



# A Medical Anthropologist's View on Posttransplant Compliance: The Underground Economy of Medical Survival

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COMPLIANCE is, without question, an issue of survival for the posttransplant patient: Recipients' lives hang in the balance; they rely on powerful immunosuppressants and other medications to stay alive. At stake in professional understandings of their survival is a collective perception of "noncompliance." Compliance is hardly a static state of being, but a compelling dialectical process.<sup>1</sup> As a medical anthropologist concerned with recipients' lives, this report will focus on one aspect of this process: economic hardship. Many professionals, unfortunately, overlook its complexity, although it is all too familiar to their patients. As some would argue, the stance of professionals may render them susceptible to a collective form of denial: Swept away by the miracle of transplantation, many are blind to transplant's "survival paradox." As this report will show, patients may engage in creative forms of medication sharing, an activity we automatically consider dangerously self-destructive and, ultimately, terribly noncompliant. Such labeling, however, renders us blind to the economic realities of the lives we work so desperately to save. By displacing blame onto recipients, we refuse to assume responsibility for their long-term economic well-being.

## THE ANTHROPOLOGICAL ENTERPRISE

Anthropology offers particularly helpful methodological tools and theoretical perspectives for exploring this survival paradox. The author's work involves the detailed study of health and healing cross-culturally, driven by a strong interest in how the human body lends itself to understanding medical praxis. In the context of transplantation, qualitative research methods prove especially valuable, for they generate new understandings of social beliefs and behavior, and they reveal subtle nuances of human experience. A primary method is one-on-one, open-ended interviewing, where rapport and trust are essential. Further, questions are designed to enable informants (research subjects) to express opinions candidly and in detail. The strong code of ethics<sup>2</sup> of anthropologists also ensures privacy and anonymity, and independent funding and affiliations enable these professionals to work free from the influence of institutions with vested interests. The anthropologist typically works with a small sample of informants (perhaps 50 to 100 over a year or two). Thus, anthropologists specialize in small communities, be they surgical teams, procurement staff, or

patient groups. The anthropologist is often dedicated to giving informants a voice, and thus often quotes them directly (albeit while using pseudonyms).

A second essential strategy is participant observation, where the anthropologist becomes immersed in the research setting and develops a strong empathy for informants. Thus, the anthropologist will often attend support-group meetings, shadow hospital staff, spend time in recipients' homes, and attend donor family events. Anthropology is committed to understanding power dynamics, and the study of both those with little power and those who hold the power,<sup>3</sup> a focus that is crucial to understandings of noncompliance.

## THE ANTHROPOLOGY OF NONCOMPLIANCE

Unfortunately, anthropologists have neglected medical compliance. An exception is J. Trostle,<sup>4,5</sup> whose careful literature reviews reveal a burgeoning interest over the past three decades.<sup>4</sup> As Trostle argues, certain trends characterize this literature, which is "dominated by a series of ideological conceptions of the proper roles of patients and physicians. Though presented as a literature about improving medical services, . . . [it] is preeminently, although covertly, . . . about power and control . . . It reveals the medical profession's worldview." In Trostle's opinion, "The topic is better approached as an ideology supporting the authority of medical professionals than it is as a legitimate topic for behavioral research," since this ideology reinforces the physician's power while ignoring behavior that contradicts the professional point of view. In the past, "compliance" was in fact labeled "control"; further, until 1975, compliance appeared in *Index Medicus* under the heading of "patient dropouts,"<sup>4</sup> underscoring themes of assumed delinquency and culpability.

This notion of responsibility—of blame—is likewise pervasive in the transplant literature. Because recipients are

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rightfully assumed to be well-informed of their medications' importance, an overwhelming professional assumption is that noncompliance is evidence of irrational, delusional, and, ultimately, willful and self-destructive behavior. Failures are viewed as dangerous acts of defiance that place the precious organ *and* the life of the patient in serious jeopardy, yet such an approach belies the serious impediments recipients face, where long-term survival may, ironically, generate a host of dangerous economic perils.

#### THE UNDERGROUND ECONOMY OF MEDICAL SURVIVAL

Compliance as a topic surfaces with astonishing frequency in the context of this author's research. Coordinators speak of patients who miss appointments, are sloppy with medications, or defy dietary guidelines. Recipients, too, generate their own mythology about those who successfully wean themselves from their medications.<sup>6</sup> But there is another realm of experience that is far less understood—rarely is it voiced publicly, nor does it appear in the literature. This is transplantation's underground economy. Recipients (and some social workers) know of it, yet most professionals typically ignore or deny its existence. When economic hardship is raised, most often it falls under the rubric of "quality of life" or the "cost-effectiveness" of "maintenance costs."<sup>7,8</sup> The underground economy bears important policy implications; from a recipient perspective, it lies at the very heart of daily survival.

