

# Desperately seeking “normal”: the promise and perils of living with kidney transplantation

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## Abstract

Organ transplantation offers a dramatic example of the promises for health held out by biomedicine—and thus, a productive vantage point from which to interrogate those promises. Drawing on ethnographic research on kidney transplantation in Guadalajara, Mexico, this article examines the version of “health” offered to patients through transplantation. The paper explores patients’ transplant trajectories as they move from learning to desire a transplant to actually receiving one and living with it over the long term, all within particular structuring sociocultural and political economic conditions. The article analyzes how transplanted patients are forced to come to terms with the contingent states of “health” and “normality” wrought by transplantation as they carve out an existence in the persistently liminal spaces between the roles of “sick” and “healthy,” dependent patient and fully contributing family member.

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It’s like we get the transplant and then nobody cares what happens next. We get sent off to our local clinics and that’s it... I thought everything would change, once I got my kidney. And it has—but not always like I thought it would...I thought I would be healthy again, and normal, but really I’m just a different kind of patient now. Felipe (IMSS, traveling salesman)<sup>1</sup>

## Introduction

As the “gift of life,” organ transplantation operates as a powerful popular symbol of the wonders of biomedical

achievement, of the ability of science to triumph over illness and even death itself. The mechanistic image of replacing a failed organ with a new one is often imagined to restore health in a fairly straightforward way, analogous to simply replacing a faulty motor part. As such, organ transplantation offers a dramatic example of the promises for “health” held out by biomedicine—and thus a productive vantage point from which to interrogate those promises. Social scientific approaches to health and medicine have often focused on the sociocultural construction of illnesses and their treatments, but less on how ideas about what constitutes “health” are simultaneously and similarly constituted. Yet particular understandings of “health” and “life” form the often-unexamined ground against which biomedicine wages its battle against illness and death, and offers its promises for salvation. Ethnographic research on kidney transplantation in Guadalajara, Mexico allows us to bring some of this “unexamined ground” to the fore so as to examine the version of

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<sup>1</sup>Names have been changed to protect identities. As approximate markers of socioeconomic status, patient quotes are identified by hospital and a brief occupation descriptor.

“health” being offered through transplantation, and to explore how the ability to attain this version of “health” is conditioned by gender and socioeconomic differences.

Social scientific analyses of organ transplantation have focused broadly on two key areas: (1) issues of hybridity and boundary crossing raised by the act of moving an organ from one body to another; and (2) the local and global political economies governing the flow of organs from donors to recipients. At a symbolic or interpretive level, the sometimes uneasy mixture of self and other in the body of the transplant recipient has preoccupied some scholars (Fox & Swazey, 1974; Sharp, 1995), while others have focused on the blurring of boundaries between life and death, nature and culture, and human and machine in the brain dead organ donor (Lock, 2001; Hogle, 1999). The nature of relations between organ donors and recipients has also provoked myriad debates over “gift” vs. “market” models for circulating human organs (Fox & Swazey, 1974, 1992; Peters, 1991; Murray, 1996). Further exploring the issue of bodily commodification, recent political economy analyses have focused on the global traffic in human organs, tracing out open and clandestine networks through which organs flow along familiar resource paths from South to North and poor to rich (Scheper-Hughes, 2000; Cohen, 1999).

This analysis brings together interpretive and political economic approaches to interrogate the promises and realities of “health” as they unfold over the long-term course of living with kidney transplantation in Guadalajara, Mexico. The realities of not just *receiving* a transplant, but *living* with one over time to date have received inadequate attention (Joralemon & Fujinaga, 1996). Focusing on what happens *after* the transplant calls into question the popular vision of transplantation as a death-defying triumph of science over sickness. This paper examines the sociocultural and political economic conditions of kidney disease and transplantation in two kidney transplant programs in Guadalajara and explores the particular discourses that motivate patients to look to transplantation as the way out of illness and the sick role to which they have been consigned. The paper then takes up the realities of living as a transplanted person, using the concept of “persistent liminality” to make sense both of these patients’ hopes for transition into a new social role, and of what happens when they find themselves caught “betwixt and between” the roles of “sick” and “healthy,” “patient” and “normal person.” Ultimately, the lived experiences of these patients reveal a much more contingent and often deeply-vexed version of the “gift of life” and the possibilities for “health” offered up by transplantation.

### Research context

This research was conducted in the city of Guadalajara, Mexico during the periods of July–August 1998,

August 1999–June 2000 and February 2001. Guadalajara, Mexico’s second largest city, is located several hundred miles northwest of Mexico City and serves as a major resource and service hub to the six surrounding states. As such, Guadalajara has two elite tertiary-level hospitals that draw people seeking specialized health-care—such as transplantation—from all over western Mexico and beyond.

These tertiary-level hospitals represent the two major government-run healthcare systems in Mexico, the Instituto Mexicano de Seguro Social (IMSS—Mexican Institute of Social Security) and the Secretaria de Salubridad y Asistencia (SSA—Ministry of Health and Welfare). The IMSS is the largest of the federal healthcare systems, providing coverage for slightly over half of the Mexican population (INEGI, 1998). In general, the IMSS serves a working/middle-class patient population—with important exceptions. Broadly speaking, the IMSS serves people employed in the formal sector who (along with their employers) pay into the national Social Security system. In addition, formal and informal mechanisms exist by which people who are self-employed and/or working in the informal sector (such as domestic workers or the ubiquitous street food vendors) can also often obtain rights to the IMSS system. Nationally, the IMSS possesses the most well-developed infrastructure of clinics, hospitals and specialized equipment of any of the Mexican healthcare institutions—including the private sector. IMSS coverage entitles beneficiaries to all necessary medical treatment at no cost, at least theoretically without limits on expense, type or duration of treatment. Importantly, it also includes rights to prescription drug coverage. The IMSS system consists of a national network of local-level clinics, community-level hospitals and a handful of tertiary-level specialty hospitals. IMSS patients are assigned to a local-level clinic and officially require referrals upward through the system to obtain more specialized care.

At the time of this study, the IMSS Centro Medico de Especialidades (Specialty Medical Center) in Guadalajara housed the country’s most active kidney transplant program. Although the hospital’s first successful kidney transplant was in 1976, transplant activity was sporadic until the mid-1990s when a US-trained nephrologist took over with ambitious plans for expansion. Under his leadership, the IMSS program grew dramatically and in 2000–2001 was doing an average of 200 kidney transplants annually and was also initiating a liver transplant program.

The Secretaria de Salubridad y Asistencia (also known as the Secretaria de Salud) is a public charity system run by state-level government ministries. More loosely organized than the IMSS, the SSA system provides in-patient healthcare for those without coverage or resources to pay for private care. Importantly, the

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