

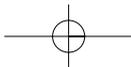
## 1

## Why Communicating about Health Matters

As the daughter of a career military man in the US, I never had to worry when I was growing up about whether my family could afford to take me to the doctor or whether a doctor was available. In the US, the federal government has the power to regulate commerce with foreign nations and tax for the general welfare. So the military and their dependents receive basic health care to satisfy the nation's economic aims. Just because I had access, however, doesn't mean that I spent much time at the doctor's office. In fact, I learned the same lessons that most people learn about going to the doctor. Make an appointment and then, "show up and shut up." By following these rules, I also learned what most others would agree with. It can all be a little embarrassing, so we don't talk about it much.

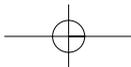
I remember well what it was like to get a school physical. Not much different than the way the movies depicted it for military recruits. The kids in my school were bussed to the military hospital and lined up in this large sterile brightly lit area. We got undressed with girls on one side of a long curtain and boys on the other. The doctors moved along the line to examine us, after which there was some pronouncement such as "good," and then "next." I hoped for a "clean bill of health" and that no one saw me naked while the doctor checked me out. I don't remember ever having a conversation with one of those doctors, unless perhaps to nod or shake my head – if that counts.

I didn't think much about having a role to play in talking to doctors about my health. After all, the doctor couldn't even hear me when using



a stethoscope, so why bother talking. They had all those mystical and magical tools, x-ray pictures of my insides and lab studies of my blood. I carried my naïve notions into my civilian adulthood. It was then that I began to realize why communicating about health matters. When first presented with a medical form asking about my family health history, I couldn't answer many of the questions. Cancer? Heart disease? Diabetes? All formed part of my health heritage, but the who, how, when, and where parts of the stories didn't come so easily. I just often didn't know. So I mostly maintained a "cloak of silence" during my medical appointments, speaking when spoken to, avoiding eye contact, and keeping it all as private as possible. Just like the young girl who stood in line to get her physical, practically naked, I wished for a "passing grade" on my health status.

Years later, after I'd married and given birth to two children, I realized how literally life-threatening my attitude could be. As I began to do research in which I listened to doctors and patients talking about health, I formed an appreciation for why doctors and patients behave as they do. We're really all caught in the "eye of the storm" swarming around all the talk about health, trying to make sense of it in the best ways we can. Doctors can't possibly address it all with us in the time they have for our appointments. We don't know what are the most important details about our health to reveal. Over time, I realized that all the talk is affecting our sense of who we are and who's responsible for health. It guides us and government to make decisions about how much time and money to devote to health. It forms our understanding, and sometimes our misunderstanding, about health. It leads us to make more and sometimes less effort, to feel good and sometimes bad, and to make excuses when we don't do what we know we should do. These effects emerge out of talk about health relating to six questions: "Am I normal?" "What are my risk factors?" "Why don't we get care?" "Is acting on public messages about health good for me or just good for society?" "Who makes a profit from my health?" and, "What's politics got to do with it all?" With a little practice, the consistencies and conflicts to be found in all the talk about health can be sorted out. We can decide for ourselves what to act on and what to leave behind, recognizing that these decisions frequently will be based on our overall sense of self and answers to the question, "Who am I?"



## It Answers the Question, “Who Am I?”

How we define our *self* connects to communicating about health.

When you answer the question, “Who am I?”, a long list of roles and even values are probably part of your response. Talking about health also forms an endless list of possible answers to the question, “Who am I?” Visually impaired. A vegetarian. A runner. An alcoholic. Diabetic. Cancer survivor. Disabled. Pregnant. Impotent. Addict. If we don’t have personal experience with a condition, news and entertainment media, including our favorite primetime dramas and many movies, present images to form our understanding. Mary Tyler Moore is internationally known for her ground-breaking roles in TV series aimed at showing women in independent roles. She also manages living with diabetes in her personal life, a role model of independence. Magic Johnson, internationally identified as a basketball player par excellence, also assumes an identity linked to living with HIV. Ronald Reagan and Alzheimer’s. Christopher Reeves and spinal cord injury. Michael J. Fox and Parkinson’s. However we describe our health, the meanings linked to it have to fit into all the ways we define our “self.” But these connections are seldom simple. Take “the smoker,” for example.

