2010

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Recommended Citation

Parrott, R., Miller-Day, M., Dillard, J., & Peters, K. (2010). Societal, expert, and lay influences. In C. L. Gaff and C. L. Bylund (Eds.), *Family communication about genetics: Theory and Practice* (pp. 34-67). Ed(s). Clara L. Gaff and Carma L. Bylund. Oxford: Oxford University Press.

3

SOCIETAL, EXPERT, AND LAY INFLUENCES

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Families are influenced by many messages about genetics and health, which then affect communication with health-care practitioners and communication within the family. Using a discourse approach, this chapter identifies the various sources of these messages and explains the influences they might exert.

At the start of the twenty-first century, publication of a working draft of the human genome sequence appeared in special issues of the journals *Science* (February 16, 2001) and *Nature* (February 15, 2001). Most families, of course, did not read these articles, but the news coverage and fanfare with which the research was received reached anyone watching televised reports or reading newspaper or online headlines. The stories suggest promise for revolutionizing medical care and preventing disease. In reality, the results of this research are far from therapeutic. Rather, this research was only a beginning, motivating patients and their families to ask questions about the role of genetics in health, while leaving clinical and public health professionals to answer those questions. As a result, our current era of "genomic health care" includes efforts to educate and train a wide range of health-care practitioners to guide the understanding of families with genetic concerns. The time and expertise that various health-care practitioners have to bring to conversations with families vary, as does the knowledge families bring into these interactions, affecting the outcomes arising from these consultations. Thus, how will families decide whether to be tested for these genes linked to health, nutrition, and even aging? How will family members explain to one another that they need more or less of a medication than some other families because a genetic test says their make-up enables their bodies to more readily metabolize important drugs? How will they understand the validity of needing to supplement with some vitamins in excessive amounts based on having inherited mutations linked to deficits in uptake and use? Why will families even be motivated to seek testing when possible employment or insurance discrimination looms at the end of results? In this chapter, we examine the influences that are often implicitly (and only sometimes explicitly) considered as families communicate about genetics and health. We apply a multiple discourse approach [1, 2] to this analysis of communication with families about genetics and health.

What is a discourse approach? At the broadest level, the term *discourse* encompasses conversations we have, talk we overhear others having, and dialogues in decision-making bodies (e.g., government), as well as a whole spectrum of verbal, visual, and nonverbal messages coming from different sources and through different modalities. A discourse approach emphasizes that, despite this vast array of sources and content, patterns appear across texts, messages, talk, dialogue, or conversation and reflect the context in which they occur [3]. As suggested by Figure 3.1, family communication about genetics and health simultaneously reflects three discourse fields: societal, expert, and lay domains. While only one arena may be the explicit focus, acknowledging the implicit influence of all spheres may enhance understanding about what takes place when families talk about genetics among themselves and with health-care providers. Contemplating communication about genetics in families from a discourse perspective enables one to consider the bigger picture by challenging one to step back from the individual theories and research. The ability to sort through a maze of sometimes confusing, contentious, and conflicting content can be enhanced from this more macro view.

Considering the bigger picture can enhance genetic counselors' and other health-care practitioners' communication with patients in several ways. First, it can lead to a more refined understanding of a patient's perspective, an important prerequisite to patient-centered care. For instance, understanding the religious discourse of a particular faith may help the practitioner to understand why a patient is reluctant to tell her sister about a diagnosis that could lead to suggesting the use of invasive fetal therapies such as blood or stem cell transfusion, gene therapy, or surgery which would rarely be approved within their religious doctrine. Second, awareness of these discourses may assist the counselor in helping a patient to plan how she will talk to her family. For example, being aware of images related to genetic mutations presented in movies or other entertainment venues suggests a starting place to discuss the meaning and implications of inheriting a mutation. Third, awareness of discourse about insurance or employment discrimination may contribute to practitioners' efforts to explain how information about a patient's genetic

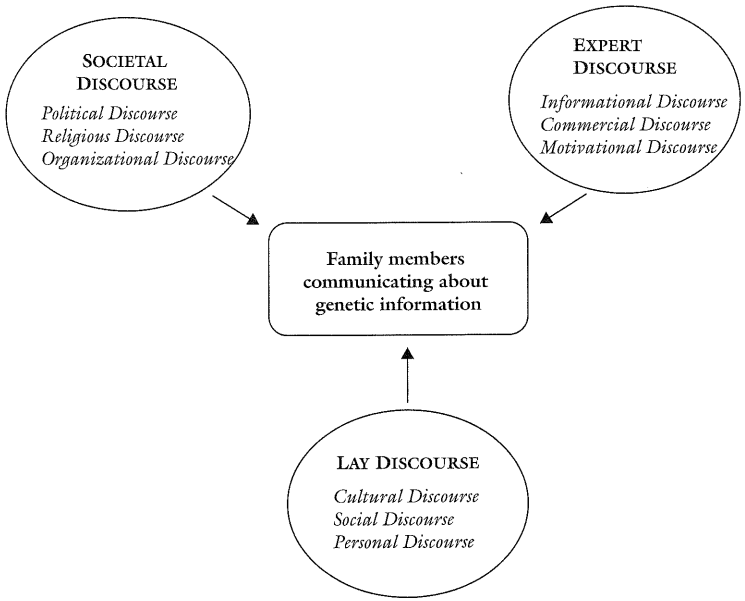

Figure 3.1 Types of discourse.

health will be safeguarded. For these and a myriad of other issues that contribute to the ways that interactions unfold for families when discussing genetics and health with counselors and other practitioners, a macro framework relating to the multiple discourses about health warrants consideration.

SOCIETAL DISCOURSE ABOUT GENETICS AND HEALTH

Societal discourse is the talk representing nations, rather than individuals, that we hear expressed in the news, that we talk about at the dinner table, and that we read about in Internet headlines. This discourse sometimes focuses on health and health care, addressing the allocation and use of a nation's resources, such as dollars for research and monies for health-care delivery. Societal discourse about health and health care is shaped by political, religious, and organizational agendas that guide decisions that lead to health knowledge and services [4]. This communication may not have anything explicitly to do with health education and everything to do with what is known about health and how this knowledge will be used to make diagnoses. Debates about what research to fund and who gets how much care at what expense is based on evidence that comes from many disciplines, including epidemiology, which provides support to determine

how many people may be affected by a condition and its consequences [5]. Societal decisions about the allocation of scarce resources are frequently guided by the numbers of persons affected by a condition or its severity. Knowledge and comprehension of the patterns of health and disease are used in formal ways to encourage decision makers (such as law makers) to manage limited health resources and deliver health services in particular ways.

For families, their own communication about genetics and health, and the communication that they encounter in public health and clinical messages, reflects research completed and research yet to be done. Thus, prior to the identification of a link between thrombosis and the Factor V Leiden mutation, health-care practitioners could not talk with accuracy to families about possible genetic predispositions to risk of forming blood clots. With research dollars allocated to understanding the role of genetics in health and the findings linking mutations in the Factor V gene to thrombosis, clinical communication can reflect this new knowledge. Public health messages may follow, as in the case of the U.S. acting Surgeon General's "call to action to prevent deep vein thrombosis and pulmonary embolism" [6]. The press release emphasized the numbers of Americans affected, "350,000 to 600,000 each year," with "at least 100,000 deaths each year," and a role for "an inherited blood clotting disorder." Families thus reflect the politics associated with genetics and health when communicating about these issues, including ethical, legal, and social effects.

