Hidden costs: The direct and indirect impact of user fees on access to malaria treatment and primary care in Mali

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A R T I C L E   I N F O

Article history:
Available online 1 August 2012

Keywords:
Mali
Health financing
Fee-for-service
Access to health care
Health seeking
Primary health care
Malaria

A B S T R A C T

About 20 years after initial calls for the introduction of user fees in health systems in sub-Saharan Africa, a growing coalition is advocating for their removal. Several African countries have abolished user fees for health care for some or all of their citizens. However, fee-for-service health care delivery remains a primary health care funding model in many countries in sub-Saharan Africa. Although the impact of user fees on utilization of health services and household finances has been studied extensively, further research is needed to characterize the multi-faceted health and social problems associated with charging user fees. This ethnographic study aims to identify consequences of user fees on gender inequality, food insecurity, and household decision-making for a group of women living in poverty. Ethnographic life history interviews were conducted with 24 women in Yirimajo, Mali in 2007. Purposive sampling selected participants across a broad socio-economic spectrum. Semi-structured interviews addressed participants’ past medical history, socio-economic status, social and family history, and access to health care. Interview transcripts were coded using the guiding analytical framework of structural violence. Interviews revealed that user fees for health care not only decreased utilization of health services, but also resulted in delayed presentation for care, incomplete or inadequate care, compromised food security and household financial security, and reduced agency for women in health care decision making. The effects of user fees were amplified by conditions of poverty, as well as gender and health inequality; user fees in turn reinforced the inequalities created by those very conditions. The qualitative data reveal multi-faceted health and socioeconomic effects of user fees, and illustrate that user fees for health care may impact quality of care, health outcomes, food insecurity, and gender inequality, in addition to impacting health care utilization and household finances. As many countries consider user fee abolition policies, these findings indicate the need to create a broader evaluation framework—one that can measure the health and socioeconomic impacts of user fee polices and of their removal.

Introduction

An increasing number of countries are removing user fees for health services, as part of efforts to improve health outcomes and to make health care access more equitable (Castro, 2008; McPake, Brikci, Cometto, Schmidt, & Araujo, 2011). However, across sub-Saharan Africa, many health systems continue to charge fees paid at the point of care (WHO, 2010; Yates, 2009). Gender inequalities, compromised food security, and lack of access to education have each been associated with health vulnerability and poorer health outcomes (Anema, Vogenthaler, Frongillo, Kadiyala, & Weiser, 2009; Campbell et al., 2009; Cochrane, Leslie, & O’Hara, 1982; Farmer, Connors, & Simmons, 1996; Gunderson & Kreider, 2009; Hudelson, 1996; Mturi & Curtis, 1995; Tulasidhar, 1993; Weiser, Fernandes et al., 2009; Weiser, Frongillo et al., 2009)—yet the specific association between these structural problems and user fees requires further examination. With more countries across Africa considering removing user fees and development agencies considering broad support for such initiatives, careful consideration is merited to rigorously measure the impact of user fees and their removal.

At the 1978 International Conference in Alma Alta, 134 health ministries signed a commitment to achieve universal access to primary health care, declaring health to be a human right (WHO &
UNICEF, 1978). In the following years, however, and in the context of inflation, recession, foreign debt, and structural adjustment programs of the 1980s, African governments faced pressure to reduce public spending on health care while also improving the reach and impact of their primary health care systems (Cueto, 2004; Stanton & Clemens, 1989). To address these competing pressures, the Bamako Initiative of 1987 and a World Bank policy document (Akin, Birdsall, & De Ferranti, 1987) urged countries to adopt user fee policies aimed to improve equity by supporting the development of a decentralized primary care system (Akin et al., 1987), improve efficiency (Musgrove, 1986), enhance quality and sustainability through cost recovery, and encourage community engagement in primary health care delivery (Jarrett & Ofosu-Amaah, 1992; Keshavjee, 2004). Such policies—tagged as ‘cost-sharing,’ ‘cost-recovery,’ or ‘user fee for service’—were adopted by a large number of countries in subsequent years.

