

# Internet use by parents of infants with positive newborn screens

Jane M. DeLuca · Margaret H. Kearney ·  
Sally A. Norton · Georgianne L. Arnold

Received: 27 October 2011 / Revised: 25 December 2011 / Accepted: 29 December 2011 / Published online: 2 February 2012  
© SSIEM and Springer 2012

## Abstract

**Background** Internet searches on health topics are common, but not enough is known about online use during serious health concerns. The aim of this study was to investigate parents' internet use and responses to online information following the referral of their newborn screen-positive infants.

**Methods** Forty-four parents were interviewed about their internet use during their infants' evaluations for a potential metabolic disorder. Responses to open-ended questions were audio taped and transcribed. Content analysis was used in analyzing the interview data.

**Results** An overwhelming majority of parents (89%) accessed the internet and most went online before meeting with genetic providers at metabolic treatment centers. Primary and genetic providers did not routinely recommend websites to parents. Online descriptions of metabolic disorders increased parents' anxieties. Some parents allayed their distress by enlisting others to search and filter information for them and by seeking optimistic internet content about the disorders. Parents with fewer years of education were often baffled by complex disease information. Parents found limited information about treatments or what to expect during the clinical evaluations of their infants.

**Conclusions** The internet is an integral part of health care and an important source of information for newborn screening parents. Parents may benefit from recommendations of credible websites and discussions of internet information with health care providers.

## Introduction

According to the Pew Internet and American Life Project, 59% of U.S. adults accessed the internet for health-related information in 2010 (Fox 2010). The internet has increased public access to health information and transformed patient behaviors and provider services. People look online for information about their health issues, to learn about treatments, strategize their self-care, and network with others about specific health concerns (Caiata-Zufferey et al. 2010; Cameron Hay et al. 2008; Dolce 2011; Gundersen 2011; Schaffer et al. 2008). The internet has been used by health care providers to advance clinical practices through innovations in treatment and web-based education (Beaudoin et al. 2011; Carrad et al. 2011; Kaufman 2010). The broad implications of online information and its intersection with clinical care are emerging areas for investigation.

Health crises are consistent predictors of increased internet use by patients for health information (Chisolm 2010). In newborn screening, the notification of a referral of an infant for a potentially severe illness is unexpected and traumatic for many parents. Parents' distress is exacerbated when, as is often the case, they have limited knowledge of the metabolic disorders and newborn screening processes. Parents go online to meet their urgent needs for information, but there is limited understanding of how parents use the internet and apply online information during the newborn screening evaluation process.

In a previous paper on a larger study of parents' experiences of newborn screening evaluations, we briefly outlined

---

Communicated by: Jean-Marie Saudubray

---

Competing interest: None declared.

---

J. M. DeLuca (✉) · M. H. Kearney · S. A. Norton  
University of Rochester, School of Nursing,  
601 Elmwood Ave, Box SON,  
Rochester, NY 14642, USA  
e-mail: jane\_deluca@urmc.rochester.edu

G. L. Arnold  
University of Pittsburgh, School of Medicine,  
4401 Penn Ave,  
Pittsburgh, PA 15224, USA

parents' internet use during screening processes (DeLuca et al. 2011). Here we examine those results more closely. The aims of this inquiry were to identify parents' patterns of internet use, and describe their perspectives and their responses to online information during evaluations of their infants for presumptive positive newborn screening results.

## Materials and methods

### Procedures

A qualitative descriptive design was employed for the study (Sandelowski 2000). IRB approval was issued by the University of Rochester Research Study Review Board. The care of families enrolled in the study was according to New York State screening policy standards (NYS Department of Health 2003). Primary care providers were notified about infants' abnormal screening results by the state screening laboratory. Primary providers discussed the screening results with parents and referred families to a designated treatment center for evaluation of the infants. At the treatment centers, genetic providers counseled parents, examined the infants, and obtained confirmatory diagnostic testing.

Parents of screen-positive healthy newborns were eligible for the study. Parents were excluded if they had prior experiences with newborn screening, additional children with metabolic disorders, or if infants were ill or premature. Non-English speaking parents were excluded due to lack of translation services for parents' interviews. Parents were recruited over an 18 month period between 2008 and 2010.

The interview guide was developed from discussions with parents who were recruited early in the study (Table 1). After obtaining informed consent, open-ended, semi-structured interviews were audio-recorded with individual parents or both parents of couples. Parents were interviewed twice if time permitted—first after their treatment center visit and then after parents received their infants' confirmatory results. Otherwise, parents were interviewed only once shortly after they received confirmatory results for their infants from genetic providers. Two interviews were conducted with 60% of study parents. Face-to-face interviews were performed for 57% of participating parents with

remaining interviews conducted by telephone. Interviews were transcribed and entered into ATLAS.TI a software data management program (Muhr 2004).