Political Discourse: Government and More

> If an employer, or educator, or insurer can make the case that the "predicted" future status of their client matters, then discrimination—denial of opportunity for medical care, work, or education—can occur with impunity. Indeed, predictive genetic typing may create an underclass of individuals whose genes seem to have marked them for the nowhere track. [7] (p. 167)

Macro-level decisions linked to politics and government in society affect micro-level interactions about health, including not just what we talk about in a general way, but what we have to talk about in the first place. While doctors seek information that promotes the ability to diagnose conditions and prescribe suitable treatments, these conversations are guided by the existing state of knowledge. The knowledge base that is used to guide communication about genetic health depends fundamentally upon the origins and outcomes of debate by policy makers and funders about the status of knowledge and the need for research. That is because in the United States, France, Canada, and many other nations, political debates about whether to support some research compared to other research ultimately determines what research is funded and, thus, what knowledge will be generated and amplified.

The course of medical research toward the achievement of mapping the human genome included Mendel's discovery of the laws of heredity, identifying DNA as hereditary material, determining the structure of DNA, understanding the genetic code, developing recombinant DNA technologies, and discovering automated methods for DNA sequencing [8]. The research necessary to understand how genes and environments interact requires families to participate. Families are solicited to cooperate in giving lifestyle information, family health histories, personal medical information, *and* biological specimens [9]. Why? So that genetic databanks might be assembled with linkages to the multiple determinants of health, promoting better research and presumably the development of better treatments for many common diseases. This is largely the promise associated with an era of genomic health care in which genes have assumed a prominent role. But to achieve it, families will have to disclose information in ways like they never have before, and doing so will demand that they can trust that their participation will not be used to disadvantage them.

The study of political discourse highlights its strategic nature with links to coercion, information control, opposition and protest, as well as legitimization [10]. The implications of this reality make consideration of the role of political discourse on families' communication about genetic concerns critical. Such an analysis should address whether families feel coerced to give genetic samples, regard results linking their genetics to health status to be protected from disclosure and abuse, or feel inclined to protest the use of genetic information in some situations while supporting it in other cases. Barriers to families communicating about genetics and health often form around worries about discrimination, an arena in which government actions and policies may reduce or increase these concerns [11].

Concerns about discrimination are multifaceted [12], encompassing worries about employment and insurance, fears about reproductive rights and social standing, and anxiety that genetics will be inappropriately used in criminal investigations. Concerns that genetic testing will lead to insurance discrimination and lack of coverage pose a formidable barrier to the efficacy of the counseling process. These concerns must be addressed by societal policies, as individuals, families, and even health-care practitioners can only do as the rules prescribe that they do [13]. Insurance companies in the United Kingdom have negotiated with government to reach an agreement not to use information from genetic tests that predict disease risk when setting insurance premiums until 2011 [14]. This illustrates a core concern around this issue as genetic testing becomes more important to diagnosis and treatment. It also emphasizes the reality that these debates are linked to lobbying by health insurers and others, widening the gap between families and their ability to control or even predict how personal genetic health information may be used.

A role for government in issues linked to health broadly is often justified by reference to "safety" and "quality." These terms form core constructs in efforts to expand and contract a role for government, and therefore awareness of their use should be promoted. Personal and professional reflection on the validity of invoking these terms to justify a role for government in genetic health and health care should be fostered. While current use of these terms commonly relates to quality of services and safety of the population, any changes in the definition of these terms should be recognized and care taken to avoid an approach that veers towards eugenics where questions are raised such as: What constitutes "quality" in terms of genes? Who decides how to enforce quality control when it comes to genes? What about the safety of genetic testing? Preimplantation genetic diagnosis? Age limits? Do effects on mental health count when "safety" is being discussed?

Families may have relatively little understanding about the specifics of sociopolitical matters relating to genetics and a rather short memory relating to issues such as eugenics boards, but they still have doubts that link back to these events. Daar and Singer [15] suggest that increased understanding of human genomic variation points to a greater need to look at interpopulation differences rather than interindividual differences. In part, this focus on difference is motivated by linkages between ethnic groups and vulnerability to certain diseases. A movement toward focusing on interpopulation differences, however, when juxtaposed with historical abuses of minorities in health care and contemporary health disparities, is being resisted by many for fear that it may exacerbate discrimination of minority groups [16].

The persistent belief that genetic testing needs to have value above existing tests for such diseases as heart disease has generated efforts to categorize genetic testing [17]. This is a partial response to the reality that there is a range of genetic testing "safety" and "quality" factors that can be operationalized. For example, some tests appear to have little to no harm and much benefit aligned with them. A child's test to determine if she has a rare allele of the thiopurinemethyltransferase (TMPT) gene can predict impaired ability to metabolize mercaptopurine, a chemotherapy agent commonly used in treating acute childhood leukemia. Children who are homozygous for this gene version may benefit by having other therapies and appear to suffer little or no societal harm. On the other hand, some genetic tests, such as APOE testing in the context of dementia, have lower accuracy in predicting a phenotype and may also be of less value at a societal level [17]. Policies are needed that represent efforts to acknowledge that not all genetic testing has the same promise to yield benefits for society and families. Policies are needed that reflect the reality that some genetic testing has more threats for the violations of individual rights which, in turn, cause families anxiety and worry.

Individuals, families, and health-care practitioners can advocate on behalf of such policies. Advocacy efforts among lay members of society

who have been diagnosed with a genetic condition are too few. This is evident when science reporters seek lay quotes relating to genetics and behavior. Reporters have found activists and advocates among homosexuals who are willing to speak on the record about genetics and sexual orientation but have been unable to find advocates experiencing mental illness or diagnosed with alcoholism to speak on the record about possible genetic links to these behaviors [18]. Societal discourse framing these behaviors in ways that blame individuals or make reference to religion and God may also contribute to such reticence.

Religious Discourse: God and More

A second type of societal discourse that functions as a vital backdrop to families' reactions to communicating about genetics is religious discourse. Religious discourse relies on faith-based resources and perspectives to guide discussions and decisions about the derivation and delivery of health information and services. Faith-based positions do not have the authority associated with making laws and upholding policies relating to health. They do, however, have the power associated with invoking our conscience, our spiritual compass, and our morality. Religious discourse about health and health care may originate from personal faith, religious dogma, and spiritual beliefs and practices—partially illustrating the connectedness of religious freedom to fundamental values and decision making associated with health and health care in the U.S. [1]. Rabbis, pastors, Imams, and other religious leaders often counsel members regarding what political candidates' positions to support and how best to conserve and demonstrate regard for the sanctity of human life. These official positions may be spoken to individuals, couples, or families in religious counseling sessions, as well as from podiums, and also be posted as "rules for living" on Web sites.

Members of faith communities may perceive that the goal of promoting the sanctity of life limits interventions in which the individual appears to be "playing God." Thus, while there may be no direct awareness of doctrines denying the value of genetic testing and therapies, there may be a more broadly held doctrine that appears to deny the appropriateness of these activities. This may contribute to families' reticence to ask their faith leaders for guidance about such matters, as it may just seem so integral that asking itself is inappropriate. Faith discourse may be perceived to define defective genes as punishment for sins committed *or* as a life lesson. The former may contribute to an individual's resistance to disclose the need for care, while the latter may promote conversations with others who have similar views. Religious discourse may guide some to seek genetic testing to support the sanctity of life.