Approximately 25 years later, a large body of evidence indicates that the introduction or increase of user fees increases inequalities in access to care, by disproportionately reducing health care utilization by the poorest segments of society (Bennett, 1989; Gertler, Locay, & Sanderson, 1987; Haddad & Fournier, 1995; James et al., 2006; Sauerborn, Nougartera, & Latimer, 1994; Sepehri & Cheramah, 2001; Washington & Enyimayew, 1990, 1999; Yoder, 1989). Studies have also repeatedly shown that user fees lead to delays in health-seeking by patients living in poverty (Jacobs & Price, 2004; Kremers & Miguel, 2007; Lennock, 1994; Weaver, 1995). The World Health Organization has identified point-of-care fees as “the most inequitable method for financing health-care services” (WHO, 2008, p. 28).

In recent years, the removal of user fees has been associated with increases in service utilization, particularly by the poor (Batungwanayo & Reymtjens, 2006; Deininger & Mpuga, 2004; Masiye, Chitah, & McIntyre, 2010; Meessen, Van Damme, Tashobya, & Tibouti, 2006; Nabnyonga et al., 2005; Ridde, Diarra, Heinuillar, & Mahaman, 2009; Walton et al., 2004; Xu et al., 2006). A 2011 review examined the relationship between user fees and utilization in 16 studies, finding that utilization decreased with the introduction or rise of health services fees and increased with the removal or reduction of fees in all but two studies that had combined user fee introduction with quality improvement interventions (Lagarde & Palmer, 2011). In a health facility in Rwanda supported by the Ministry of Health and the Millennium Villages Project, the subsidization of public insurance and the suspension of co-payments tripled the utilization of health services within a month (Dhillon, Bonds, Fraden, Ndahiro, & Ruxin, 2012). Removal of user fees has also been associated with improved mortality: preliminary data show that after removal of all user fees at Médecins Sans Frontières clinics in Sierra Leone, mortality decreased from 1.7 deaths per 10,000 persons per day to 0.7; the mortality in children under five decreased from 3.5 to 1.3 (Médecins Sans Frontières, 2008). A study modeling the impact of increased utilization in reducing child mortality estimated that 233,000 [153,000–305,000] deaths of children under five could be prevented annually by removing user fees in 20 African countries (James, Morris, Keith, & Taylor, 2005).

A randomized control trial comparing patients receiving free care to patients paying user fees in Ghana found a modest increase in utilization amongst the group receiving free care, but found no significant difference in their primary outcome measure—the prevalence of malaria-associated anaemia among children under five (Ansah et al., 2009). While user fees were removed across all age groups and diagnoses, the study only examined one primary health outcome for one disease in one age group. Thus, it did not provide conclusive evidence regarding the relationship between user fee removal, increases in utilization, and health outcomes (Ridde & Haddad, 2009). However, the study highlights the limitations of using utilization as the sole indicator of the success of an intervention, particularly when its ultimate objectives relate to improvements in health outcomes. A review of the impact of ill health on impoverishment in poor households in developing countries concludes that households struggling to cope with health care finances in poor countries “adopted unsustainable strategies that damaged asset portfolios and caused or sustained impoverishment” (Russell, 2004, p. 153). It called for further research into the hidden cost of illness at the household level.

As countries consider revisiting or removing user fee financing approaches, it is important to define as comprehensively as possible the impacts of user fees and to assess the potential downstream impact of user fee removal. The current study hypothesizes that user fees may impact not only health care utilization but also the completeness of care, timeliness in access to care, food security, gender inequity, and household decision-making. This ethnographic study is designed to provide a nuanced characterization of how user fees impacted the lives of study participants and, in doing so, to identify domains for further qualitative, quantitative, and applied policy research.

The study was conducted in Yirimadjo, Mali. With a population of 15 million people, Mali ranks 175 out of 187 countries in the United Nations Human Development Index (United Nations Development Program, 2010). Yirimadjo is a rapidly growing peri-urban area located in the municipality of Bamako, the capital of Mali. The National Statistical Office estimates the population of Yirimadjo at just over 45,000 residents. At the time of this study, Yirimadjo was not connected to Bamako’s municipal running water, sanitation, or electricity infrastructure. Local leadership includes the Yirimadjo deputy mayor’s office and a Yirimadjo-wide traditional chief. The area is predominantly Muslim, with a minority Christian population. Polygyny is widely practiced. The infant mortality rate in Mali is estimated at 99 per 1000 live births and the under-five child mortality rate is estimated at 178 per 1000 live births (UNICEF, United Nations Population Division, & United Nations Statistics Division, 2011). In Mali, malaria accounts for 38.4% of reasons for seeking care, with 1,633,423 cases and 2331 fatalities reported in 2009. In Yirimadjo, malaria accounted for 49% of outpatient visits in 2006 (Ministry of Health of Mali, 2007).

