

# The Growth of Health Communications—A Story of Consumer Power and Medical Innovation

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## LEARNING OBJECTIVES

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By the end of this chapter, the reader will be able to:

- Describe the role of the communications specialist in aiding the growth of the healthcare industry over the last half century in the United States.
- Explain how societal trends, as well as a changing media landscape, increased public awareness of health conditions and changed public attitudes towards the sharing of information about personal health issues.
- Provide an example of the shift from a national focus on care for the acutely ill to wellness.
- Describe the paradigm shift from a physician-centric to a consumer-centric healthcare system.
- Describe the role of the Internet in fueling healthcare consumerism.
- Discuss the effect patient advocacy groups have on building public awareness and influencing healthcare reform.

## Introduction

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Health care represents one sixth of the US economy and touches every aspect of our lives. We are living longer and better today than at any time in history. In the 1940s life expectancy was 65.7 years; today it is 77.7 years (National Center for Health Statistics, 2007). Rates for the top three leading causes of death—heart disease, cancer, and stroke—continue a long-term decreasing trend. Innovations in the science and delivery of health care have made this possible. It is an amazing story, and communications professionals are at the fulcrum of this story.

## The Growth of the Profession

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Communications as a function has long been integral in the healthcare industry. From the mid-1900s, hospitals were staffed with professionals who issued patient condition reports and the occasional news release about a new facility. Pharmaceutical companies similarly used communications consultants or in-house staff to announce the approval of new drugs.

Yet the growth and importance of communications in the healthcare industry has been most dramatic over the past 30 years. As opposed to the lone public relations man or woman, who often had human resources responsibilities as well, we now have large staffs in a sophisticated marketing matrix of public relations, advertising, and digital communications at major health systems. Healthcare companies that used to only have investor relations now have extensive staffs for brand and corporate communications.

Consulting companies have mushroomed in the past decade in response to industry demand. The Kennedy Consulting and Research Advisory noted that healthcare consulting is one of the few areas of growth, expected to grow at 5.3% through 2012 (Kennedy Consulting Research & Advisory, 2009). Major consulting companies such as Booz Allen Hamilton, PriceWaterhouseCoopers, and Accenture all have thriving healthcare practices.

Healthcare has long been a staple in public relations firms, but the specialty grew dramatically in the 1980s and 1990s. Most international firms such as Ketchum, Burson-Marsteller, and Edelman have large healthcare practices with a significant portion of the firms' revenues coming from healthcare clients. Within the practice of health care, there are professionals in health policy, social media, and other specialties. It is a function with depth and breadth in every major public relations firm.

In addition to the rise of health care in public relations, the 1980s and 1990s saw growth in medical advertising. In the 1970s that term would have been an oxymoron. Hospitals and physicians looked askance at advertising as beneath their professional standards. With the advent of the prospective payment system of Medicare in 1984, the age of hospital advertising began. Providers found that certain service lines, such as women's health care, were more profitable under the new reimbursement system. They reached out to consumers with advertising to tout these service lines. Advertising is now a substantial part of every hospital marketing budget.

Australia and the United States are the only countries that allow direct-to-consumer (DTC) advertising of drug products. In the United States, this began in 1997 and has been a source of great profit as well as great controversy for the pharmaceutical industry. To detractors, the ads propel consumers to seek drugs they don't need; to proponents, DTC advertising educates consumers and empowers them with information. Regardless of where one stands on the issue, there is no denying the economic impact of DTC advertising. Spending on DTC advertising increased from \$220 million in 1997 to over \$2.8 billion by 2002 (Sheehan, 2003). It appears this was a good investment for the pharmaceutical industry as the prescription rates of DTC drugs increased by 34% compared to a 5.1% increase in other drugs (Sheehan, 2003).

The first decade of the millennium saw an acceleration of public relations “boutique” firms that catered only to healthcare clients. Often these firms developed from expertise with the biotech sector, mirroring a repeated theme in this story—communications growing in tandem with growth in the industry. The development of biologically based drugs and the rise of companies like Amgen and Genentech is one of the great stories of medical science.

