

Coming to Terms With Language

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Over the years, I have been moved by many wonderful Flaherty lectures, and I am grateful to the Oncology Nursing Society for maintaining the tradition of this lecture as a time for us to remember the heartfelt issues that are the touchstone of oncology nursing. Twenty-two years ago, I was in the audience as Judi Johnson, PhD, RN, FAAN, gave the first “Mara lecture” (Johnson, 1982). She shared with us the vision she and Mara had of living a healthy life in spite of having cancer. I was touched and inspired by Judi’s words and her memories of Mara as a vibrant, active human being who lived life to the fullest. My message is dedicated to Mara and to all those who have shown us what it means to try to maintain balance, dignity, humor, health, and sense of self when confronted with cancer. My message is about language and how we use it.

I have had a lifelong love affair with words, yet the broader concept of language—how it evolved and what it means—did not hold much intellectual or emotional weight for me until the heartrending day when I learned with certainty that my beautiful 18-month-old baby boy was deaf. I had never felt such personal pain. I grieved. I mourned. When I would finally drop off to sleep, it was only to awaken with waves of the awful truth washing over me all over again. Even the simple act of listening to music was intensely painful because I thought the joy it gave me would be unattainable for my son. I also imagined that among the many things that would be lost was any future ease of communication between us. It struck me as particularly cruel that we would not be able to share a love of words—words that are the very essence of all incidental and formal learning, words that form the bonds of relationship, and words that uniquely express personality and humor.

There were few guideposts for the journey we were about to embark on, and every twist and turn in the road brought me back to the question of language. Emily Perl Kingsley (2003) described this awakening better than I can in an essay she called, “Welcome to Holland.” She said,

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared the unique experience to understand it, to imagine how it would feel. It’s like this: When you’re going to have a baby, it’s like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. Michelangelo’s “David.” The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, “Welcome to Holland.”

“Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.” But there’s been a change in the flight plans. They’ve landed in Holland and there you must stay. The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It’s just a different place. So you must go out and buy new guidebooks. You must learn a whole new language. And you will meet a whole new group of people you would never have met. It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy . . . and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.” And the pain of that will never, ever, ever, go away, because the loss of that dream is a very, very significant loss. But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

By coincidence, she was writing this at precisely the same time that I was groping my way through my own “Holland.” I was coming to understand that the world of deafness was peopled with opposing factions and there was precious little consensus to help parents. This is a real obstacle because most



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parents of deaf children are not deaf themselves and have little or no personal experience with deafness.

Most of the dispute centered on the choices parents must make. These are not trivial choices; they are intimately tied to a parent's sense of being a "good parent." Still reeling from the diagnosis, parents must decide whether to align their child with an "oral approach" using speech therapy to teach the child to voice words and master speech-reading skills, whether to expose their child to sign language (and, if so, would that be American Sign Language or Signed Exact English?), or whether to combine all of it in an approach that is termed "total communication." Should a child's educational environment be bilingual or bicultural? Indeed, I had never before appreciated that there was such a thing as deaf culture, with its own customs, etiquette, poetry, and jokes all intimately tied to American Sign Language. A parent's choices would have a profound effect on a child's eventual cultural identity, intellectual potential, and ability to function in the hearing world. I should mention that the impact of a child's deafness is vastly different when the parents are themselves deaf. I remember my shock, participating in a parent meeting when my son was in preschool, as a deaf mother explained how happy she was when she learned her little girl was deaf. She was relieved that her baby would be like the rest of the family.

What I was to learn is that deafness is not about hearing as much as it is about language and communication. The greatest risk to a deaf child is missing out on language acquisition during the brain growth spurt of early childhood. Being without language, as neurologist Oliver Sacks (1989) described it, is

... one of the most desperate of calamities, for it is only through language that we enter fully into our human estate and culture, communicate freely with our fellows, acquire and share information. If we cannot do this, we will be bizarrely disabled and cut off—whatever our desires, or endeavors, or native capacities (pp. 8–9).

Studying the history of the deaf, I learned the tragic story of how their natural language had been suppressed over the past 100 years with an accompanying loss of control over their own destiny; it was a history of oppression of a linguistic minority by those who believed that speech, not language, is what makes us human (Lane, 1984; Ree, 1999). Fortunately, having a deaf child in the latter part of the 20th century meant there was a growing body of neurologic research evidence supporting the use of sign language (Emmory, 2002; Klima & Bellugi, 1979; Sacks, 1989). Contrary to the common myths about sign language (see Figure 1), researchers were showing that American Sign Language is a fully developed language with its own grammar, rules, and capability for subtle communication (Ogden, 1996). In addition, pride in deaf culture was

Sign language

- Is a loose collection of pantomime-like gestures for rudimentary communication
- Is universal
- Is a collection of gestures representing words of spoken language
- Cannot convey the subtleties and complex meanings of spoken language.

Figure 1. Myths and Misconceptions About Sign Language

Note. Based on information from Hickok et al., 2002.

at an all-time high after the "Gallaudet Revolution" propelled the naming of the first deaf president, Irving King Jordan, to Gallaudet University in 1988 (Lane, Hoffmeister, & Bahan, 1996). These factors helped me to make decisions based on what I thought was the most effective route to my son's development. I reasoned that he could not learn to hear, but I could learn to sign. Giving him access to language visually paved the way for him to learn English and then to learn everything else. In trying not to miss any potential channel for learning, we capitalized on my son's residual hearing and he got hearing aids, auditory training, and speech therapy, too. Most importantly, we gathered around us a supportive family of deaf friends who could show my son that it is possible to grow up deaf and have a full life—that "the deaf can do anything except hear" (I.K. Jordan, personal communication, March 16, 2004).

The truth is that while I was struggling with decisions about his education, language, and communication, my son was becoming one of my own best teachers. Now a young man of 18, he has taught me about the resilience of the human spirit, about how deeply encoded is the human hunger for communication, and about the painful reality of injustices and stigma for people in a minority. He also has taught me that living life differently does not mean living without fun and laughter, everyday garden-variety problems, the usual losses in life, and a healthy dose of adolescent attitude! I have learned that a child's life cannot not be lived as a tragedy, or it is no life at all. I have learned that living with deafness is different, but it is a difference that can be accommodated. And sometimes, it has even been a gift. Part of the gift, I believe, is what this experience has brought to me as a nurse. The loss of my healthy and perfect baby boy was a core level loss, but accepting it gave me a sense of focus.