My father, a Korean and Vietnam War veteran, smoked when I was a child growing up. This was not unusual. My husband’s father smoked as well. Both men began smoking during their military careers. My father-in-law began when he received cigarettes in his K-rations as a US Marine during World War II. My father began smoking when airmen got breaks to “smoke ‘em if you’ve got ‘em.” If you didn’t have “smokes,” you didn’t get those breaks. Since all the fathers I knew smoked, and some mothers did, too, I didn’t think much about it. At the time, it was an affordable pleasure. As medical research began to link smoking to infertility, lung and other cancers, heart disease, and a host of health harms, communication about smoking and health formed an identity around being a “smoker.” A smoker is someone without the willpower to safeguard their own well-being by quitting, stressed out, frenetic; at best, mindlessly addicted. Or, as the billboard along a US highway pictured in Figure 1.1 claimed, “A ‘butt’ head.” This public health message played on the burned-out ends of those tobacco sticks – butts



**Figure 1.1** Photograph a billboard placed along a busy highway in the US, taken by the author.

– filling an ashtray atop a young man’s head. But there are also those media images of smokers which include a rugged individualist sitting atop a horse and that “can never be too thin” actress in our favorite movie or TV series. These competing images may help to explain what has been called “phantom smokers,” people who smoke occasionally, but don’t want to be identified with the label “smoker.” So they don’t answer, “Yes,” when asked by their doctors on health history forms, “Are you a smoker?”<sup>1</sup>

The identities that form from talking about health affect how, and even *if*, we talk with our doctors, our families, and our friends about health. So both what we *do* talk about and what we *don’t* talk about relating to health comes from our sense of how it connects to our self-concept or how it may affect the ways in which we answer the question, “Who am I?” As a result, we’re more likely to talk to our doctor about some things even when we aren’t asked, because the identity linked to the behavior or symptom is a positive one. For example, being asked about our sleep



**Figure 1.2** Photo of the author at age three with fractured right leg.

habits isn't part of the usual medical interview. But we may tell our doctor we're having trouble sleeping if being diagnosed as an insomniac, someone with persistent problems sleeping, is a sign of being a hard worker. If, however, insomnia is viewed as a sign of being a depressed worker, we may be less likely to tell the doctor about our sleeplessness.

The absence of an identity relating to health may also affect talk about health. I had two children and was well into my thirties before telling a doctor about the broken leg I had as a three-year-old. Family photos like the one in Figure 1.2 and family stories about the event are what I know about it. I don't have an identity related to being "broken bone survivor." Come to think of it, "Have you ever had any broken bones?" has never appeared on those medical history forms. I can think of no images linking broken bones to any of my other roles or, as far as I knew, any of my symptoms across the years. It turns out that having experienced a broken leg at the age of three mattered a great deal and explained many little health problems across the years. But it wasn't until I was nearly

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40 years old and developed osteopenia, a mild thinning of the bone mass, in the hip area of the shorter leg that I learned my broken leg grew to be nearly an inch longer than the leg that didn't suffer a fracture. I might have avoided osteopenia if I'd worn a lift in my shoe all those years to counterbalance the force being put on the joint. Of course, that would've meant that I told my doctor about the event, and it never seemed important to do so.

Identities form not just around our health status but also around those who work in health care and the places where care is given. If we get care from a chiropractor, an acupuncturist, a general practitioner, a physical therapist, a physician's assistant, or an internist, differences in their training contribute to differences in how they view health and how they treat us and our bodies. When a certified nurse midwife delivers or assists with the delivery of a baby compared to an obstetrician, women often view their care as more holistic, personalized, integrated, and flexible.<sup>2</sup> When a hospital reorganizes to provide long-term care, social support services, and other programs not usually considered to be part of the hospital, they become a "health care system" – a site for one-stop shopping related to our care. These identities, too, guide our notions of how things will be. And they form our sense of who's responsible, a second reason why communicating about health matters.

**It Answers the Question,  
"Who's Responsible?"**

Blame for health comes from communicating about health.