The dominant religion in the United States, Christianity, influences political discourse and decision making about health and health care at many levels. In 2001, the Evangelical Lutheran Church in America published a booklet called "Genetics!: Where Do We Stand as Christians?" It

was designed to be an adult study group guide. As such, it begins with a chapter that is a primer in genetics. The second chapter advances a deterministic view of the role of genes for health and the age of genomics. It is called "Theology for the Age of Biological Control." The chapter reflects on the historical events linked to the eugenics movement. Included is a case study of a couple that has maternal serum testing and learns that there is a possible abnormality. Amniocentesis confirms that the fetus has an extra chromosome 18, which indicates Edwards syndrome. The guide includes chapters discussing genes and human behavior, gene patenting, and genetically modified organisms as well. As such, the guide serves as a concrete example of the role of religious discourse in communicating about genetics, as it will disseminate into the families who participate in discussions using the guide.

One review compiling the survey results of responses from representatives identified to speak on behalf of 31 major religious denominations in the United States revealed much consistency in the doctrines and practices relating to prenatal genetic issues linked to prenatal diagnosis and treatment [19]. Most representatives indicated that their members were free to elect or decline ultrasound or maternal serum screening, with the latter usually being conducted in the second trimester to identify certain birth defects, including Down syndrome. For both procedures, exceptions included the Mormon Church, which indicated that the decision should be made in consultation with Church leaders, while Conservative Judaism and Reform Judaism both specify it to be approved in order to make appropriate treatment decisions. The Eckankar Church was explicit in its statement that the Church has *no* position statement about any prenatal diagnosis or treatment decision as it is viewed as an individual decision. The Evangelical Free Church of America regards both choices to be individual ones so long as they are not performed with the intent to pursue an abortion. The Orthodox Church in America's position was that members are free to choose but often reject these procedures, as they are viewed as encouraging abortion—which is not allowed. Orthodox Judaism deems that the intent of having the procedures must be considered in deciding. The Unity School of Christianity asserts that the decision to elect or decline these procedures should be based on prayer and communion with God.

The positions of the churches surveyed on invasive prenatal testing [19], which requires entry of an instrument such as a needle into the womb (e.g., CVS, amniocentesis) and carries a risk for infection, fetal damage, or miscarriage, was similar to views on ultrasound and maternal serum screening with few exceptions. An emphasis on use to save the life of the fetus was emphasized by the Evangelical Lutheran Church in America. The General Association of Regular Baptist Churches emphasized the importance of having a corrective therapy to improve the "outcome of the fetus" if testing is performed. We do not have surveys or interviews of the various church members to assess how their personal views about

what their church doctrine states align with published church dogma. Both statements reflect what may often frame a family's decision in these situations—do it if it will save the life of a fetus. There is less agreement among the doctrines relating to the use of such invasive fetal therapies as stem cell transfusion.

Faith-based doctrines influence the pursuit of medical science by taking positions on such issues as cloning or stem cell research. Religious discourse is often recorded in opposition with respect to genes and health, raising questions and challenging the science. Unfortunately, there is a tendency to pit science against religion in discourse associated with frontiers of discovery. The implicit assumption is that belief in God's role for humans denies belief in science and scientific explanations. Such simplistic conceptions have been and continue to be challenged and debated, with families sometimes caught in the middle of these debates and efforts to advance health and health care.

Organizational Discourse: Clinical and More

During the 19th and early 20th century, public health and genetics shared common ground through similar approaches to health promotion in the population. By the mid-20th century there was a division between public health and genetics, with eugenicists estranged and clinical genetics focused on single gene disorders, usually only relevant to small numbers of people. Now through a common interest in the aetiology of complex diseases such as heart disease and cancer, there is a need for people working in public health and genetics to collaborate. This is not a comfortable convergence for many, particularly those in public health. [20] (p. 894)

A third type of societal discourse in societies that affects what we know about health and our access to care occurs in and around organizations, specifically those that address the allocation and use of resources to provide clinical and public health care and services. Here, too, what health-care practitioners and patients do in relation to communicating about genetics and health is constrained by their access not only to valid tests with value added but also the availability of knowledgeable medical technicians to draw and prepare the blood for new genetic tests and skilled laboratory professionals to read and interpret the results. Payment policies also come into play. Thus, organizational discourse spans a broad array of content with consequences for families and genomic health care. These consequences often illuminate the tension between availability and affordability in promoting access to genetic health and health care. Interestingly, organizations often adopt broad practices linked to communicating about health, such as public health and clinical organizations' increasing tendency to promote the importance of knowing our "family health history." As family history "represents the contributions and interactions of unique genomic and ecologic factors that affect the metabolic profile and life course of a family and its members" [21] (p. 143), it has been progressively promoted as a tool to identify individuals with increased susceptibility to disease [22].

When it comes to the structural resources allocated to genetics and health care, the largest genetic screening program in the United States is the newborn screening program [23]. The Institute of Medicine of the National Academies of Sciences in the United States convened a study about "Educating Public Health Professionals for the 21st Century," and genomics emerged as a new area for training. The goals of training were defined as learning to apply public health science to genomics and identifying both ethical and medical issues associated with genetic testing as part of public health programs [24]. The strategic aims aligned with these goals include being able to use genomics to attain public health goals. This implicitly means communicating about genes and health with families who will be the targets of new science and products and businesses that emerge around genomics. The latter includes an array of genetic testing services, some already being offered online and through a myriad of other direct-to-consumer (DTC) advertisements in the United States, as we discuss later in this chapter.

Newborn screening programs have in many cases been the only experience individuals have with genetic screening. In the past, parents have not given newborn testing much thought because they were seldom asked whether they wanted to participate, but instead participated through "implied consent." This sets an unfortunate precedent when it comes to communicating in families about genetics and genetic testing. In the case of parents responding to a positive newborn screen for cystic fibrosis (CF) for their infant, there is documented evidence of organizational units failing to provide promised information, then offering conflicting instructions regarding where to obtain care [25]. None of the stakeholders were acting with malice, but the overall effect of completely decentralized communication was to increase the stress on parents at an already stressful time in their lives. As suggested by the newborn screening programs, organizational practice guides public policies and vice versa. Newborn screening policies worldwide challenge families and health-care practitioners to keep up with current standards in order to give informed consent and make informed choices [26].

In the mix of standards of care relating to whom to test, and for what, as well as why and when, organizational discourse reveals decisions about practices relating to counseling relatives of significant genetic test results. This often does not occur, raising debate about the need for genetic services to assure that relatives are informed [27]. Sometimes it does not occur because a patient has died before receiving test results and so is unaware of genetic status [28]. It can also fail to occur due to a lack of understanding about genetics. Health-care practitioners may be able to predict those most in need of genetic counseling services based on identifying and assessing family communication norms. However, practitioners can face further barriers *within* families, where risk *should be*

communicated to other family members but doing so is difficult and lost in the translation of not understanding inherited risk information [29]. At a public health level, interventions related to genetics and health may need to emphasize the important role to be played by unaffected family members in conveying the relevance of hereditary disease information inside the immediate family and beyond [30].

