Catching Patients: Tuberculosis and Detention in the 1990s*

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The resurgence of tuberculosis (TB) in the early 1990s, including multidrug-resistant strains, led health officials to recommend the use of involuntary detention for persistently nonadherent patients. Using a series of recently published articles on the subject, this paper offers some opinions on how detention programs have balanced protection of the public’s health with patients’ civil liberties.

Detained persons are more likely than other TB patients to come from socially disadvantaged groups. Health departments have generally used coercion appropriately, detaining patients as a last resort and providing them with due process. Yet health officials still retain great authority to bypass “least restrictive alternatives” in certain cases and to detain noninfectious patients for months or years. Misbehavior within institutions may inappropriately be used as a marker of future nonadherence with medications.

As rates of TB and attention to the disease again decline, forcible confinement of sick patients should be reserved for those persons who truly threaten the public’s health.

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Abbreviations: DOT = directly observed therapy; MDRTB = multidrug-resistant tuberculosis; NYCLU = New York Civil Liberties Union; UHF = United Hospital Fund

It is unethical, illegal, and bad public health policy to detain ‘noncompliant’ persons before making concerted efforts to address the numerous systemic deficiencies that make adherence to treatment virtually impossible for many New Yorkers.”1 So wrote the New York City Tuberculosis Working Group, a coalition of activists evaluating efforts by New York in 1992 to use coercive measures to control a resurgent epidemic of tuberculosis (TB). American health departments have forcibly detained TB patients since 1903,2 but the statement of the Working Group, plus a public hearing on proposed changes to the New York City health code, represented milestones in the use of public health powers. Prior to the 1990s, TB officials had encountered little resistance to the involuntary confinement of persistently nonadherent individuals. TB, after all, is a highly communicable disease spread by airborne respiratory secretions. Yet as New York and other cities addressed a precipitous rise in TB in the early 1990s, including highly lethal multidrug-resistant (MDR) strains,3 AIDS activists and other civil liberties advocates argued that detention should not be used to punish disadvantaged persons unable to adhere to antibiotic therapy.

As of 1998, rates of TB have again decreased.4 Officials have attributed much of this decline to measures designed to improve adherence,5,6 most...
notably directly observed therapy (DOT), in which patients take twice- or thrice-weekly medications under the supervision of a health-care worker.\textsuperscript{7–9} While a voluntary service for most patients, those unwilling or unable to adhere to antibiotic treatment may be mandated to have DOT. In addition, several health departments have detained patients after concluding that mandatory DOT was either unsuccessful or unrealistic. Using a series of articles on detention published in 1997, this paper will offer some opinions on the use of forcible confinement in the 1990s. How well have detention programs balanced the need to protect the public’s health with the civil liberties of TB patients? Has forcible isolation been used as a substitute for addressing the underlying causes of nonadherence?

Devising Ethical Detention Strategies

New York was the first municipality to segregate persons with TB. In 1903, 21 years after Koch demonstrated the communicability of TB (or consumption, as it was also known), the city opened a detention facility at Riverside Hospital. Detention, only one part of a program designed by Hermann Biggs to control TB in New York,\textsuperscript{8} was reserved for patients who repeatedly disregarded regulations to prevent the spread of the disease. In practice, however, Riverside became less a public health facility than a repository for “fractious and intractable” immigrants, vagrants, and alcoholics.\textsuperscript{10} The blurring of medical and social indications for detention is revealed in a quote by Biggs: “Homeless, friendless, dependent, dissipated and vicious consumptives are likely to be most dangerous to the community.”\textsuperscript{11} Especially aggressive detention of nonadherent TB patients occurred in the 1950s and 1960s, after the introduction of curative antibiotics. More than 30 states employed compulsory hospitalization.\textsuperscript{12} Recognizing the potential abuse of public health powers, officials attempted to limit coercion to individuals who repeatedly violated regulations. Nevertheless, as in the past, nonadherence was often reflexively equated with a “skid row” alcoholic lifestyle. As recent research has demonstrated,\textsuperscript{12} Skid row alcoholics in this era were often forcibly isolated, even if their TB was inactive; in contrast, health officials at times declined to detain nonadherent middle-class persons who were truly public health threats. Although civil liberties groups occasionally mounted challenges, courts continued to grant health departments broad power to control TB.\textsuperscript{12}

