Chronic Conditions, Fluid States
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Chronicity and the Anthropology of Illness

EDITED BY
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CONTENTS

Preface and Acknowledgments vii

Introduction: Chronicity and the Experience of Illness
LENORE MANDERSON AND CAROLYN SMITH-MORRIS

PART ONE
The Idea of Chronicity

1 The Chronicity of Life, the Acuteness of Diagnosis
CAROLYN SMITH-MORRIS

2 Globalizing the Chronicities of Modernity:
Diabetes and the Metabolic Syndrome
DENNIS WIEDMAN

3 Is "Chronicity" Inevitable for Psychotic Illness?:
Studying Heterogeneity in the Course of Schizophrenia in Yogyakarta, Indonesia
BYRON J. GOOD, CARLA RAYMONDALEXIS MARCHIRA,
NIDA UL HASANAT, MUHANA SOFIATI UTAMI,
AND SUBANDI

PART TWO
Gender and the Experience of Illness

4 Male Infertility, Chronicity, and the Plight of
Palestinian Men in Israel and Lebanon
MARCIA C. INHORN AND
DAPHNA BIRENBAUM-CARMELI

5 "Half a Woman": Embodied Disruptions and Ideas of
Gender among Australian Women
LENORE MANDERSON
Preface and Acknowledgments

People strive to be normal; however, the realities of life are very different from the ideal. People have compelling concerns and precious stakes to defend; and although they would be "quite helpless without the power of cultural templates to guide and sustain them" (Urie Wikan, quoted in Becker 1998), they live their lives uniquely. In other words, events occur continu- mously that do not fit with a vision of how life should be, and when they do they affect people's individualized views of the world. (Becker 1998: 16)

Gay Becker's work on asthma and infertility highlights the ongoing nature of chronic health conditions—apparent, persistent states that in their everyday presentation, and in their lived experience, are always variable. Our book is a critical inquiry into this variability and fluidity, and into the value of chronicity as a way of theorizing poor health in diverse cultural contexts and political and economic settings.

Gay Becker's 1998 book, Disrupted Lives, was also the centerpiece text for a graduate seminar designed to explore the themes and questions of this volume. Becker was worried that anthropologists became, sometimes, distracted by larger social forces, failing to see the details in everyday lives. "Continuity is an illusion" (1998: 110), she wrote, part of American cultural ideology alongside independence, physical capacity, and progress. As she illustrated, these values were embodi- ment, metaphors in the lives of those who had lost control over self, whose identities were fractured, who no longer had (or no longer believed in) a predictable, everyday life.

For ethnographers whose gaze, whose obsession with the details of everyday lives, led them to study the so-called chronic diseases, Becker's words are a plat- itude. But her words bear repeating and amplification to others whose gaze is on other the shorter currents of suffering, or the larger social forces under which suffer- ing can be homogenized. And so, much in our volume will amplify and expand upon the notion that continuity is illusory. Becker's other insight—the particular- ity of the cultural environment of the United States—is equally important, and throughout this volume, individually and collectively, we tease out the chronicity of experience in different social, economic, political, and cultural settings, and the different features of inequality that shape the lived experiences of disease.
Medical anthropologists have embraced the nomenclature of biomedicine, including the idea of chronic. But the meaning and effects of illness labels have altered dramatically in the twentieth and twenty-first centuries, affecting irreversibly our ethnographies and their impact. While categories such as chronic and acute enable us to communicate across disciplinary boundaries, their use has produced a tense ambivalence. The volume now in your hand has grown from this tension.

