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9.6 Case 1: To Reveal or Not to Reveal Potentially Harmful Findings: A Dilemma for Public Health Research

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This case is presented for instructional purposes only. The ideas and opinions expressed are the authors' own. The case is not meant to reflect the official position, views, or policies of the editors, the editors' host institutions, or the authors' host institutions.

9.6.1 Background

In 1987, African health ministers met in Mali to address access to quality primary health care, particularly in rural areas (Anonymous 1988). The resulting Bamako Initiative promoted universal accessibility, though it drew some early criticism for its support of user fees (McPake et al. 1993). For the next decade, user fees were implemented in many African countries to finance health care services. The World Bank supported the measure as part of its Structural Adjustments Programs, which also included austerity measures, trade liberalization, and privatization (McIntyre et al. 2006). However, user fees have since been shown to create access barriers that tend to affect the poor disproportionately (Macha et al. 2012), suggesting that many vulnerable individuals have been prevented from accessing needed health care services. Against this backdrop, mounting international pressure led to the reform of many user-fees programs, particularly in the last decade. One primary strategy for increasing health care access has been the introduction of selective exemptions of user fees for specific groups (Ben Ameur et al. 2012; Meessen et al. 2011; Ridde et al. 2012). Although this strategy was originally planned in the Bamako Initiative, it was not uniformly implemented. Given the scale of the changes that user fees removal implies for health care systems, there is ongoing research to evaluate their impact (Lagarde and Palmer 2011). Health system investigations such as these may raise ethical questions (Hyder et al. 2014), especially since they involve the study of a public health intervention, often focus on individuals in extreme poverty, and tend to be international and collaborative in nature.

Collaborative international public health research offers the opportunity to build local capacity (Mayhew et al. 2008). However, such research raises a number of issues about researchers' obligations and responsibilities. First is the responsibility to protect research participants from harm, an obligation recognized by all research ethics guidelines. This duty of protection is heightened when the research participants are from vulnerable populations (Hurst 2008), especially when they are recruited from extremely impoverished populations. Researchers' responsibilities toward research participants also include ensuring that they benefit from the results of the research whenever possible. For example, the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* directs that "any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community" (Council for International Organizations of Medical Sciences 2002, guideline 10). A second researcher responsibility is to support students and staff hired as part of the research project and to protect them from harm (Wilson 1992). This responsibility can be thought of both as the duty of an employer and the fiduciary duty of an academic supervisor and must extend to situations of whistleblowing. Third, researchers involved in collaborative research have a responsibility to colleagues and collaborators, especially given that research may play a crucial role in capacity building (Garcia and Curioso 2008). Although partnerships with local researchers have been touted as highly valuable (Costello and Zumla 2000), these ties may also result in unexpected ethical dilemmas for local researchers if conflicts arise

between their research activities and their established local obligations and responsibilities (Richman et al. 2012). A fourth responsibility of researchers is dedication to the research enterprise. The conduct of public health research can have significant implications for the well-being of large segments of the population, but it requires the trust of the public and of relevant authorities. Endangering the relationship of trust in the context of one specific public health study may jeopardize or ruin other research initiatives (Corbie-Smith et al. 1999). Finally, a fifth responsibility of publicly funded researchers is their duty to the public in whose name they conduct research. Good stewardship requires that researchers strive to maximize the relevance and usefulness of their efforts and that they disseminate their findings (Arzberger et al. 2004). Researchers conducting collaborative international public health research may encounter ethically challenging conflicts among these five lines of responsibilities.

9.6.2 Case Description

Dr. Milena A. is the principal investigator of a large research program that is examining approaches for decreasing inequities in access to health care services in a low-resource setting. She works for an American university, and her research is funded by a U.S. agency. One member of her research team, Dr. Timothy N., is a local physician studying toward a public health degree at Milena's institution. He is back in his country after finishing his coursework and is ready to conduct fieldwork research. Timothy has taken leave from his position at a local hospital to pursue his studies and, although he wants to continue his clinical work at the hospital, he also wants to expand his focus to include population-level health issues and, eventually, work with his country's ministry of health. His studies are co-funded by Milena's research grant and by the ministry of health.

Timothy's research consists of an examination of the impact of his country's recent abolishment of health care user fees for children younger than 5 years. User fees had been implemented uniformly in the 1990s without special consideration for poorer families with young children. Initial indicators suggest that health care services continue to be underused in some districts, especially by poor children, despite the recent removal of user fees. Despite the limited uptake, the ministry of health touts the policy abolishing user fees for children younger than 5 years as an important success. Timothy is conducting his study at several urban health centers, including the hospital from which he is currently on leave. The research project has received ethics approval from Milena's institution and from the relevant local review boards.

Recently, Timothy requested a meeting with Milena saying that he needed advice. He reports that he has identified a system of informal fees that undermines the ministry of health's official policy by making health care once again too expensive for many families with young children. From what Timothy understands, the fees are levied primarily to fund better obstetric care locally, but some indicators point toward senior administrators keeping a small share for themselves. Timothy worries that making his findings public is too risky for him, especially since his involvement in this fieldwork is well-known. He does not think it possible to share

his findings without identifying himself as the source of the information. His hospital is one of the sites where he has identified the system of informal payments. He also has good reasons to believe that some members of the ministry of health are already aware of the situation but have not taken action to address it. Disseminating his results will jeopardize his employment at the hospital, his relationships with government officials, and, potentially, the plans to improve obstetric care.

Milena is also conflicted. She recognizes that she has multiple roles, responsibilities, and interests, and that individual and communal goods are at stake. Identifying and seeking to address informal payment structures could improve accessibility of health care services for children, which is the primary goal of her research program. However, the team has responsibilities to Timothy as their student and colleague. Demanding that he upend his career, either for their benefit or for the improvement of health care accessibility, might fail to respect him as an individual. In addition, bringing the situation to light could embarrass the ministry of health. Because the research program depends on the ministry of health's authorization, tensions in relationships could lead to premature termination of the research. Such an event would have unpredictable outcomes on the careers of everyone on the research team and on the future of health care accessibility locally.

9.6.3 Discussion Questions

1. How should Milena and Timothy prioritize their responsibilities, and what should they ultimately do?
2. What preemptive actions could the research team have taken to limit the likelihood that the situation described above would happen?
3. How should the fact that, aside from Timothy, the research team members are not citizens in the country where they are conducting research be considered in the assessment of their obligations?
4. Is this a case where developing partnerships with local researchers might be counterproductive? Or, could a more robust partnership with local researchers have positioned the team to better address this issue?
5. How would the ethical analysis differ if, instead of identifying unequal access due to informal fees, Timothy had observed that those exempted from the fees were being offered a lower standard of care than patients whose fees were not waived?

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