Online Therapy & Patient Engagement

Jan Oldenburg

Before DeeAnna Nagel began practicing online therapy, and before she co-founded the Online Therapy Institute, she was a patient, and an **e-patient.** In early 2000, she was nearly incapacitated with a mysterious lung disease. Her medical journey took her from specialist to specialist, each baffled about her symptoms,

This article is a chapter excerpt from the book *Engage! Transforming Healthcare Through Digital Patient Engagement,* based on an interview with DeeAnna Merz Nagel. Read more about the book and order it from our Love of Books page.

while she got sicker and sicker. She discovered an online forum for lung disorders, where she found a disease that matched her symptoms and information about the tests that would prove it. She went to her doctor and explained what tests she wanted and what disease they were testing for. Her doctor was skeptical and patronizing, but did the tests, which confirmed the diagnosis of **sarcoidosis** Ms. Nagel had found through the online forum.

During the next year, Ms.Nagel was unable to work outside of her home while she recovered from her disease. She began working as an online therapist with eClinics, Help Horizons, and Here to Listen, all arranged so that a therapist can make him/herself immediately available to a client for drop-in chats. With the benefit of hindsight, Ms. Nagel noted that these are not recommended conditions for an e-therapy relationship, as it means you are doing triage with a patient before you are established as a trusted and contractual clinical relationship.

As a result of this experience, however, Ms. Nagel became intrigued by the opportunities for online therapy, but also was deeply aware of the need for an ethical framework that would govern its practice and the use of online tools within a therapeutic framework. Peers from the International Society for Mental Health Online came out with a set of original guidelines in 2000, but Ms. Nagel and colleagues felt there needed to be more. The American Counseling Association (ACA) issued their last code of

WHAT IS AN E-PATIENT?

We who've become e-patients don't wait for our providers to tell us everything; we get it in gear, we ask questions, we do what we can to help.

Don't think you're qualified? Consider the advice on the magnet at right:

Trust yourself.
You know more
than you think you do.

Radical new advice? No, it's the opening line of Dr. Spock's Baby and Child Care, first published sixty years ago, in 1946.

~DAVE DEBRONKART
widely known as "e-Patient Dave"

Excerpted from
http://epatientdave.com/for-patients/

WHAT IS SARCOIDOSIS?

Sarcoidosis *(pronounced SAR-COY-DOE-SIS)* is an inflammatory disease that can affect almost any organ in the body. It causes heightened immunity, which means that a person's immune system, which normally protects the body from infection and disease, overreacts, resulting in damage to the body's own tissues. The classic feature of sarcoidosis is the formation of granulomas, microscopic clumps of inflammatory cells that group together (and look like granules, hence the name). When too many of these clumps form in an organ they can interfere with how that organ functions.

For more information,
visit the Foundation for Sarcoidosis Research.

ethics in 2005. While the code covered most issues related to online therapy, there have been significant changes in cyberspace with the advent of Web 2.0. For example, social media was not fully in existence in 2005 and, therefore, the ACA code did not address how social media can impact a therapist's work and professional presence. Their next code of ethics will not be issued until 2014. To fill the gap, Ms. Nagel and a colleague started the Online Therapy Institute. They created a set of guidelines and issued them as a starting point for others practicing in the field. Ms. Nagel is clear that the standards of practice are still evolving and will continue to change as practices and technologies to support them continue to evolve.

Many therapists who practice in traditional face-to-face settings are finding that communication that formerly happened by phone or in the context of a session has moved to email. As a result, they need to determine how to weave online tools into the fabric of face-to-face practice. The American Psychology Association's (APA) Center for Workforce Studies conducted a study that showed that overall email use with clients for service delivery more than tripled among practicing psychologists from 2000 to 2008, with approximately 10% of those sampled using it weekly or more in 2008. Practitioners' use of videoconferencing with clients, while still rare, increased from 2% to 10% among survey respondents during that same time period (Novotney, 2011). This brings a host of both opportunities and problems. Even therapists who do not think of themselves as practicing "online therapy" need to determine such things as when an email exchange becomes an e-visit and requires payment, when an issue can be addressed by email and when it

needs to come back into a session, what their response time to emails will be, and how they set boundaries and expectations when email is a part of the therapy mix. An online code of ethics needs to address these types of issues both for therapists who use online tools as an adjunct to their practice, and for those who primarily practice using online tools.

