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Exploring the Public Understanding of Basic Genetic Concepts

Angela D. Lanie,[1] **Toby Epstein Jayaratne,**[2] **Jane P. Sheldon,**[3] **Sharon L. R. Kardia,**[4] **Elizabeth S. Anderson,**[5] **Merle Feldbaum,**[2] **and Elizabeth M. Petty**[6,7]

It is predicted that the rapid acquisition of new genetic knowledge and related applications during the next decade will have significant implications for virtually all members of society. Currently, most people get exposed to information about genes and genetics only through stories publicized in the media. We sought to understand how individuals in the general population used and understood the concepts of "genetics" and "genes." During in-depth one-on-one telephone interviews with adults in the United States, we asked questions exploring their basic understanding of these terms, as well as their belief as to the location of genes in the human body. A wide range of responses was received. Despite conversational familiarity with genetic terminology, many noted frustration or were hesitant when trying to answer these questions. In addition, some responses reflected a lack of understanding about basic genetic science that may have significant implications for broader public education measures in genetic literacy, genetic counseling, public health practices, and even routine health care.

KEY WORDS: genetic counseling; genetic education; genetic literacy; public understanding of genetics.

[1]Department of Human Genetics, University of Michigan, Ann Arbor, Michigan.
[2]Institute for Research on Women and Gender, University of Michigan, Ann Arbor, Michigan.
[3]Department of Behavioral Sciences, University of Michigan – Dearborn, Dearborn, Michigan.
[4]Department of Epidemiology, University of Michigan, Ann Arbor, Michigan.
[5]Departments of Philosophy and Women's Studies, University of Michigan, Ann Arbor, Michigan.
[6]Departments of Internal Medicine and Human Genetics, University of Michigan, Ann Arbor, Michigan.
[7]Correspondence should be directed to Elizabeth M. Petty, MD, Division of Medical Genetics, University of Michigan, 4301 MSRB III, 11 50 W. Medical Center Drive, Ann Arbor, Michigan 48109-0638; e-mail: epetty@umich.edu.

INTRODUCTION

Within the past hundred years, significant advances have been made in our current knowledge of the biological basis of heredity and the genetics of human traits (Collins and McKusick, 2001). The pace of genetic discovery has accelerated even more over recent years with the identification of many genetic alterations that cause or contribute to human health and disease. The completion of the Human Genome Project and an increased effort to learn more about human variation will undoubtedly lead to an even greater emphasis on genes and genetics by virtually all members of our society, especially as related to health care and reproductive issues.

There are likely to be many areas of medicine and public health affected by genetics in the near future, with immense opportunity for far-reaching benefits (Subramanian *et al.*, 2001; Williams, 2001). These benefits, however, can be enhanced if people have an understanding of basic genetic concepts and terminology (Burke *et al.*, 2002). Health care professionals will need to be better trained in human genetics (Suther and Goodson, 2003), and the National Coalition for Health Professional Education in Genetics exists to help in that endeavor (Collins and McKusick, 2001). However, there is no such organization dedicated to the education of the public, who will be the future beneficiaries of genetic breakthroughs that provide new diagnostic and treatment options, such as genetic testing and gene therapy. Currently, genetic counselors are available for those seeking information about a personal or familial risk of genetic diseases. However, it is probable that not all people will employ the services of a trained genetic counselor or medical geneticist before making health care decisions utilizing genetic information and related technology. Even those that do seek consultation may have deeply rooted misconceptions of how genes function and the mechanism for inheritance of genes. When they bring such misconceptions into a session, the counseling process becomes more challenging and the decision process can be impeded. Attempts at education that disregard the prior knowledge and assumptions of the learner have an increased likelihood of being unsuccessful (Richards and Ponder, 1996). Recent research has shown that clinical management of patients may be improved when health care providers ascertain their patients' general understanding and beliefs about basic medical concepts (Campbell *et al.*, 2001). This suggests that it may be helpful for health care providers, including genetics professionals, to ascertain what patients currently understand about genetics when genetic-related health care issues are discussed. By gaining such understanding providers will be better equipped to correct any misconceptions patients may have and build appropriately on their level of understanding to enable them to make more informed decisions about their health care and to increase compliance.