Sixty-two parents from four treatment centers were approached for the study. Thirteen parents refused participation and four parents were ineligible. One parent consented to the study but could not be reached for the interviews.

### Sample

A total of 44 parents (14 couples and 16 individual mothers) participated in the study (Table 2). Parents' ages were not recorded, but the majority of parents appeared to be from their mid 20s to early 30s. More than half of study parents had at least 2-year college degrees. Sixty-eight percent of mothers and fathers were first-time parents.

The infants were referred for evaluation of a dozen different inborn errors of metabolism. By the conclusion of the study, 30% of infants received positive diagnoses, 27% of infants had negative results, and 43% of infants had inconclusive findings from the initial round of confirmatory testing.

### Data analysis

Content analysis was used for analyzing the interview data (Miles and Huberman 1994). A coding scheme was developed using an inductive approach for examining the transcripts. Codes were organized into categories capturing how, when, and why parents used the internet, and parents' reactions and perspectives of online information. Emblematic quotations were selected to illustrate thematic statements about parents' internet use.

## Results

### Internet use across the trajectory of the newborn screening referral and evaluation

Thirty-nine parents (89%) accessed the internet or had online information given to them after they received notification of the referral for their infants. Of these parents, 30 (77%) reported using home computers, with remaining

**Table 1** Interview question guide

---

Did you look for information about the newborn blood test or the condition your baby might have?
• What kinds of information did you find?
• What did you think about the information?
• Did your providers suggest websites for you?
• What websites did you visit?
• Did you return to the internet after meeting with providers?
• Did you return to the internet after you received your results for your baby?

---

**Table 2** Parent demographic characteristics

Sample	<i>n</i>	%
(N=44)		
Gender		
Mothers	30	68
Fathers	14	32
Partner status		
Married	25	57
Living as married	8	18
Single	11	25
Race		
White	32	73
Black	8	18
Asian	4	9
Hispanic ethnicity	3	7
Education		
< High School	4	9
High school	9	20
Some college	7	16
College, 2-or 4-y degree	13	30
Master's degree	7	16
Doctorate	4	9

parents accessing the internet from public libraries, community centers, or computers belonging to family or friends.

Nearly every parent acquired online information in the first hours and days after learning of the referral and before visiting the treatment centers. Two parents did not access the internet until after they received confirmatory test results. They stated they did not want to be upset by the information or indulge in negative speculation about their infants. They approached the screening process with a degree of fatalism and reasoned internet information would not alter a positive diagnosis. As one remarked, "I wanted to leave it. The way I'm looking at it is, I'm waiting for the results, it is what it is, and there is not a whole lot that can be done about it."

According to parents, few primary providers recommended websites to them at the time of the referral. In some instances providers discouraged parents from using the internet from concerns the information could be distressing. One parent said, "She said we could look on the internet if we wanted to, but it would probably make us more upset."

#### Parents' approaches to searching the internet

The main objective for parents was to find information about the metabolic disorders and therapies, "what it is, what is going on, how is it going to be treated, is it curable?" Some parents sought information for the purpose of helping their partners and families through the crisis. Parents looked for information to help them explain the disorders to others. In some cases, parents searched for content that would

support the possibility the referral could be a mistake due to processing or handling of the sample. A few parents looked for information on the chances a referral would end in a false positive result or a diagnosis. The majority of parents (60%) discussed their internet research with friends or family.

Five mothers and one father described themselves as wanting to learn about the disorders, but too anxious to directly search the internet. They were concerned the information would overwhelm them, further fuel their anxieties or they would obsess over negative content. To manage their distress they asked others to search and screen information for them. These parents controlled their exposure to information in efforts to help limit their distress. One parent affirmed, "It was good because she was able to filter out all of the stuff I probably didn't want to be hearing." Similarly, several parents sought information that was optimistic in nature as a way of reducing their anxieties by indicating disorders were treatable or had favorable outcomes.

Two couples and one other parent claimed they did not go online at all even after they received the confirmatory results for their infants. They wished to avoid upsetting information, maintain their beliefs their infants were healthy, or they wanted to rely on advice of older family members. These parents preferred learning about the disorders only from their doctors and specialty providers. As one parent asserted, "A lot of people diagnose and treat and cure and whatever from the internet. I don't want to do that. I want to get the facts from the doctors for his specific situation."

