

Author's Commentary on "Pregnancy Results?"

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Pregnancy Results?

Collection of human samples in epidemiological studies has increased over the years, especially with the emergence of biomarkers as clinical indicators of outcomes (in this case pregnancy). This case is a good one for new students who may not know whether researchers should inform research participants of their test results. The case is designed to provoke discussion regarding the release of test results to participants, the use of consent forms, and the problem of conflict among committee members.

The case begins by introducing the basics of the study, but only for the female participants. Deliberately, the first paragraph mentions the female role in the study, but subsequent paragraphs gravitate back to the couple. Even the first two questions use the word "couples" instead of female participant. Keep this distinction in mind when discussing the case.

Question 1. Should Wilma notify the couples about their pregnancy test values? Does Wilma have an obligation to inform all participants of their results, as Ready suggests?

Immediately, most new students will say that this is an easy question. Of course the couples should be notified about their test results. Re-emphasize that these test

results will be coming to the participants at least a year after the fact. Ask how the results should be reported to the participants: as quantitative values? as qualitative values? What kind of explanation should accompany the results? Then start to play on emotions here. What about couples that had pregnancy losses? How will you inform them and explain their results? Should discussions with these couples differ from discussions with couples who had successful pregnancies?

Next, direct discussion away from the couple to the female participant. "What if the female participant does not want to know her results? Do we send them to her anyway?" At this point, the role of the consent form should be considered. Help the students come to an understanding that on the consent form, a box can be checked off specifying whether the participant wishes to receive test results. This box should be preceded by a paragraph describing the testing procedures that clearly informs that participants what kind of results will be available.

Another discussion can arise from this question: "What if the female participant does not want to know her test results, but her husband or partner does? Does he have a right to the test results?" Again, this question points out the ambiguity of a study based on couples in which individuals provide data.

Question 2. Is there any medical benefit in informing couples of their pregnancy results?

Most couples experiencing infertility receive a recommendation to see a specialist after 12 months of unsuccessful attempts at conception. The research results would be beneficial for the doctor, especially if an early spontaneous loss occurred. This result would indicate to the doctor that the couple is able to conceive, but is having problems maintaining the pregnancy.

Question 3. How should Wilma handle the conflicting opinions of her

committee members?

When researchers work together, conflicting opinions may appear. However, conflicting opinions among committee members can cause panic for students. The following are some suggestions based on one institutional perspective. Adapt the discussion to your own institutional practices.

Deliberately, the case does not indicate that Knowledge offered an opinion. He is Wilma's adviser, and Wilma should utilize him when conflicts of this nature occur. Wilma and her adviser should discuss the opinions of her committee members and make a decision together. Ultimately, establishing a compromise, as suggested with the check-off box on the consent form, will help in Wilma's situation. What if Ready is not willing to reach a middle road, but still believes that all participants should get a copy of their test results no matter what? Again, the student should ask the advice of her adviser. Knowledge needs to back his student.

Ultimately, the committee is composed of individuals chosen by the student. The student has a right to dismiss anyone from his or her committee. This step is recommended only as a last resort.