The fields of human and medical genetics are relatively new, yet it is evident that the American public commonly uses related terminology, such as "genes" and "genetics." However, many adults who may use these terms in their everyday conversations likely lack a formal science education that explored basic concepts in human genetics as we understand them today. The last thorough science training many Americans have had was high school biology. Today such education is generally not comprehensive enough in teaching basic genetic science applications that may impact Americans from now into the future (Reilly, 2000; Trumbo, 2000). This suggests that the public's understanding of genetics seems to derive from the use of genetic terminology in a multitude of nonscientific venues: from soap operas and advertisements to art galleries and magazines (Nelkin and Lindee, 1995).

Much work has been done by the Human Genetics Commission in the United Kingdom to coordinate studies that examine public attitudes and knowledge of human genetic information (Human Genetics Commission, 2001). This work has likely been conducted in response to the finding that the populace of the United Kingdom has, in general, a negative view toward biotechnology (Pardo *et al.*, 2002). U.K. investigators have asked general questions, such as "When I say 'genetics,' what, if anything, springs to mind," to start to understand the knowledge of its constituents (Human Genetics Commission, 2001). As an example of confusion in the United Kingdom, in 1996, a Eurobarometer survey concluded that one third of the general public in the United Kingdom believe that only genetically modified tomatoes contained genes, and that ordinary tomatoes did not (Voss, 2000). Very few studies have been done on the general United States population to discern Americans' understanding of genetics; most studies focus on public attitudes for policy discussions instead of knowledge that Americans have on the subject. Other studies have focused on how patients understand genetic principles and genetic risks and most of these have demonstrated some degree of misunderstanding, even as related to basic concepts of inheritance (Emery *et al.*, 1998).

There are myriad ways by which genetic terms enter into the public consciousness, but exposure does not equate to understanding. During a project designed to examine individuals' genetic explanations for group and individual differences in human abilities and characteristics, we investigated how respondents understood the genetic terms (e.g., "genes" and "genetics") that were used during the interview. We were interested in learning what American adults actually mean when they say something is "genetic." We also wanted to discern how people understood what "genes" are and how they work by first asking them about where they thought "genes" are located. Because genetics will soon become a very intimate part of everyone's health care, we believed that addressing these simple questions could help us begin to assess how informed the public is about basic genetic concepts.

We hypothesized that, although people have a general understanding of the inheritance of traits within families and are familiar with some genetic terminology, many would be unable to adequately explain basic genetic terms and concepts and thus may have difficulty in interpreting genetic information given to them through health care providers. As this is a small study, it is not our intent to claim our data represent the genetic literacy of all Americans. This is an exploratory study meant to begin to gain insight into the public understanding of basic concepts and to be used to stimulate larger studies in this very interesting and important area of research.

METHODS

Participants and Procedure

The data reported here are from Phase I of a multiphasic 3-year NIH-ELSI study to examine how Americans use and interpret genetics as related to their underlying beliefs about individual and group differences for human traits. Phase I included administration and analyses of qualitative survey instruments. One objective during Phase I was to examine individuals' comprehension of genetic concepts especially as related to how they define specific terms and concepts. Results were used to develop a quantitative survey for Phase II studies.

Data were gathered from two separate studies in Phase I. In total 62 adults in the continental United States, ranging in age from 22 to 80 years, were interviewed in Phase I over the phone by professionally trained interviewers (Market Strategies Research, Livonia, Michigan), as approved by the University of Michigan Institutional Review Board. Interviewers used initial screening questions in order to identify the race of participants. All participants' responses were tape recorded and then transcribed for data analyses.