What does online therapy look like? It can take many forms and both therapists and patients gravitate toward the mix that fits them best. Ms. Nagel loves written language and believes that writing can be a powerful healing experience for patients, so she gravitates toward email and chat. She notes that for her patients the experience is rather like keeping a journal, but with a listening ear on the other side. Her Employee Assistance Program (EAP) work is all email-based. Sometimes her face-to-face clients will see her online, so online therapy becomes an adjunct to in-person consults. She uses video conferencing, chat, email, and phone in her work. For her, personal video is the least-preferred option, in part because the still- jerky head movements and lack of direct eye contact make it difficult to "read" her clients.

One of the important lessons that Ms. Nagel has learned is that whenever technology is a part of the mix, there will be glitches. The problems may be as diverse as emails that are lost in cyberspace, chat or video Internet connections that don't work when they need to, messages that are garbled because of fat fingers on the keyboard or inappropriate auto-corrections, simple misunderstandings based on the written word, or timing issues based on asynchronous communications. Therapists need to prepare themselves and their patients for these kinds of problems and create back-up plans to address them. Technical problems cannot entirely be avoided, but a clear communication plan and agreed-upon strategies for dealing with problems will go a long way toward mitigating their effects.

Ms. Nagel believes that several things are required for e-therapy to become more mainstream. One is a reimbursement model that consistently acknowledges and enables payment for therapy using online tools. She

suggests that additional studies comparing the effectiveness of online therapies to in-person therapies will be required to create the impetus for a consistent reimbursement model and consistent way of coding for online therapy. Several studies and meta-analyses have shown that the outcomes are the same or better than in-person approaches and that it can be delivered at lower costs. Her fear, however, is that as it becomes mainstream, organizations will expect therapists to use online tools without any training or guidance. Ms. Nagel is advocating for a continuing education requirement that involves taking a course that will provide guidance about online therapy and teaches therapists an ethical framework for online engagement.

The other dimension that Ms. Nagel suggests will be required for online therapy to become mainstream is more and better tools. Advances in secure person-to-person video will certainly enhance the options available to therapists and patients alike. She and her colleagues dream of online therapy tools that will create a multi-dimensional experience, in which patients could securely send and receive messages, watch a video, post pictures or status updates, and perhaps interact with other patients.

Ms. Nagel also notes that there is tremendous research and energy going into exploring Avatar therapy and the use of virtual worlds for therapy. She notes that the Online Therapy Institute does a monthly meeting in Second Life, and that InWorld Solutions has a Health Insurance Portability and Accountability Act (HIPAA)-compliant platform for virtual world therapy. However, as she notes, many therapists feel like "digital immigrants" struggling to make sense of their options and how to interact in a virtual world. The capabilities are easier for 5 year olds to use than 55 year olds, and full adoption may need to wait until the next generation comes of age.

The potential is huge for online therapy to become an effective tool for delivering mental health support to a broad audience in a cost-effective way, and it is well- worth an investment in technology, training, and ethics to achieve the potential. ■

ABOUT THE EDITOR

Jan Oldenburg is the primary editor of HIMSS' *Engage! Transforming Healthcare through Digital Patient Engagement* (2013) and is Vice President, Patient Engagement in Accountable care Solutions from Aetna. Read an interview with Jan about the book here!

REFERENCE

Novotney A. (2011). A New Emphasis on Telehealth: How can psychologists stay ahead of the curve – and keep patients safe? Monitor on Psychology. June 2011; Vol. 42, No. 6.