The psychological, social, and material benefits that derive from the labeling of illness, for those living with illness, limited functions, or underlying pain or poor health, relate as much to one’s position(s) in society as to the quality and character of the affliction. But when we first began the collaboration that led to this volume, we felt that too little attention was being paid to these structural, social, and circumstantial positions so fundamental in shaping poor health outcomes and the particular difficulties of living with illness. So we began to work to bring together scholars engaged by these contradictions and complexities, working in diverse contexts in which the uncertainties of chronic illness were always set against and complicated by the uncertainties of structural inequalities. The first opportunity we had to tease out these issues occurred in the 2007 Presidential Session at the American Anthropological Association’s annual meetings, held in Washington DC. Entitled “Inequalities, Chronic Illness, and Chronicity,” the session was dedicated to Gay Becker, whose work had inspired so much of our own and who sadly died early that year. The 2008 panel of the same title at the Society for Applied Anthropology annual meetings rounded out the conversation, and led to our finalization of this volume’s prospectus. We were extremely gratified to begin work promptly with Rutgers University Press, and to join its series Studies in Medical Anthropology.

Lenore Manderson: My work on chronic health conditions and disability has been supported by an Australian Research Council Federation Fellowship, Victorian Science, Technology and Innovation Award, and project grants from the Australian Research Council and the National Health and Medical Research Council. I am also very grateful to the support provided by The University of Melbourne and Monash University. Across the globe, in working in this field, I have sustained established friendships and cherished the development of the new: in Malaysia, Zaliha Omar and Rameezan Abdul Rahim; in Thailand, Siriporn Chirawat; in Laos, Phouminth Bourath; in Burma, Than Toe. I owe many intellectual debts to graduate students, colleagues, and friends. To name some is to overlook others, and so I am mindful that I risk offending. I thank especially, even so, Pascale Allotey, Elizabeth Bennett, Elizabeth Hoban, Milica Markovic, Devva Kasnitz, Renata Kokanovic, Bhensri Naemiratch, Susan Peake, and Narelle Warren. Coediting can lead to great tensions and disappointments, but not in this case: I am very fortunate to have had Carolyn Smith-Morris as my coeditor and collaborator, and still to have her as a dear friend. Although this was challenging, various members of my family ensured my sensitivity to the personal dimensions of the chronic and acute. My husband Pat provided me with flesh examples of the value of creatively resisting the conventional trajectories of aging and chronic conditions; as ever, he is also my stalwart supporter and friend. And Tobi, my son, and Kerith, my daughter, as always, ground me, challenge me, tease me, and make the personal the greatest reward.

Carolyn Smith-Morris: In the years of thought and research that produced this volume, my professional tutelage came from Carolyn Sargent, Caroline Brettell, Victoria Loeblwood, and Lenore Manderson herself; abiding mentors, tenacious advocates, and fast friends. I am also grateful for the sage advice and guidance of Van Kemper in the SMU Department of Anthropology, and to Mark Richter, Harris Inhorn, and Lynn Morgan who have so generously taken interest in my work during the pre-tenure years. The good humor and proper perspectives of these mentors were salve and antidote when my errors became embarrassingly great. I am genuinely honored and grateful to several other sources of intellectual and professional navigation: Nanette Barkey, Susan Erikson, Tim Leatherman, Sunday Eiseht, and Nia Parson who will forever be among my favorites in the field. I would be remiss not to express my gratitude for the professionalism, reliability, and humor of those who made the daily work hours pleasant, especially Pamela Hogan. I am likewise indebted to my students, both graduate and undergraduate, at SMU. I am especially grateful for the intellectual contributions of students in the Fall 2007 seminar on Globalization and Chronic Disease at SMU: Shana Mens, Kyle Burn, Linda Farrell, Jessica Lott, Amir Mehdizadeh, Fiona Nicholson, and Morgan Rains.

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Is "Chronicity" Inevitable for Psychotic Illness?

Studying Heterogeneity in the Course of Schizophrenia in Yogyakarta, Indonesia

BYRON J. GOOD, CARLA RAYMONDALEXIS MARCHIRA, NIDA UL HASANAT, MUHANA SOFIATI UTAMI, AND SUBANDI

Schizophrenia has long been viewed as an almost inevitably chronic degenerative form of mental illness. This chapter examines the course of schizophrenia-spectrum mental illness in Yogyakarta in central Java, based on a seven-year longitudinal study that follows a small series of cases of individuals with mental illness and their families. It examines questions about the role of culture in shaping the trajectory of illness over time, as well as the effects of mental health services on the course of mental illness.

