Compassion Knows No Border: The Research of Patricia Radin

Kevin Kawamoto
University of Washington

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Compassion Knows No Border: The Research of Patricia Radin

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By Kevin Kawamoto, Ph.D.

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.01 Journalist/Scholar Patricia Radin (return to index)

This column is a departure from previous ones in that it pays tribute to an extraordinary person who devoted a number of years to the field of health informatics – in particular the online communication dynamics of people dealing with serious health concerns. Patricia Radin was an award-winning journalist and editor who made a mid-life career change to academia after many years of working at daily newspapers. She went back to school to obtain advanced degrees – a master’s degree in science and technology policy at the Research Policy Institute at the University of Lund, Sweden, and a Ph.D. in communications from the University of Washington, Seattle – and was hired as an assistant professor of communication at California State University – Hayward. Professor Radin died unexpectedly of a massive heart attack on June 1, 2003 just less than a month shy of her 58th birthday.

I first met Pat in the early 1990s when I was a graduate student at the University of Washington School of Communications. She was a prospective graduate student who had been accepted into the doctoral program. At the time the school had a practice of matching up current grad students with incoming grad students – it was called the “Adopt a Grad” program. I’m not sure
how Pat and I got matched up, but as it turned out I was her adopter and she was my adoptee, even though she was two decades older than me. My responsibility was to be available to her if she had any questions before she arrived in Seattle and to help get her acculturated to the city and the school once she arrived. She was in Europe at the time, so we corresponded by mail and e-mail prior to actually meeting face-to-face. I suppose we began our relationship as cyberfriends or virtual friends.

I mention how we first met because it ties into her research focus as a graduate student. Pat was interested in the “communication space” that opens up on the Internet when people with serious health concerns find one another and begin forming relationships to share information, give moral support, and develop friendships. Her dissertation was a comprehensive case study of one such group, the Breast Cancer Action Nova Scotia (BCANS), based in Canada but accessible globally to those with a connection to the World Wide Web.

For all the talk about health informatics that my previous columns have touched on, none have really delved into the deeply humanizing potential that the Internet can have among people who are seeking not only information but also virtual relationships with others who can relate to the experience of serious health concerns. The BCANS online community members provided one example of a group of people who used the Web to reach out to others and for others. Pat’s dissertation poignantly described the importance of virtual communities in the lives of people who often had few other outlets to speak honestly about their feelings and emotions, to get access to the experience of many others facing similar predicaments, and to learn about a wealth of resources through which they could learn more about their disease, treatment, survival strategies. This online social interaction often seemed to have a quasi-therapeutic effect on many participants.

In *Digital Journalism: Emergent Media and the Changing Horizons of Journalism* [1], Pat described the phenomenon that captured her attention as a doctoral student:

“This collage of support and information, assembled by strangers around the world, is an example of a new type of niche communication – online, mutual-help, medical communication among peers, a blend of personal anecdotes, advice, encouragement, and mostly amateur research. Because of its global reach and many-to-many configuration, the Internet can provide spaces for people with common concerns to find and communicate with each other in this new way. As a result, there are thriving online discussions among people with chronic conditions such as diabetes, multiple sclerosis, leukemia, organ transplants, and depression. Participants give advice and support; sometimes they locate and comment on research papers, news articles, and other information sources relating to their shared concerns. Essentially, active participants of these online communities all become content providers, and at the same time they are passionately loyal audiences.”
Pat spent several years studying the BCANS phenomenon, not just as a dispassionate scholar, but also as a woman and compassionate human being. This was not just another research project for her but became part of her life, part of her mission to understand and learn from this virtual community so that she could apply this knowledge to other aspects of online mutual-help communication research. What she discovered with BCANS was promising and inspiring and demonstrated that the Web can be a positive force in the lives of people who need a community of fellow travelers.

“Over the years, many postings referred to the isolation of having breast cancer,” Pat wrote in her chapter. “Many said it was a relief to find a group of women in similar circumstances. An Australian reflected, ‘I cannot imagine how isolating it would have been to go through it alone.’ A number of participants commented that above all, they preferred information from ‘others who have been there.’”

.03 Pat’s Involvement with BCANS (return to index)

Paula Leaman is the BCANS webmistress. “Pat’s contribution to our online community goes beyond research for her dissertation and papers,” Paula wrote when I asked her to describe Pat’s relationship with the BCANS community. “She was, of course, one of the first who ‘got it’ – it being that this small community was meeting the support and information needs for those affected by breast cancer in a way that traditional methods had not” [2].