- The pain of questioning why this happened to my son gave me a new perspective on parents' perceptions of the cause of their child's cancer and led me to consider patients' and families' search for meaning after diagnosis.
- Making difficult decisions under profound emotional turmoil gave me a new perspective on the decision making we expect from patients and families.
- Advocating for my son's needs in various healthcare settings and acting as his interpreter sharpened my interest in how we explain complicated diagnosis and treatment information and obtain informed consent, and deepened my passion for developing services that meet patients' and families' psychosocial needs.
- Serving as an occasional sign language interpreter for patients and parents in my hospital reinforced my empathy for the patients and families who live with the particular vulnerability of being dependent on healthcare providers who do not share their language or culture.

My experience with deafness has helped me see the world, especially language and communication, with new eyes. With this article, I hope to remind you of the power of language as potentially healing or toxic in the practice of oncology nursing. But before we can consider how we use spoken, written, and nonverbal language to communicate, we need to look at what science is learning about the human capacity for language.

The Meaning of Language

When I first took my son to visit a Montessori preschool for deaf children, I was struck by a teacher's comment that his most pressing need was to develop language. I am sure I

looked puzzled because she went on to say that she did not mean he needed to develop speech—he needed language. The origin of the word language illustrates why language and speech are often thought of as equivalent or overlapping. The very word language comes from the French root *langue*, itself a relative of the Latin word *lingua*, meaning tongue. Language is defined as “the words, their pronunciation, and the methods of combining them [that are] used and understood by a community” (Merriam-Webster Online Dictionary, 2004a). Further, language is “a systematic means of communicating ideas or feelings by the use of conventionalized signs, sounds, gestures, or marks having understood meanings” (Merriam-Webster Online Dictionary, 2004a). It is fascinating, indeed, that to define “language” requires . . . language. That we can talk about what language means is itself a distinguishing human characteristic.

Language Is Uniquely Human

Language connects us as members of a community into an information-sharing network (Pinker, 1994). Language enables us to pool knowledge and allows us to communicate with others “who are beyond the reach of our voices, both in space and in time” so that we do not need to rediscover what others have already discovered, making progress possible (Hayakawa & Hayakawa, 1990, p. 6). According to S.I. Hayakawa in the classic book, *Language in Thought and Action*, all the coordination needed for society to function is achieved by language or it is not achieved at all.

Although other species communicate, they do not use language in the same way that people do. Many animals and insects can communicate about things in their immediate environment (e.g., when bees signal other bees about where to find honey) or convey simple preprogrammed information, but there is a vast difference in the language ability of human beings and that of other animals in terms of complexity, subtlety, flexibility, and capacity for limitless expressive power (Hauser, Chomsky, & Fitch, 2002; McWhorter, 2001). If we tell our dog that she can have a bone tomorrow, poor Fang will sit there and drool because although she recognizes the word “bone,” she cannot appreciate that the bone will be hers in the future. In contrast, human beings can communicate abstract concepts and use language to talk about past and future events. Unlike our primate relatives, human beings are capable of vocal imitation and our children acquire immense vocabularies seemingly effortlessly early in life. Even though our children are exposed to a limited number of sentences in their language, they can construct a wide variety of new sentences (Hauser et al.). And only humans can lose one modality (e.g., hearing) and make up for the deficit by communicating with complete competence in a different modality (such as signing) (Hauser et al.).

Do you know the story of Helen Keller? Born in 1880, Helen was left both deaf and blind by a febrile illness before her second birthday. Language was lost to her until a teacher named Annie Sullivan transformed her life by finger-spelling words into her hand. Keller (2003) called this discovery her soul’s sudden awakening.

Language is so fundamental to our being that it is hardly possible to imagine life without it. It is so tightly woven into our human experience that anywhere on earth where two or more people gather together they likely will be communicating in some way (Pinker, 1994). In fact, if there is no one around to talk to, people will talk to their pets, their plants, or

themselves. The physician and writer Lewis Thomas (1990) once observed

. . . the gift of language is the single human trait that marks us . . . setting us apart from the rest of life. Language is like nest building or hive making, the universal and biologically specific activity of human beings. We engage in it communally, compulsively, and automatically. We cannot be human without it; if we were to be separated from it our minds would die, as surely as bees lost from the hive (p. 68).

The Evolution of Language

Our earliest ancestors did not have the gift of language. Roughly 50,000–200,000 years ago, something dramatic happened: The human brain increased in weight by about 54%, with much of this increase occurring in the cortex, especially in those areas implicated in the perception and production of speech (Percy, 1991). We do not know why this happened or whether it was a gradual or sudden change. Maybe it did not even occur for the purpose of language. Mutations may have given a survival advantage to individuals with the propensity for language. From the original protolanguage, approximately 6,000 languages have evolved (McWhorter, 2001). A surprising feature of human language is that it is sophisticated across all cultures. Languages in remote and primitive cultures are no less complex, and may be more so, than the major languages with which we are most familiar (McWhorter).

A language in use is alive. Words are evolving and changing meaning, new expressions are being incorporated, and seldom-used words are withering and disappearing from use. Everything about language is changeable, including the actual sound of words. Languages mix and borrow from each other; in fact, 99% of the words in English today are borrowed from other languages (McWhorter, 2001).

English is fully alive with new words constantly being added, some imported from other languages, some newly created (neologisms), and some older words being reinvigorated with new meanings. Several thousand new words and meanings were added to the most recent editions of the *Oxford English Dictionary* and the *Merriam-Webster Collegiate® Dictionary*. Some of these are Botox, chat rooms, dot-commer, fashionista, Frankenfood, identity theft, Taliban, wannabe, and Viagra (Hoge, 2002; Merriam-Webster Collegiate.com, 2004). Almost certainly we can think of others that will be added to future editions: spider hole and perhaps even wardrobe malfunction. We have examples of evolution in the language of nursing, too. Once upon a time, “capping” meant a quaint candlelit ceremony where novice nurses received their school’s cap, usually while reciting the Nightingale pledge; now we hear capping used in reference to census management when there are not enough beds or nurses to admit patients to the hospital, or when enrollment is capped for healthcare programs like Medicaid.

English may be permanently affected by the abbreviated instant messaging vocabulary of “g2g” (got to go) and “POS” (parent over shoulder). This is a language we adults may not be using but one that our children have already mastered (Warner, 2003). Scientists are contributing to language change, too. Not all scientific language is serious and boring; scientists express a sense of humor in the names they give to

newly discovered species, genes, and molecules. Scientists who study fruit fly genes have been quite inventive, with names such as Tinman (mutants with no hearts), Ken and Barbie (mutations that result in flies without external genitalia), and Cheap Date (mutants that are especially sensitive to alcohol) (Flynome, 2004). In addition, the puberty gene has been dubbed Harry Potter (Maugh, 2002). But while all this tongue-in-cheek fun has been going on, some biologists have been pushing to bring order out of the chaos by setting up standard systems for naming, at least partly because of the need to search and find information within and between databases that catalog genes (Pearson, 2002, 2003; White, Maltais, & Nebert, 2001). In nursing, too, organizations are working to standardize language to make it possible to mine data to show how our unique function relates to outcomes (Simpson, 2003a, 2003b).