The association of the powerful and stigmatizing terms—chronic and degenerative—with schizophrenia is rooted in the history of Western psychiatry. Emil Kraepelin (1913), the early twentieth-century German pioneer of psychiatric diagnosis, still influential today, argued that psychoses should be defined in part by their typical longitudinal course (forthcoming). He distinguished manic-depressive or bipolar psychoses from "dementia praecox," later schizophrenia, not only in terms of symptoms but in terms of the normal, expected course of the condition. Manic-depressive disorder was seen to fluctuate between periods of mania, produced in part by excess of "will," and depression, by a loss of "will." He conceived schizophrenia as an early on-set form of dementia, marked by disorders of thought and almost inevitably chronic. Over his lifetime, Kraepelin became increasingly pessimistic about the potential for recovery from dementia praecox, and his early "optimistic" estimates of 11 percent recovery downward to 5 percent.

A chronic course of psychotic experience was thus identified as a characteristic of schizophrenia in Kraepelin's early work, influential when the term chronic, when applied to persons with mental illness, meant individual for life.
persons once diagnosed with schizophrenia can expect a life of profound disability, has contributed to hopelessness, despair, and stigma.

The view that schizophrenia is almost inevitably chronic and degenerative is formally enshrined in contemporary diagnostic manuals. The American Psychiatric Association’s *Diagnostic and Statistical Manual, Third Edition* (1980) stated this in strong terms: “A complete return to premorbid levels of functioning in individuals diagnosed with schizophrenia is so rare as to cast doubt on the accuracy of the diagnosis” (American Psychiatric Association 1980). While the 1994 edition, *DSM IV*, is somewhat more measured, it gives the message: “complete remission (i.e., a return to full premorbid functioning) probably not common in this disorder” (1994: 282). This view is widely held among clinicians, and from colonial times to the present has been taught to psychiatrists worldwide.

Over the last several decades, a variety of forces have begun to change this pessimistic view of schizophrenia. First, the development of the initial antipsychotic pharmaceuticals beginning in the 1950s raised hopes that people could live in the community and manage psychotic symptoms, even if they did not recover completely, and that more effective medications would be forthcoming. These early medications contributed to a powerful “deinstitutionalization” movement, which focused on civil rights and led to the closing of a large number of stand-alone hospitals in North America and Europe. These early changes, along with the development of second-generation antipsychotic medications and the explosion of brain sciences, provide renewed hope that this complex illness will one day be at least partially understood, treatable with a range of pharmaceuticals and psychosocial interventions, and even potentially prevented.

Second, a series of longitudinal epidemiological studies, going back to the 1960s, have raised more basic questions about the “natural history” of schizophrenia, challenging assumptions held by many clinicians and the public that schizophrenia is inevitably chronic. The International Pilot Study of Schizophrenia, which initiated more than twenty-five years of WHO supported investigations of the long-term course of schizophrenia in eighteen developed and fourteen countries, may have been wrong in its claim that outcomes were better in “developing” than “developed” countries (Cohen et al. 2008). However, the initial findings that in some cultural settings as many as half of people with schizophrenia recover within three years were enormously provocative, suggesting that social and cultural environments may be more important than “natural history” in determining the course of psychotic illness (Hopper 2007). The WHO studies were followed by research in Switzerland (Blum et al. 1980) and Germany (Huber et al. 1975) that documented good outcomes for half to two-thirds of persons with schizophrenia when followed over periods of time. The findings of Courtney Harding and her colleagues that one-third of the most severely ill persons from the back wards of the State Hospital recovered completely when moved into community settings were particularly revealing. Together, these studies began to suggest a different picture of psychotic illness and raised questions about what recovery might look like and about which persons recover from schizophrenia when and why.