Most parents were confident about their internet skills for finding information. Only one parent claimed she was unfamiliar with computers. For most couples, both parents sought information, but the parent with computer expertise or science background took the lead in these searches. To find information, parents targeted specific websites or entered the name of the disorders in search engines. Many parents could not remember the names of the websites they visited. One parent remarked, "I don't remember, I just googled the disorder, and visited 3 or 4 different sites, and googled each one even more so I could get more information on it." Parents who remembered the internet sites described a mix of governmental agencies, professional medical, corporate, and support group websites (Table 3).

#### Parents' reactions to internet information

*Frightening, confusing, and disappointing information* As predicted by their primary providers, many parents were distressed by internet information. Parents recalled internet content depicting signs and features of the disorders such as vomiting, seizures, developmental delays, and SIDS. This information put parents on the alert to observe for any potential symptoms or changes in their infants' behaviors.

**Table 3** Websites recalled by parents in searches for information

---

Centers for Disease Control and Prevention (CDC)
<a href="http://www.cdc.gov/">http://www.cdc.gov/</a>
Fatty Acid Oxidation (FOD) Support:
<a href="http://www.fodsupport.org/">http://www.fodsupport.org/</a>
Hunters Hope:
<a href="http://www.huntershope.org/site/PageServer">http://www.huntershope.org/site/PageServer</a>
Mayo Clinic:
<a href="http://www.mayoclinic.com/health/DiseasesIndex/DiseasesIndex">http://www.mayoclinic.com/health/DiseasesIndex/DiseasesIndex</a>
National Center for Biotechnology Information:
<a href="http://www.ncbi.nlm.nih.gov">http://www.ncbi.nlm.nih.gov</a>
National Organization of Rare Diseases
<a href="http://www.nord.org">http://www.nord.org</a>
Newborn Screening Branch, California Department of Health
<a href="http://www.cdph.ca.gov/programs/nbs/Pages/default.aspx">http://www.cdph.ca.gov/programs/nbs/Pages/default.aspx</a>
Newborn Screening Program, New York State Department of Health
<a href="http://www.wadsworth.org/newborn/">http://www.wadsworth.org/newborn/</a>
Wikipedia:
<a href="http://www.wikipedia.org/">http://www.wikipedia.org/</a>
WebMD:
<a href="http://www.webmd.com/">http://www.webmd.com/</a>

---

Although parents were encouraged by information indicating the disorders were treatable, they found limited detailed information on the actual treatments. In addition, parents stated they could not locate information on what they might expect during the evaluation of their infants. One parent said, “I guess it was kind of scary initially because you do some research on the internet and you read all this crazy stuff, but there is really nothing helpful about newborn screening.”

Parents with more education often described being satisfied with the information they found. Parents with fewer years of education thought websites were too medically-oriented and contained complex terms they did not understand. Some parents described difficulties pronouncing the names of the metabolic disorders. Others were unsure of the spelling of the disorders and whether they were researching the correct disorder on the internet.

*Mixed interest in stories of others* Several parents sought support group websites for “links to local groups, people who have lost kids, and see what they do when they get sick.” In some instances parents found the personal stories of families inspiring. One parent recalled feeling less isolated after reading about families living with the disorder. Other parents were not ready to read about others’ experiences or expressed little interest in support websites. One parent reasoned the websites were not useful for families when a diagnosis was not yet ascertained. She noted, “Once you start to get into personal accounts of different things,

you lose perspective for what percentage of patients is this really going to happen to. This is not doing you any good to be reading about that.”

#### Impact of the treatment center visit on interpretation of internet-based information

Genetic providers, as did primary providers, cautioned parents about negative internet content and few parents received recommendations for websites from the geneticists. Most parents arrived at the treatment centers after conducting extensive internet searches. It is important to note that a number of parents stated they would have appreciated more guidance from primary or metabolic providers to appropriate newborn screening websites.

Parents were not asked, as part of the interviews, if they discussed their online information and research with primary or genetic providers. Only a few parents volunteered they had spoken with their providers about their online research. Several parents reported that information from genetic providers validated the information they found online. As one parent stated, “When you look up and you get information that confirms what you get at the doctors, you take a little more weight on it.”

However, parents also identified differences between the information on the internet and what they received from genetic providers. In some instances, parents thought genetic providers were more optimistic than the internet about the prognoses for the disorders. Parents identified discrepancies in information about treatments for the disorders. As noted by one parent, “It says you can still fully breast feed and all, and it’s contradicting the information we’re getting from the clinic.”

#### Providers viewed as the reliable sources for information

On the whole, parents stated they were skeptical of the credibility of the internet and believed website information was potentially unreliable. Parents thought information they received from their providers was more dependable than what they found on the internet. One parent offered, “Not everything on the internet is accurate. There is a lot of information that anybody can put out on anything. I would trust more on experts than just going on the internet itself.”