"Why is this happening to me?" "Why can't I get pregnant?" "Why do I have cancer or heart disease?" "How come I'm the one changing my husband's surgical bandages? I'm not a nurse." Our answers to the question, "Who's responsible for health?" emerge from communicating about health. There's tension in decisions about where to draw the line between self and society as being responsible. Smoking illustrates this reality. My father, for example, developed a persistent cough when he was in his thirties, which would have been the 1960s. The military doctor said it might be linked to his smoking. There was, however, no advice to stop the habit. When Dad was on a tour of duty in Guam

during the Vietnam War era, he had some particularly bad episodes of coughing. This time a military doctor told him, "Quit smoking or die." My father quit. He smoked a pipe occasionally for a while after that, but the pipes eventually disappeared from our family home as well.

As the science evolved linking smoking to lung cancer and other health harms, smokers began to be told to quit, first by their doctors, then through public health messages, and increasingly from family and friends. Smokers were blamed for their poor health caused by their smoking. Over the years, however, evidence mounted to show that tobacco companies knew that their product was both harmful to health and addictive. Awareness that nicotine addiction challenges efforts to quit smoking shifts some responsibility and stigma from smokers to tobacco companies. These companies also developed identities ranging from "monstrous," to "shameful," and "unethical." And because companies hid the evidence of health risks, consumers lacked information to make informed choices about their health and smoking. Smokers and their families blame the companies and seek some compensation to balance such deception.

Communicating about health and responsibility builds our understanding of both personal and societal responsibility for health, and our beliefs about whether we have control over our health. Behaviors like exercise, eating, and alcohol consumption are all ones over which we have some control. When research finds that people living in areas with lower forest coverage in Japan have higher rates of cancer compared with people living in areas with higher forest coverage,<sup>3</sup> we feel less in control. If deforestation contributes to increased risk for cancer, we don't really have any alternative to reduce our personal risk through our own behavior. We can, however, hold society responsible and ask our policy-makers to limit destruction of forests in the future.

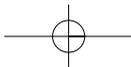
Unfortunately, communicating about health too often presents one-dimensional views of responsibility. Bits and pieces of talk about causes and explanations for health sit waiting to be organized into action. For example, who's responsible for more children being obese? Pediatricians? They may play a role by avoiding discussions of short- and long-term negative health consequences of obesity. Children? They eat too much food, too many high fat foods, and get too little exercise to use the food they eat. But who's responsible for making so much food available to kids? While parents play a role in making high-fat foods accessible, they buy what's affordable and accessible on store shelves. Food manufacturers play a role in producing high-fat food. Public schools play a

role in reducing the number of physical education classes. Government plays a role in reducing resources for having physical education classes. Crime plays a role in reducing the safety of children playing outdoors in their neighborhoods or walking to school. Pollution plays a role in reducing the air quality outdoors which often limits recreation. Communication that represents most any health event as one dimensional fails to give us a realistic view of the situation.

Communicating about health should be examined for its tendency to overemphasize personal responsibility *or* societal responsibility. Prenatal care for women, for example, has long been promoted as a strategy to improve the birth outcomes of newborns. To reap the benefit, women must show up for appointments to receive such care. Society bears some responsibility for making care available to pregnant women. Both are necessary to achieve the positive response promised as part of prenatal care. But even this is an incomplete way to talk about the birth outcomes of newborns. The March of Dimes in the US has tried to communicate the reality that “men have babies, too.” The behaviors and exposures of men affect the quality of their sperm and thus the outcomes of pregnancies. Men who use drugs or are exposed to some products may find the quality of their sperm affected, with a higher risk of birth defects. The twenty-first-century movement toward communicating about *preconceptional* health represents an opportunity to emphasize a role for men *and* women. But once more, society’s efforts will be part of the success or failure linked to promoting preconceptional health. If men experience harmful exposures at work, it will likely take action outside their own sphere of control to reduce the risk. Such actions are seen in policies, for example, which require personal protective equipment to be worn when handling products that pose health harms.