Consumer advocacy began to place issues of recovery clearly on the agenda. The terms, representatives of the consumer movement have fought to change, public perceptions of illness, demonstrated how professional assumptions are implicated in stigmatizing those with mental illness, and lobbied for health policies and research that focus on recovery (Davidson et al. 2004; Roberts and Wolfson 2004; Schiff 2004). Today, recovery can be defined in the same sentence with schizophrenia in a way that even a decade ago was not possible. Increasingly, a focus on chronicity and deficits is supplanted by genuine efforts to promote recovery as a reasonable goal of mental health care.

Over the past several decades, a new “paradigm of recovery” from mental illness and cultural processes contribute to the course and outcome of illness, and how do these interact with biological processes, including pharmaceutical agents? In what way do local worlds of meaning and experience of illness, and how do these contribute to the experience of illness and the potential for recovery?

Questions are particularly important in cross-cultural research on schizophrenia. The WHO studies raise questions about the potential for better outcomes in Asia and Africa, a view challenged by Cohen and Knapp (2008). At the same time, mental illness is profoundly stigmatized in China and in many low- and middle-income countries (Desjarlais et al. 2000). We frame the questions our team has addressed in over a decade of research.
how are differences obscured by the terminology of classical psychiatry? And what dimensions does the course of illness vary, and how can anthropological research open up new understandings of such dimensions? Are there significant differences between “clinical course” and “social course” of schizophrenia—the heart of our argument will be the claim that heterogeneity of psychotic experience—both across cultures and between individuals within a culture is far greater than often recognized and that an examination of heterogeneity offers clues to understanding what constitutes better care for persons with serious mental illnesses.

A Longitudinal Study of Cases of Psychosis in Java

This project grew out of more than ten years of collaboration between the author (Byron Good) and a team of researchers in both the Faculty of Psychology and the Department of Psychiatry of the Faculty of Medicine at Gadjah Mada University in Yogyakarta, Indonesia. Our collaboration began in 1999. Byron Good and Subandi began ethnographic research with persons suffering psychotic illness in Yogyakarta, exploring their experiences and explanations of illness, the place of psychosis in Javanese culture, care-seeking, religion and spiritual healing, and mental health care. The study found that psychosis is deeply influenced by the presence of threatening spirits and spirit forces, by attacks of black magic, and by diverse forms of religious healing of the unexpected findings of the study was that a significant number of cases of psychosis seemed to have very rapid onset, with little sense of the slow, “insidious” onset often described as typical of schizophrenia (Subandi 2004; Good et al. 2007). An epidemiological study, conducted by Good and Subandi in 2000, supported this initial impression, finding that 37.5 percent of all first episode first contact cases of psychotic illness had “rapid onset,” defined as progressing from suffering an initial prodromal symptom to being frankly psychotic in two weeks or less.

In 2001, Good joined with Dr. Carla Marchira from the Department of Psychiatry and colleagues in the Department of Psychology at Gadjah Mada University (including the other three authors of this chapter) to undertake an intensive, longitudinal study of eight cases of psychotic illness. This provided the data for this chapter. Because rapid (acute) onset psychosis is associated with better outcomes than slower onset psychosis, we undertook this project as a pilot study to develop methods that would allow us to establish the relationship between onset of illness and its course and outcome. We set out to determine the feasibility of following patients and their families longer periods of time, to gain experience in using clinical rating scales to develop an in-depth understanding of a small number of cases of illness, based on longitudinal qualitative and ethnographic interviews of patients and their families in their homes during the first year, and we conducted annual follow-up interviews through 2002. We thus have relatively intensive, longitudinal data on families over a seven-year period.2

The next step was to examine several hypotheses about the relationship between the onset of illness and its longitudinal course. We integrate into our analyses further the cases of several of the cases to explore possible social processes that affected the course of illness. Our research indicates just how complex any account of onset and course of psychotic illness is, and this finding will offer observations about the variety of psychotic experience.