Recipients typically report medication expenses ranging between \$1000 and \$2000/month. The payment strategies they employ are endless and often ingenious. Transplant social workers are key, as they are well-versed in the rules governing insurance plans, employment discrimination, and Medicare, Medicaid, and disability coverage. As one recipient, Edna, explained, "You're really a slave to your insurance company. I'm working [a part-time job] for my insurance for \$267 a month. I take 21 pills a day! No one could afford \$1200 a month—that's the *average* cost for most medications for a new organ. You'd have to be a millionaire. I can't even consider a new job unless I know I can count on [keeping my current] insurance, because with a transplant you're slotted to the category of having a "previous condition." It's a lifetime thing. I don't know how [some people do it. Your medications alone] cost more than rent, more than a mortgage."

Spouses are often the guarantors of economic *and* medical survival. Many healthy spouses turn down new job opportunities out of fear of losing adequate coverage. Transplantation can easily impose a significant and steady drain on individual and family finances, where bankruptcy proceedings can begin even in anticipation of surgery-as-survival. Financial problems are only exacerbated posttransplant, so that recipients may question the integrity of their decisions and even the value of their own lives.<sup>9</sup> Typically, many rely on a patchwork of federal and state programs for support. They also experience a radical drop in their standard of living and in their socioeconomic standing, as

they cope with horrendous medical bills, and the shift from high-powered full-time work to short-term, part-time, or no employment.

These situations uncover a disturbing paradox: Ironically, long-term transplant survival can place one's life in serious jeopardy, for Medicare and disability insurance often cease after only 3 years, and opportunities are further complicated by any Social Security support one receives.<sup>10,11</sup> One husband, whose company's new insurance plan denied his wife coverage, phoned the wife's surgeon and cursed him as the wife sobbed and spoke of suicide. In response, the hospital team drew upon its own research funds to pay her bills. She was, after all, their first successful transplant.

Few recipients are so fortunate. The most extreme cases involve those who lose their insurance and who lack such exceptional safety nets. In times of extreme desperation, recipients turn to private networks for survival when professional ones fail. Specifically, they engage in an underground economy of medication exchange, an extreme form of clandestine activity carried out when all other resources are exhausted. For Debbie, a kidney-pancreas recipient, insurance was always problematic: Her mother had to fight for coverage following a divorce. When her mother died, Debbie turned to a friend who willingly "shared" her medications, as Debbie, too, had once done.

At first I assumed this story was a rare anomaly, but others have since related similar tales. As Jeff, a liver recipient explained, "This happens all the time. We go to our support group meeting . . . [and then] it's afterwards in the parking lot where this stuff happens." Another woman similarly confided, "Patients do that all the time, but they can't do it in front of [the staff]. If I have a new medication . . . I tell others I have this [other one left over] and I'm not using it. Or we'll go to [our support group leader]—he knows who needs what and, well, he gives it to them . . . But you're afraid to say anything [to the staff] because you then think, God, what if I went into rejection? [If they] ever find out you took something [outside of] your medication regimen [they'll] say it's your fault and you can just forget it if you need to be retransplanted." Participation in this underground economy exiles recipients to the category of "noncompliant" when, in fact, they are engaged in a desperate battle for medical survival against enormous financial obstacles. They are acutely aware of the power dynamics that shape definitions of "noncompliance," and that the blame falls squarely on them. Their frequent references to death underscore that their involvement is paramount to survival.

#### NONCOMPLIANCE AND SOCIAL RESPONSIBILITY

As sociologists Fox and Swazey have argued so forcefully, transplantation has been plagued by controversial policy battles. The financial arena is particularly troubling, generating "substantial socioeconomic disparities . . . and great stress and uncertainty for patients and their families. [Transplantation renders] millions . . . medically indigent or

uninsured.”<sup>12</sup> One may pay thousands for pre- and post-transplant expenses, yet the transplant community has typically shied away from these ethical and moral dilemmas.<sup>13</sup> In essence, this represents a potent form of collective professional denial. When recipients are held responsible for the financial burden of posttransplant success, the profound suffering and tragedy that can accompany this great medical miracle is often ignored by professionals. This oversight is further exacerbated by the burgeoning field of “pharmaco-economics,”<sup>8,14–20</sup> where an obsession with “cost benefits” and “containment” sadly overlooks human survival and social responsibility.

In conclusion, professionals must consider their own culpability. The mission of transplantation must also include a long-term commitment to solving recipients’ financial burdens. For, ironically, long-term posttransplant survival rates may generate horrendous economic hardships, which in turn could endanger recipients’ lives. It is hoped that an awareness of this paradox will reshape the way transplant professionals envision their roles as steadily employed professionals, where the economic complications that characterize this paradox ultimately undermine a naive vision of transplant recipient survival.

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