As TB declined in the 1970s and 1980s, so, too, did detention. By 1992, however, TB had returned. The number of cases in the United States had increased to 26,673 from 22,101 in 1985.\textsuperscript{13} Between 1979 and 1982, the incidence of the disease in New York City had tripled.\textsuperscript{14} Moreover, MDR strains of TB, which could not be treated with conventional antibiotic regimens, were causing outbreaks in homeless shelters, jails, and hospitals. Fatality rates for multidrug-resistant tuberculosis (MDRTB) approached 90% for persons co-infected with the HIV virus.\textsuperscript{3,15} The rise in TB and drug resistance was multifactorial, but nonadherence played a major role. A 1991 study found that 89% of patients at New York’s Harlem Hospital did not complete their prescribed course of antibiotics due to either personal issues or obstacles in the system.\textsuperscript{16}

In response, clinicians, ethicists, and health departments devised a series of strategies for ensuring that TB patients completed their medications\textsuperscript{17–22} The most comprehensive of these recommendations came from a 1992 panel convened by New York’s United Hospital Fund (UHF).\textsuperscript{23} The panel stressed the dramatic changes that had occurred in civil commitment and patient autonomy since the 1970s. The courts, responding to revelations about the inappropriate and often violent hospitalization of the mentally ill,\textsuperscript{24,25} now insisted that potentially confined patients receive full due process protections.\textsuperscript{26} Meanwhile, the rise of a vocal patients’ rights movement—embodied by HIV-positive individuals demanding involvement in treatment decisions—reminded the public health community to respect patients’ rights.\textsuperscript{27} Given this history, detention of the tuberculous truly needed to be a measure of last resort, used only when an individual posed significant risk to the public. Drawing on cases regarding the mentally ill, the UHF panel and other authors advised health departments to use a strategy of “least restrictive alternatives” for enhancing patient adherence. These options ranged from a series of enablers or incentives, such as tokens or food coupons, to mandatory DOT.\textsuperscript{28,29} Only if patients remained nonadherent would detention be appropriate.

In addition to least restrictive alternatives, potentially detained individuals were to receive other due process protections, including judicial review and provision of counsel.\textsuperscript{18,19,23} Commentators also strongly encouraged the use of locked hospital wards—rather than criminal facilities—as the sites of isolation. Such units, wrote a New York Academy of Medicine committee, should not be “punitive or custodial but therapeutic.”\textsuperscript{30} Those confined to locked wards “are not convicted criminals undergoing punishment but noncompliant patients who require medical and social assistance.”\textsuperscript{30}

Authors explicitly acknowledged that detainees were likely to be socially disadvantaged. The home-
less, recent immigrants, injection drug users, and persons with HIV were especially susceptible to TB. As such, health departments not only needed to avoid discriminating against such individuals, but also to consider how social problems potentially predisposed the poor to nonadherence. Patients diagnosed with TB, wrote the UHF panel, were entitled to “a social and psychiatric assessment and a plan to provide appropriate medical and social services, including housing, drug abuse treatment, and mental health care.”

Even as they called for improved social services, commentators argued that health departments should be entitled to detain noninfectious patients until cure, a standard not previously allowed. In other words, long-term detention was permissible for patients—regardless of the immediate public health threat they posed—because their past behavior indicated likely future nonadherence. Confinement until cure was likely constitutional, wrote ethicist George Annas, if clear and convincing evidence existed that no less restrictive alternative would succeed.

Despite the inclusion of due process protections, some criticized the proposed plans. Such arguments were most evident in the report of the New York City Working Group, in dissenting statements to the UHF report, and at public hearings held in December 1992, before the revision of New York’s health code. At the hearings, in particular, there was extensive discussion about providing TB patients the same civil liberties protections that HIV-positive persons had demanded.

The revised New York health code, adopted in March 1993, contained the exact provisions that the UHF panel had advocated. Indeed, the New York code served as a model for other health departments initiating detention programs. Yet critics, such as Virginia Shubert of Housing Works, attacked two initiatives: reduction in the extent of psychosocial support offered, officials in Denver, Massachusetts, and New York regularly offer some rehabilitative services to patients prior to detention. For example, in Denver and New York, homeless persons have been given housing to try to improve their adherence. Clinic patients in Denver have “ready access” to alcohol and drug detoxification and treatment programs. Health officials have also offered repeatedly uncooperative patients a series of chances. In New York, Marie C., a 33-year-

Has Detention Been Used Appropriately?

Were Hansell’s fears warranted? As of 1997, reports have been published on four detention programs: Denver (20 patients detained from 1984 to 1994), Massachusetts (166 patients from 1990 to 1995), California (67 patients in 1994 and 1995), and New York City (46 patients in 1993 and 1994). New York’s report was preliminary; the city has detained more than 250 patients since 1993 (Gasner R, JD; personal communication; February 19, 1998). Although these reports do not necessarily reflect the use of detention everywhere, the four programs are among the most active in the country. Moreover, they have all attempted to devise strategies that balance public health powers with civil liberties concerns. As a result, their efforts are worth scrutinizing.

