deletion syndrome described searching the internet during the wait time between the test being conducted and the result being confirmed as a way to expand on what the providers had mentioned at the testing visit:

> …I think I went into inquiry mode…I did start to do some research about what the FISH test was and what it could possibly bring up, and then I, of course I was Googling, which my husband asked me not to do [laughing], I kind of did go into a little bit more of an anxious mode in terms of anxiety around what it could bring up because I did feel like something was different with her…. (P21)

Participants reported searching the internet for information for rare diseases as sometimes frustrating and unsatisfying. A parent of a child with a chromosome 3p deletion said that after receiving the genetic result by phone, but before the in-person clinic visit, "I tried looking it up on the internet and found nothing." (P6)

Some parents made explicit choices about when to search the internet for information about specific diagnoses, in order to manage potential emotions. A parent with a child with facioscapulohumeral muscular dystrophy (FSHD) said: "I learned sort of long before [genetic testing for the child] not to delve into things unless I know I learned it. I'm old enough that I could scare myself on the internet. … So, I waited until the diagnosis was confirmed and then went on the websites to see exactly what this was and what the implications were." (P8)

One parent described using specific internet-based genomics tools from the research community to address a sophisticated kind of informational need: further analyzing their child's genetic result, when the provider seemed to lack specific knowledge about the rare condition:

> "We literally figured out it was a stop codon by going, the NIH publishes gene sequences and so you can read through and find the reading frame…so we literally, like, went to the internet and figured out exactly what the, you know, the biochemical issue was that our son had…the neurologist who, pediatric neurologist who helped us….he was an older man and I'm not sure how much genetic, you know, genetic schooling he had actually had, even when he was in school, so he may not have understood, you know, really what was going on, on either. And he was not an expert in this condition, I mean his background and expertise was more like, you know, treating ADHD and some of the more common, you know, typical, because [son's] condition is also very rare, I mean it strikes they estimate about 1 in 40,000 live births, so it's very rare and not that many people know that much about it." (P20)

Use of social media

Parents described using social media, and specifically Facebook, to identify other families with similar experiences for interactive education, support, and guidance (Fig. 1). Parents sought and joined social media groups after receiving results, but continued and expanded this use beyond the initial post-result return period. Most parents said that social media filled the perceived vacuum of social support and informational resources for families like theirs, with their unique diagnoses and experiences. The previously described parent of the child with the chromosome 3p deletion who failed to find information about her child's condition in a simple internet search was much more successful when she used social media: "…before Facebook and before social media…. we didn't know anybody else that had this. We really didn't have any resources of anybody else that we could reach out to. There is [sic] no books. There is no website." (P6) She added, "I am grateful for the database of other families that we've been connected with…." (P6)

A parent of a child with Usher syndrome echoed this appreciation, and described how Facebook facilitated their ongoing communication with families from around the world, whom they would not have otherwise identified:

> "…we're part of, I know this is silly but part of just like a Facebook group, it's like a bunch of parents of kids with Usher syndrome, it was, it turned out that there's a lot of parents there from everywhere, and in fact like three or four families from Australia actually, which is interesting, and they all had young kids like kids between the ages of like 2 and 8 or whatever that, that had Usher. And so, those parents kind of formed a little group and so we, yeah, we have that and we kind of keep in touch with them." (P14)

Participation in Facebook and other interactive social media and online support groups not only provided support and connection, but also helped some parents more practically in managing their child's condition and interacting with health care providers more effectively after diagnosis. A parent of a

child with tuberous sclerosis said "…finding an online support group [after receiving genetic results/diagnosis] is, was the best thing that I did… through that and reading posts on there, then that's where I come up with my questions that I wanted to ask [providers], 'cause that helped me to know a little bit more about the disease going in." (P19)

Even parents who did not get a confirmation of a diagnosis through genetic testing found some support from their participation in Facebook groups. The parent of the child with FSHD talked about the tenacity required of parents as their children undergo diagnostic odysseys that include genetic testing. She said, "So that's what we have a responsibility to our kids to sense something's wrong and keep seeking an answer until you're satisfied." (P8) She described finding other mothers with similar experiences through social media: "Mothers, I am on some of the Facebook parent sites and there are people that just spend a couple of years trying to figure out what's wrong as their children's muscles deteriorate and they're just sad, sad stories." (P8)