Since 2006, many African countries have removed user fees for some or all of their citizens (Government of Sierra Leone, 2009; Yates, 2009). In Mali, the Ministry of Health has adopted policies to provide selected services free of charge, including Caesarean sections, HIV testing, antiretroviral treatment, and artemisinin-based combination therapy for malaria. However, the country’s public sector health system charges fees at point of care for all other consultations, diagnostic testing, medications, and care services. Though Mali hosted the original Bamako Initiative conference that led to widespread adoption of user fee systems, the Malian Ministry of Health is actively examining the possibility of changing its user fee policies, as it convened a conference in 2011 to evaluate the impact of user fees and their potential removal.

Methods

Ethnographic life-history interviews were conducted with 24 female participants, as part of a study approved by the Harvard Medical School Committee on Human Studies (Protocol M14272-101). Enrollment was restricted to adult women to focus on characterizing the impact of user fees on gender inequalities faced by women. Names have been changed to protect participant anonymity. All women interviewed were residents of Yirimadjo and participants in education and microfinance programs as part of Project Muso Ladamunen, run by a non-governmental organization.
Study participants were selected by purposive sampling. To capture a wide social spectrum, purposive sampling identified and selected participants who: 1) dropped out of the NGO’s program or had significant problems with participating, 2) experienced considerable social or economic challenges over the course of a program, or 3) became successful leaders within a program. Through either their leadership or the challenges they faced, these groups had direct experience with and could provide insight upon the process of accessing health care in Yirimadjo. Demographic characteristics of study participants are summarized in Table 1.

Interviews were conducted in June, July and August 2007 in the Bamanankan language, through a translator, in two 2–3 h sessions, in a private space at the participant’s home. Interviews employed a structured, open-ended interview guide, with questions addressing participants’ past medical history, access to health care services, social and family history, educational background, socio-economic status, household decision-making processes, and participation in the NGO’s microfinance and education programs. Interviews examined the impact of direct costs of care—including consultation fees, medication and equipment costs, and diagnostic testing fees—as well as the impact of indirect costs of care. Results pertaining to the impact of the NGO’s programs on health care access are beyond the scope of this manuscript and will be reported elsewhere.

Each interview was recorded and transcribed. Qualitative analysis was conducted with NVivo software to code and analyze transcripts according to five categories—access to health care, interactions of poverty and health, women’s decision-making power, aspirations for the future, and the NGO—and 31 subcategories. These categories, which explored interactions between user fees, conditions of poverty, and gender inequality, utilized structural violence (Galtung, 1969) as the guiding analytical framework; that is, a concept that posits inequality in health outcomes as an indirect form of violence created by social structures of inequality that constrit individual agency. The framework of structural violence thus facilitates the characterization of complex bidirectional relationships between social structures, economic conditions, and health policies. After initial coding, these categories were regrouped to capture two themes: 1) user fees leading to delayed and incomplete care and 2) the impact of user fees on food security, financial security, and women’s decision making agency.

Results

Women’s life histories described multifaceted direct and indirect consequences of Mali’s fee-for-service health care system. Health care fees prevented participants from seeking and receiving health care for themselves and their families. However, their impact on participant health extended beyond decreased utilization. Fee-for-service for health care had indirect consequences on the health of participants and their families, including late treatment initiation, inappropriate or dangerous home-treatment, extended illness without treatment, inability to work, loss of food security, a decline in women’s agency, and compromised access to education.

Fee-for-service and delayed or incomplete care

The interviews revealed that three types of costs act as barriers to utilization in Mali’s fee-for-service health care system: 1) the indirect costs that constitute “the means to go to the hospital,” which include lost work time and transportation costs, 2) the fixed consultation user fee charged at entry, and 3) the cost of medications, diagnostic studies, and services to be prescribed, which is unknown a priori to the patient. Aissata, a 37-year-old mother of five children, explained, “Malaria kills so many people in the neighborhood; not everyone has the means to go to the hospital. You go to the hospital and you have to pay for the consultation and the medicine.” Participants also described how the indirect consequences of paying for health care—for example, the potential for compromised food security or indebtedness—led them to delay seeking care at government clinics or hospitals. Nine out of 24 participants described a process of waiting several days before seeking medical care, assessing the severity and the duration of the illness at home first, and weighing the dangers to their family’s welfare posed by paying user fees against the perceived danger of the illness.