Communicating about responsibility for health sometimes leads to unintended consequences, even when the focus of blame is accurate. Mothers Against Drunk Driving (MADD), illustrates this reality. Established in 1980 in the US as Mothers Against Drunk *Drivers*, the name clearly assigned responsibility for drunk driving on the drivers, labeling those who drink and drive negatively. Drunk drivers became the targets of abuse, taking attention away from the real victims. As a result, in 1984, MADD changed its name to Mothers Against Drunk *Driving*. The focus emphasizes disapproval for the behavior of driving under the influence of alcohol rather than stigmatizing drunk drivers.

Communicating about responsibility and health also frequently forms our sense of who’s responsible for care. When my son had his impacted



wisdom teeth removed, I was given the responsibility for changing the blood-soaked gauze at the back of his mouth and monitoring his symptoms – including bleeding and fever. When the mother of one of my friend’s had a mastectomy, she was sent home the day following the surgery with tubes radiating from her chest, and my friend had the responsibility for draining the tubes. When my niece had pneumonia, my sister was handed a breathing apparatus that she was asked to “sign-out” together with a list of instructions about how often to empty her young daughter’s congested fluid-filled lungs. These are not exceptions. These are the rule. Knowledge and technology help us to avoid infection and death from impacted wisdom teeth, suffering and early death from breast cancer, and early death from pneumonia, but it’s often our responsibility to manage after-care and follow-up. This illustrates the reality that communicating about health also leads to decisions about the allocation of resources, a third reason why it’s so important.

### **It Opens the Gate for “Resources”**

Time, money, products, services, people – all come from talk about health. Or *not*.

What do you do to be healthy? Exercise 20 minutes a day, three times a week. Get six to eight hours of sleep each night. Annual check-ups. Monthly breast or testicular self exams. Daily consumption of water. Communicating about health guides our understanding of where we as individuals and the societies we live in should invest time, money, and other resources to promote health. Stop smoking messages, for example, frequently refer directly or indirectly to the economic costs of smoking. For individuals, life insurance, car insurance, and health insurance rates may be higher for smokers than nonsmokers. Debates about whether society or smokers should pay for smoking cessation efforts are weighted against costs of cancer, heart disease, and other health problems linked to smoking. Should tax dollars be used for nicotine gum or services such as therapy to learn stress reduction techniques?

The resources needed, according to most talk about health, center on money. But there are multiple meanings of money as a resource linked to health. For example, the costs for US employers to treat the effects of employee obesity have been estimated to be \$45 billion a year.<sup>4</sup>

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Despite these costs, economic models suggest that helping obese employees slim down may cost even more, so few companies are tackling the issue head on. How can this be? In part, it's due to the high employee turnover rate. Many US workers stay at one job only four to five years on average, so a company's investment in their long-term health doesn't benefit the company. No one's talking to US workers about this reality or offering creative approaches to the situation. No one's saying, "Make a commitment to us, and we'll make a commitment to your health."

Novel approaches do exist to address the costs related to health. For example, Japanese workers are reaping the health benefits of companies and government investing in their well-being. Japan, too, has had an increase in obesity that accompanies an era of technology and a culture that rewards being a workaholic. Japanese citizens are also eating less fish, vegetables, and rice than was usual in the past, while consuming more fast food. Among nearly 64,000 male workers between the ages of 20 and 54, rates of obesity were examined in 1992 and 1997. In 1992, 21.3 percent of the workers were obese. Just five years later, 24.7 percent of the workers were found to be obese, a significant increase representing more than 2,000 additional men afflicted with this condition. Among younger workers, the increase was 6.3 percent during the five-year period.<sup>5</sup> Workplaces in Japan offer fitness programs over the lunch hour and *require* employees to get their waistlines measured regularly to track progress. The government has tied costs for the national health insurance to employee obesity, and higher costs for contributions from companies are linked to having obese employees.<sup>6</sup> Japan's approach shows a shared sense of responsibility and cost. It includes a national level, where decisions about how to pay for universal health care for citizens are tied to organizations. It also includes an organizational level, where decisions about how to pay for benefits for employees are tied to individuals.