Barriers to use of internet and/or social media

Parents spontaneously described three potential barriers to using both the internet and social media for support and information (Fig. 2). The first was the challenge of not having a diagnosis/genetic result to use in searching the internet, or to use to identify and connect with condition-specific social media communities. The parent with two children with an undiagnosed developmental disorder (the same one who unsuccessfully Googled symptoms to try to find a diagnosis before testing) expressed this frustration about her inability to use social media for this purpose:

> "I really want to know exactly where we stand. Cause I want to know what I can do, and at this point, because we've discussed this before right, like do I use social media to try to find other kids like them? But I have so little information? Ok, really, I have two kids with developmental delay..." (P3)

A second challenge mentioned by parents was that some health care providers actively discouraged them from searching the internet, perhaps because of concerns about misinformation, false hope, or the chance of increasing feelings of anxiety and distress. A parent of a child with pyruvate dehydrogenase complex deficiency described being desperate for more information on the new diagnosis that their child had been given, about which they knew nothing:

> "We were given [at the return of results appointment], I think, three articles, and they said, "this is all you're allowed to read, because this is all we can say is accurate on what she has right now, do not go searching the internet," you know, cause immediately we're going into the question mode "where can I find more information, what can I do here." (P12)

A third challenge, which was only mentioned spontaneously by one parent, was anxiety and concern about privacy. One mother described how her worries about violating her son's privacy were barriers to using disease-specific social media sites for support. She said, "…. when we had been diagnosed, I was very iffy about, you know, joining some kind of social media group like that because it was, you know it's my son's medical information, it's his, his information, not really mine." (P20) Instead, she described choosing a more traditional, non-digital path: joining the Dravet Syndrome Foundation and attending their national in-person meeting. She commented that her reluctance to use social media likely delayed her ability to find support: "…it took a while to kind of find a network of people, but some of that was because I was more closed to the social media, you know, avenue for that…." (P20)

Discussion

While several previous studies have described how parents of children with genetic conditions use the internet to seek out

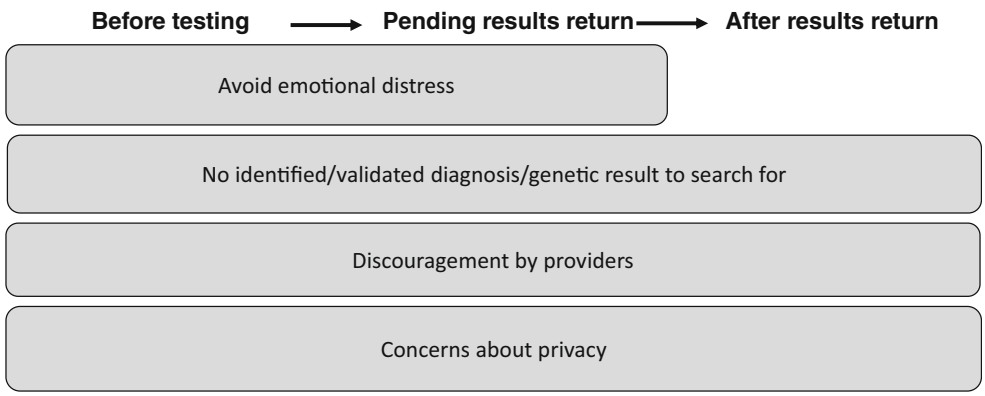

Fig. 2 Barriers to internet/social media use during the genetic testing

information and support organizations, all but two of these studies are 5–11 years old. (Roche and Skinner 2009; Schaffer et al. 2008; Skinner and Schaffer 2006; DeLuca et al. 2012; Gunderson 2011; Jacobs et al. 2016; Nicholl et al. 2017) All but one pre-date, and therefore do not describe, the use of social media. They also do not take into account the significantly increased pervasiveness of internet and Facebook in just the last few years, or the ubiquity of smart phones and concomitant increased social media and internet usage. These very recent demographic patterns have also led to shifts in notions about the privacy of genetic and health information: most parents in our study were comfortable sharing information about their child's condition and genetic results on the internet and social media and perceived the benefits of sharing to outweigh possible risks to privacy, with only one expressing concerns.

