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A Knotty Problem of Intertwined Rights

Ross E. McKinney Jr, MD

Duke University School of Medicine

One of the most challenging problems for ethicists is a situation where there are multiple actors, each of whom has rights and fair expectations, and those rights do not squarely align. In this case, there are at least four main parties. To start with the encompassing set of actors, we should consider the rights of the parents, particularly the mother, the child (now a teen or adult), the investigators, and the future sexual partners of the child.

The first actor to consider is the parents. There is little question the mother of the child is HSV-2 infected, given the route of neonatal HSV-2 transmission. In most cases, the mother acquired HSV-2 as a sexually transmitted disease. This mode of transmission makes HSV-2 societally stigmatized, with the further result that parents may not want to discuss the mother's HSV status with their child. It's harder for a parent to hold their child accountable for sexual behavior when there is clear evidence that when one or both parents were in the same position, they failed at least once to choose or effectively use barrier protection. In essence, in failing to protect themselves from a sexually transmitted infection, parents lose the moral high ground, and their sense of authority may erode as well.

My interpretation of the failure of parents to recruit their adult children for the study is that it's most likely they didn't want to have a difficult discussion with them about where the HSV-2 originated in the family. So the first set of rights has to do with the parents' privacy, even within a family.

The second actor is the adult child, who has the right to their own medical history and the right to make medical decisions based on it. If the adult children are, for example, shedding HSV-2 from their genital mucosa, they may opt to suppress the virus using acyclovir or a similar medication. The adult children can choose how to handle their sexuality with more knowledge of their HSV status, including the potential for abstinence. And while the risk is extremely low, a pregnant woman might want to know about her HSV-2 status to prevent transmission to her child.

The investigators don't intrinsically have a right to discuss the case with the adult children, given all of the privacy concerns. Instead, their most important role is to represent the interests of the class of people who had HSV as an infant and who might want to know their own status and potential contagiousness. I believe it has been a significant misconception to believe that the investigators are doing research primarily for their own good, whether it be for fame, grants, money, or curiosity. Instead, their most important role is to represent the

broad needs of affected subjects, who would like to know more about their condition generally and, perhaps, about their own situation personally. It can be argued that the investigators are self-appointing themselves to be those representatives, and that by such self-appointment lack real authority. However, despite advances in community-engaged research, it is unlikely that anyone from a class of patients such as grown perinatal HSV-2 survivors could find a mechanism to self-represent in a situation like this one. Thus, investigators do play a key role, checked by IRB or ethics board review.

The final set of actors in this hierarchy of rights is the future sexual contacts of the infected adult children. While some might argue that the general *caveat emptor* that relates to sex with anyone applies, I would argue that the risk of HSV transmission can and should be minimized whenever possible. And in this case it is possible.

While the actors can be defined, the challenge is to sort the rights in some type of reasonable order. Among the actors, I believe the infected child intrinsically has the highest status in this case. First, the infected children, now teens and young adults, deserve to know their own condition, and to control their own sexuality and fertility. They should know whether they have the potential to infect another person, hopefully someone about whom they care. The question of shedding is an open one, scientifically, so the information is useful both to the infected individuals, and to the class of people perinatally HSV infected— an increasing number with more effective perinatal treatment. Counterbalancing this right are a few factors: the probability of shedding is most likely low, HSV-2 is present in the community and might be acquired by other means, and the probability of a second generation of mother-to-child transmission also seems very low. In short, the self-knowledge is useful, but probably of marginal utility in a situation with basically low risk. The right to know, however, is substantive.

Prioritization of the infected adult child would seem to argue that the investigators should be able to contact the adult children directly. What are the costs if that approach is taken? Almost certainly, the biggest issue is how the now-adult children will view their parents. They now know that their mother was HSV-2 infected. They may also learn that there was important medical information withheld by their parents, who either didn't consider it important, or prioritized some aspect of their parental role and self-esteem (i.e., their own medical privacy) over the health rights of their child. We don't know why parents did not act to contact their children when asked, but some aspect of the privacy and respect equation seems most likely.

As a final note, there is another important counterbalance to the rights of the adult children and their sexual partners. Through the act of doing this research, particularly if contact is with the adult child, the investigators potentially have perturbed the current relationship between the parents and their child. The investigators have done this through what is essentially an intrusive step, contacting the adult child with whom they do not really have a relationship (the age of the research relationship was one where the investigators would be interacting with the parents). The failure of the parents to refer the investigators to their child is empirical evidence that the parents did not want to alter this aspect of the parent-child relationship. So I would judge that the new information to be gained is not a sufficient

justification to intervene between parent and child, and so I would work harder to communicate more effectively with the parents so that they understand the importance of this information for their child, while at the same time the parents have an opportunity for an honest conversation, even if it is a difficult conversation to have.