**Postprint**

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# Clinical Genetics and the Problem With Unqualified Confidentiality

Duncan, R. and Newson, A.J. (2006)

In his article "A Defense of Unqualified Medical Confidentiality," Kipnis provides a persuasive argument as to why maintaining unqualified confidentiality is the most effective way of preventing harm to third parties in the health-care setting (Kipnis 2006). However, difficulties emerge when it is applied to the field of clinical genetics. The familial context of clinical genetics means that routine sharing of information is a fundamental aspect of good clinical practice. We argue that, reflecting this premise of sharing information in clinical genetics, the most effective way to prevent harm to third parties is to advocate a "qualified confidentiality."

In making this claim, we challenge two assertions Kipnis relies upon in his argument for upholding unqualified confidentiality: 1) that unqualified confidentiality combined with attempts at "creative" means to elicit disclosure to at-risk third parties is the most effective way to minimise harm; and 2) that under unqualified confidentiality, individuals will actually become more likely to take responsibility for their own actions and health (Kipnis 2006, 7).

We illustrate this challenge with reference to the following Case of The Ill Father:

> *Steve and Jenny separated 10 years ago but still see the same doctor. Their daughter Kate is 16 years old and lives with Jenny, along with a younger brother and sister. Recently, Steve has been diagnosed with a form of bowel cancer called Familial Adenomatous Polyposis (FAP), a genetic condition that causes small polyps to develop in the bowel. These polyps develop into cancer if left unchecked but screening and surgical intervention reduces morbidity and mortality. Because Steve carries the FAP gene mutation, Kate has a 50% chance of inheriting it as well. If she knew of this risk, Kate could choose to have a genetic test and if positive, commence annual screening. However, Kate is not aware and Steve has said he does not plan to tell her.*

Dilemmas like these are experienced by many professionals in clinical genetics, with studies reporting that almost half of genetic counsellors and 60% of clinical geneticists have had a patient who refused to notify an at-risk relative (Dugan et al. 2003; Falk et al. 1998). Despite these figures, failure to tell third parties has been estimated to occur in only a fraction of the total number of consultations, and breaching confidentiality to warn at-risk relatives occurs very rarely (Clarke et al. 2005). This suggests that the qualified confidentiality already operating in clinical genetics is

effective; individuals are certainly not put off contacting genetics services even though their information may be shared.

The case of The Ill Father is different from The Infected Spouse in two ways. First, FAP is a familial disease. When genetic information is revealed about one person there are inevitably implications for other genetically related family members. Second, not every individual in the population is at risk of developing FAP whereas, theoretically, every individual is at risk of contracting HIV. In other words, all individuals should be aware that, if they engage in risky behaviors, they may contract the HIV virus. Only the small proportion of people with the relevant gene change will manifest FAP. Thus for genetic disease, even if individuals take responsibility for their own health they necessarily rely on relatives to become aware of their 'at-risk' status. We now consider each of these differences in turn.

Consider Kipnis's utilitarian claim that if unqualified confidentiality is made routine, more third parties will be helped than when confidentiality is qualified. He argues that, if confidentiality is qualified, people such as Andrew (from The Infected Spouse) will not present to doctors for fear of their information being shared. Thus, there will be no opportunity for doctors to prevent harm to third parties. However, if confidentiality is unqualified, people like Andrew will continue to present for treatment and, as some individuals may be "creatively" persuaded to disclose information to at-risk third parties, more harm can be prevented (or more third parties can be helped). The strength of Kipnis's argument relies on the assumption that when confidentiality is qualified, people will cease presenting to their doctors.

However, we believe that an alternative assumption is equally plausible. If individuals are aware that their information will be shared with at-risk third parties and they do not wish this to occur, they have to make a choice weighing two options. Option 1 entails presenting for treatment and having information disclosed to third parties. Option 2 entails forfeiting treatment but ensuring their information will not be shared. It is not clear that all individuals will choose option two, as Kipnis seems to assume.

Given the familial nature of genetics, under qualified confidentiality it is also likely that for every person who does decide to attend clinical care, more than one additional person will be helped. For example, in the case of Steve, if information is shared his three children will be helped (as will any of their future children). Therefore, under qualified confidentiality it cannot be assumed that most people will stop seeing their doctor. In fact, in the case of genetics it may be equally plausible to assume that most people will continue to see their doctor. Further, under unqualified confidentiality it cannot be assumed that more third parties will be helped.

The second difference between The Ill Father and The Infected Spouse is risk status. All individuals in the population should theoretically be aware that they have a chance of contracting HIV if they engage in risk activities such as unprotected sex. However, for certain genetic conditions like FAP, this is not the case. Individuals are only aware of their risk status (and therefore eligible for predictive testing and screening) if they know the condition runs in their family. Thus, this is not a risk that one can leave to individual awareness and responsibility, as is possible with HIV.

Clinical genetics services tend to operate using a 'familial' model of health information. Although explicit data (for example, a particular individual's mutation status) is kept confidential as much as possible, health information is routinely kept in family files and shared, with permission, amongst

other family members. Although this conception of health information—the "joint account" model—is not unproblematic and is certainly not the only model used, it may provide an appropriate starting point for the provision of clinical genetics services (Parker and Lucassen 2003, 2004). Genetic information is not shared only when a significant harm can be foreseen by the person wishing to maintain confidentiality.

This familial model, when related to the Case of The Ill Father, means that the default position would be to disclose the information to Kate (supposing, of course, that she is mature enough to understand its gravity). If Kate is not informed of her risk status, she is unable to engage in preventative measures to avoid the manifestation of bowel cancer. Further, if she is informed, the information may not only help her, but also her brother, sister and possibly her future children.

Unqualified confidentiality, we suggest, is not an appropriate default position for policy-making in the setting of clinical genetics. It is not obvious that more people will be helped (or less will be harmed) if such a policy were employed. It is also likely that in cases where people do come forward for testing, and information is shared with other family members, several people will be helped for every one person who comes forward for testing, increasing the number of people who are helped (or for whom harm is prevented). Second, disclosure of such information to other family members is the only means these individuals have of engaging in predictive testing and preventative measures. At least so far as single-gene genetic conditions are concerned, they have no "population risk" and so no other way of finding out that they are at risk. These two factors render the context of clinical genetics relatively unique. They also make the clinical genetics setting different enough from the scenario presented by Kipnis to warrant an alternative policy.

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