Our study also provides a new perspective by identifying three time points during the genetic testing process when parents use the internet and social media to meet informational needs: before testing, pending results return, and after results return (Fig. 1). The informational needs of parents are different at each of these time points. Before testing, parents describe searching for information about diagnoses that have symptoms resembling those they see in their children. Before and during the testing process, parents describe interest in information about the genetic testing process itself. After receiving results, parents describe searching for information about their child's new diagnosis and possible treatments and services. If parents do not receive genetic results, they describe continuing to use the internet and social media to search for potential diagnoses.

Parents' support needs also vary across these time points, with more disease/condition-specific support needs manifesting in the aftermath of receiving a previously unknown diagnosis—especially one for which parents know no other similar children/families. Several studies have found that parents of children with rare diseases and genetic syndromes feel a lack of social support and have a desire to connect with parents of children with similar diagnoses and experiences. (Pelentsov 2015; Rosenthal 2001, Yanes 2016) Our findings reinforce this conclusion and highlight the specific roles that social media and disease-specific groups can play in filling unmet and specific support needs. Social media groups can help parents navigate the diagnosis, explore potential interventions, strategize to obtain services, and feel emotional connection with others like them. Joining these groups may facilitate parental empowerment, improve outcomes, and mitigate harms of social isolation.

Our results may be part of a larger recent trend of people using social media to find and network with those with similar/less common experiences, who are hard to find through other, more traditional channels. Facebook reportedly recently changed its corporate mission to emphasize the role of private groups, to "give people the power to build community and bring the world closer together." (Roose 2017) As part of this effort, Facebook Chief Financial Officer Sheryl Sandberg recently met with women who founded and/or led Facebook groups on diverse topics, including health conditions. One group leader described how members who do not have in-person access to people with shared interests/concerns consider the Facebook group "a lifeline." Sandberg said, "You think you're the only one…[f]rom not liking your hair to wanting to build a bridge to another religion to waking up paralyzed because most people don't know anyone else." (Hassler 2017) As mentioned previously, several recent papers have documented the increasing use of Facebook groups for patients and families with specific medical conditions. Similarly, Facebook, as a company, and communities of parents with genetic conditions may be taking advantage of the current social media landscape to expand this kind of networking.

It has been reported that health care providers sometimes discourage internet and/or social media use, remain silent about it, or are uninterested in what parents/patients find. (Nicholl et al. 2017) Several of our participants confirmed this finding. Our results suggest that in doing so, providers may ignore the potential risks and harms of informational and support gaps, as well as potential benefits of filling those gaps.

These findings point to several possible recommendations for providers. Instead of discouraging internet and/or social media use, providers could, and perhaps should, help parents connect with reputable and trustworthy internet and social media sources that correspond to their varying needs at different stages of the testing and diagnosis process. Early on in the testing and diagnostic process, providers could direct parents to sites describing the genetic testing process itself, as well as information otherwise provided in pre-test genetic counseling, so that parents could consume that information at their own pace and formulate questions. Such an approach could optimize in-person counseling time and lead to improved informed consent and satisfaction.

In the past, providers may have given parents a brochure or even the name of website for a disease-specific advocacy group at the time that genetic testing results were returned, but this kind of referral may no longer be sufficient to fit parent needs or internet and social media use patterns. Furthermore, these kinds of resources may be far less effective than social media for facilitating networking for rare genetic diseases across physical distances or for meeting a diverse array of informational needs in real-time. One possible recommendation stemming from these results is that providers could consider providing a set of vetted links to internet resources and social media groups for specific conditions when a child receives a genetic diagnosis. This would allow parents to connect quickly with others with similar experiences, providing support and guidance as they cope with diagnostic

information. Such an approach may be especially important for rare diseases, when parents, patients, and providers could benefit from disease-specific information about obtaining care and services, treatment, and future planning.

More detailed research is needed about how and when parents use social media, across disease/patient groups and across time points in the genetic testing timeline. Studies could examine the content of the social media sites and query users about impacts on diagnosis and treatment, including characterizing parent-provider discussions about internet and social media use. Future studies should also explore parent views about benefits and risks of sharing personal information about their children online, and whether these vary by phenotype, age, and developmental/cognitive ability of the child, or concern about stigma and discrimination. Such data could substantially influence the patterns of the delivery of genetic results and clinical management of genetic conditions by providers. Given reports and concerns about security breaches at Facebook since this study was conducted, (Wren, 2018, Domonoske 2018) further research is needed to characterize any influence of these developments on parents' views of use of social media related to genetic testing and privacy.

