

# Communicating the Experience of Illness through Patient Blogs

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**Theoretical Background and research questions/hypothesis:** Currently 13% of e-patients write a blog about their diagnosis and treatment, where e-patients refers to the 61% of US adults who use the Internet for health information. The number of people writing patient blogs is likely to grow with more than 133 million individuals living with chronic illness in the US, the popularity of blogs and other forms of social media, and the increased visibility of health blogs on hospital and media Web sites. Our primary question was what motivates people with chronic disease to start and maintain a blog. Our secondary question is what are the educational and emotional benefits for these bloggers, their family and friends, their healthcare providers, and others with the same disease.

**Methods:** We conducted a qualitative preliminary survey study of individuals diagnosed with chronic illness. The 24 respondents, 20 of whom wrote health blogs, were self-selected to participate by responding to a request by email or on Twitter.

**Results:** The reasons the 20 bloggers had for starting and maintaining a health blog included, in prioritized order, to help others with the same diagnosis, communicate with family and friends, express feelings, and track the progression of the disease and treatment. Respondents kept a blog for between a few weeks and a few years; most identified themselves by name in the blog wrote on average twice per week; and valued readers' feedback. Most responded that they never thought to show their doctor or would be concerned about offending their doctor with what they wrote. Four respondents did not blog; the reasons included that they never thought to, were too depressed, didn't want to think about their illness, or were concerned about privacy.

**Conclusions:** Patients who blog are very committed to the process and write very openly about the devastating experience of diagnosis and the physical and emotional toll of treatment. While people write journals and books about their experience of chronic disease and use email to communicate with family and friends, blogs offer visibility and immediacy. Many patients who blog are highly motivated to communicate with their family and friends and to help others, but less so, by the ability to communicate with healthcare professionals. Since the number of health bloggers is likely to grow, there is value in better understanding the motivations and perceived benefits of blogging.

**Implications for research and/or practice:** This study indicates that there is a need for additional research to more deeply understand the benefits of health blogging. The goal of the next phase of this study is to investigate the benefits of health blogs for patients, their family, friends, other patients, and healthcare providers through a survey and interviews. Another goal is to understand if there are patients who would not otherwise consider it yet could benefit from a recommendation from their healthcare provider to start a blog. An additional goal is to analyze the content of patient blogs to understand if their text indicates the need for better educational and emotional support.