Talk about health frequently focuses on an economic model of costs and benefits connected to a role for society in allocating resources to health. In the US, the Centers for Disease Control and Prevention (CDC) published a report called, *An Ounce of Prevention . . . What are the Returns?*<sup>7</sup> Bicycle-related head injuries, flu in the elderly, and sickle cell screening for newborns are among 19 issues examined for the number of citizens affected and the cost, compared to the effectiveness of prevention and its cost. Their conclusions reveal what savings in direct

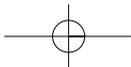
medical costs are achieved for each dollar spent. And in cases where there's a net cost, the report considers whether the money invested in prevention reaps value for the investment. They conclude, for example, that yearly mammograms carry a net cost but give considerable value for the money invested. Childhood vaccines, on the other hand, are shown to have direct medical savings for each dollar spent.

Family budgets include many resources devoted to health, both directly and indirectly, which are linked to all the talk about health and prompt some choices in lieu of others. The success of a campaign to get us to eat "five fruits and vegetables each day" depends in part on our having the resources to obtain fruits and vegetables. As we spend a lower percentage of income on food, we are becoming more overweight, with energy-dense foods being the lowest cost options. These include refined grains, fats, and added sugars.<sup>8</sup> Add the cost of recreation and leisure, including food and drink, products for personal care such as toothpaste, soap, and shampoo, and resources to stay warm in winter and cool in summer – it all adds up. My baby book reveals that I was admitted to the hospital for pneumonia when I was five months old. I was born in early September, so that would have been early February – the middle of winter. When I asked my mom about this, she said their apartment had no heat in it. The only source was the oven which they turned on and opened in an effort to bring some heat into the area. It apparently didn't work very well.

Resources go well beyond money, of course, in our efforts to be healthy. Social support, which is our access not only to information but also the tangible things we need to be healthy and the skills to follow through, is a resource persistently found to be of vital importance in efforts to manage our well-being. Someone living with diabetes who should take medication every day, test glucose levels, exercise, and maintain an appropriate diet to manage their health is far more likely to do so with support from family and friends.<sup>9</sup> This is true across conditions ranging from heart disease, cancer, and arthritis to back pain, as well as the need to follow safety rules in nearly all areas of our lives. It's the teen whose parent reminds him or her to wear sunscreen at the pool who's more likely to do so, the worker whose work site has safety posters with the steps to follow in being safe posted next to equipment who remembers to do so, and the public school students whose cafeteria posts the calories and fat grams included in different food options who make better eating choices.

Resources for health also link to the availability of doctors and other care providers, of course, the focus of talk about health all around the world. A lack of doctors is a structural barrier to getting care. Rural areas often face this dilemma. My husband, for example, grew up in Tombstone, Arizona, one of seven children, four of them boys – he the oldest. The family had a ranch made up of 32 sections of land, mostly leased, with one boundary along the border with Mexico. The boys spent countless hours in the hot Arizona sun, sans sunscreen, and without hats. Then two decades later, we spent more than a decade of our married lives living in Tucson, Arizona. During those years, he returned to the family ranch on a regular basis, this time usually wearing a cowboy hat but still without sunscreen. In middle age, suspicious spots on his skin began to appear. Some have been removed, but most recently, the dermatologist observed that he needed to have a complete body skin cancer exam. While we live in a university town, it's in a large rural area and the dermatologist he saw is the only skin specialist. So it took six months for my husband's appointment to be scheduled. As the time for the appointment approached, he tried to move the appointment due to a conflict. The appointment receptionist warned him that there were 60 people on a waiting list for skin biopsies and minor surgeries. "In other words," she said, "keep your appointment and don't count on getting in any earlier. If you cancel the appointment, it will be seven months before we can reschedule it."