In contrast to living languages, it is estimated that 90% of the world's languages are dying or endangered (Krauss et al., 1992). Just as we are losing biologic species at an alarming rate, most of the languages that now exist will very likely become extinct within this century (McWhorter, 2001). The definition of a healthy language is one that acquires new speakers (Ostler, 2000), but many languages are no longer being learned by children. James Matisoff, a specialist in rare Asian languages, noted, "Language is the most important element in the culture of a community. When it dies, you lose the special knowledge of that culture and a unique window on the world" (Gibbs, 2002, p. 80). Thus, we could lose opportunities to learn more about how languages evolved, about how the mixture of tongues reflects the migration of people, and about what aspects of language are innate versus acquired (Gibbs). Fortunately, there are projects under way to preserve indigenous languages. One example is the Rosetta Project (2003), "a global collaboration of language specialists and native speakers working to develop a contemporary counterpart of the historic Rosetta stone" on a disk that can be used for linguistic research and education (Singer, 2002).

Unlocking the Black Box

We know language is important to us as human beings, but how the brain understands and produces language has been a great mystery. Linguists have long debated whether the elements of language are universal and hardwired into our brains or acquired through our social interactions (Whitfield, 2001).

The famous (and controversial) linguist Noam Chomsky referred to this puzzle as a black box he labeled the "language acquisition device," whose contents were unknown (MacFarquhar, 2003; Percy, 1954). Now we have new tools—functional magnetic resonance imaging and positron emission tomography scans—for exploring that black box. With these tools, we are learning more about all language by studying deaf people who use sign language.

The brain's left hemisphere has been linked with speech production and comprehension since the work of Broca and Wernicke in the 19th century (Hickok, Bellugi, & Klima, 2002). Patients with damage to what became known as Broca's area have difficulty with speech production, and patients with damage to the area named for Wernicke have difficulty understanding speech. The right hemisphere of the brain was understood to be involved with spatial perception,

so we might expect that American Sign Language, produced by the hands and perceived by the eyes, would be based in the right hemisphere, but that is not exactly the case. In studies of brain-damaged and neurologically intact signers, researchers have shown that although the right hemisphere has some role in sign language processing, the left hemisphere is as critical for sign language as it is for spoken language (Emmory, 2002; Hickok et al.; Klima & Bellugi, 1979; Petitto, Holowka, Sergio, & Ostry, 2000). People do seem to be hardwired for language.

How infants learn language is another part of the mystery. Scientists have wanted to know whether baby babbling is a building block for human speech. Most parents would say so. Recent studies of babies born to deaf parents have shown that they babble in sign at the same developmental milestone that babies babble in sounds and that this is controlled by the left hemisphere (Holowka & Petitto, 2002; Petitto et al., 2001). This work tells us that the communication centers of the brain are among the first neural structures to mature (Hotz, 2002). We are born to communicate.

The Language of Genes and the Genes of Language

The science of language is evolving, and a fairly recent trend is cross talk between biology and linguistics. For some time, scientists have used imagery about the language of DNA and called the human genome the book of life or an "autobiography of a species in 23 chapters" (Pollock, 1994; Ridley, 1999). Now, linguistics is borrowing methods from genetics to estimate the age of a language's roots (Whitfield, 2003). And the reverse is also true: Analytic methods and ways of thinking used in linguistics are being applied to RNA, proteins, and genes (Searls, 2002, 2003). According to Searls (2002), further interweaving of linguistics and biology ". . . will be instrumental in extending our understanding of the language of life" (p. 211).

In addition, the first gene to be definitively linked to language has been found. This gene, called FOXP2, is on chromosome seven. Scientists localized the gene after studying several generations of a family that had problems controlling their lips and tongue, forming words, and using and understanding grammar. With data from the Human Genome Project and an unrelated boy with similar difficulties, they were able to pinpoint this gene (Lai, Fisher, Hurst, Vargha-Khadem, & Monaco, 2001). Two functional copies of the gene are needed for normal speech. Genes similar to FOXP2 are present in animals ranging from mice to orangutans to chimps and have changed very little in 70 million years of evolution. A mutation of two amino acids occurred in the human version about the same time that modern humans emerged (Enard et al., 2002). The gene switches other genes on and off and could be the first glimpse of a very complex system involving numerous genes working to influence our linguistic ability (Whitfield, 2001).

The challenge ahead is interdisciplinary collaboration to develop a unified theory of language that draws on the expertise of linguists, biologists, geneticists, psychologists, and anthropologists, among others (Hauser et al., 2002). Clearly, we do not need a new science of language to communicate effectively with our patients and their families, but the spectacular progress in understanding the human gift of language at the anatomic and molecular level underscores what an amazing and essential ability it is. Now we can consider how we put language to use.

The Language of Meaning

A long time ago, the mother of a child with cancer told me that her most vivid recollection from the time of diagnosis was of standing at the window of her daughter's hospital room at night, watching the moon and stars above and the headlights of the traffic below. She said her overwhelming feeling was that she and her family had somehow been cut off from the rest of the normal world. They were on one side of that window and everyone and everything else was on the other side. Her world had tilted on its axis, and it never really went back to where it had been. When people find themselves in this strange and parallel universe, we are often the ones they turn to as they try to grasp the meaning in the scary language they hear. What they hear a lot is language filled with metaphors.

Metaphors

The word metaphor comes from ancient words meaning to transfer or carry across. Metaphors are words or phrases that denote one thing but are used for another to suggest a similarity between them (Merriam-Webster Online Dictionary, 2004b). Describing the human genome as the book of life is a strong and evocative metaphor, and when it was first used, it opened up a whole new way of looking at things. Another is the metaphor of cancer as a journey that was so movingly described in Ellyn Bushkin's (1993) memorable Flaherty lecture, "Signposts of Survivorship." That image of cancer as a journey also did what a metaphor should: It created a new perspective for us. The metaphors that people choose tell us something about how they view the world. Metaphors define and reflect deeply entrenched cultural understandings (Arroliga, Newman, Longworth, & Stoller, 2002). Metaphors can be good things: They enliven ordinary language, encourage interpretation, and give maximum meaning with a minimum of words (Online Writing Lab, 2004).