In Study 1, we conducted qualitative interviews with 44 individuals from January through March of 2000. These participants included 10 African American males, 10 African American females, 14 Caucasian males, and 10 Caucasian females (Table I). Interviewers and participants were matched on gender and race. All participants were obtained using random digit dialing methods, within the

Table I. Demographic Characteristics of Respondents

	Study 1 (Whites)		Study 1 (Blacks)		Study 2 (Whites)	
Demographics	*N*	%	*N*	%	*N*	%
Gender						
Men	14	58	10	50	8	44
Women	10	42	10	50	10	56
Highest level of education						
Less than 12th grade	1	4	0	0	1	6
Graduated high school, GED	7	29	5	25	5	29
Some college	7	29	9	45	4	24
Bachelor's degree	4	17	5	25	5	29
Advanced degree	5	21	1	5	2	12
Age	*M*: 42.87, *SD*: 15.02		*M*: 39.65, *SD*: 12.69		*M*: 45.72, *SD*: 20.52	

constraints necessary for obtaining the quota of participants needed in each race by gender category. Interviews lasted approximately 30 min and participants were paid $25 for their participation. The cooperation rate was 96.61%.

In Study 2, conducted during December 2000, 18 additional participants participated in a pretest for a larger quantitative study. The pretest included a few open-ended questions along with the quantitative measures, but due to time constraints, the open-ended questions were subsequently not included in the larger study. The qualitative portion of this pretest is referred to as Study 2. The participants in this study, also obtained through random digit dialing methods, consisted of 8 Caucasian males, and 10 Caucasian females. Interviewers and participants were not matched on gender and race. Pretest interviews lasted about 45 min and participants were paid $15 for their participation.

Measures

Participants in Study 1 were asked two open-ended questions at the end of the interview to assess their perceptions and understanding of basic genetic concepts. The first question was, “Can you tell me what you mean if you say that an ability or behavior is genetic?” The second question concerning the understanding of genetic concepts was, “Where do you think genes might be located in someone’s body?” Participants in Study 2 were asked, “Where do you think genes might be located in someone’s body?” However, because of time constraints they were not asked about their understanding of the term “genetic.” Although the context that prefaced the “gene location” question was different in each study, the question itself is specific enough for us to reason that the answers should not be influenced by that context. There are right and wrong answers to the question of where genes are located; if an individual knows the correct answer, the context should be irrelevant. Extensive pilot testing was performed on the survey instrument in order to ensure respondent comprehension.

Determining Emergent Themes and Coding of Data

We categorized participants’ responses by using the technique of inductive content analysis, the procedural guidelines of which have been explained by research methodologists (e.g., Boyatzis, 1998; Patton, 1990). Responses with similar meanings were combined into higher order themes. Two of the investigators conferred to reach consensus before moving to the next stage of analysis. Consensual validation is necessary to reduce researcher bias and to obtain the most accurate depiction of participants’ understanding.

Although there are basic genetic concepts and mechanisms that the majority of the scientific community agrees upon, such as the location of genes and basic patterns of inheritance, there are some concepts that may be more ambiguous and difficult to narrowly define, even by scientists. For example, our first question regarding what participants meant when they used the term "genetic" falls into the latter category. Therefore for this question, rather than coding responses as correct or incorrect, we coded them according to higher order themes. Four of these higher order themes emerged: innate potential, the basis of physical characteristics, inborn elements, and learned characteristics. Most individual responses to this question fell into one or more of these categories, as determined by the investigators. Answers to this question were sometimes difficult to categorize fully. People often seemed to have problems expressing their thoughts and opinions. In addition, people talked about "genetic" in different contexts, and some respondents reported one meaning but then offered other meanings that were very different, if not contradictory. Because participants' responses could fall into more than one category and some responses did not cleanly fall into any of the categories, it would be misleading to attempt to quantify these data beyond these broad categories or perform any statistical analyses.

For the question concerning where genes are located in the body, many responses could be considered correct or incorrect based on scientific consensus. However, because participants often gave more than one response or offered responses that were only partly correct, we coded their answers not as simply "right" or "wrong," but rather as thematic categories that reflected a broader range of ideas. Two different higher order categories of themes emerged. The first category had to do with the specific body parts that individuals mentioned (see Fig. 1). Responses