Talk about health determines how much money will be devoted to medical research and for what purposes. Arguments that guide how resources will be allocated for medical research are often invisible to us, but have tremendous effects on our well-being. They form the evidence base about "health," both what is known and what isn't known. Funded research in the National Institutes of Health in the US, the National Institute for Health Research within the National Health Service in the United Kingdom, the National Institute of Health and Medical Research in France, and the National Institute of Health in Japan all illustrate this reality. Medical research contributed to evidence to support a link between smoking and lung cancer, for example. Until that evidence was available, disputes continued about such links. Similar debate has surrounded the question, "Does passive exposure to smoke contribute to disease?" Individual, institutional, and societal biases affect what research gets funded, leading to disparities in understanding and care,



as discussed in Chapter 7. And, as with the scene in *The Wizard of Oz* in which Dorothy reveals the “great and powerful Oz” to be simply a man behind a curtain standing at a control panel designed to make him appear to be so much more, we frequently feel that someone besides us controls these decisions, someone who knows more and can make better choices. When we realize, however, that both what we know and what we don’t know about health depends on these decisions, it’s a further revelation as to why communicating about health matters.

### **It Promotes (Mis)Understanding**

Our abilities to understand symptoms, give informed consent, and make informed decisions about health come from communicating about health.

Are you ever surprised, puzzled, or even annoyed by the fact that one message about health says one thing and another message says something quite the opposite? Communicating about health is often misunderstood because the vocabulary is both complex and unfamiliar. The words used are ones that we don’t use in our everyday conversations – even when we do talk about health. We say we have a pimple on our face, not a cyst. We say we have a growth on our arm, not a tumor. We talk about family history but don’t say “hereditary.” Consistently, only about one-third of us are found to know the meaning of these words and others that doctors often use and expect us to know.<sup>10</sup> One of my friends has been dealing with an injured knee and after a visit to an orthopedist, returned to the office upset. She told me,

He talked about things that were in my records about which I had no awareness. He said I had “repetitive strain injuries” and “a popliteal cyst” – which I asked him to write down so I could look it up later. The orthopedist said these were the diagnosis a couple of times when I had seen my primary care doctor for knee pain in the past. I told him, “I think I would remember if my doctor *told* me I had a cyst.” The orthopedist said my doctor might’ve called it a “Baker’s Cyst.” It’s the collection of too much joint fluid in the back of the knee being caused by inflammation in the knee.

We often rely on doctors to explain medical terms they use when talking to us, but even when they do, many too frequently rely on the use of metaphors. When asked why, doctors say that the difficulty of translating medical and scientific terms is most easily achieved by using language that can be easily understood by lay audiences – metaphors.<sup>11</sup> There's little evidence to suggest that this is the case. In the United Kingdom, for example, among 105 people asked about the meaning of terms doctors use such as “spots in the liver” and “seedlings” to explain the metastatic spread of cancer, only about half understood that they meant the cancer was spreading.<sup>12</sup> Describing the role of genes for health as “a blueprint of our future,” is understood by some to mean that genes set an absolute path for our future health, while others see it as meaning that genes are a framework that can be revised or even dramatically reworked.<sup>13</sup>

When our doctors don't explain it and our friends or family don't know either, we often turn to the internet. When my girlfriend and I tried that by entering “Baker's cyst,” it resulted in 388,000 hits in 0.08 seconds. The question, “What is a Baker's cyst?” returned 228,000 hits in 0.12 seconds. The first three responses explained that such a cyst is a soft and often painless bump, a closed sac or bladder-like structure that is not normal, and a firm, *walnut*-sized fluid-filled lump behind the knee. “A walnut?” my girlfriend said. “I've never had anything on the back of my knee that was like a walnut.” So the same strategies doctors use to translate medical content to us are used in online health information as well.

Communicating about health also causes confusion when it doesn't make intuitive sense. Women's risk for cervical cancer, for example, has been linked to smoking, but women have stated that it makes no sense to them.<sup>14</sup> While smoking and lung cancer are seen as having a logical connection, the same cannot be said for smoking and cervical cancer. Our understanding depends upon our willingness and ability to integrate research evidence that may make no intuitive sense. This lack of integration poses a barrier to thoughts and action. In looking back, and with prompting from an orthopedist, my girlfriend who was struggling with knee pain remembered that her primary care doctor told her a long time ago to get some physical therapy for her knee and that her insurance would cover several visits. “That made no sense to me,” she said. “The doctor had told me to limit my jogging, tennis, and biking. Then he says to get therapy to build my calf and thigh muscles.” She wasn't making

the connection between building those muscles and gaining strength to support her injured knee. She was seeing both as work-outs involving her knee.