The four health departments all report using detention as a last resort, only after less restrictive approaches, such as DOT, have failed. Although compulsory DOT is itself restrictive, it appears that it can prevent broader reliance on confinement. During the first 2 years of New York’s efforts, for example, 174 of 233 patients (75%) placed on mandatory DOT did not subsequently require detention (Gasner R, JD, unpublished data). In the four localities, forcible isolation has been employed for only 1.3 to 5% of all TB patients.

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old woman with active pulmonary TB, left hospitals against advice, used aliases, and even threw away medications in the presence of health workers. Rather than detaining her, city officials devised several strategies to help her adhere to mandatory DOT. It was only when she had failed all of these efforts that a detention order was issued. The order was upheld in court.39

TB in the 1990s has disproportionately affected groups such as the homeless and substance users, but available data indicate that detained patients are considerably more likely to have such problems.33,35 Of the 20 people detained in Denver, for example, 18 were alcoholic and 19 were homeless.33 Yet health officials have reiterated that they have detained patients not because of social characteristics but because such individuals have remained persistently nonadherent despite numerous interventions. Officials have bolstered this point by showing that high percentages of patients with multiple social problems have completed treatment without being detained. For instance, 86% of Denver’s alcoholics never required isolation33; in New York, 91% of patients with a history of homelessness were treated without confinement (Gasner R, JD; unpublished data).

Once detained, patients are given opportunities to address sociomedical problems. Massachusetts, for example, has developed a “therapeutic milieu” that uses education, psychotherapy, and leisure skill development to confront mental illness, substance use, and homelessness.34 New York City’s Goldwater Hospital provides similar services, including exercise equipment, a library, and a computer room. Both Massachusetts and New York reward good behavior with privileges, including early release.40 In Massachusetts, 75% of detained patients completed therapy at home.34

Although the published articles do not document either the frequency or outcomes of patient challenges to detention, legal authorities appear to support current health department methods. Data obtained from New York show that the Department of Health lost only one of 150 hearings between 1993 and 1997. In this case, the judge ordered mandatory DOT as opposed to detention. (The patient did not cooperate and later was detained.) (Frieden T, MD; personal communication; February 19, 1998.)

A New York court also supported the Department of Health in 1994 when several civil liberties organizations challenged the city’s ability to detain a nonadherent patient without first exhausting all least restrictive alternatives. In this case, a woman with MDRTB objected to confinement at Goldwater without an initial chance at mandatory DOT. The court ruled the city had provided clear and convincing evidence of the patient’s inability to comply based on “her history of drug abuse, unstable or uncertain housing accommodations, apparent inability, as demonstrated by her own testimony, to understand the nature and seriousness of her condition, and refusal to cooperate with . . . voluntary forms of directly observed therapy.”41

The final necessary component of a just detention program is evidence of efficacy. Coercion—however well-implemented—would be hard to justify if detainees were not completing therapy. The four jurisdictions report treatment completion rates ranging from 83 to 97%.33–36 Given that those confined represent an extremely recidivist population, such statistics are impressive.

**CONTINUED ETHICAL CONCERNS**

Yet, as ethicists and civil libertarians emphasize, the ends may not justify the means. Despite demonstrating major strides in respecting patients’ civil rights, the current data raise several concerns. For one thing, more sophisticated models of civil detention are not being used everywhere. In California, detained TB patients, most having committed no crime, are tried under criminal statutes and confined in jail. As Oscherwitz et al35 note, “using jail to detain nonadherent patients is ethically problematic.” This principle is especially important to remember as rates of TB decline and funding for locked hospital facilities may be cut.

The published studies also reveal striking differences in duration of confinement. Although California, Massachusetts, and Denver at times detain patients until cure, most patients are discharged while taking medication. In Denver, for example, 17 of 20 patients (85%) completed therapy at home.33 In New York, in contrast, noninfectious patients are detained with the expectation that they will remain until cure. In 1993 and 1994, city officials permitted early discharge for only 10% of confined patients.42 As a result, the median length of confinement in New York was more than twice as long (186 days) as in any other location. One patient stayed for 654 days.36

The long periods of confinement in New York likely reflected the fact that many patients in 1993 and 1994 were coinfected with HIV or had MDR strains. If curable at all, MDRTB generally requires 18 to 24 months of therapy as opposed to 6 to 9 months for uncomplicated cases.43 Indeed, once MDRTB declined, the length of stay at Goldwater Hospital decreased. The duration of confinement in New York may also partially be explained by case selection. Detainees in New York had higher rates of illicit drug use, particularly crack, which is associated
with a disordered lifestyle. In addition, because New York has relied heavily on mandatory DOT, it may not have isolated persons who might have required only short periods of confinement.

