Ethical Considerations about Reporting Research Results with Potential for Further Stigmatization of Undocumented Immigrants

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A broad spectrum of infectious diseases is studied in vulnerable populations. However, ethical considerations of reporting research results that could increase stigmatization of socially marginalized and vulnerable populations are not often discussed in the medical literature, particularly not in the context of transmissible diseases. This article addresses ethical considerations that arose when one of us (J.M.A.) recently published the results of a study in Clinical Infectious Diseases that imply that undocumented persons are more likely to transmit tuberculosis than are documented foreign-born persons or persons born in the United States. These study results have the potential to further fuel the often fierce debate regarding undocumented immigrants in the United States. To our knowledge, such ethical considerations have not been discussed previously in the medical literature.

IMMIGRATION AND TUBERCULOSIS IN THE UNITED STATES

The highly politicized topic of illegal immigration continues to attract national attention. Among the 37.9 million immigrants living in the United States, nearly 1 of 3 is undocumented, and it was estimated that more than one-half of the 10.3 million immigrants who arrived in the United States from 2000 through 2007 were undocumented [1]. Barriers to health care services for such a large and socially marginalized population could have a significant negative impact on cost and public health in general [2, 3].

A study published by one of us (J.M.A.) was, to our knowledge, the first to evaluate the impact of place of birth and documentation status on the clinical presentation of pulmonary tuberculosis (TB) in patients [4]. In this retrospective study, 194 patients with culture-proven pulmonary TB who were admitted to a large public hospital in New York City over a period of 5 years were categorized into 3 groups (US-born, documented foreign-born, and undocumented foreign-born persons), and the clinical findings and symptoms at the time of initial hospital evaluation were compared among the groups. The results revealed that undocumented foreign-born persons with TB, compared with US-born persons with TB, presented with significantly higher frequencies of cough and hemoptysis and had a significantly longer median duration of symptoms. In contrast, no statistically significant differences were observed between documented foreign-born persons and US-born persons. Furthermore, in multivariate analysis, being an undocumented relative to a US-born person remained independently associated with prolonged symptom duration (>8 weeks).

On the one hand, publication of such findings could lead to improved access to health care services for persons at risk of active TB, regardless of their immigration status [2]. On the other hand, such findings could cause a public health alarm, because previous studies have revealed that a delayed diagnosis of TB is associated with higher rates of transmission to close contacts [5, 6].

Despite the decreasing number of cases, TB is far from eliminated (<1 case per 1 million persons) in the United States; the Centers for Disease Control and Prevention set 2010 as the goal year for elimination of TB [7]. In 2006, nearly 14,000 cases of active TB were diagnosed in the United States, and the majority (57%) of these cases were detected in foreign-born persons, who have an almost 10-times higher case rate than do those born in the United States (22.0 cases per 100,000 persons vs. 2.3 cases per 100,000 persons) [8]. A recent publication by Cain et al. [9] that addressed the growing problem of TB in foreign-born populations has attracted the
attention of the media and has raised public concerns in the United States [10]. Although most molecular epidemiology studies do not indicate that TB in immigrants is associated with increased transmission to native-born persons [11–15], a study published in Clinical Infectious Diseases a few months ago found evidence of recent TB transmission between the immigrant and native populations of Spain [16]. Taking the publication of these latest studies into consideration, we examined the potential short-term and long-term effects (in both legal and nonlegal contexts) of the publication of results that imply that undocumented foreign-born persons may be more likely than documented foreign-born persons or US-born persons to transmit TB.

ETHICAL CONSIDERATIONS

In general, physicians do not ask foreign-born patients about their documentation status; however, social workers or other hospital employees frequently inquire about documentation status to determine the patient’s eligibility for health care–related services. When foreign-born persons report being undocumented, they do not likely anticipate that this information will be used to distinguish them from other patients in research studies. As in most retrospective studies, obtaining of consent from individual patients was not feasible in the study by Achkar et al. [4], and consequently, all identification information was destroyed after completion of data collection. Had the study been prospective, a Certificate of Confidentiality would have been obtained from the National Institutes of Health to provide additional protection of the participants’ identities [17]. These certificates allow the investigator to refuse to disclose identification information in any civil, criminal, administrative, legislative, or other proceeding at the federal, state, or local level. Nevertheless, in a time of aggressive measures targeting undocumented immigrants, we have to question whether research participants are sufficiently reassured that their undocumented status will not be revealed, even if they were informed about the certificates.

Physicians strive to separate their political opinions from their professional duties. Their main goal and responsibility is not only to provide care for patients regardless of their backgrounds but also to prevent harm. Investigators have similar responsibilities toward the communities that they study. Taking this and the recent political climate in the United States into consideration, we question whether any harm to the studied population could arise from publishing results like the ones in the study by Achkar et al. [4]. Even with a new administration in the White House and a newly elected Congress, anti-immigration sentiment may remain high, especially in southern border states. Could publication of such results increase fear of exposure to immigration authorities among undocumented persons? Should some research results not be published because they could lead to further stigmatization of vulnerable populations? Finally, what implications do the findings have for public health?