There is a dark side to metaphors, too. When people want to describe something awful, the metaphor of cancer is often invoked. In 1977, Susan Sontag wrote the classic book called *Illness as Metaphor*. Confronting cancer herself at the time, she talked about the many stigmatizing metaphors linked with cancer. The word cancer is used as a metaphor for death and hopelessness, as well as for something ugly, unchecked, evil, corrupt, immoral, ferociously energetic, and sometimes—even today—possibly contagious. Sontag realized that "any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance" (p. 58). We know that patients with cancer and parents of children with cancer develop their own private scenarios linking the cancer diagnosis to things they did, things they did not do, or significant life events (Mayer, 1998; Ruccione, Waskerwitz, Buckley, Perin, & Hammond, 1994). For example, one young mother told us that she was under a lot of stress in an abusive marriage while she was pregnant, and she firmly believed that was the reason her daughter developed leukemia. Another parent attributed her son's tumor to the fact that she did not breast-feed him. Even as treatment has improved and causality is being better illuminated, cancer metaphors affect people's causal attributions. In addition, because cancer metaphors are powerful influences on what people believe, they may affect what they do about seeking medical attention and how they make their treatment decisions.

This was very much in my mind in the summer of 2000 when my father died a shockingly short time after being diagnosed with lung cancer. He had been one of those young World War II soldiers who smoked the cigarettes the Army gave him in his rations and continued to smoke until he had an abdominal aneurysm when he was 60. Eighteen years after that, he presented with what first appeared to be a stroke but was actually a metastasis in the language center near the motor strip in his brain. My father had experienced increasing problems with his gait and balance during the six months or so before his brain metastasis was discovered. When we talked, he attributed these difficulties to his two previous strokes. Yet his private actions spoke much louder than his words. He was an engineer, disciplined and well organized. After he died, we found in his home office—a room he called his command center—the daily records he made of his deteriorating handwriting: It was, in effect, a meticulous flowchart of disease progression that was heartbreaking in its objectivity and precision. And there was clear evidence of his efforts to get his affairs in order. He knew that something was very seriously wrong, but he did not name it or actively seek care until it was too late to do anything else. I wondered how much the common metaphors of cancer contributed to his passivity and perhaps to feelings that this was a punishment he deserved for smoking cigarettes. Of course, I will never know the answer. But I think it is helpful for us to be more aware of cancer metaphors and how broadly applied, unconscious, and pervasive they may be for our patients and their families.

And what about our own attitudes and actions? Are we affected by cancer metaphors? I had many concerns about my dad's care in the small community hospital where he was admitted. I do not mean sophisticated oncology nursing concerns; my greatest worries were about basic needs, his safety and comfort. When I arrived in his hospital room, this brilliant, funny, and articulate man was unable to speak clearly without huge effort. His left arm was limp from his strokes, and his right arm had become useless because of the brain metastasis. Although he could nod his head in response to questions, none of his nurses thought about improvising a simple communication system for him to express his needs. No one had asked him what he would prefer to eat or drink or offered to brush his teeth. When doctors made their rounds, they talked to me or other family members, ignoring him even though he was alert and aware. Certainly, I had questions about competence and staffing, and more than a couple of heated conversations with nurse managers and doctors about his care, but I did wonder whether his care was less humane and compassionate than he deserved because the staff, however unconsciously, thought he had brought this on himself. I was troubled by the feeling that they could not see the person beneath the metaphor. The oncology nurses I know are the most loving and generous caregivers in the world, but that does not mean we can shy away from a close look at the metaphors that influence us. They may be affecting the care we give in subtle but important ways.

Not only is cancer used as a metaphor for terrible things, but metaphors are used in cancer care, especially military metaphors. That has been true since President Nixon declared the war on cancer when the National Cancer Act was signed in 1971 (Surveillance, Epidemiology and End Results Program, 2004). We have all heard the language (see Figure 2). It has been used to garner funding and resources for research and

• Advanced	• On the front lines
• Armies of invading cells	• Post-traumatic stress disorder (battle fatigue)
• Attack	• Renegade cells
• Battle against	• Salvage
• Battlefield	• Staging
• Cell-kill ratios	• Subterfuge
• Conquered	• Target and control
• Defensive medicine	• Therapeutic armamentarium
• Dropping the bomb (giving the diagnosis)	• Treatment failure
• Enemy	• Treatment regimen
• Heroic treatment	• Triage (or telephone triage)
• In the trenches	• Victim
• Invasive	• Victory
• Infiltrating	• War on cancer
• Killer cells	• Won or lost
• Magic bullet	• Related: surgeon general, house officers, doctors' orders, operating theatre
• Marshall resources	
• Mutinous cells	

Figure 2. War of the Words: Military Language in Oncology

treatment, and it is nearly impossible to find media coverage of oncology issues that does not refer to the cancer war (Gordon, 1992).

The problem is that war metaphors can backfire on individual patients and their caregivers. Military language implies that “good” patients battle their cancer and win. What does that say about people whose disease does not go into remission or if there is a relapse or recurrence? If we say they have lost the battle, we imply that they were responsible to win it. How many times do you still hear people say, “The patient failed that therapy”? Because of war metaphors, patients may interpret treatment failures as reflections of their own personal inadequacies (Parsonnet & Altilio, 1997). Just when patients need all of their resources, they may be confined to a set of expectations that is narrow and confusing, and that they somehow did not have the right stuff, the positive attitude, and the will to fight.

By focusing on the medical battlefield of research laboratories and high-tech treatment modalities, war metaphors also tend to discount the effort nurses and other team members make in helping patients and families deal with the day-to-day psychosocial and health-related consequences of the disease (Gordon, 1992). How often do you see a story about intelligent and arduous oncology nursing care in your local newspaper or on television? It is rare because we do not fit the war metaphor. The all-or-nothing pursuit of total victory defined as total cure misses the mark of what we know as the continuum of care for all people living with cancer, whether newly diagnosed, on active treatment, in survivorship mode, or at the end of life.

When it comes to war metaphors, the language we use in talking about cancer can be demoralizing, isolating, and limiting for all of us. By contrast, the language of the newer biology-based treatment approaches seems much gentler, almost musical, and reminiscent of nature (see Figure 3). There are pathways and islands; things move upstream or downstream; there is expression (or overexpression), enhancement, inclusion, tolerance, transformation, amplification or inhibition; and there can be fusion, but there are also protein chaperones. This language reflects strikingly different metaphors.

Some researchers and commentators are studying the value of metaphors we and other members of the team use to talk about medical conditions, health care, and nursing research (Annas, 1995; Arroliga et al., 2002; Hodgkin, 1985; Kangas, Warren, & Byrne, 1998; Olweny, 1997; Shafer, 1995; Spiro, 1990). Other researchers are focusing on the metaphors that patients themselves use to talk about their experience (Kelly, 1997; Mabeck & Oleson, 1997; Skott, 2002). If we can learn the metaphors that patients use as they tell their own stories, we can better tailor our explanations of disease and treatment. Because one size does not fit all, it is worth remembering that there will be patients for whom a war metaphor is useful. We just need to know who those patients are. It would help us to have a good mental file of metaphors that have been shown to be effective and evidence based to communicate complex clinical concepts to patients and families.

