

# Sociology's Contribution to Understanding the Consequences of Medical Innovations

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The recent film *The Social Network* featured as its tagline: “You don’t get to 500 million friends without making a few enemies.” Likewise, you don’t get to screen 4 million newborns without getting some critical scrutiny. Many sociologists take this as a vital part of our job description: to consider whether there are unanticipated or underappreciated downsides to major social and policy changes. Such work represents a key contribution of the profession to society, and a longstanding part of it is understanding whether institutional criteria for evaluating policies fully reflect the actual, lived experiences of all individuals affected by them, especially those individuals whose voices might otherwise be easiest to ignore. Primary strengths of ethnographic sociology are its capacity to articulate patterns in the lived experience of those it studies and the latitude investigators have to “follow” phenomena to unanticipated and overlooked aspects.

In this spirit, Timmermans and Buchbinder’s (2010) study (hereafter TB) represents exemplary sociological work. They selected a case that is both timely and consequential: Newborn screening has expanded in a brief period of time to a mandatory matter covering conditions that are sufficiently rare that even many pediatric physicians know little about them. Their work highlights the experience of those parents who receive an initially ambiguous diagnosis, and it makes plain that the resolution of their case from the perspective of medicine does not mean the matter is resolved for the parents. The study does not “pass ‘broad negative judgment’ on expanded newborn screening” (Watson et al. 2011:278), but it may raise awareness about the complexity of some issues surrounding ambiguous and false-positive

results and might have implications for how parental counseling is conducted.

All this said, I suspect that years from now, any reader of the exchange between TB and Watson et al. (2001; hereafter WHR) is liable to be confused. WHR take great exception to TB’s article, questioning even how it got through peer review in its published form. WHR present the article as primarily a critique of newborn screening and as only incidentally about diagnostic uncertainty, and they do not acknowledge the concept of “patients-in-waiting” at all. Yet, the reader can reasonably regard TB’s article as being essentially about patients-in-waiting, a theoretical contribution to understanding the social consequences of advances in risk assessment technology that go far beyond newborn screening. Of course, TB’s study of newborn screening was necessary for developing these insights and for illustrating them, but in broad terms, similar conclusions might have followed from similar attention to a different case. This makes WHR look like they missed the point, or, as TB say in their reply (2011), like they are imposing “biomedical criteria upon a sociological project” (p. 279).

Yet, in fairness to WHR, their reaction makes much more sense if one examines the media coverage associated with TB’s publication. The study was not a major science news story, but an online

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search reveals numerous sites in which accounts of the study appear. These are all based closely, if not verbatim, on overlapping press releases issued or reposted by the authors' institution, by the organization that owns this journal, and by a federal agency that helped fund the research.<sup>1</sup> These press releases present TB's study in much the same way as what WHR argue against, with a takeaway message quite negative about the unanticipated consequences of newborn screening.

Consequently, even though TB's original article does not pass broad negative judgment on newborn screening, when one of the study authors is quoted as saying, "Expanded newborn screening has called into question whether screening targets correspond to actual diseases or just benign forms of human variation," it is understandable how scientists intimately involved in newborn screening might interpret this as being both broad and negative. Even more so when the quote appears in a press release that summarizes the study as "cast[ing] doubt on the medical efficacy of the battery of screenings administered widely in America." Likewise, someone who reads a story about how "some families are so traumatized that they follow unwarranted and complicated regimens for years afterward" might be surprised to learn, from TB's reply, that these traumatized parents all "viewed newborn screening in a positive light, despite the difficulties and uncertainties that it created for their families" (2011:279).

TB's findings do not speak to whether mandatory newborn screening is good public health policy, for several reasons. First, TB appear to present two incorrect details that understate the value of screening. As TB acknowledge in their reply, it is not presently the case that "in more than 90 percent of the cases, the retesting will reveal that the initial screen was a false positive" (2010:414), and WHR also contradict their assertion that "For some [of the 29] conditions no treatment is available" (2010:409). Second, evaluating the social costs of protracted unresolved physician diagnoses requires reliable information about the prevalence of the phenomenon, which demands population data. Neither counts from an ethnographic sample (by TB) nor references to personal communications (by WHR) are authoritative, and they differ dramatically in this exchange. Third, the appropriate level for policy intervention seems almost certainly that of specific programs or specific conditions, rather than screening in general, and neither the sample nor presented details are adequate to draw conclusions at this

level. Consequently, if TB's purpose was to advance a specific challenge against current policy, then WHR would be correct in contending that more specific information should have been provided about the cases described.

Fortunately, TB take some pains in their reply to clarify that this was not their purpose. For the stated goals and contributions of their study, the data and its level of reported detail are fully appropriate, and neither the authors nor the peer review process can be faulted for its being less adequate for other purposes. To be clear, beyond improvements in counseling, it is hard to see what changes in screening policy would follow from their findings (which is not to dismiss others' critiques of extant policy). If the people who might be interpreted as suffering most from the collateral consequences of a policy still are observed uniformly to report overall satisfaction with it, then it would seem to require some kind of false consciousness argument to interpret this as cause for policy reversion. Even so, if parental Internet searches do lead to erroneous interpretations of the severity of conditions, or parents do leave clinic visits confused about the diagnostic status of their children, of course this can and should be improved, and sociological research highlighting these problems serves medicine well.

As the technical apparatus of screening improves, we need parallel improvements in communication with patients and their caregivers. As TB argue, we should not expect that technical improvements will eliminate ambiguities; if anything, overall ambiguity may increase as innovations illuminate further the heterogeneous and continuous nature of conditions, challenging ever more fundamentally the lay tendency to think of people as either having a disease or not. Large-scale medical programs, especially those for which individual participation is mandatory, require carefully scrutiny on technical, ethical, and social fronts. TB's study is a valuable contribution both as a case study of newborn screening and as a general contribution to the medical sociology of "patients-in-waiting," and TB and WHR together have provided a public exchange that usefully illustrates the strengths and challenges of ethnographic inquiry in contributing to the understanding and evaluation of policy consequences.

## ACKNOWLEDGMENT

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**NOTE**

1. At this writing, these press releases can be found at the following URLs: <http://newsroom.ucla.edu/portal/ucla/new-ucla-study-raises-questions-180295.aspx> (University of California at Los Angeles); [http://www.asanet.org/press/Press\\_Release\\_UCLA\\_Study\\_Raises\\_Questions\\_Genetic\\_Test\\_ing.cfm](http://www.asanet.org/press/Press_Release_UCLA_Study_Raises_Questions_Genetic_Test_ing.cfm) (American Sociological Association); and [http://www.nsf.gov/news/news\\_summ.jsp?cntn\\_id=118210](http://www.nsf.gov/news/news_summ.jsp?cntn_id=118210) (National Science Foundation).

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**Bio**

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