Could publication of the research results increase fear of exposure to immigration authorities among undocumented persons? Although we are not aware of any federal or state law currently in effect that requires physicians or hospitals to report the documentation status of their patients, several attempts to do this have been made. Proposition 187, approved by California voters in 1994, required publicly funded health care facilities to deny care to illegal immigrants and to report them to government officials [18]. Although the proposition was defeated by several lawsuits because of challenges to its constitutionality, various other laws and initiatives have sought to incorporate its elements. For instance, the 1996 Federal Personal Responsibility and Work Opportunity Reconciliation Act restricts the provision of many federal, state, and local publicly funded services, including most nonemergency health care services, to undocumented immigrants [3,19]. In 2004, the House of Representatives overwhelmingly rejected the Undocumented Alien Emergency Medical Assistance Amendments, which would have prohibited federal reimbursement of hospital–provided emergency services to undocumented persons unless the hospital provided information regarding the immigration status of foreign-born persons [20]. These legislative attempts have created much confusion and mistrust among members of the immigrant community.

This is of considerable concern because fear of discovery by immigration authorities has been shown to be associated with a delay in diagnoses of communicable diseases, such as TB [21, 22]. It is entirely possible that the publication of the results of the study by Achkar et al. [4] could contribute further to the mistrust in the immigrant community and, thus, worsen the problem identified in the study.

Should some research results not be published because they could lead to stigmatization of vulnerable populations? A classic example of this situation was the study of associations between race and intelligence. In 1969, Jensen [23] reported that African American persons had lower IQs than did white persons in the United States and concluded that genetic factors might contribute to the difference detected. This study sparked one of the greatest controversies in medical research and generated global ethical and scientific debate [24, 25]. If such studies could lead to either positive or negative outcomes (e.g., better educational services or early intervention versus stigmatization or discrimination), how can it be determined whether they should be conducted and whether their results and conclusions should be published?

Institutional review boards (IRBs) do not provide guidance for such questions, and they are not they permitted to provide such guidance, according to federal regulations. The IRB Guidebook, issued by the Office for Human Research Protection, contains the following statement: “Some behavioral research involves human sub-
jests in studies of heredity and human behavior, genetics, race and IQ, psychobiology, or sociobiology. Vigorous ethical debates about these studies arise out of the fear that scientific data may be used to justify social stratification and prejudice, or that certain groups will appear to be genetically inferior. The possible use or misuse of research findings, however, should not be a matter for IRB review, despite the importance of this question” [26]. Furthermore, in the Code of Federal Regulations, the following statement appears: “the IRB should not consider possible long-range effects of applying knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility” [27].

In the case of the study by Achkar et al. [4], an ethical concern was that publication of the results would lead to increased stigmatization and discrimination of undocumented persons in the United States and to harsher measures, such as deportation, when these persons receive a diagnosis of TB. On the other hand, the results suggest that reduction of barriers to health care services for undocumented persons could enhance TB control. Therefore, if such barriers are further identified and addressed, publication of these research results could not only benefit the studied population but also ultimately benefit public health.

Implication of our findings for public health. The study results by Achkar et al. [4] provide evidence that the consequences of barriers to undocumented immigrants seeking health care services could extend beyond the individual person to the entire community [2]. Undocumented persons, who often work in food service, household settings, and other service industries, may transmit TB to a greater number of close contacts if they are symptomatic for longer periods than may documented foreign-born persons or US-born persons. In addition, despite the fact that treatment for communicable diseases, such as TB, is an exception to the public service restrictions for undocumented immigrants [19], some may attempt to self-treat a respiratory illness to avoid health care services. If inappropriate antibiotics are used to self-treat TB, the development of drug-resistant disease could be facilitated [28].

The implications for public health are clear. The American Thoracic Society, the Centers for Disease Control and Prevention, and the Infectious Diseases Society of America list the following 3 of the 5 most important challenges for successful control of TB in the United States: (1) prevalence of TB among foreign-born persons who reside in the United States, (2) delays in the detection and reporting of cases of pulmonary TB, and (3) deficiencies in the protection of contacts of persons with infectious TB [29]. The results of the study by Achkar et al. [4] suggest that the reduction of barriers to health care services for undocumented immigrants may help confront these challenges.

CONCLUSIONS

We remain concerned that publication of the research results by Achkar et al. [4] could lead to further stigmatization of undocumented immigrants. However, the importance of the knowledge obtained for public health, including the health of undocumented immigrants, warrants wide dissemination of the results. It is obvious that the findings need to be confirmed by larger, population-based studies. However, publication of even these limited findings should lead to an awareness that the reduction of barriers to health care services for undocumented immigrants could help improve TB control in the community. For these reasons, the publication can benefit both the studied population and public health in the United States.

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References