Because metaphors are so closely tied to culture, we need to include choices that can be matched to a patient's cultural background. I remember, for example, a very young couple that had just arrived in Los Angeles after making an arduous and dangerous trip, much of it on foot, from Central America. When their daughter became sick on the journey, they brought her to the emergency room and, from there, she came to us. After the bone marrow biopsy showed acute myelogenous leukemia, the doctor sat down with them. She had a daunting task ahead: to explain the disease, the induction therapy, the possible side effects, and the bone marrow transplant to come. They spoke no English, and Spanish was not their first language. They were indigenous people from a very primitive farming village, and they had little or no schooling. Step by step, the doctor explained everything (through an interpreter) in terms of a growing or farming metaphor: the weeds in the garden that needed to be removed, the new seeds that would be planted, and the healthy garden that would grow. She chose a metaphor that was entirely in context for these young parents and helped them begin to understand what was happening in this strange and frightening place. Adopting a conscious and conscientious use of metaphors can improve our communication with patients and families. This is an exciting area for further research.

Talking Heads

Of all the communication tools we have at our disposal, the spoken word is used in almost every patient encounter, and it can significantly affect patient care outcomes (Frazier, 2001).

• Amplification or inhibition	• Inclusion
• Complement	• Integration
• Conversion	• Islands
• Coupling	• Linkage
• Culture	• Mediated transport
• Enhancement	• Neighbor restoration
• Equilibrium	• Pathways
• Expression or overexpression	• Protective antigen
• Fidelity	• Protein chaperones
• Fusion	• Silent allele
• Host	• Sensitive strain
• Housekeeping genes	• Tolerance
• Immortal	• Transformation
	• Upstream or downstream

Figure 3. Living Naturally: The Language of Biology

Because most patients do not speak “medicalese,” misunderstandings are inevitable. For example, anywhere else but in the pathology laboratory or the radiology suite, positive means good. It is no surprise that patients can be confused when we talk about positive findings on x-rays or positive nodes as bad news, but then we say there is a positive response to treatment and that is good news. In fact, according to a recent study, a substantial proportion of the lay public would not understand much of what an oncologist tells them (Shilling, Jenkins, & Fallowfield, 2003). The researchers found that only one-third to one-half of the study participants understood the meaning of common oncologic words such as “metastasis,” “remission,” and “tumor progression.” And we see everyday evidence that euphemisms for cancer such as “abnormal cell,” “spots,” or “lesions” can leave patients unsure of their condition. Such euphemisms, although they are meant to soften the blow, can have the unintended effect of either alarming or falsely reassuring patients.

Euphemisms and vagueness are reflected in a real fear many healthcare providers still have of using the “D” word. Last summer, a lifelong friend died about six months after being diagnosed with metastatic pancreatic cancer. She sustained hope of a cure until almost the very end, bolstered by reassurances from her oncologist that there was “something else” to try if a given chemotherapy regimen lost effectiveness. She finally asked her doctor point-blank whether she would die from her cancer and, when he answered yes, she went to bed, turned her face to the wall, and died two days later. Would things have been better for her if the “D” word had been used earlier? In the delicate dance of communication between patient and physician, who was taking cues from whom? Ultimately, she died a peaceful death with hospice support, but I cannot help but believe that her quality of life in her final months would have been better if a good death had been a goal, discussed and shared from the beginning; if she had been asked how she felt and what she wanted; and if questions had been framed in such a way that she would not have been misled or coerced (Meyer, 1992). But the truth is, we still do not have adequate language to deal with death and pain. And we will not, until we have learned this language from our patients and their stories (Albarrañ, 2002; Duggleby, 2002; Pembroke, 2003).

There are other ways that medicalese can hurt. Words can be insulting, patronizing, demeaning, sexist, or alienating. Of course, that is not unique to oncology. Think about common medical language such as the “patient denies a history of . . .” or the “patient complains of. . .” These phrases serve as medical shorthand and unite us by virtue of shared language, but they also may subtly convey a connotation that the patient is a liar or a whiner (Campo, 2003; Foreman, 2004). How about “incompetent cervix” (with no equivalent male term) or “elderly primip”? Or how about “speech pathologist”? That certainly sent a message to me that hopes of normality for my deaf son’s future communication were dim.

Think about other hurtful or degrading words and phrases in everyday use. Consider “doctor’s orders.” Rethinking the language and intent of that label, two nurses recently wrote an opinion article advocating the change of “doctor’s orders” to “requests for services” (Kovach & Morgan, 2003). They argued that “doctor’s orders” implies an outdated power differential between physicians and nurses and ignores other healthcare professionals who use this section of the medical

record. Similarly, have you ever heard yourself described as Dr. _____’s nurse? That is a phrase you would never hear in reverse. The possessive terminology reflects a subordination that is truly antiquated (Dracup & Bryan-Brown, 2002).

An example of how thoughtless speech can be less than helpful and possibly injurious is found in a haunting story that was published in *The New Yorker* (Moore, 1997). Titled “People Like That Are the Only People Here,” the story is fictional but it rings true. Early in the story, a mother waits for the results of an ultrasound for what will turn out to be a Wilms tumor in her baby boy. The radiologist and surgeon talk with her, and the reader is privy to the mother’s inner thoughts, her razor-sharp observations, her dark humor, and her terror. There is nothing remotely two way or truly supportive about this mother’s first communication with her baby’s doctors.

Communicating bad news is stressful for both patients and providers. Done well, it can assist understanding, acceptance, and adjustment; done badly, it can cause confusion, long-lasting distress, and resentment (Fallowfield & Jenkins, 2004). Most of us who have received bad news about a child’s disability or a cancer diagnosis have strong memories of where and how we were given the news. Some people call these “flashbulb memories” because they seem crystal clear and permanently etched, but perhaps it is just that we revisit and reinforce them as we try to make sense out of the bad news over time. And if some details of the event fade, what stands out in sharp relief is how well or how poorly the news was given.

Not everyone is skilled at communicating bad news. Yet we have all seen that some people give bad news better than others. Ideally, the information should be delivered in a quiet, private, and comfortable setting; sufficient time should be set aside to communicate the information, allow for questions, and express emotions; bad news should be given in person; the person should be forewarned that bad news is coming; what patients or families already know should be explored so information can be tailored; the provider should have up-to-date and accurate information; and some measure of hope should be conveyed (Baile et al., 1997; Girgis & Sanson-Fisher, 1995, 1998; Parker et al., 2001; Ptacek & Eberhardt, 1996; Rabow & McPhee, 1999; Scope, 2003).