The world of academia has enjoyed a growth spurt in healthcare communications comparable to that of private industry. Thirty years ago most university communications programs did not even mention health care, let alone focus on it. Today there are 50 graduate schools that offer degrees in “health communications” (GradSchools.com, 2010). These are some of the nation's most preeminent institutions including the University of Southern California (USC) Annenberg School of Communication; Tufts University School of Medicine; Harvard University Graduate School of Arts and Sciences; and Boston University College of Communication. These universities often have alliances with private firms on communications initiatives. For example, USC Annenberg School of Communications partners each year with Ketchum on the “Media: Myths and Realities” survey.

## Media Mirrors the Health Story

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News organizations mirror the growth and diversity in healthcare communications. From the sole newspaper health reporter of the 1970s, who also covered sports, to the depth of seasoned health reporters at every major daily, healthcare reporting is one of the most specialized areas of journalism. According to the Association of Health Care Journalists, there are over 1000 healthcare reporters in the United States (Association of Health Care Journalists, 2011). Despite the cuts in newspapers throughout the country, healthcare news coverage remains strong with online outlets supplementing traditional print and broadcast coverage. According to Technorati, there are an estimated 20,000 healthcare blogs, with such prominent journalists as Tara Parker-Pope and Katherine Hobson contributing well-read blogs in addition to print columns.

Every decade has yielded big headlines in the world of health—in the 1950s we learned the Salk vaccine would eradicate polio; President Nixon announced the war on cancer in the early 1970s, ushering in an era of progress and setbacks against this disease; the 1980s saw the first

artificial heart and the advent of a new disease called AIDS. This millennium, with the human genome mapped in the 1990s, has given us the age of personalized medicine and the debut of blockbuster drugs like Avastin and Herceptin.

Perhaps nothing illustrates how communications has developed in health care than the coverage of some of these stories. In 1982, Dr. William DeVries implanted the world's first artificial heart, named the Jarvik-7 after its inventor Dr. Robert Jarvik. The recipient was a retired dentist named Barney Clark. For 112 days, the world followed the progress of Mr. Clark until his death. There were frequent press conferences throughout this period with both Dr. DeVries and Dr. Jarvik. Heart transplants continued with the next recipient living 620 days. Despite international headlines and repeated broadcast coverage, only 7% of Americans had heard of the Jarvik-7 heart by 1983 (<http://www.jarvikheart.com/basic.asp?id=69>). This can largely be attributed to a news era that did not have 24/7 cable and online coverage, and far less outlets for health news.

To see how news coverage has changed, you need only to look at the story of the conjoined twins, Trisha and Krishna, one of the biggest news stories of 2009. The twins, from an orphanage in Bangladesh, were separated in a 32-hour operation by a surgical team at the Royal Children's Hospital in Melbourne, Australia. The successful surgery drew worldwide attention and continues to do so as media organizations follow the girls' progress. Google news, not available in Jarvik's time, cites over 148,000 results with more than 14,000 news stories about the twins. Health news today is magnified in ways that were not possible just a generation ago.

## Diseases Come Out of the Closet

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The evolution of healthcare communications was fueled not only by stunning advances in medical science but by societal trends that brought an openness to once whispered diseases and a move from sick care to wellness.

It is hard to believe in an era where ads about erectile dysfunction fill the airwaves, but 30 years ago many health conditions were deemed “too personal” to discuss publicly. In the early 1970s, Betty Ford was widely praised for openly discussing her breast cancer. News organizations covered such topics with great reluctance and only when a well-known person was involved.

The shift in more openness toward diseases and conditions considered highly personal came about from the changing mores of the 1960s and 1970s with a “let it all hang out” philosophy. Even though the times favored more candor about health, these “silent” conditions would never have found a voice without effective communications campaigns.

Incontinence came out of the closet in the early 1990s. This condition, which affects millions of Americans, was never mentioned publicly, and a Yankelovich poll found that women would take, on average, 7 years to even discuss it with a physician. The condition has devastating quality-of-life consequences, yet treatments were unknown to the public.

In 1995, Bard Urological Division partnered with the American Urological Association to create Bladder Health Week and launch a landmark public education campaign on stress urinary incontinence.

The campaign received extensive media coverage, and more than one television anchor said, “This is an important issue. It’s about time we’re talking about it.” This campaign, and others that followed, changed public attitudes about incontinence.