Brief Descriptions of Eight Longitudinal Cases of First Episode Psychosis

A. Rapid onset, single episode, complete recovery

Anto is a young man from a village near Yogyakarta with his mother, sister, and stepfather. His father left when he was four years old, and he has one older brother. Anto completed only eight years of school though he was very bright. He worked for one year as a servant in a wealthy house and then began working at a factory. Two weeks later, at age nineteen, he fell sick. One night his mother heard him work late, obviously troubled. When asked what was wrong, he became angry and would only say that when he rode his bicycle past the nearby mosque, spirits tried to take him into the graveyard. Anto went to work, but when he returned after disappearing for two days, his condition was poor. He became very silent, walked around like a “zombie” with a hollow look, and acted very frightened. He tried to destroy any clothes he could find, which were red and black. He felt ants were crawling in his body. He was visited by a black pig and crawled around on the floor making strange noises. He was visited by the great Queen of the South Sea, who hypnotized him. He was visited by the Sultan of Yogyakarta. He feared being laughed at or being angry with his mother, claiming she had made a deal with the devil for him and exchanged for money. He was taken to a private psychiatrist, where he was prescribed antipsychotic medication. He stopped taking the medications after a month when the psychiatrist from our team provided him with a note and encouraged him to continue them for about four months until his symptoms subsided. He visited several traditional healers during this time, who proved...
unable to cure him. When we visited him at four months, he appeared better, had returned to work, and told us he could not remember what had happened. We have followed Anto for nearly seven years. His illness has gone. He has taken no medication since his episode and shows no residual impairment. Although he is happy to talk with us, he is not interested in mentioning or discussing his illness. He is more concerned with the loss of his job and with finding enough work to move forward with his life.

**Case 2 Mas Tri—Sudden onset, five brief psychotic episodes, mild impairment**

Mas Tri lived in a household with extended family in Yogyakarta when we met him. Unlike his three siblings, he completed high school with high grades. Because his family was poor, he was unable to attend university, and instead moved to Sumatra, lived with his uncle, and worked on a coffee plantation. He had occasional alcohol and marijuana use while in high school and Sumatra. Contracting malaria, he returned home to Yogyakarta; upon recovery, he began a laborer job in an oil distribution agency. One week after his new work, he suddenly became psychotic. He had difficulty sleeping and his behavior strangely. One night a voice told him to go to a house nearby and a young woman, whom he now thought was his high school girlfriend, actually the current girlfriend of his mate. Wearing only his underpants, he called loudly for her, and soon afterward was hospitalized. He was released and a week, appearing recovered within a month. Over the next six years, he had four relapses, each brief yet some requiring short hospitalizations. These occurred when he was attending a religious service, another time when he was walking by his aunt. He used medication sporadically, with family often complaining of the cost. Between episodes, he worked intermittently, expressing some worry about falling sick again. To us he appears socially functioning, yet he seems to take little initiative, complaining that potential jobs are beneath his friends now have.