Good communication skills can be learned. Many training courses and guidelines on breaking bad news are available now, with the best combining information, opportunities for practice, and time to explore feelings evoked by communicating about difficult issues (Fallowfield & Jenkins, 2004). Fallowfield, a nurse before becoming an experimental psychologist and now a pioneer in teaching communication skills, has made the point that perhaps too much emphasis is placed on the communication of bad news by any one individual. We need to think about multidisciplinary team approaches so that each team member knows his or her own communication role as well as what and how others have communicated any bad news.

Advise and Consent

For parents of children with cancer, the next topic of conversation after learning the diagnostic bad news is likely to be whether they will consent to their child’s participation in a clinical trial. Over the years, numerous studies have shown that parents may have little recall or understanding of the

protocol to which they have consented (Kodish et al., 1998, 2004; Kupst, Patenaude, Walco, & Sterling, 2003; Levi, Marsick, Drotar, & Kodish, 2000; Ruccione, Kramer, Moore, & Perin, 1991; Simon et al., 2001; Wiley et al., 1999). People are in a state of extraordinary emotional distress about the diagnosis and what it may mean. They are hearing unfamiliar medical and research language. They often feel a sense of time pressure. The topics that have to be covered to meet regulatory requirements are many and they are complicated. As one parent described it, "At that point, I could not focus on a word. I couldn't function at all" (Levi et al., p. 8). Certainly this happens with adult patients, too. After a consent conference, what nurse has not been asked to explain at least some of what the doctor said?

We have known for a long time that the "see one, do one" model of medical education is not an ideal way to teach new oncologists how to explain a clinical trial. It is good to be able to share that we are doing something to improve the consent process through a line of nursing and multidisciplinary communication research whose roots go back about 20 years (Kodish et al., 2004; Ruccione et al., 1991; Wiley et al., 1999). This is work that has tapped into what clinicians and parents tell us could be improved; we have audiotaped consent conferences and analyzed the transcripts. We interviewed parents before and after the consent conference and used focus groups to help guide us.

We recently completed a multisite study, led by Eric Kodish, MD, and funded by the National Cancer Institute, of informed consent for childhood leukemia randomized clinical trials (Kodish et al., 2004). Not surprisingly, we found a discrepancy between what was said and what was heard. Although 83% of physicians explained randomization, fully half of the parents did not understand this key aspect of their decision. Discussion of specific clinical trial details and the presence of a nurse during the conference were associated with better understanding. Now we have begun a new study, in collaboration with Kodish, that will test two interventions based on these findings. One is a physician-directed intervention based on teaching improved management of the consent conference. The other is a parent-directed intervention based on an anticipatory guidance model implemented by nurses. We want to determine whether nurses can teach and support parents to be active listeners, note takers, and question askers in the consent conference because these behaviors are associated with better understanding (Roter, 1977). Lessons learned from this work also may apply to adult patients with cancer.

Communicating With Children and Adolescents

The developmental stage has everything to do with how we talk with children and adolescents. Not long ago, a seven-year-old patient crafted a set of commonsense rules for adults who work in hospitals so they would know how to communicate with children (McIntyre, 2002). Her advice was: (a) don't surprise me, (b) always think of a less painful way of doing things, (c) be honest, (d) ask my permission before you put any part of your body on mine, (e) get down on my level, (f) try to keep the doctors and nurses who come into my room the same, (g) try not to wake me up so many times, (h) dress normal, (i) get cable, and (j) stop saying it's no "big deal."

In a little more than my professional lifetime, we have moved from not telling children their diagnosis to a philoso-

phy of open communication tailored to the age and developmental level of the child, prior experience with illness and treatment, and the child's knowledge of cancer. We have learned that discussion with children needs to be initiated periodically because a child will understand different aspects of the information at different times and their understanding will change according to their medical and emotional realities. We also have learned that some of the most important conversations with children happen spontaneously as part of the fabric of a day. A story that illustrates this is from a classic editorial written by Hinds (1994), telling about her conversation with a seven-year-old little girl who would die of leukemia. They were coloring together, sharing a box of crayons.

"Pass me the yellow," she said. I did. "Do you think I'm going to die?" she asked. I swallowed. "This is serious," I said. "But I'm concentrating on you getting well again." "Pass me the red," she commanded. I did. "I figured out it's serious," she said. "And I'm thinking the same thing you are. But if I did, will you be there?" "Yes, for sure," I said. "O.K., good," she said. "Pass me the blue" (p. 43).

For me, this story illustrates a beautiful nursing intervention, using language and self to reassure a child about the one thing that most mattered to her. Surely this happens with adults, too, when we allow it.

We know that adolescents speak their own language (and this is true whether they are deaf or hearing). Yet it seems to me that adults can be hopelessly unhip and still communicate well with adolescents if they are honest, authentic, have a sense of humor, and treat the adolescent with respect. My colleagues who run the teen support group (Teen Impact) at Childrens Hospital Los Angeles have taught me that communicating with teens means leaving your ego at the door, that humor goes a long way, and to remember that they are normal teenagers in an abnormal situation (A. Kuperberg, personal communication, January 15, 2004).

Teenagers experience tremendous disruption in their lives when they are diagnosed with cancer. Giving them ways to communicate with other teens with cancer can be very helpful. I remember one teenage girl, a patient at another hospital, who had been diagnosed just recently and was starting treatment. Our Teen Impact staff reached out to her and made her feel comfortable enough that she accepted their invitation to come to a holiday party. When she arrived, she slowly walked into the room and took it all in. A little stunned, she turned to one of the social workers and said, "My God, I thought I was the only one."

Fortunately, teen communication and connection can also happen now with two Web sites: Planet Cancer (www.planetcancer.org) and the GroupLoop (www.grouploop.org). Perfectly pitched for older adolescents and young adults, Planet Cancer offers moderated forums for people to post their thoughts and concerns, essays and articles, tips and advice, and humor—lots of it. There are top 10 lists (e.g., ways to disrupt a waiting room, ways to break the ice with your nurse, benefits of a prosthetic limb) and a comic strip called "Brain Tumor Man." The GroupLoop has online support groups, discussion boards, an "info zone" covering various topics, a section on school, and a featured teen with his or her story. The section on relaxation offers links to relaxation audio files. Web site technology is offering us new ways to enable teenagers to communicate, learn, and find support.

Lost in Translation

Every day I see them streaming into the hospital: the young mothers with several children in tow, eyes downcast, trying to corral the children and find their way, not always able to read the directional signs in English or Spanish, shyly smiling, and obviously relieved when someone shows them which way to go. At my hospital, those who speak no English or have limited English proficiency make up 60%–70% of our patient population.

