

Parents of children with cancer distrust and fear online sources of health information, study shows

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(Medical Xpress) -- Parents and adult caregivers of pediatric cancer patients prefer personal consultations with trusted health care providers over online sources for information about their child's illness, according to a University at Buffalo research study.

Despite the accessibility of online medical information, the UB study found that parents not only distrusted information found through the Internet, they often feared what types of information they might encounter.

"Respondents were telling us they were uncertain of the information online and that they were afraid of the unknown," says study co-author Elizabeth Gage, PhD, professor of community health and [health behavior](#) in the UB School of Public Health and Health Professions. "They didn't want to run into stories about 'the [worst case scenario](#).'"

Gage, along with Christina Panagakis, a graduate student in sociology at UB, and colleagues at Roswell Park Cancer Institute, interviewed 41 parents of [pediatric cancer](#) patients in the U.S. to learn how caregivers use the Internet as an information source about their child's illness, its prognosis and potential treatment options.

The study, "The Devil You Know: Parental Online Information Seeking after a Pediatric [Cancer Diagnosis](#)," will appear in the May issue of

Sociology of Health and Illness.

Beyond a distrust and fear of health-related Internet sites, the study's findings also suggest that online searching for information about an illness might vary between patients dealing with routine conditions and those faced with life-threatening problems.

"The likelihood of a patient going online might depend very much on context," Gage explains.

Previous studies looked at what Gage described as routine, contested or stigmatized illnesses, while her research contributes a piece of knowledge relative to severe pediatric illnesses.

"One of the reasons we were interested in exploring this issue is that so much research and media coverage had examined how the Internet was breaking down barriers between patients and caregivers and their physicians. But that wasn't that case in our study," Gage says. "Perhaps because of the severity of the diagnosis, parents and caregivers preferred to receive their information from sources other than the Internet."

The information-seeking behavior of parents and other caregivers appears to be influenced by the volume of available information, Gage says. Patients with routine illnesses might find minor details online that better inform their conversations with [health care providers](#), but respondents in this study who were confronting a more serious diagnosis were overwhelmed by the often conflicting sources of online material.

"Families in our study did not know where to begin or how to sift through such a huge mound of information," Gage said.

Those who did look for information through the Internet tended to limit their searches to what they considered more credible sources, such as

medical journals and hospital libraries, the study found.

"A lot of families used the Internet to establish connections with other families in a similar situation, as much for emotional support as for reasons to share medical [information](#)," Gage says. "However, many families ascribed a certain expert status upon these individuals, almost elevating the experience of what they call 'the veterans' to the same level as that of a trusted hospital-based site."

Provided by University at Buffalo

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