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

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### Abstract

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 (JA) recently published the results of a study in this journal which imply that undocumented persons are more likely to transmit tuberculosis than documented foreign-born persons or those born in the US. These study results have the potential to further fuel the often fierce debate regarding undocumented immigrants in the US. To our knowledge, such ethical considerations have not been discussed previously in the medical literature.

### Keywords

ethical issues; immigrants; foreigners; vulnerable populations; tuberculosis

### Immigration and Tuberculosis in the US

The highly politicized topic of illegal immigration continues to attract national attention. Of the 37.9 million immigrants living in the US, nearly one in three is undocumented, and more than half of the 10.3 million immigrants who arrived in the US between 2000 and 2007 were estimated to be undocumented [1]. Barriers to health care services of such a large and socially marginalized population could have a significant negative impact on cost and public health in general [2,3].

The study published by one of us (JA) is, as far as we are aware, the first to evaluate the impact of place of birth and documentation status on the clinical presentation of persons with pulmonary tuberculosis (TB) [4]. In this retrospective study 194 patients with culture-proven pulmonary TB admitted to a large public hospital in New York City over a period of 5 years were categorized into three groups (US-born, documented foreign-born and undocumented foreign-born), and their clinical findings and symptoms were compared at the time of initial hospital evaluation. The results showed that undocumented foreign-born compared to 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 significant differences between documented foreign-born and US-born persons were observed. Furthermore, in

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multivariate analysis, being undocumented relative to US-born remained independently associated with prolonged symptom duration  $\geq 8$  weeks. On the one hand, publication of such findings could lead to improved access to health care services for persons at risk for active TB regardless of their immigration status [2]. On the other hand, such findings could cause a public health alarm, as previous studies have shown that a delayed diagnosis of TB is associated with higher rates of transmission to close contacts [5,6].

Despite declining numbers of cases, TB is far from eliminated (less than 1 case per one million persons) in the US - a goal set for the year 2010 by the Centers for Disease Control and Prevention (CDC) [7]. In 2006, nearly 14,000 cases of active TB were diagnosed in the US, with the majority (57%) detected in foreign-born persons who have an almost 10 times higher case rate than those born in the US, 22.0/100,000 versus 2.3/100,000, respectively [8]. A recent publication by Cain et al. addressing the growing problem of TB in foreign-born populations has attracted attention of the media and raised public concerns in the US [9-11]. Although most molecular epidemiology studies do not indicate that TB among immigrants is associated with increased transmission to native-born persons [12-16], a study published in this journal a few months ago did find evidence of recent TB transmission between the immigrant and native population of Spain [17]. Taking the publication of these latest studies into consideration, we have to wonder about what kind of short- and long-term effects in both legal and non-legal contexts could be caused by the publication of results that imply that undocumented foreign-born persons may be more likely to transmit TB than documented foreign-born or US-born persons?

## Ethical Considerations

Physicians generally do not ask foreign-born patients about their documentation status while 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 consent from individual patients was not feasible in the study by Achkar et al. [4], and consequently all identifying information was destroyed after completion of data collection. Had this been a prospective study, a Certificate of Confidentiality would have been obtained from the National Institutes of Health (NIH) to provide additional protection of the subjects' identities [18]. These certificates allow the investigator to refuse to disclose identifying information in any civil, criminal, administrative, legislative, or other proceeding, whether at the federal, state, or local level. Nevertheless, in a time of aggressive measures targeting undocumented immigrants, we have to wonder whether research subjects would be sufficiently reassured that their undocumented status would 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 take care of patients regardless of their backgrounds, but to prevent harm, as well. Investigators have similar responsibilities towards the communities they study. In that regard, taking the recent political climate in the United States into consideration, we have to question whether any harm to the population studied could arise from publishing results like the ones in the study by Achkar et al. 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? And lastly -What implications do the findings have for public health?

## Could publication of the research results increase fear among undocumented persons of exposure to immigration authorities?

While we are not aware of any federal or state law currently in effect requiring physicians or hospitals to report the documentation status of their patients, several attempts in that direction 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 the government officials [19]. Although it was defeated by several lawsuits due to challenges to its constitutionality, various other laws and initiatives have sought to incorporate elements of Proposition 187. For instance, the 1996 Federal Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) restricts the provision of many federal, state, and local publicly funded services, including most non-emergency health care services, to undocumented immigrants [3,20]. 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 provides information regarding the immigration status of foreign-born [21]. 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 [22,23]. It is entirely possible that the publication of the results of the study by Achkar et al. 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 where this question arose was the study of associations between race and intelligence. Arthur Jensen reported in 1969 lower IQs in African-Americans compared to whites in the US, and concluded that genetic factors might contribute to the difference detected [24]. This study sparked one of the greatest controversies in medical research and generated global ethical and scientific debate [25,26]. If such studies could lead either to 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 their results and conclusions published?

Institutional review boards (IRBs) do not provide guidance for such questions, nor may they according to federal regulations. The IRB guidebook issued by the Office for Human Research Protection contains the following statement: "Some behavioral research involves human subjects 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." [27]. Furthermore, in the Code of Federal Regulations under 45 CFR 46.111 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." [28].

In the case of the study discussed here, one ethical concern is that publication of the results could lead to increased stigmatization and discrimination of undocumented persons in the US, and a call for harsher measures such as deportation when diagnosed with TB. On the other hand, the results suggest that reducing 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 population studied, but ultimately be beneficial to the health of the public.

## Implication of our findings for Public Health

The study results by Achkar et al. provide evidence that the consequences of barriers to undocumented immigrants seeking health care services could extend beyond the individual person to the entire community [2,29]. 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 much longer periods than documented foreign-born or US-born persons. In addition, despite the fact that treatment for communicable diseases such as TB is an exception from the public service restrictions for undocumented immigrants[20], some may attempt to self-treat a respiratory illness in order to avoid health care services. If inappropriate antibiotics are used to self-treat an illness that is TB, the development of drug-resistant disease could be facilitated [30].

The implications for public health are clear. The American Thoracic Society, the CDC, and the Infectious Diseases Society of America list the following among the five most important challenges to successful control of TB in the US: 1) prevalence of TB among foreign-born persons residing in the US; 2) delays in detecting and reporting cases of pulmonary TB; and 3) deficiencies in protecting contacts of persons with infectious TB [31]. The results of the study by Achkar et al. suggest that reducing barriers to health care services for undocumented immigrants may help confront these challenges [4].

## Conclusions

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

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