As new treatments for incontinence became available, drug companies created a new lexicon for clinical terms. *Urge incontinence* became *overactive bladder*, and DTC ads made this term widely used by patients. By 2004, there were five drugs on the market for overactive bladder. When Novartis was about to introduce Enablex, the sixth drug for this condition, it was clear that a creative campaign was needed to reach consumers and position the drug in a crowded market.

Ketchum worked with Novartis and the National Association for Continence to create an award-winning campaign that focused on the needs of people with incontinence who liked to travel. Research revealed that many people suffering from this condition were reluctant to travel. Enlisting travel guru Arthur Frommer, the “Where to Stop, Where to Go” campaign was launched, including a guide to well-kept restrooms in various travel destinations.

The guide was so popular that many people without the condition sought copies. The campaign generated more than 24,200 guide requests via Web site and toll-free line in just 8 months, produced a 961% increase in call volume to the Novartis Customer Interaction Center compared to precampaign levels, and stimulated a 318% increase in unique visitors to the product site, Enablex.com, compared to precampaign levels.

The campaign achieved the awareness objectives of Novartis—more than 104 million media impressions—and was another milestone in removing the stigma from incontinence.

Many other diseases, such as irritable bowel syndrome (IBS) and colon cancer, have been stigmatized by public education campaigns. The fact that Katie Couric could have a colonoscopy live on television demonstrates how far we have come in dealing openly with once unmentioned health conditions.

## Health Care Becomes “Well Care”

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Just as communications professionals were instrumental in opening the closet of health care, they played a major role in ushering in an era of wellness.

We so take for granted the prominence of wellness in health care that it is hard to imagine a time where this wasn’t ascendant. Yet for many years our healthcare system was a sick care system. The great thrust of medical science and our highly evolved healthcare delivery system was aimed at managing acute care. Health care was all about “fixing” what was broken, not preventing that breakage.

Health maintenance organizations (HMOs), formed in the 1940s, pioneered disease prevention and wellness programs as part of their mandate to keep patients as healthy as possible.

These group health organizations were often dismissed as “group death” by the medical establishment of the 1950s and 1960s who only saw value in the sick care model.

The wellness revolution had its roots in a generational shift in values. Baby boomers coming of age in the 1970s rejected their parents’ sedentary lifestyles and embraced physical activity and better nutrition. You only have to watch television’s “Mad Men,” where harried advertising executives in the early 1960s chain-smoked, drank three-martini lunches, and only ran to catch a train to see how far we have come in valuing wellness.

Many landmark education campaigns such as the American Cancer Society’s Great American Smoke-Out were responsible for changing health behaviors. Healthcare providers were key to promoting healthy behaviors as well. Most hospitals by the 1980s were offering smoking cessation programs, stress management, and nutrition classes.

The battleship of health care was beginning the slow turn from sick care to well care. By 2004, Kaiser Permanente had launched a \$40 million advertising campaign called “Thrive” (Kaiser Permanente, 2004). This landmark campaign with its emphasis on preventive care is credited with significantly building the Kaiser brand and for pioneering a new approach in healthcare advertising.

Just as consumers were taking more responsibility for their own health and providers were seeing an increasing role to help them in that process, mainstream medicine was morphing in a new direction. Alternative medicine was always popular with consumers, especially those not satisfied with conventional treatments, but it was looked down upon by the medical establishment for decades. Driven largely by consumer demand, as well as a growing body of medical knowledge, this began to change most noticeably in the 1990s.

By October 1998 the National Institutes of Health had established a National Center for Complementary and Integrative Medicine to address the increasing interest in wellness-promoting activities that are not typically addressed in conventional medical care. In the center’s 2007 survey, 3.1 million adults reported using acupuncture, up from 2.1 million in 2002. Between 2002 and 2007, acupuncture use among adults increased by three-tenths of 1% (approximately 1 million people) (Centers for Disease Control and Prevention, 2007). Even the venerable Mayo Clinic had established a Complementary and Integrative Medicine Program by 2001.