**Case 3 Mbak Yanti—Sudden onset, two brief psychotic episodes, mild impairment**

Yanti, a daughter of unskilled laborers, lived in a small neighborhood in Yogyakarta. One of five children, she was born the smaller of twin girls. Developmentally slower than her twin, she dropped out after primary having failed to pass to the next grade several times and becoming smaller at being older than the other children. Often fearful and hesitant, she was opposite of her bright sister who graduated high school and eventually married. At age seventeen, during afternoon prayers one day, her great-grandfather, whom she loved and who had died five years earlier, appeared to her to take a "flower bath." While alive, the great-grandfather had claimed Yanti's grandmother for claiming that Yanti's "brain was rotten." The move was that she needed to bathe. Yanti was terrified by the appearance of an angel in the white dress. She became confused, talked to herself, had difficulty sleeping, became violent, and tried to run away. Her family tied her to a wardrobe, she pulled herself to the window and the glass with her head. After a religious leader's prayers failed, she was hospitalized for three months. She returned home largely unimpaired and another episode and was hospitalized two years later, again after treatment. It is difficult for us to tell whether Yanti suffers negative symptoms related to her illness, or whether the description of her behaviors, such as therapy, complies with developmental disorder. Though she does general housework, she is not at work and then spends hours watching TV. Her family considerably sensitive and takes care not to criticize her. Since 2002, she has been taking low-level first-generation antipsychotic medications, which help for her sleep. She has had no further episodes of psychosis. She lives with her parents, does housework, shows little motivation, has few friends, and has a limited life, though her illness seems less significant than her psychiatric diagnosis.
Mbak Sur’s mother remains quite authoritarian, often ridiculing her daughter and expressing anger at her. She and her husband sometimes refuse to give her medications, accusing Sur of only pretending to be sick. Sur remains psychotic and lives at home in a back bedroom. Her parents are hopeless about her future.

**Case 5 Mbak Wi—Sudden onset, continuous psychotic symptoms, modest impairment**

Wi was a thirteen-year-old schoolgirl, daughter of two schoolteachers in a village just outside of Yogyakarta, when one day in 2001 she experienced a sudden onset psychosis. There was no evidence of a prodrome, decline in performance, or major stressor. That day, a Javanese spirit—Butojop, a large green snake—appeared to her while she was in school. When she came home, her bedroom filled with spirits, including a man with orange clothes and a rible face. She saw a man who had killed himself hanging in her room and a green snake threatening to attack her. She felt someone wanted to rape her and that others wanted to kill her. Her father appeared to be her mother, and mother her father. Wi was taken to the university hospital and given medications. She returned home but soon became violent. Two days later she was sent to a private psychiatric hospital, treated for nine days, and returned home better. Within a few weeks she returned to school. Wi’s father, a Javanese schoolmaster, felt that some black magic from one of his students must have been reflected from him to his daughter. Her mother accused an extended family member who held a grudge over a land deal had caused the magic and attacked her. Wi, however, told the psychiatrist that she experienced no more spirits. However, she finally confessed that she continued to hear two spirits, the man in orange and a woman in green, speaking with each other. Despite this, she was able to continue school, where the other children could hear spirits and would ask what they were saying. She had friends in her classes, and showed relatively little impairment. She has continued to take medications since she became ill, at her mother’s insistence. Over time her performance in school, however, declined. She failed the high school graduation examination, which prevents her from entering nursing school. She has been enrolled in a school to train teachers.

**Case 6 Mbak Arti—Traumatic onset, unremitting illness**

At age twelve, in 1999, Arti returned home from school one day to learn that her mother had just been killed. Her parents had been riding their bicycle to market when the mother was hit by a passing truck. Within two weeks of her death, Arti suddenly became acutely psychotic. She began screaming, wandering around aimlessly, laughing and talking, and complained of seeing *piomong*, a kind of ghost wrapped in a black cloak. This began a long process of unremitting psychosis. Arti’s elderly grandfather took her to healers around the village, but it was not until December that she was referred to a psychiatrist. Arti’s mother placed her in a *pesantren*, an Islamic boarding school for girls, where she stayed for twelve days. Upon her release she refused to go home. Her father placed her in a *pesantren*, an Islamic boarding school for girls, where she remained for six months. In July 2000, Arti became violent and was again admitted to a hospital. For five weeks, then for six months more. She returned home, still living around the village, would disappear for periods of time, and was reported home pregnant. Her child was delivered by a village midwife, but she is not sure if it was her child. She is not aware of what is happening to her. The local community is skeptical about her mental health. Arti’s father and sister accept her illness as a kind of fate. They try to remain patient and supportive, but her mental state has deteriorated and she often disappears. Arti can no longer consent to treatment. She was included in the study.
saying her real problem is that she is tired from overwork. Occasionally her (deceased) father come into the kitchen. She says she has been black magic, but that she has been treated by a healer who has monitored her house and protect her. Overall, her mother has lost hope and most deeply about whether any of her siblings will care for her daughter if she is no longer able to do so. She wonders if she would be better staying in a hospital.

