The internet 2006

Each year Developmental Medicine and Child Neurology (DMCN) invites the President Elect of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) to compose a guest editorial. As we mark the 60th anniversary of the Academy, I welcome the opportunity to make a few observations on the emergence of the internet as a medium that, within the space of two decades, has had an increasing influence upon both medical research and its dissemination throughout the world. Although the Academy’s founding fathers certainly recognized that communication was the key to future progress, it is unlikely that they could have imagined what was ahead in terms of instantaneous information exchange or how that capability would promote collaboration at great distances, speed up the decoding of the human genome, and empower patients with information that previously had largely been the province of academia. This September, portions of our annual meeting will be webcast from Boston to 10 locations in four different countries around the world. Individuals who cannot attend the meeting in person will have an opportunity to view the lectures, and then, in special sessions, to engage in real-time exchanges with many of the presenters. In addition, the AACPDM now presents a monthly 1-hour webcast for entitled members concentrating on timely subjects by world-renowned authorities.

Patient care has also been directly affected. It is second nature for many of us to utilize a computer in patient encounters, whether it is for record retrieval or researching unfamiliar conditions. More and more institutions and practitioners are converting to an all-electronic record format including digital X-rays. The latter may be interpreted off-site from where they are actually obtained. Some of this is done for convenience, but economics increasingly plays a role as well. It is not yet clear where the legal liability will come to rest when records and opinions can so easily cross geopolitical lines for interpretation and consultation. What is clear is that the internet is progressing toward fulfilling its promise of closing the information gap between rural and urban, developing and developed world, and the poor and rich among us.

Transition to the digital revolution has not been entirely smooth. Costs can be prohibitive and many senior physicians have resisted the technology until the last possible moment, when they were required to have e-mail and expected to review it routinely. More recent generations reared as youngsters on internet access and instant messenger services have transitioned more naturally. Wherever you are in the digital revolution, it is evident that the very nature of medical publishing is in upheaval. Medical manuscripts are composed electronically and submitted by the internet to journals where reviewer’s comments are digitally solicited, distilled, and then sent back to the authors for resubmission. The nuts and bolts of publishing have changed so much so quickly that only a few large medical publishers have survived. Enormous pricing power has been concentrated in fewer and fewer hands. Predictably, prices have risen and many institutions are considering bypassing traditional publishing altogether, arguing that they should not have to re-purchase their own academic work. As we transition to virtual libraries, debates rage over the preservation of traditional intellectual property.

While one can easily envision the positive benefits of a streamlined publishing process, there is a darker side to easy accessibility. Individuals and companies who need not concern themselves with the vagaries of the scientific process have the same access to the masses as do conventional medical publishers. Families with children affected by chronic disabling conditions such as cerebral palsy often turn to the internet as a source of information, particularly when they believe that conventional medicine is failing them. What they find is a plethora of plausible but unproven treatments promoted by charismatic individuals, frequently in a commercial context, complete with newsletters, a home-base institution, training programs, and sports-like testimonials as to their efficacy. Against a background of political correctness and legal liability, these methods are referred to as simply unproven, falling under the umbrella context of complementary and alternative medicine. These practitioners often believe in what they are doing, so it is not a matter of fraudulent intent, but the effects, in terms of time and expense, can be the same for the families involved. This then is the dark side of the internet. It is a medium that, by its nature, is eminently democratic, but also relatively lawless, and a place where one website can appear persuasive merely by employing electronic gloss, dramatic appeal, and seemingly simple sincerity. When hope is the commodity that is being offered, all of us are vulnerable. These sites are in contrast to the seemingly more bland websites offered by DMCN, the AACPDM, and other major mainstream publishers and specialty societies. We now face a challenge in educating users without alienating them as they access millions of websites, and billions of pages that today constitute the internet. How we meet this challenge may be more important than the technology itself. ‘Trust the source, trust the site’ has never had more validity than today. Journals such as DMCN, and professional societies such as the AACPDM are important beacons of integrity to those who are in desperate need, now more than ever. When it comes to the internet, the medium is most definitely not the message.

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