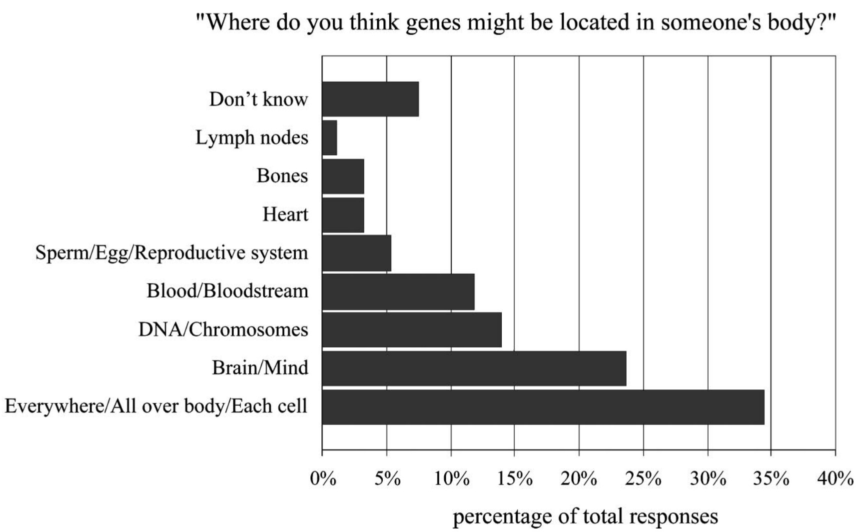

Fig. 1. Responses to the gene location question. *Note*. Many interviewees gave multiple responses to this question, resulting in 93 answers for 62 respondents. All answers were then tallied, and the percent calculated by dividing the total for each category by the total number of responses.

within this category were relatively straightforward and therefore easy to quantify. The second category of themes was related to individuals' metacognitive knowledge (i.e., knowledge about knowledge). This category related to participants' awareness (or lack of awareness) of their own understanding. The themes included in this category were general certainty in one's knowledge and a corresponding overall accuracy (i.e., knowing that genes are located in nearly every cell); knowledge of one's own uncertainty or confusion (i.e., not knowing where genes are located); and general certainty in one's understanding despite the lack of accuracy of the information (i.e., thinking they knew, but giving an incorrect response). The importance of this last category of themes stems from the fact that it is individuals' perceptions of their own understanding, rather than their actual understanding, that will guide their search for knowledge and influence their receptiveness to new information (Richards and Ponder, 1996).

RESULTS

Open-ended responses to questions were often complex, sometimes surprising, and frequently relevant to each respondent's own experiences. Almost all respondents tried hard to give what they thought would be the "correct" answer, often considering possibilities out loud, or checking for positive feedback from the interviewers who remained neutral but supportive regardless of their answers. About 10% of respondents noted frustration/embarrassment when they could not easily answer a question.

The Meaning of "Genetic"

There were indications that respondents may have found the question about the meaning of the term "genetic" particularly difficult to answer. First, we found slightly more than a third of respondents openly expressed their difficulty in responding to this question. Second, about half of the participants gave multiple answers, possibly in a search for an acceptable response. However, despite these apparent difficulties, it is interesting that elsewhere in the interview about three quarters of respondents had no trouble giving an example of at least one nonphysical, nonmedical "genetic" characteristic that ran in their families, even if there was no scientific research in support of their beliefs.

In terms of the higher order themes that emerged, 20% of responses included a comment about innate potential; 25% referred to "genetic" as the basis of a concrete physical characteristic or one's appearance; a quarter of responses focused on "genetic" as something someone is born with; and 8% of responses reflected the belief that "genetic" was learned or had to do with education. Of those in this last category, a few further explained that inherited characteristics were influenced by upbringing. Finally, one quarter of the responses did not fall into any of these four categories. Beacuse they did not constitute an additional theme, they were coded as "other/miscellaneous." The following interesting and representative responses reflect the full categorical spectrum of understanding among respondents.

Respondents described "genetic" as

. . . Innate Potential

> It's like the virus that lays dormant that becomes active after it's been agitated or aggravated through stress. . . . Alcoholism, the gene is there and the more that I guess you drink the more active or alert it becomes and the more it affects you to want to drink more and leads you, I think, further down the road to alcoholism. – 45-year-old female.

> They have the potential to succeed at that task. They cannot – but then it needs to be nurtured in order to develop. So they have the potential sitting there, it's built in, but something's got to make it work, environment, parents, somebody's got to make it then come out and work. – 52-year-old female.