Case 8 Mbak Ismi—Gradual onset, unremitting illness, severe impairment

Ismi is the second of two daughters in a poor family living in a village in the city of Yogyakarta. Her father is an agricultural laborer; her mother pass small food items. From the time she was young, Ismi was quiet, withdrawn, of below average intelligence. She failed to advance in school three times, in middle school, other children began to tease her, calling “water buffalo,” and joked that she was pregnant. When she asked her parents to enter a different school, they refused, so Ismi stopped attending. In 1999, at the time she was having difficulties in school, Ismi became very sometimes cried, and felt afraid. Her sister describes these symptoms as begun after a stone fell into their house with a loud noise at night, while she was asleep. A week later, while taking a bath, she suddenly began to scream and became confused. Her symptoms worsened over time. She talked to herself. She heard voices. She saw pocong, the dead was shrouded, floating about. She became more emotionally withdrawn and taking care of herself. Finally, after almost a year, and after several healers had failed to help, her family took her to a psychiatric hospital in January 2001. After a brief improvement, she became worse again, refused to eat and bathe, and was rehospitalized in 2003. When she returned home, she twice “fell” (jumped?) into the well, the second time at the time of her voices, and was returned to the hospital. Her illness has continued to worsen. She becomes violent and sometimes wanders about aimlessly, talking people talking about her, calling her names, and commanding her to harm self. She watches television to make the voices go away. She has lost essentially. Increasingly her father feels hopeless, particularly after a nurse suggested she could not be helped. When Ismi becomes out of control, she is kept in a room behind the house or kept in restraints.

Analytic Observations

Many of the cases described here would be quite familiar in psychiatric care. The basic symptoms of psychosis, described in terms—hallucinations, delusions, ideas of reference, paranoid ideation, symptoms—may be present in nearly all of these cases. The term “psychotic illness” used here is not to be confused with the term “psychosis,” which is often used to describe a condition of clinical description, these terms hide what is distinctive about psychotic experience in Java clinically, culturally, and in terms of case history. Indeed, when described in these clinical terms, the most characteristic features of psychotic illness that vary across societies and within societies disappear. How then might these cases in ways that highlight important clinical and cultural features suggest a way of thinking about psychotic illness? What are the significant and raise questions about the classic descriptions of psychotic illness?