#### Returning to the internet after meeting with genetic providers

Most parents of likely-positive infants returned to the internet in earnest after meeting with genetic providers to learn as much as they could about the disorders. Other parents returned to the internet to check a fact or two from

provider's counseling but 25% of internet-using parents did not resume any online research after the treatment center visit. One parent did not go back to the internet to avoid uncovering differences between provider counseling and online information. Another stayed away to "keep down" anxieties while waiting for confirmatory results.

The majority of parents who received negative or inconclusive confirmatory results for their infants did not return to the internet for the duration of the study after receiving these results from the genetic providers. Two parents went back to investigate treatment alternatives for their infants. One parent searched for information about commercial infant formulas containing the lowest amounts of protein. Another parent sought information for modifying her diet to alter the nutritional content of her breast milk.

## Discussion

The internet was used for health information by the majority of parents in the study regardless of their educational backgrounds or ethnicity and even when barriers to computer access existed. It is likely the unfamiliarity and seriousness of the disorders drove parents to the internet. Although the 'digital divide' may reflect disparities in regular computer use and computer literacy, previous studies have made a case for the ubiquity of internet use among parents with serious health concerns. In a study by Knapp et al. (2010), 76% of parents of children with life-threatening illnesses used the internet for medical information with 49% using the web on a daily basis. DeSantis et al. (2010) found 57% of callers to a teratogen information center first sought online information pertaining to exposure risks during pregnancy.

According to parents, website content did not extend beyond descriptions of the diseases to detailed information about potential treatments or what they could expect during the screening process. Difficulties locating specific information on the internet are common and have been noted in a number of previous studies of online health information seeking (Knijnenburg et al. 2010; Scullard et al. 2010). Araia and Potter (2011) applied newborn screening information guidelines in analyzing educational content of screening websites of 46 U.S. state programs and six Canadian provinces. Informational content from 85% of website documents alerted parents to the possibility of retesting infants, and roughly half the documents contained explanations of the purpose of retesting and the importance of responding to requests for retesting. Information on the risk of false positive results was noted in 54% of documents. Limited information was devoted to descriptions of false negative results (23%) and pain or infection related to testing (9%).

Parents in the study were more likely to trust provider information and counseling than the information they located from internet sources. This was noted in additional studies where parents and patients considered providers' information more reliable with online information viewed as supplemental to that of providers (Khoo et al. 2008; Knapp et al. 2010; Moseley et al. 2011; Stevenson et al. 2007).

A portion of parents did not return to the internet after meeting with genetic providers and most parents of non-diagnosed infants did not resume online searches after receiving results for their infants. This suggests that parents received sufficient information from their genetic providers, but could also reflect feelings of depression, anxiety, emotional depletion or information overload for parents.

This study had a number of limitations. Protocols for referral notifications and clinic visits may differ outside of New York. Participants were recruited from only a portion of the treatment centers in one state. No state-wide, national or international comparisons of internet use were possible. The short time period for the study did not allow for expanded data collection or examining internet use over time. The sample size for the study met criteria for a qualitative inquiry but was too small for subgroup analyses or comparisons of responses based on gender, family composition, potential diagnoses for the infants, or illness severity. All the findings in the study were based on parents' self-report. Parents were not observed while they used the internet or during their interactions with providers.

## Recommendations and conclusions

Additional research can be conducted to examine and compare internet use by parents in different regions and countries with diverse follow-up procedures for abnormal screen results. Interventions targeting parent and provider discussions of online information can be tested to advance newborn screening counseling and clinical practices.

In the meantime, medical providers have an important role in guiding parents to credible internet sites. At the time of referral, state laboratories could suggest select websites to primary providers for families' use. Primary and genetic providers can familiarize themselves with reliable online sources to recommend to parents. Direct discussions of parents' internet research can provide opportunities for clarifying online information and remedying discrepancies between provider and internet information. It may be reasonable for providers to suggest newborn screening parents contact them for discussions of alternative treatment information they may find on the internet. Conversations between patients and providers about internet information have led to increased patient satisfaction and patient

empowerment in other settings (Bylund et al. 2007, 2010; Chiu 2011; Sommerhalder et al. 2009). Discussions of internet information may not be welcomed by every newborn screening parent, but providing online sources and an environment for parents to share their online information may improve their understanding of screening and lessen their distress.

**Acknowledgments** We wish to thank the International Society of Nurses in Genetics (ISONG) and personnel from the metabolic treatment centers for their assistance and support. We thank the parents in the study who generously gave of their time to share their experiences with us.