The role of interpreters in medical settings is becoming essential with increasing numbers of non-English-speaking families, and not just in areas like Southern California where 224 languages are spoken and 40% of Los Angeles County residents are born in another country (Allen, 2000). The number of different languages spoken in the United States has increased dramatically since the 1970s (Perkins, Simon, Cheng, Olson, & Vera, 1998). Under the Civil Rights Act of 1964, hospitals and clinics that treat non-English-speaking patients through federal programs such as Medicaid or Medicare must provide interpreters; however, this and other federal and state laws requiring linguistic access are little known and rarely enforced (Perkins et al.).

Sometimes clinicians rely on untrained interpreters, which can result in inaccurate or “editorialized” translations. For example, the Hmong language has no word for cancer or even the concept of the disease; as a result, an inexperienced interpreter once tried to explain radiation treatment by saying, “We’re going to put a fire in you,” which the patient quite understandably refused (Morse, 2003). Clinicians may try to improvise with their own limited proficiency in the other language or by pantomiming instructions. This can result in unfortunate situations such as a child with otitis who was brought back to a pediatric oncologist at my hospital when the infection did not get better, only to find that the parents had been putting the liquid oral amoxicillin into the child’s ear instead of giving it by mouth. Children or other family members may be asked to interpret, with all the traumatic implications that can have, especially when intimate or troubling news must be given. The use of children as interpreters has happened so often that there is a name for them: language brokers. Being a language broker is a fairly common experience for children of immigrant parents and for hearing children of deaf parents, even at a very young age.

There are published guidelines for the effective choice and use of interpreters now (Flores, 2000). However, it can be nearly impossible to find a suitable interpreter when the family’s language is extremely rare. Such was the case with a four-year-old boy who came to a colleague’s bone marrow transplant unit. He was a member of a very small tribe of Inuit that lived in a village close to the Arctic Circle. One day, a team of physicians and medical students flew into the village to immunize the children and found the seriously ill child. He was transported to a medical center where he was diagnosed with acute myelogenous leukemia. He, his donor brother, and mother were sent to another center for a bone marrow transplant. This family’s village spoke a dying language, and the team looked everywhere for an interpreter. Finally, an elderly retired professor was found who knew the language. His family brought him the 50 miles or so to the hospital where he helped with interpreting and taught the team a bit about the culture. The boy had his bone marrow transplant, and his

mother settled in. She walked to the cafeteria for meals, slept in the boy’s room, and helped to care for him. When he was napping, she often sat on a bench by the elevator, watching people come and go. When the boy needed an open lung biopsy, the team was able to get the interpreter to come back for a short time, and the surgery was explained. The mother gave her consent, but as she saw the boy’s gurney being rolled onto the elevator, she began to sob. With the interpreter’s help, the mother told the team, “You would cry, too, if they put your boy into that little room that changes people” (F.M. Wiley, personal communication, January 19, 2004). There were, of course, no elevators where she came from.

In our outpatient oncology area, we pilot tested and adopted a focused delivery model of language and cultural services beginning in 1998 (Estany & Guadarrama, 2001). Using this model, we now have a full-time Spanish-speaking interpreter on site in both our ambulatory and inpatient units. The interpreter is an essential part of the team, building trust with families and conveying culturally important information to clinicians. This is a difficult role in oncology because the interpreter is so often the “voice” of bad news. Sadly, the interpreter who pioneered this role with us died unexpectedly last Christmas. This talented interpreter showed me that bilingual-bicultural interpreters can help us greatly reduce cross-cultural miscommunication. She embodied sensitivity, linguistic skill, and cultural competence. We hear a lot about developing cultural competence these days and for good reason. Culture affects clinical care because it is fundamental to health-related behavior. Guidelines and strategies for reducing cross-cultural miscommunication and achieving cultural competency are available now, and we need to incorporate them into practice (Betancourt, Green, & Carrillo, 2002; Flores, 2000; Kagawa-Singer & Kassim-Lakha, 2003; Oncology Nursing Society, 2000).

Body Language

In an open letter to clinicians, a patient who did not speak English wrote,

Even though I can’t speak or understand English . . . I do . . . understand the gentleness of your voice, the smile on your face, and the concern in your eyes. I can feel when you are in a hurry, if you’re impatient, or if you are not truly present. I know when you are having a bad day. I know when you are doing a good job with my care and when you enjoy being at work. Even though I may express my fears and concerns in different ways, I can still touch your heart and contribute to you (Gonzales, 2002, p. 47).

This patient was talking about the power of presence and the importance of nonverbal communication. This is something my deaf friends have taught me, too. It is impossible to communicate fully in sign language without facial expressions and body movement. But even when we communicate with our voices, what we say with our eyes, our faces, and our touch can convey the unspoken language of caring.

The mother of a young girl with leukemia once wrote a very moving piece about an anesthesiologist who took the time to really look at her daughter before she went into the operating room to have her port removed, noticed her fears, and transformed the experience into what she called a “gentle triumph” (Keene, 1997). In another example, when my friend was having a liver biopsy as part of her staging workup, she was

terribly frightened. She told me that while she was having the procedure, the nurse laid a hand on her arm. She asked the nurse to keep her hand there, saying it felt so comforting and warm. She overheard one of the staff commenting that each time the nurse touched her, her vital signs returned to normal. This was an effective nursing intervention through nonverbal language.

There also is language in silence. The nurse who is truly present, mindful, and listens to the patient takes in not only what is said but also what is left unspoken. We might define this mindfulness as one aspect of expert practice. On the other hand, sometimes our own silences as clinicians virtually “scream” to patients and families. In that awful waiting and wondering period when scans are being examined or laboratory reports are being interpreted, patients and families are reading every tea leaf. If it takes us longer than usual to get back to them, they may assume our silence means we have bad news that we are reluctant to share.

Accommodations for Deaf or Hard-of-Hearing Patients

When my son was in the hospital for tests or surgeries, reactions to his deafness were varied. Some people shied away from interaction, but the best smiled and used facial expressions, gestures, and body language to reassure him and make a connection with him. In their intake assessment, it was important that staff knew he was prelingually deaf, could speak and sign, and had hearing aids for both ears. Communication modes vary with the way a person is brought up as well as when they became deaf. If American Sign Language is the primary language, English will be a second language with the same challenges to communication as for any nonnative English user.

One of the things I have learned is the importance of communicating directly with the patient (age and developmental level permitting) rather than through family members. There is an implicit message that deaf individuals are not competent if the conversation goes on all around them but not with them. Your gestures and facial expressions can help to get your message across, and you will find deaf signers much more animated in conversation than hearing speakers.