The degree to which Americans embrace disease prevention and wellness is reflected in a 2009 survey conducted by the Trust for America’s Health and the Robert Wood Johnson Foundation. This survey on attitudes about healthcare reform revealed Americans ranked prevention as the most important reform priority and overwhelmingly supported increased funding for programs to reduce disease and keep people healthy (Trust for America’s Health, 2009).

A remarkable transformation had occurred. A country that was once indifferent to maintaining good health was now embracing it with a vengeance. By the end of 2010, more than \$1 trillion dollars was spent by consumers on wellness products (Pilzer, 2007). This sea change was brought about by many factors—societal trends, medical advances—but indisputably health communications propelled wellness into a whole new level of consciousness with the American public.

## Growth of Consumerism Fueled by the Internet

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If communications accelerated with big developments in medical science—diagnostic and surgical innovations, personalized medicine, and blockbuster drugs—it was spurred on by a trend at least as big: the rise of the healthcare consumer.

It is hard to overstate this phenomenon and how it has affected the healthcare system. For the majority of the 1900s, consumers were passive players while physicians dominated all phases of healthcare decision making. From treatment to hospital choice, the physician voice was dominant. Patients did as they were told by their physicians, knew little about prescribed treatments, and rarely questioned them if they did.

By the end of the millennium this paradigm was changing dramatically. Fed by the Internet and multiple news outlets, consumers had access to medical information that was unprecedented. Internet sites like WebMD, launched in 1999, provided information on health and health care, including a symptom checklist, pharmacy information, blogs of physicians on specific topics, and a place to store personal information. This site received over 17.1 million average monthly unique visitors in 2007, and today it is the leading health portal in the United States (comScore, 2010). Today there are more than 200 million sites on health care including more than 19,000 health policy blogs.

Seventy-nine percent of Internet users have searched online for information on at least one major health topic, according to the Pew Internet & American Life Project. That translates to about 95 million American adults who use the Internet to find health information. Certain groups of Internet users are the most likely to have sought health information online: women, Internet users younger than age 65, college graduates, those with more online experience, and those with broadband access (Fox, 2005).

The growth of social media has further fueled outlets for health communications. Surveys indicate that 60% of Americans turn to the Internet first when seeking health-related information. At least half of this group uses social networks to consult one another on symptoms, diagnoses, and treatments. Despite the popularity of these sites, health industry groups have been slow to embrace social media. The drug industry allocated less than 4% of the \$4 billion spent on direct-to-consumer (DTC) advertising to Internet outlets in 2008, and only a small portion of that was for social networking sites (Arnst, 2009).

The reasons for this “late adopter” stance can be traced to regulatory challenges with social media. Since pharmaceutical and medical device companies are required to report “adverse events” to the US Food and Drug Administration (FDA), there is a reluctance to engage in sites where there is potential for false reporting, as well as the appearance of off-label marketing. In 2009, there was an FDA public hearing on social media, which was seen as the first step toward developing regulatory guidelines for social networking sites.

In 2003, a survey of US doctors showed that 85% of patients brought the health information they gathered on the Internet to appointments (Murray, Lo, Pollack, Donelan, Catania, Lee, et al, 2003). Patients were now empowered to be active participants in their own health care.

Sometimes the instant availability of information outpaced the ability of physicians to receive medical news before their patients. In 2002, the National Institutes of Health released a long anticipated study on women and hormones. The *JAMA* publication was embargoed, but news of the study, linking hormones to a higher rate of breast cancer, leaked out to news outlets before physicians could read about the study in the journal. Many physicians were caught by surprise as worried women patients called them about the study.

Physicians are also increasingly getting their information online. Instead of reading print journals, according to a Manhattan Research Study, they are spending an average of 8 hours a week seeking professional information online. In addition, 60% of physicians use such online physician communities as Sermo or WebMD's Medscape Physician Connect (Manhattan Research, 2010).

The online revolution in health care has had profound implications for the way communicators reach consumers and professional audiences. There is no longer the distinction between old media (print, broadcast) and new media (online). Communications strategists see only "media." Top-tier print media like the *New York Times* and the *Wall Street Journal* all have widely read healthcare blogs. News placements on these sites now carry the same clout that was once reserved for national print and broadcast.