Sometimes, science makes different recommendations based on the same behavior having different effects for our health, once more causing the talk about health to be confusing. Sun exposure provides an apt example. As a child growing up, I walked miles and miles of shorelines along the Great Lakes with my paternal grandmother in the summers, leaning over to look into the waters and collect stones as souvenirs, some of them the treasured Petoskey stones with fossil forms etched into their surfaces. I swam with cousins in cold water and then baked warmth back into my body as we had relays on the beach. No one talked about skin cancer yet because there was no science to support a risk due to over-exposure to the sun. There was, however, science relating a lack of sun exposure to vitamin D deficiency and rickets.<sup>15</sup> As people began to talk about skin cancer and the sun, I heard my mother express confusion over the conflicting health messages associated with the need for sun exposure to avoid rickets and the need to avoid sun exposure to reduce skin cancer risk.<sup>16</sup> “How much sun is too much sun?” she asked.

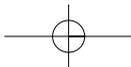
Misunderstanding may arise because communication about health reflects the fact that different medical evidence may apply to different people. Some people will *not* be advised to behave in ways that others are, because research didn't include participants with characteristics like their own. These may include biological sex, age, or race. Minors under the age of 18 years, for example, are often not included in research unless the topic is considered to address children's health. As a result, complications arise from the use of some medications or other therapies for them. Media stories have reported about this happening for some medications used to treat depression, for example. Concern has emerged about whether the use of these medications may actually increase the risk for suicide among teens using them. Cold medicine was never tested on children under the age of two, and use has been found to lead to serious and even life-threatening effects.<sup>17</sup> Thus, prescription and over-the-counter medications, as well as other therapies, have been developed based on their efficacy with some groups while excluding other groups.

Sometimes new science conflicts with old science and affects our understanding. Too few efforts are made to tackle this head on. I've known women in my mother's generation who say that they were told that the “womb” was a safe place for a baby to grow. Their behaviors like

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smoking and drinking, they were told, didn't influence a newborn's health. This may help to explain why, despite public health efforts to get women to give up smoking while they're pregnant for the benefit of a child, some women don't. Their mothers may tell them that they smoked and their babies were healthy. Some organizations may make different recommendations relating to our health than other organizations do based on "new" science, which adds to our confusion. Cervical cancer screening guidelines, for example, differ between the American Cancer Society (ACS), the American College of Obstetricians and Gynecologists (ACOG), and the US Preventive Services Task Force (USPSTF).<sup>18</sup> How often to be screened varies, depending on the type of screening used and the organization making the recommendation. With a conventional Pap test, the ACS and ACOG recommend screening annually *or* every 2–3 years for women 30 years of age and older who have had three negative cytology tests, while the USPSTF recommends at least every three years. The recommendations are even more varied when using the liquid-based cytology screening method, with the ACS recommending every two years, while ACOG recommends annually, and USPSTF states that there is insufficient evidence to make a recommendation. For women 30 years of age and older who've had three negative cytology tests, ACS and ACOG assert that every 2–3 years is appropriate. All these recommendations may contribute to women's confusion about when to be screened. All three organizations do agree that screening should be started within three years of onset of vaginal intercourse, but not later than the age of 21.

Our ability to understand communication about health may also depend upon awareness that often there simply is *no* science to guide communicating about health. This isn't because the sample used in research didn't include someone like us. It's because the issue hasn't yet been addressed in medical research. That doesn't necessarily make it unsafe. Just untested. We often don't tell our doctors we use nutritional supplements such as herbs because we aren't asked about it. We often aren't asked because there's no medical evidence to say that nutritional supplements are either safe *or* unsafe for use. Since the study of complementary and alternative medicine and practice hasn't been funded in the same way that biomedical approaches using drugs and surgery have been, questions about use of herbs is a hit or miss process, with little chance that it will be included on medical history forms. In the wake of these realities, it's sometimes difficult to know how to behave in



health promoting ways. This can lead to excuses when we don't, and anger when we do and it turns out badly for us, a reality that forms a fifth reason why communicating about health matters.