We showed staff members my son’s name sign and taught them some basic signs like bathroom, hungry, and hurt. We put simple line drawings of these signs in his chart and on the wall in his room. Those who made even the smallest effort to sign won our hearts. Now that nursing units have Internet access on their computers, nurses can use sign language Web sites as resources for words and phrases in sign language. Two interesting sites to explore are Michigan State University’s American Sign Language Browser (<http://commtechlab.msu.edu/sites/aslweb/browser.htm>) and the American Sign Language University (www.lifeprint.com/asl101). There are a number of other adaptations that can help (see Figure 4). It is important to know our patients’ rights under the Americans with Disabilities Act, as well as how and when to call a professional interpreter, which is best whenever the information is vital to decision making and adherence to treatment (see Figure 5).

None of this should overshadow basic nursing care. Not too long ago I was called to do sign language interpreting for a profoundly deaf child who had just had surgery. She had pulled out her nasogastric tube, and the nurses wanted her to

- Learn which communication mode the patient prefers.
- Make every effort to communicate with the patient directly (not through family members).
- Learn whether American Sign Language is the primary language.
- Use body language and facial expressions to help convey meaning.
- Mark the call panel so staff will not answer the call light via intercom.
- For patients who sign, put the IV in the nondominant arm.
- Get the patient’s attention by gently tapping him or her or flicking the light.
- If the patient lip-reads, position yourself in good light in the patient’s line of vision (do not wear a mask).
- If the patient wears hearing aids, learn the ABCs of hearing aid care and treat them like solid gold.
- Turn on the television closed captioning.
- Provide a text telephone.
- Keep paper and pencil at the bedside.
- Use instructional videos with captioning.
- Know how to communicate via relay service telephone calls.

Figure 4. Adaptations That Can Help If Your Patient Is Deaf

understand why it needed to be put back in. When I came to her bedside, this child would not make eye contact. Without eye contact, we could not communicate. Still, I began to talk with her in sign about the cartoon on television, her room, and other things to try to connect with her, and she began to reach out to me, quite literally. She wrapped her hand around my arm and pulled me close. Her bed was wet (her nurse was beginning to change her and her linens), she was in a strange place with no family around (her mother had not arrived yet that morning), and her incision was brand new. She needed pain medication. The lesson I learned from this experience was that it was easy to miss the usual things we would assess because it was assumed that deafness was the paramount issue. But she was simply a child who was hurting.

The Written Word

For at least 5,000 years, people have been communicating in writing, from carved symbols to today’s “blogs” (i.e., Web logs). Ancient Mesopotamia, the region now covered by Iraq, is widely considered to be the birthplace of writing, although symbols carved in tortoise shells recently discovered in China may be the oldest words yet discovered (Pilcher, 2003).

As nurses, much of what we hear about words in print or on the computer screen focuses on health literacy: the ability to read, understand, and act on healthcare information. With patients being encouraged to take an active role in their own care, we put a lot of faith in written information. But health literacy can be limited by knowledge, socioeconomic factors, emotional or clinical state, or cultural background.

Call a professional interpreter when

- Discussing symptoms, history, physical examination, and medications
- Explaining treatment options, tests, surgery, and other procedures
- Providing mental health services
- Giving information about blood or organ donations
- Explaining living wills, powers of attorney, and do-not-resuscitate orders
- Discussing complex billing or insurance matters
- Teaching educational classes, such as managing the side effects of chemotherapy or radiation.

Figure 5. When to Call a Professional Interpreter

Note. Based on information from U.S. Department of Justice, 2003.

Health literacy is not a minor problem (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, 1999; American Medical Association Foundation, 2003; Institute for Safe Medication Practices, 2001; Marsa, 2000). The reality is that nearly 90 million Americans have difficulty reading bottle labels, filling out forms, or deciphering medical instructions. Almost 25% of all adult Americans read at or below a fifth-grade level, whereas medical information materials are typically written at a 10th-grade reading level or above. More than 40% of patients with chronic illness are functionally illiterate. Only half of all patients take their medications as directed (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association; American Medical Association Foundation). Low health literacy is not always readily apparent—it may be true of even the most poised and articulate patients. What is recommended now is that we assume that everyone has a literacy problem. Practices that can help include (a) offering small amounts of information at a time, (b) providing written materials at a fifth-grade reading level or lower, (c) involving patients in developing informational materials, and (d) verifying that patients understand (Institute for Safe Medication Practices).

Finally, there is a wholly different form of writing that can be therapeutic for our patients and for us: creative and personal writing. Many of us have known patients or family members who benefited from keeping a journal. There is some evidence to suggest that people who write about their most upsetting experiences not only feel better but also visit doctors less often and may even have stronger immune responses (Pennebaker & Seagal, 1999; Smyth, Stone, Hurewitz, & Kaell, 1999; Spiegel, 1999). As nurses, we understand the positive effects of storytelling (Yoder-Wise & Kowalski, 2003). Heiney (1995) taught us about that in her Flaherty lecture. Storytelling connects people, builds trust, and reduces isolation. We can often do our best teaching by sharing stories that illustrate patients' shared experiences. But I would also advocate for us to put pen to paper or fingers to the keyboard and tell our own stories.

For the past three years, my hospital has sponsored an essay contest for nurses. Many of us were surprised to realize that the challenge of writing an essay helped us come to terms with difficult experiences, better define our own perspective, and memorialize patients we cared for. In one of the essays, I wrote about a wondrous seven-year-old boy, Christopher,

who died unexpectedly during the school winter break. I described how we went to the school to help his classmates with the news. I told how the children drew pictures and wrote letters in memory of their friend. I told of my hope that what we did captured the essence of the Native American saying on his mother's calendar the day he died that "in beauty it is finished." Recently, a journal asked me to try to locate this boy's mother to ask her permission to publish the essay using Christopher's real name (Ruccione, 2004). But even without that impetus, I was already trying to find her because she and Chris had been on my mind so much since I wrote about him. Something made me try the Internet one particular evening, and—wonder of wonders—I did find her. We exchanged e-mails and after discussing it, I sent her the essay, nervous about her reaction. A few days later, I received an e-mail from her. What she said stunned me. She said, in part, "What a beautiful, moving essay. It's elegant, perfect, and true. The gift of remembrance comes in lots of forms and your timing couldn't have been better. This arrived the day after Chris would have turned 17." The universe works in remarkable ways. Perhaps if we wrote more, it would help refuel us and keep us going during the tough times. And perhaps if nurses told their stories, more people would be choosing nursing.

The Last Word

Through the thoughts shared here, I hope that I have reminded you that language is uniquely human—an amazing skill that has made civilization possible. Language is alive, ever changing, morphing, and adapting. Language is probably hardwired into our brains and encoded in our genes. Language is rich and complex whether spoken, signed, or written. Language is powerful enough to teach, forge connections, inspire, memorialize, amuse, harm, and heal. And language is our most essential tool for providing intelligent and compassionate care.

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