## Patient Groups—Hear Them Roar

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One of the most dramatic and far-reaching effects of the rise in consumerism can be seen in patient advocacy. In 1981 the first patient in the United States died of what would become known as acquired immune deficiency syndrome or AIDS. For much of the 1980s and early 1990s the diagnosis of this condition was a death sentence with thousands of men and women losing their lives.

Because the condition in the early years largely affected gay men, there was little impetus for a health policy level to find effective treatments. Gay men and their supporters mobilized, and through such groups as AIDS Coalition to Unleash Power (ACT UP) they demanded new treatments and resources for people living with AIDS. Ryan White was also a changing force in mobilizing AIDS activists.

A teenage hemophiliac, White became infected with HIV from a contaminated blood treatment and, when diagnosed in December 1984, was given 6 months to live. Doctors said he posed no risk to other students, but AIDS was poorly understood at the time, and when White tried to return to school, many parents and teachers rallied against his attendance. A lengthy legal battle with the school system ensued, and media coverage of the case made White into a national celebrity and spokesman for AIDS research and public education. He appeared frequently in the media with celebrities such as Elton John, Michael Jackson, and Phil Donahue.

Before White, AIDS was a disease widely associated with the male homosexual community, because it was first diagnosed there. That perception shifted as White and other prominent

HIV-infected people, such as Magic Johnson, appeared in the media to advocate for more AIDS research and public education to address the epidemic. The US Congress passed a major piece of AIDS legislation, the Ryan White Care Act, shortly after White's death. The act was reauthorized in 2006 and again on October 30, 2009. Ryan White Programs are the largest provider of services for people living with HIV/AIDS in the United States. They succeeded in moving this disease to much greater prominence on the healthcare agenda.

Companies like Bristol Meyers Squibb (BMS) and Gilead developed combination therapy drugs that halted the course of the disease. Today HIV infection can be managed like a chronic condition. It is no longer a death sentence; many individuals with HIV are living long and healthy lives. The most dramatic drops in both cases and deaths began in 1996, with the widespread use of combination antiretroviral therapy (Centers for Disease Control and Prevention, 2008).

During 2006 there were an estimated 28 pediatric AIDS diagnoses, compared to 195 in 1999 and 896 in 1992.<sup>(18)</sup> The decline in pediatric AIDS incidence is associated with more HIV testing of pregnant women and the use of antiretroviral drugs such as zidovudine (AZT) by HIV-infected pregnant women and their newborn infants.

Communications campaigns, like the CDC's multiyear campaign on prevention, as well as advocacy campaigns aimed at the policy level on drug reimbursement and other issues, changed the face of AIDS in this country.

Just as advocacy changed the course of HIV/AIDS, a similar trajectory was occurring with breast cancer. The number one cancer affecting women with nearly 500,000 lives lost each year, this disease did not have the industry profile or policy "urgency" that matched its devastating impact on women (World Health Organization, 2011). In 1982, Nancy Brinker founded the Susan G. Komen Foundation, named after her sister who died of breast cancer.

With the pink ribbons, Race for the Cure, and other events, the Komen Foundation put breast cancer front and center on the health issues map. Komen has raised over \$1.5 billion for research, education, and health services, making it the largest breast cancer charity and private funding source for breast health and breast cancer in the world (Credo, 2009).

Today, the Komen organization is recognized as the leading catalyst in the fight against breast cancer, with more than 100,000 volunteers working in a network of 125 US and international affiliates (Eurekalert, 2009). Since 1982, Komen has awarded more than 1,000 breast cancer research grants totaling more than \$180 million. Their advocacy and funds raised for research spurred the development of new treatments and prompted women to seek breast exams (Komen Grants & Awards, 2010).

Health advocacy groups have changed the face of many diseases and of legislative priorities in Congress. The Society for Women's Health Research (SWHR), founded by Dr. Florence Hazeltine, is credited with gaining parity for women in studies funded by the National Institutes of Health. Prior to SWHR's advocacy, most clinical trials of new drugs focused only on men.

Communications is at the heart of all of these advocacy groups. They had a story to tell, and in telling that story they have changed the landscape of health care.

## New World: Science Breakthroughs, Boomer Tsunami, and Health Reform

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If the dazzling developments in the world of health and the parallel rise of healthcare communications were not spectacular enough over the past 50 years, what is to come may outpace all of that.