## References

- Araia M, Potter B (2011) Newborn screening education on the internet: an analysis of North American newborn screening program websites. *J Community Genet* 2:127–134
- Beaudoin DE, Longo N, Logan RA et al (2011) Using information prescriptions to refer patients with metabolic conditions to the Genetics Home Reference website. *J Med Libr Assoc* 99(1):70–76
- Bylund CL, Gueguen JA, Sabee CM et al (2007) Provider-patient dialogue about internet health information: an exploration of strategies to improve provider-patient relationship. *Patient Educ Couns* 66:346–354
- Bylund CL, Gueguen JA, D'Agostino MA et al (2010) Doctor-patient communication about cancer-related internet information. *J Psychosoc Oncol* 28(2):127–142
- Caiata-Zufferey M, Abraham A, Sonnerhalder K et al (2010) Online health information seeking in the context of the medical consultation in Switzerland. *Qual Health Res* 20:1050–1061
- Cameron Hay M, Cadigan RJ, Khanna D et al (2008) Prepared patients: internet information seeking by new rheumatology patients. *Arthritis Care Res* 59(4):575–582
- Carrad I, Crépin C, Rouget P et al (2011) Randomized controlled trial of guided self-help treatment on the internet for binge eating disorder. *Behav Res Ther* 49:482–492
- Chisolm D (2010) Does online health information seeking act like a health behavior?: A test of a behavioral model. *Telemedicine and e-Health* 16(2):154–160
- Chiu YC (2011) Probing, impelling, but not offending doctors: the role of internet as an information source for patients' interactions with doctors. *Qual Health Res* 28 July doi:10.1177/104973231147455
- DeLuca JM, Kearney MH, Norton SA, Arnold GL (2011) Parents' experiences of newborn screening evaluations. *Pediatrics* 128:53–61
- DeSantis M, DeLuca C, Quattrocchi T et al (2010) Use of the internet by women seeking information about potentially teratogenic agents. *Eur J Obstet Gynecol Reprod Biol* 154:154–157
- Dolce M (2011) The internet as a source of health information: experiences of cancer survivors and caregivers with healthcare providers. *Oncol Nurs Forum* 38:353–359
- Fox S (2010) Pew Internet & American Life Project, the Social Life of Health Information. Available at: <http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info/Summary-of-Findings.aspx> Accessed 8/15/11
- Gundersen 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 Ill* 33(1):81–95
- Kaufman N (2010) Internet and information technology use in treatment of diabetes. *Int J Clin Pract* 64(Suppl 166):41–46
- Khoo K, Bolt P, Babl FE et al (2008) Health information seeking by parents in the internet age. *J Paediatr Child Health* 44:419–423
- Knapp C, Madden V, Marcu M et al (2010) Information seeking behaviors of parents whose children have life-threatening illnesses. *Pediatr Blood Cancer* 56:805–811
- Knijnenburg S, Kremer L, van den Bos C (2010) Health information needs of childhood cancer survivors and their family. *Pediatr Blood Cancer* 54:123–127
- Miles B, Huberman A (1994) *Qualitative data analysis*. Sage Publications, Thousand Oaks, CA
- Moseley K, Freed G, Goold S (2011) What sources of child health advice do parents follow? *Clin Pediatr (Phila)* 50(1):50–56
- Muhr T. Users' manual for ATLAS.TI (v.5.0) (2004) Scientific software development GmbH, Berlin
- New York State Department of Health (2003) *Newborn Screening in New York State, a Guide for Health Professionals*. Available at: <http://www.wadsworth.org/newborn/pdf/phyguidelines.pdf> Accessed 9/2/11
- Sandelowski M (2000) Whatever happened to qualitative description? *Res Nurs Health* 23(4):334–340
- Schaffer R, Kuczynski K, Skinner D (2008) Producing genetic knowledge and citizenship through the internet: mothers, pediatric genetics, and cybermedicine. *Sociol Health Ill* 30(1):145–159
- Scullard P, Peacock C, Davies P (2010) Googling children's health: reliability of medical advice on the internet. *Arch Dis Child* 95:580–582
- Sommerhalder K, Abraham A, Caiata-Zufferey MC et al (2009) Internet information and medical consultations: experiences from patients' and physicians' perspectives. *Pat Educ Couns* 77:266–271
- Stevenson FA, Kerr C, Murray E et al (2007) Information from the internet and the doctor-patient relationship: the patient perspective—a qualitative study. *BMC Fam Pract* 8:47. doi:10.1186/1471-2296-8-47