If social media and internet use are found to be effective tools for meeting informational and support needs for parents, even in conjunction with in-person clinic visits, then data are needed about which parents have challenges in accessing social media for these purposes. We identified examples of a range of barriers including lack of diagnosis to search with, discouragement from health care providers about searching the internet and social media, and concerns about privacy. While none of our study participants mentioned it, lack of access to the internet and lack of health literacy may also be important barriers to parent-driven access, provider-supported access, or provider-initiated internet return of results. More studies are needed on the groups that may face these challenges, and on how their needs and specific experiences can be addressed.

Limitations

There are several limitations to this study. Our sample size was small and consisted of only English-speaking, highly educated, Caucasian families with a subset of pediatric genetic conditions, and therefore our results may not be generalizable to others undergoing genetic testing, or to all pediatric genetic conditions. Our recruitment strategy included the use of social media sites and advocacy groups, so our results may be biased towards parents who are active users and/or have positive views of the role of the internet and social media. Our study was not designed to explicitly evaluate internet and social media use, and it is possible that we may not have fully captured the full range of patient uses or views on the topic. Because participants only mentioned Facebook and social media use spontaneously, we were not able to ask or analyze about other forms of social media use, such as Instagram, Twitter, or YouTube. Because of the diversity of conditions represented and recruitment strategies employed, as well as the limited sample size, we were not able to make cross-disease or cross-recruitment strategy comparisons.

Conclusions

In conclusion, our results suggest that the internet and social media play important informational and support roles in the experiences of parents whose children undergo pediatric clinical genetic testing. Rather than viewing the internet as a source of rumors and potentially unverified information to be contained and condemned, providers and parents should communicate and collaborate to use it judiciously and effectively to enhance, rather than detract or distract from, the genetic testing process and experience.

Acknowledgements We would like to thank the parents who shared their experiences and perspectives with us. We would also like to thank the advocacy organizations and researchers who helped us with recruitment.

Funding information Research reported on in this publication was supported by a pilot grant from the Center for Clinical and Translational Research at Seattle Children's Research Institute.

Compliance with ethical standards

This study was approved by Seattle Children's Hospital Institutional Review Board.

Conflict of interest The authors declare that they have no conflict of interest.

Human studies and informed consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all individual participants included in the study.

References

Abedin T, Al Mamun M, Lasker MA, Ahmed SW, Shommu N, Rumana N, Turin TC (2017) Social media as a platform for information about foot care: a study of Facebook groups. Can J Diabetes 41:97–101

Al Mamun M, Imbrahim HM, Turin TC (2015) Social media in communicating health information: an analysis of Facebook groups related to hypertension. Prev Chronic Dis 12:E11

Alotaibi NM, Samuel N, Wang J, Ahuja CS, Gupta D, Ibrahim GM, Schweizer TA, Saposnik G, Macdonald RL (2017) The use of social

media communications in brain aneurysms and subarachnoid hemorrhage: a mixed-methods analysis. World Neurosurg 98:456–462

Athanasopoulou C, Välimäki M, Koutra K, Löttyniemi E, Bertsias A, Basta M, Vgontzas AN, Lionis C (2017) Internet use, eHealth literacy and attitudes toward computer/internet among people with schizophrenia spectrum disorders: a cross-sectional study in two distant European regions. BMC Med Inform Decis Mak 17:136

Attride-Stirling J (2001) Thematic networks: an analytic tool for qualitative research. Qual Res 1:385–405

Bender JL, Jimenez-Marroquin MC, Jadad AR (2011) Seeking support on Facebook: a content analysis of breast cancer groups. J Med Internet Res 13:e16

Choudhury M, Dinger Z, Fichera E (2017) The utilization of social media in the hearing aid community. Am J Audiol 26(1):1–9

DeLuca JM, Kearey MH, Norton SA, Arnold GL (2012) Internet use by parents of infants with positive newborn screens. J Inherit Metab Dis 35:879–884

Domonoske C (2018) Facebook says security breach affected almost 50 million accounts. NPR. https://www.npr.org/2018/09/28/652631686/facebook-says-security-breach-affected-almost-50-million-accounts. Accessed 14 October 2018