At the time of interview, Maimouna, a 30-year-old mother of five children, was caring for her young daughter who she said was displaying symptoms of malaria. She explained why she was waiting to bring her to the local government clinic:

You know, we have financial difficulties. Why bring my daughter to the clinic and get a prescription with no money to buy it? That’s not necessary. That’s why we start with home treatment first. If we’re lucky, she’ll recover this week. If we’re not, we’ll take her to the clinic…Maybe she’ll recover at home, and the money we’d use for the treatment in the hospital will be used for other things…When [my husband] takes a child to the clinic, I know that the following day he won’t give me the complete money for food.

Maimouna weighs the known impact of paying fees for care on her family’s food security against two unknown variables. First, after incurring the cost of bringing her daughter to the health center and paying for the consultation, what is the likelihood that her family will be able to afford the prescribed medications needed for a positive treatment outcome? Second, what is the likelihood that her daughter will recover at home without treatment? Conditions of structural violence play a driving role in Maimouna’s decision to delay seeking care for her daughter and also suggest that her decision-making power may be limited because it concerns household finances controlled by her husband, who she identifies as holding the power of bringing the child for care and subsequently providing the diminished household food budget.

Ramata, a 35-year-old mother of three children, described the role of cost considerations in deciding whether to bring her son, age five, to the hospital for care:

He said, ‘I’m feeling sick.’ I showered him and dressed him. He went and lay down. When he got up, he had a very high fever. I had some fever medicine here and gave it to him. A little after he got up, he started throwing up very hard, and his body kept on warming up. In the meantime, his father came home from...
work. I told him about it. He said, ‘Well, this is the situation. I don’t have money to take him to the hospital. Give me some time. I’m going to go see the pharmacist around the corner. He’s my friend, and I’ll ask him if he can help me.’ He went and saw the pharmacist, who gave him two medicines. The pharmacist there thought it was malaria and gave us some malaria medicine and another syrup for fever. He came home, we gave [our son] those medicines, but they did not help. As the night went on, my son just kept on getting sicker and sicker. Between eleven and twelve o’clock at night, he was having seizures, jerking up and down on the bed. So we got very scared. My husband called one of his friends who has a car to help us take the boy to the hospital. We went to the community center. Before we left home, my son had already passed out. Like a corpse. His body was all cramped up. You could hardly move his body.

Ramata’s case reflects the disconnect between utilizing health care and accessing effective health care. Decisions to seek care are controlled by her husband. He makes a decision that he describes first in financial terms, and second in his own judgment of the severity of his wife’s suffering. Traditional medicines, like medicines from the pharmacist in the previous case, are chosen because they are more affordable. Yet her husband implies that treatment at the health center would be more effective than traditional treatment. This decision, shaped by user fees, results in incomplete care, adverse health outcomes, and reinforced gender inequalities. User-fees, in addition to creating barriers to adequate care, also led participants to seek treatment in unsupervised settings outside of the health care system. Participants described how, because they could not afford to pay user fees and essential medicines, they treated illnesses at home, with traditional medicine and unregulated drugs bought from street vendors. Salimata, a 41-year-old woman who has lost three of her eight children, explained: “I trust modern medicine, modern treatment. If I use traditional medicine, it’s because I don’t have enough money. Modern medicine costs so much that I cannot bring [my children] to the hospital all the time. But if I have money, I only think of the hospital because the child recovers quickly.” Kadia, a local teacher, said that people in her community “are afraid of going to the hospital, to the clinic, because they’re expecting expensive prescriptions, and they don’t have money. So they go into the bush and cut plants and boil them for treatment.” Nana, a 44-year-old mother of seven, recounted:

I remember, right after my father passed away, my brother got really sick. He had some type of growth under his shoulder. It grew so big it was like a fist. And there was no money to take him to the hospital. We couldn’t afford it. We had problems eating, moreover going to the hospital, because we knew they would give us a prescription. What’s the point of going, getting a prescription that you need to pay over 5000 CFA for [approximately $10USD]? That’s the reason why a lot of children are sick in the streets. They are malnourished and don’t get any treatment. Their mothers go to the traditional doctors, take that [medicine] home, cook it, and feed their babies with those medicines, because they don’t have a choice.