> Genetic is just a skill that you're able to do. If you're a good . . . if you can throw a baseball or pitch a baseball or field a baseball or shoot a basketball or jump high hurdles or swim or hammer a nail or skip or jump rope or ride a bike, you know those kinds of skills. You're born with those kinds of skill. . . . What I'm saying is though you are born with those skills but the community around you, the people around you will further develop those things right. – 51-year-old male.

. . . The Basis of Physical Characteristics

> Well that's with your body structure itself. . . . Let's see . . . well it's your body structure. My great uncle, he I guess has a bigger build than just about anybody in our family, whereas my dad, my pap, my uncles, they have a slender masculine build where my great uncle, I'm not sure where he gets that from. You can consider that genetics. – 22-year-old male.

> I think that when we're talking about genes we're talking about appearance, about features, about size, eye color, body build that kind of thing. – 66-year-old female.

> It's genetic when you look like someone in your family. – 24-year-old female.

. . . Inborn

> That was determined by the sperm and the egg, the genetic material that the sperm and the egg from which we came. I mean it's inherent . . . and there isn't anything that we can do at least at this point to change it. – 61-year-old male.

> It's inborn. You're born with those genes you know . . . you inherit most of what you are, I think. It's like a drug addict; you're co-dependent . . . you're born with it, that's all I can say. – 68-year-old female.

> I guess it would be something that's kind of ingrained in the person. It's passed on, not a learned thing. . . . Well its kind of inherent in the person based on the mother and father, you know, the gene pool. . . . It's inherited. – 34-year-old male.

. . . Learned Characteristics

> Education, yeah, I suppose you can consider education partly genetics. – 22-year-old male.

> I think it's genetic because that's where I got it from, my mom taught that [trait]. . . . It's something that's passed down from generation to generation. If your parents were taught by their parents, if—if their genes were healthy and wholesome and they taught healthy

> and wholesome things, they passed it down to their children and you passed it down to your children, and it goes on. – 45-year-old female.

And Other Miscellaneous . . .

> You have this set of chromosomes and genes, and the way they happen to be laid out for you. Which of course I think it's the stars, where the stars are situated in the heavens. Yes, the time you were born. Well certain types of people born at different times of the year have different attributes. – 80-year-old female.

> It's like you're a computer and that chip is in you. – 32-year-old female.

> Genetic is something that you get from both parents. As far as just growing up, your brainwave, your body wave, it's just genetic—what you get from both of your parents. I mean, like genetically, like I guess they say no two minds think alike, but as far as brainwaves, it's thinking alike. Your parents, it's just thinking alike basically. – 34-year-old female.

> Okay, let's take Grant Hill for example. His daddy . . . played football for the Cowboys. His son plays basketball for the . . . Detroit Pistons, so that he . . . got some of whatever his father had . . . through genes I guess. Genes, yeah. – 40-year-old male.

> Like if someone—they do a certain thing all the time. And every family member that he has . . . does the same thing. . . . That's what I mean, that would be genetic. – 27-year-old female.

The Location of Genes

Responses Concerning Parts of the Body

When considering the location of genes, many drew on personal experiences (e.g., in lymph glands as one respondent considered a genetic basis for lymphatic cancer) and/or considered what they felt was the most important body part or tissue associated with human life (e.g., in the brain or mind because it "controls" the body) in answering the question. As shown in Fig. 1, 24% of responses indicated that the brain and/or mind was the main location of our genes. Thirty-four percent of responses reflected the belief that genes were in every cell or throughout the body. Finally, 14% mentioned genes in association with DNA or chromosomes.

Responses Concerning Metacognitive Knowledge

Participants varied in how much they seemed aware of their own misunderstandings; therefore, it appeared important to code their responses in terms of their metacognitive knowledge. As mentioned above, we found three metacognitive themes: (a) being certain of and accurate in their knowledge, (b) being conscious of their lack of knowledge, and (c) being unaware of their ignorance or misunderstanding. The first theme in this metacognitive category was general certainty in one's knowledge and a corresponding overall accuracy. The second theme was the knowledge of one's own uncertainty or confusion. The third theme was general certainty in one's understanding despite the lack of accuracy of the information. Several responses did not fit cleanly into any of these categories, having inherent contradictions within the response and/or having both correct and incorrect elements. The following are representative responses of each of these themes.