According to Paula, Pat used her practical communication and media skills to help BCANS with its development goals. “Until Pat got involved, it was next to impossible to find funding for this already established project. With her no-nonsense, let’s just do it attitude she made several key phone calls, and conducted media interviews that helped to secure the future of the BCANS online community,” Paula wrote.

Pat was also interested in meeting – in person – some of the people in the virtual community she studied. “In one of her earlier emails to us,” Paula wrote, “she wished that one day she would be able to meet some of these extraordinary people. Her wish was granted. Pat visited with BCANS’ers at several ‘offline’ gatherings around the world and became a cherished member of our community. Swamped with school, work, and other commitments she would drop everything to help us with a letter of support to funding organizations, draft potential survey questions or really anything we asked of her. Her friendship and support have been instrumental in the ongoing success of this web site.”

.04 Mass Media and Peer-to-Peer Information Sharing (return to index)

As a former newspaper journalist and editor, Pat believed that the mass media could play an important role in disseminating health-related information to the public, but she also believed that people helping people, through cyberspace, with health concerns was part of the education and support process. “Helping one individual at a time is what the ‘grassroots groupmind’ of online
medical communication does best,” she wrote. “The complementary strength of journalism, as it should be practiced, is in delivering information that empowers a mass audience to steer its own society.”

Pat does not whitewash the potential dangers of sharing health information online. Certainly there is quackery both online and offline: con-artists trying to sell false hope or well-intentioned people passing along dubious “science.” Despite these unfortunate realities, she believed that online mutual-help communities could have an enormously positive impact on people’s lives. The information from these groups should not be substituted for professional medical assessment and expert medical guidance, but should be part of the spectrum of coping strategies when confronted with the prospect of chronic or terminal illness or disease.

One of the important lessons of Pat’s research was that we should never underestimate the importance of one person helping, or befriending, another person. In the annals of mass media research, we often look at communication impact on a much larger scale. For Pat, the interpersonal was just as significant, online or off.

.05 Digital Journalism, the Book (return to index)

When I had the opportunity to edit a book about digital journalism, I knew there would have to be a chapter about health informatics in there. Online health information is one of the most sought after kinds of information on the Internet. [3]

Pat, by then a busy faculty member at Cal State – Haywood, was excited to be part of the project. Although she contributed an outstanding chapter called, "Online Medical Communication Among Peers: The Net and Alternatives to Traditional Journalism," she died while the book was in production [4]. Ironically, and touchingly, she spent the last years of her life trying to help us better understand the importance of virtual communities among people who were confronted with the reality of disease and death every day of their lives.

As I re-read through her chapter, possibly the last thing she contributed for publication before she died, I saw reflected in her scholarship a woman who cared deeply about the subject she chose to research. Her work in health informatics was never just another line on her resume. She believed she could do some good in the world through her scholarship and her academic position, just as she did as a journalist. She was, in effect, a pioneering online participant-observer. She observed, importantly, that the fear and confusion caused by a diagnosis of cancer could be mitigated by the support and information exchange found in a functional online community like BCANS. In the midst of a lot of criticism about dysfunctional electronic discussion groups, Pat illuminated something that worked. There are others. One potentially enlightening class assignment is to have students find a peer-support online community, study it for a certain period of time, and report back on what they observed and learned. If given a choice, students tend to gravitate toward subjects about which they have a personal interest, such as a disease or illness that has affected them, a friend, or a member of their family. They often will come away
from the exercise with enhanced knowledge and insights.

I’m sure most people who knew Pat would agree that she lived each day as if it were her last. She was always full of energy, enthusiasm and curiosity, and never spared or wasted words. When she died, there was still much to learn about mutual-help medical communities. Others will have to carry the torch, using the valuable work she left behind, and her example as a citizen-scholar, to illuminate the field ahead of us.

.06 References (return to index)


[3] See past columns for more information about health informatics:

“Health Information Online Abundant and Varied”

“Teaching Students About Cyberhealth Information”
http://bcis.pacificu.edu/journal/2003/01/kawamoto.php

“Older Adults and the Internet”
http://bcis.pacificu.edu/journal/2003/02/kawamoto.php

“Computer Technology in Health Care Settings”
http://bcis.pacificu.edu/journal/2003/04/kawamoto.php

“Privacy and Personal Health Information”
http://bcis.pacificu.edu/journal/2003/06/kawamoto.php

“Healthy Learning Can Be Fun: Digital Media and Health Education”
http://bcis.pacificu.edu/journal/2003/07/kawamoto.php

[4] The book has been published. For more information, see:

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