Yet even if New York’s detainees are more “difficult” patients, the use of more rapid discharge elsewhere raises the question whether New York might confine until cure less often. Revisiting this issue is especially important because patients requiring the longest lengths of stay—both in New York and Massachusetts—have been homeless and injection drug users. Lack of social supports alone should never become a justification for hospitalizing certain populations for longer periods of time.

It should also be noted that, despite civil liberties concerns, health officials still have the ability to detain some patients without exhausting least restrictive alternatives. For example, four of Denver’s detainees were incarcerated after trying to leave the hospital against medical advice with newly diagnosed TB. Whereas New York courts have at times permitted officials to bypass certain less restrictive alternatives, such exceptions open the possibility for abuse. Thirty years ago, well-meaning Seattle TB officials overused forcible isolation once legal safeguards were relaxed.

Another issue raised in Seattle remains relevant. Seattle established a locked ward at Firland Sanatorium in 1949 to protect the community from infectious TB patients. Ultimately, however, Firland staff and Massachusetts—have been homeless and injection drug users. Lack of social supports alone should never become a justification for hospitalizing certain populations for longer periods of time.

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Another issue raised in Seattle remains relevant. Seattle established a locked ward at Firland Sanatorium in 1949 to protect the community from infectious TB patients. Ultimately, however, Firland staff members conflated public health and custodial objectives: they used their public health powers to maintain order, detaining disruptive skid row alcoholics who violated sanatorium rules. As in Seattle, modern TB officials are also assessing the behavior of confined patients, rewarding cooperative persons and punishing those who violate rules. Moreover, comportment in the hospital is one factor used to assess whether patients may be discharged early. Thus, at a recent discharge conference at Goldwater, health officials discussed how certain patients smoked in their rooms, had unprotected sex, or declined substance abuse counseling. While assessment of such behaviors is essential for operating an inpatient unit, concerns about punishing patients who are confined for public health reasons remain quite relevant. Misbehavior during involuntary confinement does not necessarily portend nonadherence to medical regimens after discharge.

Patients’ legal rights may also be obscured once they are institutionalized. Although new regulations generally call for mandatory judicial review of all cases, in practice such reviews may be delayed 60 days or even indefinitely if patients do not request them. In New York, officials estimate that as many as half of detained patients decline the option of a hearing (Gasner R, JD; personal communication; December 2, 1997).

This disinclination to pursue legal redress may result in part from the lack of a formal “triggering” mechanism. In the early years at Goldwater, the NYCLU urged hospital staff to expand patient exercise facilities, relax certain rules, and consider the formation of a patients’ organization. Over the past 3 years, however, no NYCLU representative has visited Goldwater, nor have any patients contacted the organization (Middleton J, JD; personal communication; December 2, 1997). While this development may reflect improvements at Goldwater, it also highlights the potential for lessened scrutiny once detention regulations have been debated and adopted.

CONCLUSION

When health departments in the early 1990s began to detain persistently nonadherent TB patients, the old motto, “The public health is the highest law,” had been modified. Concerns about civil liberties and patient autonomy, formerly given short shrift, took center stage. In addition, activists warned that even the new regulations still potentially discriminated against persons whose social circumstances precluded adherence.

The early published literature on detention in the 1990s indicates that public health officials have responded equitably to the problem of the nonadherent TB patient, developing sophisticated guidelines that permit coercion only as a last resort. However, the rights of nonadherent persons still remain limited. For example, courts have not obligated government to rectify problems such as homelessness or drug addiction before detention is used. In addition, health departments retain great discretion in determining how long noninfectious patients remain confined and what transgressions constitute unacceptable behavior.

It is essential to scrutinize such authority. The new detention regulations implemented at the beginning of the decade reflected a public health emergency. Rates of TB were rapidly increasing and MDR strains were causing outbreaks with high fatality rates. Now that better control of TB has again been achieved, the actual threat of nonadherent patients to the public’s health should be reassessed (Coker RJ; unpublished data). While, as Effren argues, “we should not shy away from the use of restrictive measures if necessary,” treating sick people with forcible detention must remain a strategy of last resort.

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