

The Media and Public Reaction to Genetic Research

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THE MASS MEDIA ARE PRIMARY SOURCES OF HEALTH AND SCIENCE information for many Americans, including scientists and physicians.¹ Discoveries of new disease-related genes have appeared regularly in the print and broadcast media. In our survey of the public's perception of the media coverage conducted immediately following the announcement of the near-completion of the sequencing of the human genome in June 2000, over half of the respondents reported some exposure to media coverage of the event.²

Despite widespread media coverage, the public may not be well informed about genetic discoveries. Media stories may omit important facts that can lead to misconceptions among the public about the applicability of genetics research. For instance, media reports may neglect to mention that the discovery of major susceptibility genes for common diseases such as breast and prostate cancer probably pertains to only those patients with early onset and a strong family history of the disease in question.³ Moreover, mass media reports about the discovery of genes for rare diseases may inappropriately extrapolate the results to common diseases or fail to highlight the long lag time between the discovery of a disease-related gene and the development of tests and treatments for the disease.⁴

On the other extreme, media coverage that focuses on the negative aspects of genetic discoveries may lead consumers to fear their application. For example, the media commonly report on the dangers inherent in genetic research such as insurance or employment discrimination, and the possibility of genetic enhancement and "designer babies." In our survey, the most frequently mentioned concerns about the sequencing of the human genome were privacy violations/discrimination (15.7%) and cloning (13.5%).² The concern about cloning is interesting in light of the results of our content analysis of all media coverage immediately following the announcement about the sequencing of the human genome, which revealed the complete absence of any discussion of the subject.² Nevertheless, there have been widespread media reports of plans to attempt human cloning,^{4,5} which may have colored the way people interpret news about other genetic discoveries.

Some social scientists have argued that such unbalanced coverage can lead the public to believe that traits, behaviors, and diseases are biologically determined.⁶ Others have attempted to refute this claim based on evidence that the media are no more likely to attribute disease to genetic causes now than they were 2 decades ago, despite recent increases in media coverage.⁷ The impact of media coverage of genetics on public behaviors, such as willingness to participate in genetic research, is less well understood. Nevertheless, population research will be necessary to evaluate genetic testing, prevent its misuse, and help to realize its benefits.⁸

Members of the public will need to be knowledgeable about the issues at stake in the Human Genome Project and in scientific and medical research in general⁵ in order to make well-informed and ethically sound decisions about their participation in genetics research, and the use of new genetic technologies. Since much of the public's knowledge about genetics will probably continue to come from the media, it is important to understand the factors that influence how media reports are generated.

Literature on genetics reporting⁹ suggests that the news-making process is complex and multifactorial. Research with positive results may get reported more than often than research with negative results. For example, stories reporting a gene associated with alcoholism got much more coverage than the stories that could not confirm the association.¹⁰ Biomedical scientists and journalists may also have different standards of newsworthiness, communication styles, and visions of the media's role in reporting science news.⁹ Scientists generally do not consider research findings newsworthy until they are endorsed by peers as part of the peer review process. These different approaches may result in media reports that are confusing to the public.

In order to improve reporting, researchers have been encouraged to educate news "gatekeepers" (such as editors and producers) about the true importance of a medical discovery, and scientists and science writers have been encouraged to make themselves available to each other, and to check press releases for accuracy and clarity.⁹ Whether these suggestions will be adopted, can improve the accuracy of media reports, or whether physicians can influence media coverage of genetics remains to be seen.

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