Some Knew That Genes Were Located in Nearly Every Cell

> Everywhere. In all your DNA. All the cells. – 80-year-old female.
>
> I just thought it was your whole makeup. So it was in every single chromosome, everywhere, all over the place. I didn't think it was in one spot, one location. It's your whole being. – 52-year-old female.
>
> Well they're located in every cell. I mean that's a chromosome. We have a given number of chromosomes . . . and that they don't all obviously all operate in every cell. – 61-year-old male.

Some Knew That They Did Not Know Where Genes Were Located

> The gene—genes are located—I guess—let me think. Genes are located. . . . Okay, I don't even know where genes are located at. I guess—I don't know, I guess when—when the X and Y, whatever those are genes, genetic genes that's inside—I don't know. I mean are you getting what I am saying? Do I have to spell it? – 27-year-old female.
>
> I started to say the brain, but then again, I think I don't know. I think it might be through the whole body. . . . Your brain and I don't know, it might be. It might be in the blood. – 43-year-old female.
>
> I couldn't tell you that. I don't even know. – 40-year-old male.
>
> I think it's just . . . I don't know how to say it. . . . Oh boy, science questions. – 27-year-old female.
>
> I don't know, the tailbone. . . . I have no clue. . . . They're there . . . somewhere, because they keep tracking them. – 45-year-old female.

Some Thought They Knew, but in Reality Were Incorrect

> It's your makeup, it's your mind, it's—it's in your head. In your—in your head. It's in your brain. It is—let me see, is it the cere—cerebrum or the cerebellum. It's one of the two, I can't remember. Now you're taking me back to science class . . . brain stem, brain stem. – 45-year-old male.
>
> I don't think it's a part of a body, but it's a cell in the brain. I say the brain. – 34-year-old female.
>
> It's the way you think and I would say in the mind. – 29-year-old male.
>
> The majority of genes are located in your brain. – 34-year-old male.
>
> I'd imagine in the vagina area of the woman and penis area of the man. – 40-year-old male.
>
> The bloodstream. – 33-year-old female.

Other Interesting Responses . . .

> When I think of genes I think, I just visualize a whole person. I see a person from head to toe and I see things that are very apparent, such as hair color, eye color that they may have

> gotten very clearly from mom or dad and then there are things that are not so visible on the outside, personality traits. – 42-year-old female.
>
> I'm not a doctor but the mind set from the sperm to the womb to your body . . . the mind you know. As a man think [sic], so he is. I don't know how. It's in your blood. You know, that's your DNA. It's all filtered in your whole fiber, in your whole body. – 40 to 50-year-old male.
>
> In their blood and in their brains. Might even be in their heart and in their organs and in all their bodily organs, you might have this [sic] genes in them. – 24-year-old female.
>
> Genetic, that's in every cell in your body. We could have a ten hour discussion over that question. If I had to pinpoint a specific location it would either be a toss up between the heart and the head. – 43-year-old male.
>
> I think they're located in everything. They've proven that this, I think there's 32 genes and out of everything that's made up there's—there's millions of DNA and each DNA has genes. . . . – 37-year-old female.

DISCUSSION

Over the past decade, the terms "genes" and "genetics" have become more widely used by the lay public in casual conversation and in the mass media. It is heartening that many participants in our study had at least a rudimentary knowledge of these scientific concepts. However, we found that many people also demonstrated limited understanding or unclear usage of the terms. Some respondents independently mentioned DNA or chromosomes, but often their use appeared to be simplistic and inconsistent with current scientific knowledge. This is evident from the woman who described to us the 32 genes we have—instead of 46 chromosomes. Several people also explained "genetic" by giving examples of inherited traits, and then went on to explain learned characteristics; for example, the woman who told us that a trait was genetic because she learned it from her mother. In their definitions, these respondents tended to imply that genes and the environment are intimately intertwined. This may illustrate that the public does have some grasp of the complexities of gene–environment interactions, but may also explain, in part, some of the difficulty many respondents expressed in response to this question. Given that "inherited" means different things to different people, its current usage in clinical, academic, public health, public education, and other settings may not adequately convey the intended meaning unless it is clearly defined. Even when talking exclusively of "inheriting a genetic disease," many people do not understand how something could be inherited yet never before seen in their family, as in the case of a recessive disease (Chapple *et al.*, 1995).

