Twice-told Tales: Stories about Genetic Disorders

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Rapid advances in molecular genetics are expanding the ability to screen for genetic differences between individuals that may be associated with their health status, and there is great interest in the ethical, legal, and social implications of this technology. We wish to draw attention to one very specific issue regarding how the public is informed about genetics and genetic differences: the selected messages about health and illness that are transmitted by written materials—and the great potential of such messages to influence attitudes and behavior.

As genetic tests become more widely applied, there will be insufficient human resources to provide genetic counseling and education in the traditional one-on-one approach (Wilfond and Fost 1990). This will likely lead to greater reliance on written materials to inform and educate the public about genetic tests and genetic conditions. While such a shift may seem efficient and appropriate, if not inevitable, our preliminary observations from some ongoing work suggest it is also problematic.

We have independently observed that for two conditions, Down syndrome and cystic fibrosis, the information provided to those who are considering genetic testing differs strikingly from that provided to those who have a child with one of these conditions. In both circumstances, the overall information is correct. However, the before-birth information is largely negative, focusing on technical matters and describing the array of potential medical complications and physical limitations that may occur in children with the condition, while after-birth information tends to be more positive, focusing on compensating aspects of the condition, highlighting the availability of medical and social resources, and stressing hope for the future. Analyses of the full nature and impact of these and other before/after differences are ongoing, but their existence alone merits the attention of those who seek to educate the public about human genetics with written material.

At the least, we must recognize that every description of a genetic disorder is a story that contains a message (Lippman 1991; Lippman and Brunger, in press). The story is the vehicle through which complex and voluminous information is reduced for the purposes of communication between health-care provider and health-care seeker. The message is shaped as the storyteller selects what to include and what to exclude to reduce the amount of information.

Because only some aspects of a disorder can be presented at any one time, the messages will reflect the beliefs and attitudes of the storyteller, motivated by what she or he feels is important to present. In the before stories, we have observed that the dominant message appears oriented to avoiding the birth of a child with Down syndrome or cystic fibrosis. In the after stories, the message is oriented to caring for a child with one of these conditions.

Our message here is not that one story is better or more accurate than the other but that the messages are different. And, because it is difficult, perhaps impossible, to tell more than one story at a time, communication about genetic disorders will always require choice; no single story, however balanced, can ever be neutral or value free.

All written educational materials offered to the public about genetics will tell some particular story. Consequently, we must begin to examine a heretofore ignored set of questions about the educational materials we produce. For example, who should be participating in writing these stories? How should a story be told? Why is there a difference between before and after stories? Should this difference be perpetuated?
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Should we strive to tell the same story to families considering carrier testing and prenatal diagnosis and to families who receive a postnatal diagnosis? Is telling the same story required if we are to provide sufficiently balanced information to allow potential parents to make fully informed family-planning decisions? We hope our colleagues will join us in the analyses and reflections required to answer these important questions.

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References

Lippman A, Brunger F. Constructing Down syndrome: texts as informants. Santé Culture Health (in press)