Elkarim GA, Alotaibi NM, Samuel N, Wang S, Ibrahim GM, Fallah A, Weil AG, Kulkarni AV (2012) Social media networking in pediatric hydrocephalus: a point-prevalence analysis of utilization. J Neurosurg Pediatr 20:119–124

Gunderson T (2011) 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. Sociol Health Illness 33:81–95

Harmon A (2007) After DNA diagnosis: 'Hello, 16p11.2. Are you just like me?' Retrieved from: http://www.nytimes.com/2007/12/28/health/research/28dna.html. Accessed 14 October 2018

Hassler C (2017) Here's why Facebook groups could really change the world—with a little help from Sheryl Sandberg. Retrieved from: https://www.popsugar.com/news/Sheryl-Sandberg-Lunch-Facebook-Group-Admins-43724175. Accessed 14 October 2018

Hsieh HF, Shannon SE (2005) Three approaches to qualitative content analysis. Qual Health Res 15:1277–1288

Jacobs R, Boyd L, Brennan K, Sinha CK, Giuliani S (2016) The importance of social media for patients and families affected by congenital anomalies: a Facebook cross-sectional analysis and user survey. J Pediatr Surg 51:1766–1771

Joseph G, Pasick RJ, Schillinger D, Luce J, Guerra C, Ka Yan Cheng J (2017) Information mismatch: cancer risk counseling with diverse underserved patients. *J Genet Couns* Advanced online publication 26:1090–1104. https://doi.org/10.1007/s10897-017-0089-4

Khouri JS, McChevne MJ, Morrison CS (2017) #Cleft: the use of social media amongst parents of infants with clefts. Cleft Palate Craniofac J 55:974–976. https://doi.org/10.1597/16-156

Lewis C, Skirton H, Jones R (2010) Living without a diagnosis: the parental experience. Genet Test Mol Biomark 14:807–815

Nicholl H, Tracey C, Begley T, King C, Lynch AM (2017) Internet use by parents of children with rare conditions: findings from a study on parents' web information needs. J Med Internet Res 19:e51

Pelentsov LJ, Laws TA, Esterman AJ (2015) The supportive care needs of parents caring for a child with a rare disease: a scoping review. Disabil Health J 8:475–491

Pew Research Center (Greenwood, Perin, Duggan). Social Media Update 2016. http://www.pewresearch.org/fact-tank/2016/09/07/some-americans-dont-use-the-internet-who-are-they/

Roche MI, Skinner D (2009) How parents search, interpret and evaluate genetic information obtained from the internet. J Genet Couns 18:119–129

Roose K (2017) Behind the velvet ropes of Facebook's private groups. Retrieved from: https://www.nytimes.com/2017/07/16/business/behind-the-velvet-ropes-of-facebooks-private-groups.html. Accessed 14 October 2018

Rosenthal ET, Biesecker LG, Biesecker BB (2001) Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes. Am J Med Genet 103:106–114

Saxena RC, Lehmann AE, Hight AE, Darrow K, Remenschneider A, Kozin ED, Lee DJ (2015) Social media utilization in the cochlear implant community. J Am Acad Audiol 26:197–204

Schaffer R, Kuczynski K, Skinner D (2008) Producing genetic knowledge and citizenship through the Internet: mothers, pediatric genetics and cybermedicine. Sociol Health Illn 30:145–159

Skinner D, Schaffer R (2006) Families and genetic diagnoses in the genomic and internet age. Infants Young Child 19:16–24

Smith A (2015) Chapter one: a portrait of smartphone ownership. U.S. smartphone use in 2015.. http://www.pewinternet.org/2015/04/01/chapter-one-a-portrait-of-smartphone-ownership/

Thoren EM, Metze B, Bührer C, Garten L (2013) Online support for parents of preterm infants: a qualitative and content analysis of Facebook 'preemie' groups. Arch Dis Child Fetal Neonatal Ed 98:F534–F538

Wren I (2018) Still on Facebook, but worried. NPR. https://www.npr.org/sections/alltechconsidered/2018/03/21/595770858/npr-survey-still-on-facebook-but-worried. Accessed 14 October 2018

Yanes T, Humphreys L, McInerney-Leo A, Biesecker B (2016) Factors associated with parental adaptation to children with an undiagnosed medical condition. J Genet Counsel Advanced online publication 26:829–840. https://doi.org/10.1007/s10897-016-0060-9