Our glimpse of people's ideas about where genes are located in the body and of what "genetic" means to them suggests that confusion among individuals may impact their understanding of more complex genetic concepts and phrases commonly used including gene therapy, genetic discrimination, and genetic testing, among many others. If one does not understand that there are genes in virtually every cell of the body, how can one grasp the concept of gene therapy? Furthermore, the efficacy of genetic counseling would be drastically reduced if clients were incorrectly understanding new information due to particular beliefs that they previously harbored about the inheritance of genetic material. Theory and research concerning metacognition (i.e., thinking about thinking, knowing about knowing) suggest that it is easier to educate individuals if they realize that they do not currently understand the new material, or if they know their current understanding is flawed, than it is to educate them if they are unaware of their misconceptions (Brown, 1987; Garner and Kraus, 1981/1982; Renner and Renner, 2001). The biggest challenge to health care professionals is to pinpoint this third category of people: those that do not realize their current understanding is inaccurate. For example, some clients may think that they will inherit a particular disease only if they physically resemble their affected relative who had the disease. Given this frame of reference, a person who looks more like their mother than their father may think they have no reason to worry about inheriting the Huntington's disease their father had. These types of lay beliefs can make it difficult to assimilate contrasting scientific information (Richards, 1996; Richards and Ponder, 1996). Misconceptions should be dealt with in the genetic counseling session, to make sure clients accurately comprehend the information given to them. Our results suggest that in order to optimize the benefits of the provider–client encounter, health care professionals may need to better assess the client's beliefs and comprehension of not only medical information, but relevant scientific concepts as well.

It is apparent from this study, however, that merely asking a person about familiarity with genetic concepts may not be sufficient given the number of people who felt certain about their answers despite providing responses that reflected ambiguity or misunderstanding. This point is also supported by the fact that earlier in the interview, all respondents who were asked about the genetic components of traits were willing to give answers (i.e., none asked the interviewer "What does 'genetic' mean?" before they replied). However, at the end of the interview when asked specifically about their definition of genetics, only some appeared to express a firm concept of what "genetic" meant. In addition, some used scientific terminology but applied it incorrectly, even if confidently. In fact, many respondents who used scientific terms seemed to be more confident in their answers than those who did not use them, even when they used them inappropriately. It is possible that some respondents were poor at assessing how closely their knowledge conformed with that in the scientific community because many people assess their general level of familiarity with a topic rather than their specific knowledge (Glenberg *et al.*, 1987). These findings suggest that health care providers ascertain a patient's deeper understanding of genetic concepts and terminology in order to avoid confusion and misunderstanding.

In the case of genetic terminology, many respondents have some limited comprehension despite widespread conversational familiarity. The public has frequently been exposed to genetic terms more and more often in the media, in casual conversation with friends and family, and in a variety of educational settings, including nonscience courses. Such exposure likely results in respondents feeling comfortable hearing and using these terms when voicing their opinions, even when they may not know the scientific meaning of the terms, a phenomenon described by Park (2001) as the "illusion of knowing." Given this, the public may not realize the benefits of a fuller understanding of genetics through education. However, because genetics will soon be a very intimate part of their healthcare, there is likely a great need for genetic science education, for both the public and health care providers (Emery *et al.*, 1998; Suther and Goodson, 2003). Despite the growth of many excellent educational resources in genetics, including widely available Internet sources and innovative school programs (Munn *et al.*, 1999), these resources may not be widely embraced by those who lack awareness of their misconceptions or who fail to realize the importance of genetics as related to their own lives.