Innovations in medical science, an aging population creating an unprecedented demand for health services, and the complexities of a new US healthcare system will put a premium on the value of healthcare communications.

Developments in medical technology such as gene mapping, personalized medicine, and “precision” drugs such as Fanapt, the schizophrenia drug that can target patients in whom the treatment will be most effective, open up new horizons in medical care.

Yet with these new horizons come issues of ethics and access. With the potential of gene mapping for diseases, how will patient privacy be protected, and how will this information be used in a way that does not discriminate against the patient? How will we guarantee that life-saving but extremely expensive therapies such as bone marrow transplants are available to all of our citizens? As a society we must come to grips with the ethical and policy dilemmas that advances in medical science have brought us.

Coupled with these treatment innovations, the aging of the population presents a clear challenge to our healthcare delivery system. The baby boomers will put unprecedented demands on the healthcare system. An estimated 77 million people were born between 1946 and 1964, which is defined as the baby boom era (US Census, 2005–2009). The first baby boomer turned 60 on January 1, 2006 (US Census, 2005–2009). An American turns 50 every 7 seconds—that is more than 12,500 people every day (US Census, 2005–2009). By 2015, those aged 50 and older will represent 45% of the US population, according to the AARP. By 2030, the 65-plus population will double to about 71.5 million, and by 2050 it will grow to 86.7 million people (US Census, 2005–2009).

According to a recent report by Mintel, this age group is among the most health-conscious of consumers, seeking ways to maintain vitality and wellness. Boomers place a high value on optimal health and spend annually more than \$200 million on nutritional supplements and other consumer health products. In the next 10 years, US baby boomers will increase their annual spending on wellness-based services from approximately \$200 million today to \$1 trillion (Mintel, 2007).

They expect to live longer and healthier than previous generations and will put a huge strain on the healthcare system in doing so. Pharmaceutical and consumer health companies, device makers, and providers will be reaching out with customized communications to sell products and services to boomers.

In March 2010, the Patient Protection and Affordable Care Act was passed; it is the biggest piece of social legislation in the United States since Medicare. This law will fundamentally change the landscape of health care, affording new protections for consumers and offering sharp regulations to the insurance industry. This 2400-page law that affects one sixth of the

US economy requires skilled communications to clarify what the complex provisions mean to ordinary Americans.

A 2010 Kaiser Family Foundation poll cited that 55% of US residents are “confused” by the new health reform law, and 56% say they are unsure how the law will affect them. Exacerbating this is a timeline in which some of the most substantive parts of the bill, like the state insurance exchanges, will not be implemented until 2014 ([www.kff.org/kaiserpolls/upload/8075-F.pdf](http://www.kff.org/kaiserpolls/upload/8075-F.pdf), 2010). Adding to the confusion is a plethora of misperceptions about the law that are a result of the highly polarized political debate.

There are few things Americans care about as much as their health care, and close attention will be paid to all phases of the new law’s implementation. Communications professionals in the healthcare industry will be called on to cut through the confusion with clear facts about the law and its impact on all stakeholders. Timely and accurate information will play a huge role in the law’s success. Communications professionals have an opportunity to help their fellow citizens navigate this historic piece of legislation.

## Summary

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From a minor player in the healthcare industry a half century ago, to front and center of today’s issues, health communications have become indispensable to the world we live in. Today health communication specialists play a variety of roles, including, but not limited to, developing health prevention and promotion campaigns, serving as advocates for patient and consumer groups, educating members of Congress about health issues, handling health crises, and developing integrated communication campaigns for healthcare corporate clients. With an expanding marketplace for healthcare products and services, a growing population in need of education and care, and an evolving media landscape that can be leveraged to connect them, the future is healthy for health communication specialists.

## Discussion Questions

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1. What is spurring the growth in the number of graduate schools offering degrees in health communications?
2. Explain the shift from the nation’s focus on sick care to wellness. What was at the root of this shift?
3. How has the rise of Internet affected the way communicators reach healthcare consumers and professionals?
4. What will be an effect of the aging baby boomer generation on the healthcare industry?
5. What is the Patient Protection and Health Care Affordability Law? Look it up online, and describe how this law will affect you in the next 5 years.

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