As in Maimouna’s example, in Nana’s case there are three factors in her family’s decision to seek care: indirect costs of transport, fixed consultation cost, and variable costs of treatment. Her assessment suggests that even if the family could pay for the first and second set of costs, they chose not to pursue medical care because they could not afford medication costs. There are likely to be multiple factors that influence use of traditional medicine, and biomedical and traditional medicine are not necessarily used in a mutually exclusive manner. Nonetheless, in the absence of resources to pay user fees, participants consistently reported relying upon traditional medicine. Participants also described buying inexpensive medicines from unregulated street vendors when they could not afford to pay user fees or medicines at government health centers, as well as using these street-purchased medications with inconsistent dosing and without consultation from health care providers.

User-fees compromising food security, financial security, and women’s agency

Among those who sought care at government health centers amidst financial hardship, fees charged at point of care compromised food security for patients and their families. Djeneba, a mother of seven children who sells fish in the market, recounted that after paying for prescriptions and medical care for a family member, her family was forced to reduce their food budget, eating...
one meal per day over the course of the subsequent two years. This vulnerability was not limited to the unemployed or to those whose income came through informal trade. Kadia, a local teacher whose husband is also employed, explained: “There is a time of recuperation [after paying for medical care]. When I tell my husband that a certain food is finished, he says ‘No, I’ve just finished with the medical expenses, so please, let me breathe.’” Ourokia, a 28-year-old wood seller whose husband is a bus company employee, recounted a time when buying medication for her son's respiratory infection affected the amount of money her husband gave her to buy food:

It happened one day that I was obliged to cook porridge for the whole family, because it was difficult for him... That happened for only three days and that's all... I hid it from everybody. Outside of this interview, I've never told anyone that I made porridge... I'd be ashamed if people knew that we had no food at home... If my husband doesn't have it, I have to get something for the family. If I myself don't have it, it's a big shame in the society... My husband paid for the prescription with the money we'd otherwise be using for food.

Ourokia expresses impact of medication costs both in terms of her family's food security and of resulting stigma, anticipating the potential for food insecurity to precipitate further vulnerability and social isolation for her family. Many participants described this period of undernourishment immediately following payment for medical care and continuing through the patient's illness. In addition to using money from their food budget, participants described other ways in which user fees destabilized the household's financial security. In the absence of sufficient financial resources, respondents sold assets such as clothing and took out loans in order to pay for care and essential medicines.

Participant stories also revealed indirect consequences of untreated illnesses on income. One participant, unable to afford to pay for an operation, described the impact of her continued illness: "Now I cannot wash clothes. I cannot do anything, just sit... Since the pain started, I've stopped with everything... I cannot make money now because of that pain." Nana recounted the changes in her life following the death of her father, the primary income earner of her family:

My father died and left four wives and 13 children. It was tough. He was the only breadwinner in the house. Even though he was retired, he had some pension money, and the combination of that and the farm helped us live. But when he was gone, we had too many problems. And that was the reason why I left school in the 4th grade. My mothers, none of them worked. So it made us dependent upon their husbands for making treatment decisions for themselves and their children. Maimouna, whose daughter had symptoms of malaria at the time of the interview, explained that her husband would later perform a ‘medical-financial diagnosis’ to determine whether they would take the child to the government health center or treat her at home with pills they had purchased without a prescription: “I'm waiting for my husband. When he'll be here, he'll do the diagnosis and see if it's necessary to take her to the clinic. And if he doesn't have money, I think we'll keep her here and give her the pills we have. We'll keep her at home and continue with the pills.” Oukoria explained that her husband decided when she left the house and when to provide her with financial resources to pay for health care. In the context of a fee-for-service system, her husband’s control of household finances affected her access to health care: during her pregnancy, her husband decided what prenatal testing she would get based on which user fees he could pay.

