

Chronically Ill Lack Internet Access

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Investor's Business Daily

10/8/2007

A chronic health problem affects one in five Americans. When it does, almost all who are able head online to figure out what to do.

Such people voraciously seek to learn, a new study finds, and are more eager than others to share knowledge to help fellow patients. At the same time, many chronically ill — who in general are older and less educated than the general population — lack Internet access.

“Only about half of people with chronic conditions go online compared with 70% of the general population,” said Susannah Fox, associate director at the Pew Internet & American Life Project. “But once they’re online, they’re enthusiastic users.”

The proof is that while 79% of Internet users have looked online for specific health information, 86% of the chronically ill have done so, says Pew, which has long studied the Internet’s impact on society. Its report came out Monday.

Huge Costs Ahead

The need for reliable health information is clear. America’s disease burden keeps weighing heavily. The most common chronic conditions — cancers, diabetes, heart disease, hypertension, stroke, mental disorders and pulmonary conditions — could cost \$4.2 trillion annually by 2023, up from \$1.3 trillion in 2003, says the Milken Institute. The amount is due largely to lost productivity, not treatment costs.

Nipping conditions early could save \$1.1 trillion in 2023, says Ross DeVol, director of the Milken Institute Center For Health Economics.

“We could prevent essentially 40 million cases of these chronic conditions,” he said.

When the chronically ill go online, they trade information about treatment with others.

They often act as information watchdogs for people in the same boat, to guide them to reliable resources, Fox says.

“If you are looking for a diagnosis, then everyone recommends you start with a doctor,” she said. “But if you’re looking for home care tips — how to deal with chemotherapy, how to prevent infection from having an IV — it’s often material you find online from fellow patients who are just ahead of you on the path.”

Along with its own survey, Pew collected essays from 1,680 members of the Association of Cancer Online Resources. This nonprofit runs online health-support forums.

Like others, people coping with chronic conditions can get frustrated trying to find information.

In Pew’s study, 30% said they felt overwhelmed by the amount of information they found online, 19% felt confused and 9% got frightened by the serious or graphic nature of what they found.

“The problem is not that we don’t have enough information. We have tons. It’s not categorized. It’s in complicated language,” said Vish Viswanath, an associate professor at Harvard’s Dana Farber Cancer Institute. “Last time I typed ‘cancer’ at Google, I got 15 million hits. The question is, ‘Where do I begin?’ “

Typing in “cancer” at Google.com now yields 78 million hits.

Viswanath thinks of the chronically ill as haves, who can access the Web to research, and have-nots. The latter can’t access information online or can’t process it, and education and income levels play a role.

For the haves, he says the Internet has been a big help.

“For them, the cancer information on the Internet has been quite beneficial, either in learning more about a particular treatment, to learn more about diagnoses, drugs and so on. It also has been helpful for them in communicating with people facing similar conditions,” Viswanath said. “If I’m facing some bad symptom in the middle of the night, I can go online and someone will answer and say something that is positive.”

Inequalities Of Information

Viswanath fears for the have-nots.

“People who suffer disproportionately from the disease burdens such as cancer also are those who suffer from inequalities in information,” he said. “We’ve shown that in our research.”

Seniors, who typically have the most health issues, tend to use the Web differently from others, says Tobey Dichter, founder of generationsonline.org. The nonprofit provides

software to retirement homes and senior centers. It aims to help older people teach themselves how to use the Internet.

The seniors Dichter works with are typically task oriented, she says, so a medical issue often leads them to start using the computer.

Pew's study found that people with chronic conditions were more likely (40%) than those without (29%) to say they know someone who has been significantly helped by online health information.

Among the ACOR essays Pew collected was one from "a man who described how his wife was paralyzed because the doctor basically missed a diagnosis," Fox said. "Because he was part of a listserv (online support group) on ACOR that discussed this kind of condition, he was able to prevent another person from becoming paralyzed."

The essay related: "Recently on the list a new person described his wife's symptoms. They were identical to what my wife's had been. I advised him to demand a full MRI of the spine and they found a plasmacytoma on her spine. They caught it in time to avoid the paralysis my wife has suffered. I feel good about that."