Author's Commentary on "Forbidden Knowledge"

Commentary On
Forbidden Knowledge

Recent advances in human genetic research have made it easier to identify mutations responsible for rare genetic disorders like BCK. The availability of families like those in Community Z are important for the characterization of these gene defects in order to predict and immediately treat future cases. The main purpose of this case is to stimulate discussion of researchers' moral and ethical responsibility to culturally distinct and/or indigenous populations who engage in population-specific genetic studies in return for improved health care.

The case presents several ethical dilemmas. Although clear-cut answers are not obvious, the research team must make a decision. They must consider all interested parties, including individual community members, the community as a whole, the research team, and, indirectly, the integrity of the research team's institution.

The first issue is whether to screen unmarried couples or individuals even though the elders do not recommend it. In some cultures, the concept of persons as individuals may differ from other societies' definition. Whether the choice of unmarried couples to go against their elders' wishes to be screened is wise, depends on that community member. Certainly, if the research team decides to test unmarried couples who desire screening, it may affect the researchers' relationship with the community elders. This decision could also impact these individuals' decisions to marry -- or never to marry for fear of having an affected infant. However, if the couples are not allowed to be screened until married and it is determined that they are both carriers, knowledge that they have been identified as carriers may have a negative effect on the marriage. In addition, each child they may conceive has a 1 in 4 chance of having BCK. In light of these facts, screening unmarried couples may be best. Because of the high incidence of BCK in this community, it is far better to screen the unmarried couples who desire carrier testing than to deny them.

Another issue raised by this case is respect for the community as a whole by honoring the recommendation of the elders. In the interest of maintaining their relationship with the elders, the research team should provide further education about BCK to the elders and the community, with the hope that the elders will either 1) allow unmarried couples to be screened or 2) arrange for married couples to receive genetic counseling if tests show that both partners are gene carriers.

References

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