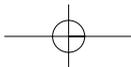
### **It Guides Effort, Emotion, and Excuse**

The energy put toward health, experiences of positive and negative feelings, and accounts of why we do what we do emerge out of communicating about health.

Have you ever found yourself thinking or saying, "If I'd only known, I would've done it to protect my health?" Regret is just one emotion we experience when we find out that we "could've or should've" when it comes to our health. Communicating about health arouses emotions, some of which are negative. We become fearful that we're susceptible to a health harm. It causes worry and dread.<sup>19</sup> We get embarrassed that, even though we knew better, we did something that caused us harm. Even when I did know the answers to some of the questions on medical history forms, it wasn't so easy to tell what I knew: medications I was taking, their names, the dosage; habits I had. We feel guilty when we eat too much, drink too much, work too hard, or drive too fast.

The effort we and others put into health can be traced back to talk about health, but there are gaps in the talk, gaps in our understanding, and so gaps in our behavior. Communicating about health is frequently intended to promote our efforts to be healthy, but may only create an overwhelming feeling of "can't." Research that included thousands of patients in Australia, Canada, New Zealand, the United Kingdom, and the US has indicated that we all feel much the same way.<sup>20</sup> Large numbers of us are dissatisfied. Our top three complaints? Poor communication with doctors. Poor coordination of care. Medical or medication errors. Poor care coordination, and medical or medication errors have direct links to poor communication. Poor communication thus appears to be all too common.

It's a ghastly dilemma we too often face. We've committed effort to being healthy, but we aren't. We've voted for those who would maintain or promised to implement programs and policies to support health and provide health care. We've given our time and energies to employers who

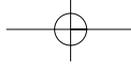


themselves are committed to programs aimed at promoting our well-being so that we can keep on working. We've devoted our income within families to being healthy. And yet, too frequently, it doesn't seem that we've achieved that aim. We know this personally because we *feel* it. We know it professionally because we see it in ourselves and others. We know it as a community because everyone's talking about health and no one's happy about how much it's costing in every kind of resource. Yet, we keep on going in the same directions – long after we know we shouldn't. We keep on hoping to make our effort pay off. We keep on because others including the experts and leaders we've elected keep on. And we keep on because there are only so many hours in a day and we can't think how to do otherwise than what we are doing. Little wonder then that too frequently we feel frustrated, mad, sad, and fearful when it comes to our health, when we should feel hopeful, happy, and glad to be alive.

Talk about health can benefit us in many ways. It acts as a guide for what to do and how to do it. It reinforces the match between our life stage and our mental and physical status. It should allow us to focus our attention on all the other things that matter to us, of which there are many as humans. These are aims that can be realized. It takes intention, however, and a harnessing of our efforts in new ways and new directions. That will be the purpose of this book then, to provide insights to redirect our energies and achieve a better understanding out of all the talk about health, together with improved well-being for ourselves and our societies.

### **Summing It Up . . .**

As I entered elementary school, President Kennedy's Council on Youth Fitness curriculum began to be distributed in the US. A quarter of a million youth were involved in pilot projects in six states – sit-ups, push-ups, rope climbing. There were charts marking the standard and we all aimed for it. My school had a jump-rope contest among other events. I won blue ribbons three years in a row. I learned that both praise and fun increase effort and commitment to physical exercise. What I didn't recognize at the time was that a political leader's agenda contributed to this effort, so that resources were allocated for its support. I also had no awareness of the underlying medical research supporting the importance

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of physical education and fitness for youth. We were still almost two decades away from the Title IX amendment in the US which supported females' participation in athletic programs in public schools. But I was already well aware that boys played sports and girls were cheerleaders. These gendered identities and roles affected the reality that girls were aiming for records in doing sit-ups, while the boys aimed for leading the count for most push-ups. Across decades of living, being a wife, a mother, a daughter, a sister, and a friend, together with the work that I do relating to how we communicate about health, six questions, sometimes with different answers, emerged at the intersection of these roles in all the talk about health. These form the nexus of why and how we do what we do when communicating about health, whether it's with our doctors, in our families, or among ourselves. In the next chapter, I start with what is perhaps the primary one, the many ways we seek to answer the question, "How 'normal' am I?"