Currently, genetics education often begins with teaching Mendelian genetic concepts, as they are relatively simple aspects of this complex discipline to teach (Trumbo, 2000). Even if people grasp and understand these basic concepts, the impact of this knowledge will likely be limited. In fact, although this knowledge may help a client who comes to a genetic counselor in search of additional information about a familial Mendelian genetic disease, it will not go far in helping the layperson understand the barrage of genetic information to which they are exposed through the media—the vast majority of which deals with complex diseases and traits. Beyond multifactorial inheritance, it would also be important to teach about gene/environment interactions, and to make sure it is understood to "look to genetics as an important contributor, not as fate" (Trumbo, 2000). An even simpler hindrance to the understanding of genetics is that the heritable "substance" is not easily grasped (Richards, 1996). Without this important piece of information, it would be difficult to make the leap to inheritance of genes through independent segregation—just because you do not look like your mother with the disease, you could still inherit it because the genes that contributed to her height and hair color are not necessarily near the deleterious disease-causing gene. Given that a sizable portion of our respondents lacked a basic understanding of human genetic concepts, we speculate that many Americans will have difficulty assimilating more complex genetic concepts when making health care and reproductive decisions.

Francis Collins, Director of the National Human Genome Research Institute, projects that by 2030, comprehensive genomics-based healthcare will be the standard of care, as will the existence of genetic applications in preventative medicine (Collins, 1999, 2000). Most primary care physicians spend an average of 16.3 min/patient (Blumenthal *et al.*, 1999). If in the future, doctors have the same time constraints, yet also incorporate a battery of genetic tests into their medical arsenal, how will they effectively offer genetic counseling or obtain informed consent, given limited genetic understanding by the public (and physicians)? Furthermore, if patients do not ask their doctors key questions, they will fail to gain an adequate understanding of their genomic-based health care. An initial assessment of individuals' understanding of genetic terms and concepts may be beneficial to help determine what, if any, misconceptions exist that may limit their ability to make appropriate and informed decisions about health needs in the context of the new genetic era.

Although further education would be predicted to enhance understanding of basic genetic concepts and positively impact informed decision making in clinical settings, education alone may not be enough. Although it is often hypothesized that the scientific literacy of Americans is poor and hinders their decision-making ability on scientific issues, studies suggest that negative reactions to new genetic technologies are not always related to level of education or lack of understanding (Condit, 2001; Doble, 1995; Laugksch, 2000). Research also suggests that some individuals do not necessarily need to know about genetics to trust new technologies, they just need to be able to trust regulatory agencies and the moral codes that guide those agencies (Condit, 2001). However, Western medicine is guided by ethical principles that emphasize patient autonomy and informed consent. The only way patients can truly attain such autonomy and make appropriate health care and reproductive choices for themselves is by being fully informed. More education and a better understanding about genetics are likely, therefore, only to enhance these goals. This reiterates the importance of a medical workforce sufficiently educated in genetics to help clients become adequately informed, as genetic-based medicine, such as pharmocogenomics, becomes more mainstream.

In summary, this study provides further evidence to support previous research demonstrating that misconceptions about genetic science are not infrequent in the general public, and suggests the need for improved genetic literacy and understanding. We acknowledge that we examined a small sample of the public's beliefs, as this is not a comprehensive study, but we do believe these data are demonstrative that more research is necessary in this area. In particular, it suggests the need to investigate systematically, the character and extent of the public's understanding of various genetic concepts in large, representative samples. Our work also raises two important questions that future research should address. First, how do we, as counselors and educators in the field of genetics, determine the general level of knowledge that is adequate for informed medical decision making in the public domain? And second, what are the consequences associated with having this general level of knowledge? Even though our research does not address these issues, it increases awareness of the critical value of and need for such exploration.

Although the questions we have focused on in this report are limited to two, examining these questions allowed us to begin assessing individuals' understanding of concepts that may provide a foundation for genetic knowledge. Despite common conversational use of genetic terminology among members of the general public, we found that many individuals responding to our survey had a limited understanding of basic genetic terms and concepts, in addition to some misconceptions about them. Given that these factors may negatively impact medical practices and patient care, it will likely be important for all health care workers, not only geneticists and genetic counselors, to appreciate and consider how their patients think about genetics, in order to tailor genetic counseling and education efforts and facilitate informed genetic decision making.

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