

Technology Stereotypes Broken When Children's Health Involved

Poverty and lack of education do not stop mothers from using the Internet to help children with genetic disorders

WHEN IT COMES TO PEOPLE'S PERCEPTIONS OF INTERNET USAGE, stereotypes prevail. There is the assumption that people living in poverty and those with less education do not log on. It is true that their numbers are lower than those of individuals with higher education and incomes. But these statistics may not paint the whole picture. In some cases, extenuating circumstances, such as health condition, increases Internet use among those with lower incomes and educations.

A study of mothers of children with genetic disorders found that the Internet served as a major resource in parents' quests for diagnosis, prognosis, treatments, services, and supports. The study, published in the January 2008 issue of *Sociology of Health & Illness*, found that 69 percent of mothers with family incomes less than \$30,000 per year and 66 percent of mothers with a high school degree or less turned to the Internet as a resource.

These numbers are higher than general Internet usage during the same year. A 2004 study by the Pew Internet & American Life Project found that only 44 percent of people earning less than \$30,000 per year and 53 percent of those with a high school diploma used the Internet.

The Internet and Health Information

The Internet is becoming an important source of healthcare information. Research shows that as a result of access to health information on the Internet, patients have better information and understanding of health issues, and a greater sense of control and more confidence in their health-related decisions. In addition, the ability to share personal stories is changing perceptions of health issues and empowering many people.

On the downside, Internet users need to carefully review information sources to assess credibility and legitimacy. In addition, users may be overwhelmed by the sheer volume of online resources and find it difficult to weigh the merits of different perspectives.



	% Using Internet	
	General Population*	Mothers in Study
Adults earning less than \$30,000 per year	44%	69%
Adults with a High School Education or less	53%	66%

*www.mediainfocenter.org/interactive/compare/demo_2004.asp

Study Background

In this study, researchers set out to examine how parents with a child with or at risk for having a genetic disorder sought out, understood, and interpreted information to make healthcare decisions. Researchers began by observing interactions between the family and medical genetics staff during a child's first visit to the genetic counseling clinic. This observation was followed by four interviews over a two-year period.

Study participants included 100 mothers of children with known or suspected genetic disorders. Families were representative of the pediatric genetic clinic population in terms of age of child, income, and ethnic diversity. When the study began in 2000, 61 of the children had confirmed diagnoses and 39 did not have a clear diagnosis. The study was conducted from September 2000 through March 2004.

The Internet as a Resource

The Internet emerged as a major resource in parents' quests for diagnosis, prognosis, treatments, services, and supports. In fact, one low-income mother saved enough money so that she could purchase a computer specifically to research her child's disorder.

Many parents first turned to the Internet out of frustration. The uncertainties inherent in the diagnostic process left parents desperate for answers. Some went online to learn more about possible diagnoses and diagnostic procedures. Some used the Internet to gather information to question a diagnosis they thought was wrong. Others sought tools so that they could diagnose their child's condition on their own.

Significantly, some of the mothers indicated that they trusted their own ability to use information from the Internet to find answers for their child more than they trusted the medical system.

In all, 83 percent of mothers used the Internet to search for information about their child's condition or to find services or support. As noted above, mothers from all backgrounds logged on—69 percent of families with household incomes below \$30,000 and 66 percent of mothers with a high school education or less used the Internet.

Specific findings are described below.

Diagnosis to Prognosis

- Mothers said they needed the Internet to learn and understand medical terms, so that could make sense of what doctors were telling them and so that doctors took them seriously.
- For some mothers, the Internet was one of many sources they used to understand the implications of a disorder, but for others it was the only source.
- Some parents were upset or confused by the information they received during clinic visits and during visits to online medical sites. To make sense of this information, they often turned to personal web pages hosted by other parents and support groups.
- Moreover, some mothers who were confused by medical sites brought printouts to clinic visits to get clarification from their doctors and genetic counselors.

Treatment Decisions

- Mothers often said the best information they had on treatment options came from other parents they found online who had already done the research, made decisions, and could discuss how it affected their child.

Challenges and drawbacks

- Mothers were skeptical about some online resources and worried about their ability to evaluate them.
- Mothers experienced anxiety because of the quantity of information available online. They felt self-imposed pressure to review everything that was available, so that they would not miss something that might help their child.

Changing Knowledge

Medical knowledge is typically thought of as something that doctors study and dispense. This study and others like it suggest that lay people also produce and contribute to such knowledge. Mothers in this study credited "lay" knowledge and thought that it should be valued to the same degree as knowledge coming from the medical community. They considered parent testimony an authoritative source.

The Internet helped parents to develop "scientific literacy" and challenge information coming from their doctors. That said, many felt overwhelmed by this task and expressed a need for an ally within the medical profession who would advocate on behalf of their child.

Becoming a Genetic Citizen

The Internet also became a means of helping mothers achieve what they believed to be were their rights as a "genetic citizen." With today's emerging access to specific genetic information, people are forming "communities" around genetic disorders. Just as a person may identify with a particular religious community, people are identifying with particular aspects of their genetic makeup.

As with any community, members feel entitled to certain rights. For example, as an American citizen, people are entitled to vote, to freely express themselves, and to assemble. Mothers as "genetic citizens" also felt entitled to certain rights, including timely and accurate diagnosis of their child's symptoms, the freedom to choose from all available treatment options, and access to up-to-date information about their child's condition. They turned to the Internet to help them achieve these rights.

In addition, being a citizen carries certain responsibilities. In the case of a "genetic citizen," mothers believed it was their responsibility to seek out information and share lessons learned. The Internet was often seen as the best means to fulfill this obligation. ■

To Learn More

Schaffer, R., Kuczynski, K., & Skinner, D. (2008). Producing genetic knowledge and citizenship through the Internet: Mothers, pediatric genetics, and cybermedicine. *Sociology of Health & Illness*, 30(1), 145–159.