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## Forbidden Knowledge

### Year

2000

### Description

This case highlights potential dilemmas encountered by postdoctoral fellows in a research setting. How should conflicts of interest between community well-being versus individual autonomy be addressed within the scope of genetic testing?

### Body

## Background

Like phenylketonuria (PKU), BCK is a significant metabolic birth defect. BCK is inherited as an autosomal recessive disorder, which means that symptoms occur only when both of the individual's BCK genes have a specific defect. BCK results from the body's inability to break down certain components of protein, and its victims must follow a restricted diet, which is the only treatment for the disorder. If treatment is not initiated within the first four weeks of life, BCK patients unfortunately suffer severe neurological damage and will die if treatment is withheld. However, if the affected individuals maintain the special BCK diet, they can live full lives.

BCK is rare in the general population, but it occurs at an alarming frequency in Community Z. Community Z is an isolated closed society, separating itself from the general population by way of religious beliefs and customs. One particular custom

relevant to this case is mate selection, which is considered a rite of passage from youth to adulthood. A young Z male must choose a partner within the limitations and rules of his church, which requires choosing a partner from within his own community based on the church's rules. This practice is strongly enforced by the church elders, who play somewhat of a "go-between" role for the families of the male and his female of choice. For researchers, Community Z provides an ideal model for studying genetic disorders like BCK since it has a "closed" gene pool and maintains extensive genealogical records.

## **Consider the following scenario:**

After the birth of several BCK infants, the elders, who hold distinct roles of authority in Community Z, approach a genetic research team and express interest in genetic screening to identify families at risk of having an infant with BCK and to provide diagnostic testing to enable immediate treatment of affected infants. At the request of the elders, the research team develops a noninvasive DNA test to identify carriers of the BCK allele. (Carriers are unaffected individuals who have only one copy of the defective BCK gene.) During the initial screening, testing is done for all who request it, and results are provided to those who inquire. The majority of individuals tested are married. The elders do not recommend testing prior to marriage.

After processing the samples, the researchers are surprised to find many more carriers than expected based on the number of BCK infants previously born in the community. If the gene pool of a group of people contains certain recessive tendencies, the probability that a child will be born with a recessive disorder such as BCK is greater when the community members intermarry. Although the incidence of BCK is higher in Community Z than in the general population, fewer affected infants than statistically predicted have been born in Community Z. This discrepancy is quite interesting to the research team. The results lead the research team to suspect one of several possibilities. Either some natural phenomenon is occurring that allows more cases of noncarrier/carrier mating than carrier/carrier mating, or perhaps the elders discourage mating between certain families because carrier status is well-known throughout the community.

At this point, the research team is puzzled by these findings. They question whether

providing testing to unmarried community members will affect their relationship with the elders and whether carrier testing will impact future mate selection and somehow intrude upon the cultural and religious norms of Community Z.

## **Discussion Questions**

1. Identify the ethical issues raised by this case. Explain why you think they are ethical issues.
2. Although the elders do not recommend it, would it be appropriate for the research team to provide testing to unmarried individuals when testing may impact mate selection? Are the cultural and religious norms of this community relevant? Explain your reasoning.
3. Is mate selection just a social issue that should not concern the research team? Keep in mind that the team's relationship with the elders is paramount in continuing the study of BCK. Provide an explanation for your response.

## **Notes**

Brian Schrag, ed., *Research Ethics: Cases and Commentaries, Volume 4*,  
Bloomington, Indiana: Association for Practical and Professional Ethics, 2000.

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## **Resource Type**

Case Study / Scenario

## **Parent Collection**

Graduate Research Ethics: Cases and Commentaries - Volume 4, 2000

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## **Publisher**

Association for Practical and Professional Ethics  
Authoring Institution  
Association for Practical and Professional Ethics (APPE)