EXPERT DISCOURSE ABOUT GENETICS AND HEALTH

Expert discourse (Fig. 3.1) consists of communication based on the derived or expert information and knowledge about health and health care collected through societal resources devoted to medical research and public health evidence. Expert discourse also often reflects knowledge not yet available or accessible, and multiple ways of conveying findings from the same research [4]. The knowledge gained about health and health care, and the services designed to support these insights form a foundation for expert discourse in health communication. This discourse impacts *both* health-care practitioners' and individuals' decision making about behavior with health implications. Expert discourse is comprised of conflicting content at times. This may happen because different expert sources look at the same evidence but reach different conclusions. It also happens because new knowledge may make old knowledge outdated, but we may still talk about and act on the old knowledge. Sometimes when new evidence about treating a disease is framed in terms of benefits for a patient with the disease, the message may suggest that benefits outnumber risks. When the same evidence is framed in terms of the financial costs related to treatment, the message may suggest that costs outweigh benefits. When discussions focus on our personal autonomy, the evidence may be mixed, as we may differ as individuals or in comparison to the expert source in views about the importance of making our own decisions or giving informed consent. Experts in varied topic domains or with training in a range of methods may also reach different conclusions about the meaning of research findings. They may emphasize different aspects of new knowledge in ways that seem contradictory at times. Expert discourse about health and health care is associated with informing, motivating, and profit making, all of which guide individuals' "informed" decision making about health.

Informational Discourse: Educating and More

> Rigid recommendations about how much information to provide to patients and about how much to involve patients in decision making are likely to be inappropriate. [31] (p. 597)

Informational discourse represents efforts to communicate about health based on disseminating the evidence of medical and public health science, sometimes with dramatic intent to draw attention to what is not known

[4]. In the midst of media fanfare and strategic clinical and public health communication conveying the promise of genomics, accurate translations of how new medical research findings affect families are needed. As illustrated above when considering newborn screening programs, societies organize to deliver these services to citizens based on the belief that the epidemiological database supports doing so, but in many settings communicating to inform parents about these tests usually only happens in the wake of test results that suggest something is wrong with the newborn's condition [32]. This truly is a worrisome and anxiety-provoking situation, not the best time to teach someone about complex science [25].

The United Kingdom's "informed consent" program to screen for phenylketonuria (PKU) is a model for strategic communication about genetics and health. If left untreated, this condition can retard brain development [33]. Per the established U.K. newborn screening protocol, a mother receives a prescreening leaflet in the third trimester of pregnancy to be discussed at least 24 hours before the baby's screening, which is prescribed to take place between 5 and 8 days after birth. The leaflet is to be used by the mother to make a decision about whether to consent. The benefits are clearly outlined in the leaflet. These include an emphasis on obtaining care at the earliest moment for any child diagnosed with PKU. Mothers are nearly unanimous in consenting, and they know what and why the test is being done. This is one path for health-care practitioners to advocate for and to assist with advancing both societies' and families' readiness to seek and be recipients of genomic health care.

News media sources of health and science information are often how individuals, including scientists and doctors, keep abreast of new knowledge [34]. Genetics and health is no exception. A number of researchers have examined the media coverage associated with genetics and health, finding that reports often accurately attribute partial causation for illness and disease to genes. For example, the headline "Obsessive Compulsive Disorder Is Partially Genetically Transmitted" [7] (p. 93) quite accurately reflects the scientific status of understanding and knowledge. Media stories about genetics and alcoholism include the following examples of such coverage: *(a)* "the susceptibility to alcoholism is inherited" (p. 11); and *(b)* "a specific gene that appears to greatly increase the risk for alcoholism" [35]. Once more, the reports do not assign total causation to inherited genes. The media do, however, tend to use shorthand phrases and terms, such as "the breast cancer gene," which may lead to misunderstanding among the general public [36]. Others find that a "narrative enlightened geneticization" characterizes the informational discourse, with factors other than genes being considered in discussions of disease causation but with genetic explanations ultimately being prioritized [37].

Beyond the news as a source of information about genetics and health, entertainment media are influential. One study that asked nearly 500 participants to indicate what was the first media message that came to their mind when they read the phrase "genes and health" generated the

name of a movie as the most frequent response [2]. Participants named 33 specific movie titles with *Gattaca*, *Jurassic Park*, and *Multiplicity* comprising the top three. The latter focuses on cloning to solve the competing demands associated with work and family lives. Little research has been conducted to examine the accuracy of information about genetics presented in entertainment media.

From episodes of *The Twilight Zone* in the 1950s to *Heroes* in 2006, science-fiction media have integrated genetics into storylines. With the incursion of biotechnology research in the 1970s, several fictional plotlines emerged in popular culture with a focus on genetics, and since the 1980s there has been a substantial number of major Hollywood and other English-language fiction films in which genetic themes figured prominently [38]. These included *Jurassic Park* (1993) and television series such as *The X-Files* (1993–2002), which popularized genetics and how genes can alter lives. Then in the 2000s, crime dramas steeped in the science of DNA evidence such as *CSI: Crime Scene Investigation* (2000) popularized knowledge of DNA testing. Yet for every *CSI* effort to include accurate, science-based depictions of genetic information, there is a depiction of genetics gone awry such as in *Repo! The Genetic Opera!* a 2008 film with Paris Hilton whose plot synopsis reads, "A worldwide epidemic encourages a biotech company to launch an organ-financing program similar in nature to a standard car loan. The repossession clause is a killer, however" [39].

News and entertainment media are not the only source of information about genetics and health, of course. The mapping of the human genome and discoveries relating health conditions such as blood clotting risk to multiple genes and their variants has changed clinical communication about health. While we have always been asked about family history at medical appointments, a greater emphasis has begun to be placed on these questions and our answers. As described in the previous section, sometimes this emphasis is prescribed within organizations and has become important for public health initiatives such as the U.S. Surgeon General's campaign, urging people to "know your family health history" [40].

The rapidly changing landscape aligned with genomic health care challenges health-care practitioners' abilities to maintain competence in this arena. For example, a survey of 1054 practitioners revealed that just 52% were aware that *BRCA1/2* mutations can be inherited from either parent, while 46% knew that a woman with a sister with a known *BRCA1* mutation has a 50% risk for inheriting the same mutation [41]. Most patients know that changes in genes can be inherited, that changes can lead to disease, and that changes can be caused by radiation. Yet only 42% of more than 800 adults surveyed in community settings realized that the sun can cause changes in genes, 63% knew that changes in genes can occur over a lifetime, and 70% that every gene is able to mutate or change [42].

Research that examines health-care practitioners' communication with patients about genetics reveals that doctors tend to rely on objective and scientific facts about test results and do not address more subjective personal information needs [43]. Genetic counselors focus on informing clients about why something has happened and what might happen in the future as a result, using language to communicate probability [44]. Most families lack knowledge about genetics and inheritance [45]. When an individual has had a family experience with a genetic condition, what is most likely to be remembered are the effects of the disorder [46]. What is seldom understood, even with personal experience in the family, is how it affects individual risk for inheriting the condition [47]. A survey of parents showed that where one parent was a carrier and the other parent was not found to have a common mutation, the parent did not appreciate that there is a residual risk of having a child with CF [48].