Discussion

The current study explores the complex effects of user fees on the lives of women and families living in poverty, to inform how to best evaluate the impact of changes in user fee policies. The United States Institute of Medicine proposed a definition of health care access as “the timely use of personal health services to achieve the best possible health outcomes” (Millman, 1993, p. 4), which focuses on well-timed utilization. The WHO has proposed an additional access measure that encompasses need, utilization, and quality of care termed “effective coverage,” defined as the proportion of a population that needs a procedure that actually receives it (WHO, 2001). Other commonly employed utilization measures capture neither the timing of care nor the quality and completeness of care. The results of the current study indicate that fee-for-service health care financing, by affecting the use, timing, and completeness of health care, is a key social determinant of health. Participant accounts identify the impact of fees 1) on the timing of care and the quality and completeness of care, and 2) on food security, access to education, women’s agency, and household financial security.

Consistent with the existing literature, participants in this study described avoiding or delaying care for themselves or their family members at public facilities due to an inability to pay user fees. Thaddeus and Maine describe three categories contributing to delayed treatment: delay in the decision to seek care, delay in arrival at the health facility, and delay in adequate care provision (Thaddeus & Maine, 1994)—all of which played a central role in participant narratives. Difficult choices between essential expenses such as food, school fees, and medical care led patients to wait until illnesses had reached severe stages before seeking care. Participant arrival at health care facilities was also delayed by efforts to access resources to pay fees, through their husbands or through loans. Participants described only paying for parts of prescriptions and not returning for subsequent appointments due to lack of funds. As in the case of Ramata’s son, presentation at later stages can increase morbidity and mortality, and lead to further transmission of communicable diseases such as malaria, tuberculosis, and HIV. This form of care rationing may endanger patients and populations and impact health outcomes even among patients who are recorded as having attended health facilities for services (Castro, 2008; Keshavjee, 2004). Additionally, there are indirect effects of reduced utilization, as participants attempted treatment with medicinal plants or other home treatment without accompanying of a trained professional. The use of drugs purchased in the pharmacie par terre—Mali’s unregulated informal sector—poses dangers to the patient through treatments that may lack efficacy or have dangerous adverse effects due to improper formulation, dosing, handling, or preservation (Goel, Ross-Degnan, Berman, & Soumerai, 1996; Goodman et al., 2004).

Participant interviews reveal that user fees not only operate as a barrier to seeking care, but also, in cases where the patient succeeds in crossing that barrier, may contribute to food and
economic insecurity. The study suggests that paying user fees may have immediate health consequences, contributing to malnutrition during and after periods of illness. The impoverishing effects of user fees have been highlighted elsewhere: fees for medications and care may create or deepen poverty, by increasing indebtedness, compromising financial security, and contributing to untreated illness with lost work time (Keshavjee, 2004; McIntyre, Thiede, Dahlgren, & Whitehead, 2006; Russell, 1996). The WHO has estimated that each year health care costs push 100 million people into poverty (Mullan & Frehywot, 2007). Further study could assess the relationship between use fees and changes in nutritional status at a population level.

The lived experiences of Maimouna, Ramata, Kadia, and Ourokia are marked by a lack of agency in making health decisions independently of their husbands in the context of fee-for-service health care. Existing studies have shown that women’s ability to pay for health care is influenced by their often-limited control over resources and decision-making (Nanda, 2002). In situations where the female participants in this study lacked personal income to pay fees for themselves or their children, they described waiting for their husbands to decide whether to provide the resources necessary for seeking care. The impact of user fees in this study traveled along gradients of structural violence, most severely affecting families living in poverty and women with limited decision-making power in their relationships, which in turn reinforced those very conditions of structural violence: food insecurity, gender inequality, and household financial insecurity. These narratives describe the role of user fees in trapping women and their families in cycles of poverty, disease, and powerlessness. The UN Secretary General’s recent Global Strategy for Women’s and Children’s Health (Ki-Moon, 2010) aimed to address this problem, advocating for the provision of free essential health services for women and children.

This ethnographic study is designed to characterize consequences that user fees can have on the lives of women, identifying potential impacts of user fees or their removal that have been insufficiently examined to date. The study has several limitations that are important to consider. The study explored one part of the user fee issue: how women reported fees in financing policy, the removal of fees are likely to underestimate the impact of this policy.

Acknowledgments

The authors would like to acknowledge and thank Fatouma Bah and Madougou Niambele for their contributions translating interviews for this study. The first author thanks the Harvard Medical School Scholars in Medicine Office for financial support of the study.

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