In the genetic counseling clinic, it is not uncommon for people to demonstrate an understanding that a condition can be inherited, while at the same time they also show that they have a limited understanding of how a spontaneous mutation could occur [49]. In reality, all of us carry mutations, but research reveals that the use of the word *mutation* to describe variation in genes is linked to negative thoughts and feelings based on media images. In a study with 243 lay participants, rankings for the terms *mutation*, *alteration*, *variation*, and *change* in perceptions of good/bad, healthy/unhealthy, normal/not normal, desirable/undesirable, changing/unchanging, and intended/unintended, *mutation* was judged to be a more negative term when compared to all the other terms with regard to goodness, healthiness, normality, or desirability [50]. Interestingly, an alteration was perceived to be intended when compared to any of the other terms. The notion that a mutation could be a variation promoting human adaptation and survival does not appear to fit within these mindsets.

A proliferation of online sites with content about genetics and health demonstrates both the public's interest and need for information to enhance understanding. One survey of 780 Internet users found that perceiving a personal risk related to genes and health increases searches for online information about genetics [51]. In the end, these informational exchanges may actually help produce a more educated patient and family. While a diagnosis affects most directly the person being diagnosed, its implications for family members when it comes to inherited risk for a condition broaden the scope for an audience in relation to communicating about the diagnosis [29].

As the epigraph for this section makes clear, inflexible rules about how much or what kind of information to provide patients with are unlikely to be successful. In the case of genetic risk information, health-care recipients may vary widely in terms of their prior knowledge and preference for dealing with uncertainty. Those who are knowledgeable to begin with also acquire and retain new information more readily [52]. And where

some individuals actively seek out genetic risk information from multiple sources, others are more passive [53], perhaps because they wish to wait for information from a medical professional or because they prefer not to deal with the possibility of genetic disease. The obvious solution would seem to be for the health-care practitioner to adapt the information to the knowledge level and preferences of the recipient. But often, in the case of genetic counseling following newborn screening, legal and/or organizational policies require standardized treatment of information recipients. In this way, informational discourse that should benefit patients is constrained by countervailing institutional concerns.

Commercial Discourse: Making a Profit

> Product placements expose us as viewers to health information, services, and products—options we may have no awareness of until viewing them in these entertainment outlets... We mostly frame medications as something to benefit our health, so we may more mindlessly respond to communication about them. We're not on our mental guard when health services and products come into scenes and settings for entertainment the same way we may have learned to be when alcohol use is being portrayed. [54]

Another very different path for the dissemination of expert knowledge derived about health is commercial discourse, which focuses on communicating to make a profit from providing products and services to support disease prevention and detection. Failure to address the profit motive of health and health care ignores the reality that where there is profit to be made from selling health and health care, a profiteer will not be far behind. The profit motive associated with health and health care occurs at many levels, as the pharmaceutical industry promotes an increasing number of products for consumers to use to treat all kinds of conditions. In this age of genomic health care, the messages families may be exposed to in relation to their health go beyond pharmaceuticals, nutriceuticals, and cosmeceuticals into the realms of pharmacogenomics, nutrigenomics, and cosmegenomics [55].

Traditional commercial appeals, such as cost comparisons, accessibility, and convenience, comprise core issues in efforts to promote products, activities, and other consumer goods related to health and health care. While published research in health communication often examines expert discourse and provides insights about both informational and motivational strategies and outcomes, far less study has systematically examined discourse in the commercial realm, especially in terms of positive effects on health and health care. Marketers aim to understand ways to sell products to consumers, and some of those products are health related or have potential health benefits. The field of advertising uses the desires of individuals to be healthy as a way to frame appeals as well. In the process of communicating to sell products and services, information may be included about how

genes contribute to the likelihood of disease but only in service of profit. In the study previously mentioned which examined the first message that came to participants' minds in response to the phrase "genes and health," 19 commercials were identified [2]. These included a commercial about stem cell research to provide a cure for cancer, commercials about women and the fight for breast cancer, commercials about cloning, commercials about how the risk of heart attacks run in families, commercials about alcoholism running in the family, and commercials about genetics labs and curing illnesses [2]. Only the United States and New Zealand allow these direct-to-consumer (DTC) ads for medications and testing services.

There are three general types of DTC ads that have emerged. *Help-seeking ads* aim to educate us as consumers about a disease while also encouraging us to consult with doctors and discuss treatment options connected to prescriptions drugs based on our health status. If the ad makes no claims, no disclosure of risk in taking a drug is required. *Reminder ads* also contain drug names and offer very limited information about a drug's safety or efficacy. *Product-specific ads* promote particular prescription drugs and must provide information about the drug's safety and efficacy. These ads are supposed to pass strict Food and Drug Administration (FDA) guidelines. Direct-to-consumer ads do not necessarily enhance the accuracy of information for consumers and may lessen a sense of choice. A survey of hundreds of general practitioners and pharmacists in New Zealand revealed that doctors view the ads as contributing to participative decision making but also view them as often being *unreliable* sources of information [56]. The ads have increased individual awareness of products connected to genes and health, as some advertisements make reference to our family health histories.

Some have expressed concerns about DTC ads' references to race and possible stereotyping and racism [57]. Although health-care practitioners are encouraged to address racial issues associated with genes and health in working with clients [58, 59], existing data seem to provide evidence that linking genetics, race, and health in messages to the public can increase racism [16, 60]. This poses a barrier to communicating with families about genetics and health. Traditionally racial groups have been treated as if they were unified types defined by characteristics such as skin color, hair texture, and head shape and size [60]. However, as Kittles and Weiss pointed out [60], the arrival of genetic data revealed that within-group differences substantially exceed between-group racial differences. Yet despite the fact that all human beings share 99.9% of their DNA with each other and most of the 0.1% of difference is interindividual rather than intergroup [61], there is a growing movement in medical genetics to promote a model of race-based medicine—using race as a criterion for diagnosis, screening, and prescribing drugs [62].

The book *The Genius Factory* by David Plotz [63] tells the true story of a millionaire who created a sperm bank for Nobel Laureate sperm. Known as the genius sperm bank or the Nobel Prize Sperm Bank, the

Repository for Germinal Choice, not surprisingly, raised tremendous controversy. Between 1980 and 1999, 215 children were conceived from sperm out of the Repository and women who met the criterion of qualifying for Mensa, the high-IQ society. Even in the absence of awareness of this reality, societies express disdain for the elitist, racist, and sexist images aligned with thoughts of choosing the characteristics of not yet conceived children—and making money doing it. This may motivate some consumers to go online in search of anonymity when seeking genetic testing and products. Genetic testing services are increasingly offered online, including parentage confirmation, identity testing, and DNA banking, as well as health-related testing for such standard tests as CF and hereditary hemochromatosis as well as unconventional tests related to behavior, nutrition, and aging [64].

Other ethical issues emerge as well, including placement of such ads. For example, a biotechnology company advertised its commercial test for *BRCA1/2* genetic mutations in playbills for a theatre presentation about a woman's painful death from ovarian cancer [65]. A lack of understandable information, complicated social contexts surrounding genetic testing, and lack of consensus about utility of some tests limit their efficacy [66]. Do-it-yourself testing is particularly problematic [67] with online sources multiplying the effect [68]. Despite the reality that only the United States and New Zealand allow such commercialism, the public's confusion and autonomy form core arguments used in the United States to continue the practice of DTC ads [69, 70].

Motivational Discourse: Activating Thoughts and Action

> Many of these women will not have a family history that suggests the presence of a highly penetrant breast cancer susceptibility gene. However, a small subset of such women will come from families with a striking incidence of breast and other cancers often associated with inherited mutations. [71] (p. 577)

The motivational discourse element of expert discourse reflects efforts to influence attitudes or behavior relating to health and health care, implicitly relying on a presumed level of knowledge or understanding. One of the most fascinating and at the same time frustrating areas of study within the strategic realm of health communication focuses on how to communicate in ways that motivate people to behave in healthy ways. Motivation often depends upon our awareness of information associating a practice with a desired or undesired outcome. Information can lead to motivation to seek genetic testing, for example, as suggested in this section's opening quotation. Women have increased their efforts to seek information regarding their individual breast cancer risk in the wake of media reports about a breast cancer gene [72]. Women who come from families with inherited mutations associated with breast and other cancers may benefit

greatly from awareness of links between genetics and breast cancer to support their decision to seek testing. Women who do not have a family history, however, may impose undue emotional and financial burdens on themselves and their families. This case may also be associated with shaping public perceptions that inherited genes determine health and disease outcomes, and that genetically related technologies can save human beings from imperfect and unpleasant disease experiences. Research has shown that 60% of smokers surveyed anticipate they would be motivated to quit smoking if they had a gene linked to smoking-related disease, while 40% say they would feel demotivated [73].

Research that supports the impact of genetics on the expression of diseases such as cancer and neurological conditions, together with communication about these advances in knowledge, may also shape individual perceptions of the ability to act on genetic testing results to limit disease onset. Exposure to movies with content about human genetics has been found to be positively related to perceptions of one's ability to act on genetic information to benefit one's health and genetic self-efficacy [74] but not to affect belief in the efficacy of genetic therapies. Exposure to prime-time medical and crime television shows was, however, directly related to belief in the efficacy of genetic therapies but had no relationship to self-efficacy [74]. Unfortunately, genetics are often appropriated in media to inflame stereotypes and provoke rather than to resolve dilemmas [75]. This is a missed opportunity, especially considering that fictional media guide the public's understanding of genetics and are influential in making uses of genetic technology acceptable or unacceptable [76].

Smith [77] pointed out that as television dramas continue to include references to genetics, awareness of genetic testing and therapies will increase, prompting individuals to form attitudes and behaviors linked to these options. She reported Nielsen ratings in 2005 of an estimated 19,737,000 viewers who watched a *Grey's Anatomy* episode focusing on a character's decision to obtain genetic testing for ovarian cancer. Smith suggested that communicating about genetics and health on TV in conjunction with new technologies—such as pairing the episode with an ABC television network Web site to address viewer questions—provides an opportunity for shaping people's self-efficacy and control over gaining access to resources to make informed choices. Messages to motivate individuals in relation to genes and health are not limited, of course, to fictional media. Other research suggests that all media can play a critical role in shaping responses. Studies such as Weiner, Silk, and Parrott [62] report that media information can be particularly salient for individuals who have had personal experience with genetics (e.g., genetic testing). In this study, news shows and other media content relating to genetics and health were most valuable for individuals with at least a small amount of genetic knowledge.

Media frequently offer contradictory and contested messages about the role genes play in health. Parrott and colleagues [74] argue that uncertainty in the medical community about genetic and modifiable cofactors of disease

leads to confusing messages in health promotion. Indeed, public messages about the role of genes in health are often overly deterministic and contribute to fundamental misinterpretations of how genetics research is done [78]. Many media messages increase fear and mistrust of genetic science [79], which, in turn, may reduce individual motivation to harness the understanding and resources necessary to benefit from testing and options linked to genetics and health. As an illustration of this point, Smith [77] reported that individuals consider one of the risks of genetic testing to be the threat of being labeled "a genetic mutant," along with the associated stigma, a further threat to the motivation to act on awareness. Smith pointed out that advertising campaigns using messages such as "Are you a carrier?" promote labeling and potential stigma. African Americans, in particular, have reported that the term *mutation* carries stigma related to race and ethnicity [80].

LAY DISCOURSE ABOUT GENETICS AND HEALTH

With the increasing reference to genes and genetic science in everyday life, it is important to understand what lay discourses influence understandings of genetics (Fig. 3.1). By "lay," we refer to people who are not trained and/or employed in genetics [81]. Cultural, social, and personal discourses guide how they think about genetics, behave in relation to genes and health, and importantly, what media they may use that will inform their understanding or when they seek clinical consultation for health. The ability to understand what health-care practitioners say and especially the value placed on medical interaction depends often on upbringing, combining family, cultural, and health experiences. A great deal of individual understanding and motivation relating to health and health care comes from indigenous knowledge conveyed through these discourses. Sometimes this information will be consistent with science and other times not. That does not mean that practices based on this knowledge will not produce good outcomes, nor does it mean that these insights and practices will not become a spark for funded research to build on the base of scientific understanding associated with health and health care. That is the reality. The channels responsible for disseminating this knowledge are the same ones that guide awareness of public health and clinical communication recommendations—interpersonal and media.

Cultural Discourse: Gendered and Racial Identities and More

> It's hard to talk about race in [the United States], but with a new medical enterprise focused on biological difference, we are forced to confront it. [82] (p. A11)

Some of what we know about health and health care comes from lay knowledge and practices associated with cultural membership and beliefs about health and health care. Cultural identities form around where

one lives, ranging from the nation to the region of a country, and even whether one lives in rural or urban areas. Cultural identities also form around race, ethnicity, and gender. Given the importance of cultural identities and the recognition of the importance of non-Western medicine in the lives of a growing number of health-care recipients, a number of studies have sought to uncover and categorize common assumptions about genetic disease and genetic testing that are common among members of minority groups. For example, surveys and analysis of the disease causation beliefs of Latinos and African Americans [83, 84], Haitians [85], and Southeast Asians [86, 87] have been conducted. The outcomes of these studies may be academically interesting, as when Singer et al. [83] found that in their sample, Latinos and African Americans were more likely to express a preference for genetic and prenatal testing. Results should not be used to form rigid assumptions about a person's intentions or response to a genetic condition or genetic testing. Rather, health-care practitioners should view the research findings of ethnocultural differences as evidence that attention to cultural identities is vital for effective communication. Thus, the question changes from, What is this person's ethnocultural identity? to How best can I learn *from her* how her ethnocultural identity will affect communication regarding genetic health and her response to health-care recommendations/choices?

Culture contributes to cognitions and emotions about self and health, as well as the underlying motivations that may guide our actions or failures to act. As ethnographic research makes clear, many cultures construct different understandings of kinship, health, and illness and these differences are likely to affect the way that genetic risk is understood [88]. Since cultural discourse influences beliefs about genetics and health, this has implications for transcultural care. For example, consanguineous marriage, particularly between cousins, is common among some cultural groups. These marriages are seen to benefit family systems across generations due to shared family traditions and knowledge [89]. However, as this marital arrangement increases the chances of both parents being carriers for the same recessive condition, communicating about genetics and health within these families will clash with the cultural discourse.

Cultural beliefs and practices guide how one interprets clinical communication or whether one will even be exposed to strategic communication about health in clinical settings due to the standards for when one will seek expert care. Culture contributes to beliefs about such issues as whether one should be told about a terminal diagnosis and the appropriateness of having male physicians conduct exams of females. Patient participation norms also emerge from cultural discourse, contributing to commitment to medical decisions at times and other times, contributing to noncompliance with medical therapies. There is a reciprocal relationship, such that patients may comply more often and be more satisfied with formal systems of medical care because they accommodate to cultural practices when possible. Research has shown, for example, that some

cultures believe that a cleft lip is caused by eating rabbit, hence the name "hare-lip" [86]. Nicolas, Desilva, Grey, and Gonzalez-Eastep's [85] discussion of Haitian beliefs reveal that Haitians often believe illnesses are supernaturally induced, rather than influenced by genetics. These cultural beliefs may present challenges for health-care practitioners who wish to respect cultural beliefs, while being reassuring about these concerns. Moreover, cultural practices may limit the likelihood that people will express uncertainty or doubt about a practitioner's diagnosis or explanation. Asian Americans, for example, are often silent partners in medical care, owing to cultural norms governing interaction [87].

In addition to the role of cultural identities aligned with ethnicity or race, gender is also a consideration when reviewing lay understandings of genetics and health. Women are the focus of much of the public discourse on genetics. Women are more often than not viewed as "kin-keepers," the center of the information network in terms of managing family health history information, and the primary client when a couple seeks genetic counseling [90, 91]. Moreover, research associated with reproductive processes and health tends to overemphasize the role of women, often excluding relevant findings pertaining to men [92]. Since women gestate and bear children, genetics information is often directed to them. Tuana [93] pointed out that lay understandings of genetics often give in to mother-blaming—holding mothers responsible for undesired traits in offspring. Consequently, women may be more inherently interested in genetic information than men.

Research that has examined whether differences exist between males and females in their actual understandings of genetic contributions to health finds few differences. Within gendered identities, race may affect beliefs. In a study that examined the lay public's perceptions of the influence of inherited genes, environment, social factors, and personal behaviors on human health, differences based on gender and race were considered [90]. For breast cancer, European American women assigned twice the emphasis to the physical environment as an influence than did African American women, and African American women perceived genes to have a greater influence on breast cancer than did European American women. The authors of this study draw attention to the need for more research in this area so that gendered understandings of genetics and health are improved.

Social Discourse: Families and More

A myriad of health habits have to be worked out through a second aspect of lay discourse, social discourse within families, which combines varied cultural backgrounds. Custodianship of genetic information faces barriers to telling linked to the reality that families vary in their communication norms and patterns of behavior. When families broach the topic of genetic health, in particular, the literal "blood ties" that link family members together may perpetuate blame, a psychological component related to disease causation

[94]. In theory, no single family member owns family health history information, because every member could potentially share certain genetic traits, links, or diseases. As a result, boundaries around disclosure of this information can be difficult to negotiate, though timeliness of the information may affect how individuals manage their well-being. Women considering oral contraception, for example, would likely prefer to be told about blood-clotting experiences and genetic risk factors within the family before making a decision to use this form of contraception. Couples planning their families would likely prefer to be informed of any clotting family history prior to the onset of pregnancy; and so on across contexts associated with increased risk for thrombosis linked to genetics [95]. Thus, health information becomes blurred when family medical history is comprised of information that may affect the health of *all* family members.

While some research suggests that media exposure to information about human genetics is related to more frequent family discussions of genetics research, there is little evidence that individuals are talking with friends or family members about their family health history [62]. This lack of exchange is concerning given the role of family communication in the formation of beliefs and behaviors of individual members. Moreover, as Phelan [96] notes, the most harmful effects of geneticization are for family members "tainted and rejected" via association with a genetically deviant relative (p. 319). Miller [97] reported a case study of one family whose members never shared information with one another about the legacy of depression and suicide among women in their family. This silence was striking because over the course of four generations there had been five suicide attempts—at least one female suicide attempt within *each* generation. It was not until a young woman in the fourth generation of this family was hospitalized for her suicide attempt that the spiral of silence regarding depression in this family was broken. The silence served to isolate individuals suffering from depression in this family and prevented each successive generation from getting necessary treatment.

Certain illnesses—or even illness itself—may be constructed as weakness in certain family cultures. As a result, discussion of the illness may be considered taboo. Moreover, actual discussions of genetic illness and history may be fraught with blame and guilt around responsibility for contributing faulty genes [98]. This situation offers unique challenges to the medical community because existing research suggests that more people with genetic disorders learn about their disorder from family members than from health-care practitioners [99, 100]. Indeed, family members are perceived to have a moral imperative to communicate genetic information to other family members [101, 102]. But do they?

While research literature in the area of family communication about genetics and health suggests that parents are responsible for disseminating information to their children, there is little evidence to suggest that they actually perform such a function and even less that uncovers the process of the information dissemination (see [103]). Studies that track

the communication of parents to children [104] do so most often through self-report and give a post facto glimpse of behavior. Because of Gregory et al.'s [105] finding that participants drew a marked contrast between the nature of communication within the clinic and within the home, more studies like that conducted by Keenen, Arden-Jones, and Eeles [106], which occur outside of the clinical context and address communication patterns and interaction within family social networks, would be instructive.

Gaff et al.'s [103] systematic analysis of 26 studies of family communication and genetics revealed a variety of considerations that warrant additional examination, including considering the effects of disclosure, what information to disclose, timing of the disclosure, and the communication strategies employed in the disclosure. This study uncovered an interesting strategy of utilizing intermediaries to disclose information, especially across generations. This analysis revealed a "cascading of responsibility" wherein responsibility for informing others in the family is handed down along with the actual information [103] (p. 4). In addition to examining active disclosure, it may also be necessary to explore how patterns of information omission and the use of strategic ambiguity function in family communication about genetic health. Gaff et al. [103] call attention to the fact that, in some families, those managing genetic information may make the decision to withhold information altogether or deliberately present the information in an ambiguous fashion. A focus on communication is central to education in the area of genetic health since beliefs about disease inheritance are an integral part of family culture in the United States and other cultures [107].

Although, as noted above, intergenerational communication of genetic information appears to be rare, the same does not apparently hold true among siblings and partners. For example, in a study of the Wisconsin newborn screening program, after a positive screening result of cystic fibrosis (CF) for their infant, 88% of parents reportedly informed other family members that they might also be carriers [108]. Similarly, 80% of Belgian parents of a child with CF informed their brothers and sisters about the genetic aspects of CF [109]. In addition, women shown to be carriers of CF actively shared that information with members of their social network. In a study of 122 Danish women, 100% reportedly informed their partner, 89% informed their parents, 80% informed their siblings, and 57% shared the result with nonrelatives other than their doctor; transferal of this information was the presumed cause of partners and siblings obtaining a carrier test –100% and 26%, respectively [110]. The latter results suggest that knowledge of the carrier status of one individual has the potential to motivate carrier testing in others, perhaps because of the implications for family planning. However, from the data available, we cannot rule out the possibility that their communication was prompted by the false belief that testing could be followed up by some action that would remedy the genetic problem.

Personal Discourse: Experience and More

No matter what scientific or indigenous knowledge disseminates to individuals about genetics and health, in the final analysis, personal experiences in this arena will sometimes take precedence. This forms the final element of lay discourse. Beyond the communication about health and health care shared or avoided within cultural and social groups, one's particular life experiences with illness and health, and with health care, vary widely, deriving lay knowledge to guide future behavior. Once more, strategic health communicators must reckon with this reality in their efforts to intervene with information and motivation to guide decision making and action. Strategic health communicators give time and effort to understanding personal experiences individuals have with trying behaviors promoted to prevent or detect disease. If the practice is unpleasant, causing embarrassment or pain, will these be barriers to participation? Genetic tests have predominantly been blood tests. Fear of needles or personal beliefs about blood and blood tests may erect barriers to testing. Alternatively, the fact that genetic testing is viewed as a simple blood test may actually encourage uptake of genetic testing. Beyond our own personal experiences with specific health behaviors that are within our personal sphere of control, many health practices depend upon the cooperation or collaboration of others.

In the face of the seemingly inexplicable, such as the role of genes in health, some people rely on religious faith to guide their knowledge and outcome expectancies. Religious faith refers to the predisposition to think, feel, or act based on his or her belief in a spiritual power greater than humans to affect the course of nature and the role of humans within that realm. Religious faith is often guided by the prescriptions associated with the dictums and practices of different religions, as expressed in religious discourse. At the personal level, extrinsic religiosity, the outward and visible signs and practices associated with religious faith that include prayer and worship, provides solace, distraction, sociability, and even self-justification [111]. Intrinsic religiosity, the internalized expressions and integrated experiences of religious faith sometimes referred to as spirituality, has been found to be used by the sick and disabled for coping [111]. Prayer may be used by some of us as a strategy to seek peace with heritage linked to genetic mutations and disease. For others, prayer may reflect that the faithful depend upon belief in God's power for healing, for being saved from the health harms linked to a condition [112]. Religiosity has been found to affect the likelihood that individuals will be exposed to media with genetic health content [12]. Extrinsic religiosity relates to a greater likelihood of watching talk shows that contain information about genes and health. Intrinsic religiosity was negatively associated with exposure to newspaper content about genes and health.

Individual beliefs about a disease and its cause can inform treatment, especially since lay understanding of disease inheritance can be at odds with medical models [113]. Clinicians need to be aware of these personal

"understandings, because they can influence patients' perceptions of their disease risk and its management" [114] (p. 584). While there are a multitude of beliefs relevant to specific genetic disorders, research by Parrott et al. [4] reveals a useful model for understanding meta-belief orientations—general frameworks people use for understanding genetics and health. This study developed a Genetic Relativism Instrument that identifies four lay frameworks for understanding the role of genes in health. Each of these frameworks includes beliefs about the role of personal behaviors, social environments, and religiosity on genetic expression. An *uncertain relativist* is an individual who is uncertain about the roles that personal behavior, faith, and environment play on genes and health. An *integrated relativist* believes that personal behavior, faith, and environment all contribute to how genes express themselves in health. A *personal control relativist* believes that personal behavior plays the most important role in the expression of genes on health—but doubts the role of faith and support. And, finally, a *genetic determinist* believes that none of these factors contributes much to how genes express themselves in health—the bottom line for these individuals is that you are born with your genetic blueprint and there is nothing that can be done. This study highlights the utility of considering the contributions of spiritual life on perceptions of genes on health.

Illness causation frameworks may be useful for health-care practitioners as a guide when assisting people in their efforts to integrate messages about health. For example, a practitioner can discuss how to combine and make sense of scientific genetic information about heart disease while presenting messages about personal lifestyle changes. This approach might help individuals integrate disparate messages about health and dispel beliefs that he or she has no control over the outcome of a genetically based disease. By applying these frameworks to better comprehend lay orientations to understanding genetics and health, practitioners may not only serve to educate patients and families, but empower them and increase personal efficacy to take control over their personal health. Lay attitudes about health care have been found to be shaped by media use, with greater overall consumption relating to pessimism about health care in the United States [115].

One vitally significant experiential and personal discourse that frames understanding and response to genetic diagnoses and testing, particularly prenatal testing, relates to disabilities. Pregnancy can be a stressful, worrisome time for virtually all couples. Even if a couple does not innately have their own worries, one trip to the obstetrician's office exposes the couple to a multitude of risk messages related to the developing fetus. Despite the strides individuals with disabilities have made in the past decades, such as the passage of IDEA (Individuals with Disabilities Education Act) and ADA (Americans with Disabilities Act), the birth of a child with a disability is often still viewed and discussed publicly, privately, and clinically as a tragedy—something that should have been avoided.

Disability and illness are grounded in real or imagined *experiences* with disability and illness. Like expert discourse (discussed earlier), discourse about disability experiences is often comprised of conflicting content and impacts both health-care practitioners and individuals making decisions in light of genetic information. Traditionally, the loudest voices of disability discourse forward the stigma [116, 117], hardships, and heartbreak associated with disability and dismiss as "denial" any attempt by others to proffer an alternative perspective on disability [118, 119]. The pharmaceutical and genetic testing companies profit from this view of disability, as negative views are related to genetic testing uptake and, in turn, growing market sales. Moreover, the media industry profits from negative messages about disabilities, as the images and stories draw viewers and readers [120].

Messages about disability presented by health-care practitioners also generally further a pessimistic view of disability in the context of genetic health [121–123]. Many practitioners have been criticized for presenting information about disability that is biomedical in nature, without sufficient context [124]. Further, some argue these same messages perpetuate discrimination against individuals themselves, not just their disabling trait. There is a plurality toward disability traits and genetic testing for disabling conditions [118]. There are significant differences in what counts as a serious trait, and many individuals with disabilities argue that negative views of disability are based on misinformation and fear. Many individuals and families with disabilities find value in the disability experience [118], even to the point of viewing the disability as an advantage [116]. As disability is a social construct, practitioners may play a role in the promotion of an improved view of disability. As clinical caregivers and advocates for individuals with disabilities, health-care practitioners can have a key voice in the promotion of improvements in society's concepts and infrastructure for individuals with disabilities.

CONCLUSION

As this chapter has illustrated, multiple discourses influence family communication about genetic information. These discourses are inherently linked. When talking to patients and families about genetic health, health-care practitioners are constrained by the state of knowledge about particular symptoms, which relates to the medical research that has been conducted. The state of such knowledge generally depends upon the funding of research associated with particular symptoms. The funding of medical research often depends upon the outcomes of political debate that shapes health policy. The arguments used in such debate depend upon social norms about what is important. These norms vary according to cultural beliefs and practices. To treat any of these events in isolation from the others limits understanding of communication about genetics in families. Efforts to communicate about genes and race must also carefully consider effects of these messages on both perceived threat relating to

susceptibility and severity, and perceptions of biological essentialism. The former may enhance motivation to act in health protective ways, while the latter may contribute to genetically based racism and genetic discrimination, outcomes associated with health disparities.

While family intergenerational communication about health histories may function to meet needs related to emotion and action, it may also be complex, difficult, and result in misunderstandings or reinforce generational stereotypes. By the same token, perceived benefits relating to concealment include the possible benefit of allowing individuals to interact "normally" with others, without the stigma associated with the disease. In view of the vital role that promoting awareness of family health history will likely play in health care for the foreseeable future, consideration of conditions likely to motivate disclosure versus concealment is warranted. When families talk about health history, one motivation is likely to be the belief that awareness will promote attention to signs of the disease for which there is a history. Such communication may also relate to belief that therapies are available to prevent or detect the disease for which one has a family history, and/or that one's own behavior can prevent the disease. That was the promise underpinning funding to complete the mapping of the human genome. Prevention and detection, however, are frequently not possibilities, making necessary conversation about this reality in clinical and public health communication about genetics and health.

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