Characteristics of the Experience and psychotic illness in Java

The characteristics of these cases, which may seem unremarkable precisely because they are so typical of psychotic illness, is noted. First, psychotic experience in Yogyakarta is rooted in religious and religious life. The Javanese lifeworld is a world of beliefs, practices aimed at enhancing the inner power (tenaga dalam, individu) in ways that protect them from dangerous or malicious forces. Feelings between seen and unseen worlds, and of the use of rituals to relate to the unseen and unseen spirits and energies both in good and for ill toward the body. It is the world of the classical princely world linked to Hindu-Buddhist spiritual world of local spirit practices, and the Islamic (or santri) world of narrative and meditative practices through Sufism and includes local Islamic cosmology (Anderson 1972; Ferzacz 2001; Geertz 1960; 1973). It is the world of the eclectic world of Christians and other minority religious groups, and healing and healing in Yogyakarta a kind of postmodern air. Psychotic experience is in direct contact with this unseen, spiritual world. Thus stories of persons coming into contact with deceased persons, with well-known types of local spirits or ghostly forms with mighty spirits such as the Queen of the South Sea (Ratu Madura) and the Sultan of Yogyakarta, and with the forces of black magic, by someone wishing them harm. Some of these spiritual forces are directly by persons who are ill; others are suspected illness. Virtually all of these spiritual forces are part of the world of persons surrounding the patient and are taken seriously. The label “crazy” simply because they “believe” that they see and are seeking for psychotic illness almost always includes the investigation of the role of the unseen world in the illness and concurrent with seeking medical care.
studies are consistent with cultural understandings of being struck by a great force. This has long made our research team suspicious that the cultural narrative about the story of how the illness suddenly began might hide evidence of lasting symptoms of illness. However, intensive interviewing with these illnesses and their families, continued over a number of years, gave us the opportunity to explore this possibility. In some cases, retrospective interviewing made it impossible to be sure (e.g., did Arti [case 6] develop psychotic symptoms for the one hundred days following the death of her mother when she was 14 and refusing to go to school, before the sudden eruption of acute symptoms? In most cases, however, we feel confident that the narratives are accurate describing the illness as occurring suddenly with few prior signs. If we for Arti developed her psychotic symptoms prior to the one hundred day ceremony following her mother’s death (and therefore was not a caused by an onset psychosis), five of the eight cases have very acute onset, a clinical picture quite different from what we have expected from North American samples.

Third, drug and alcohol use are not prominent in these stories. Only in one case of Mas Tri (case 2) is there evidence of marijuana and alcohol use to the onset of illness, and in no cases are there reports of drug use or alcohol to “self-medicate” for the illness. Again, this contrasts sharply with American, European, and Australian samples.

Fourth, all eight of these individuals have lived at home with their parents and siblings following the onset of the illness. Only Arti has spent part of this time essentially homeless, wandering around local villages and even living the streets of more distant cities in Central Java, with her elderly father trying to control her. The care of these individuals, as with the vast majority of persons with long-term psychotic illness in Indonesia, is primarily provided by family members. Relatively few persons are confined in large psychiatric institutions for much of their lives, as is true in many parts of East Asia. Some seem well attached, however, as described in the cases of Sus (case 4) and Tami (case 8). They are considered quasi-institutional, in that the individual is essentially confined to a single room with minimal care, with the family expressing a loss of hope that of more classic psychiatric asylums.

Finally, the general pattern of medical care described in these cases is typical of those parts of Java in which there is a reasonable number of private and public psychiatric facilities. The most rapid, acute onset cases tend to be seen to medical care quickly. Whether in hospitals or private clinics, individuals treated with standard antipsychotic medications, primarily first generation drugs, and many receive ECT. Inpatient treatment is often as short as ten days in private facilities or the university hospital, and as much as six months in the public hospitals. It is common that individuals stop taking medications as soon as symptoms decline, in many cases followed by relapses. Illness continues over long periods of time, the family may continue the prescriptions, using quite low doses of medications, often focusing on

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View of the Course and Experience of Psychotic Illness

That there are general patterns that distinguish schizophrenia clinically and culturally—in Java, it is important to return to the question of whether there is a single, dominant pattern of chronicity associated with psychotic illness and whether there are significant differences in the long-term course of psychotic illness. When viewed longitudinally, the illness, many of these cases appeared quite similar, even though the details of the stories varied. However, when viewed longitudinally, heterogeneity appears in the course and experience of illness.

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Is There a Single Course for Schizophrenia? Examining these cases visually makes it obvious that there is a single dominant pattern of illness course. One individual had a single episode of illness and complete recovery. Two who have had two and four episodes respectively, with the same disability but not apparent psychotic symptoms outside of these episodes. Five persons have suffered long-term psychotic illness without complete remission. One of these five has relapsed limited to the context of high functioning.

These patterns are not unique. As mentioned earlier, long-term studies of persons with diagnoses of schizophrenia for more than twenty years and similar heterogeneity. Luc Cioni (1980), in a retrospective study of 164 patients (mean age over seventy-five years) diagnosed with schizophrenia and hospitalized in Lausanne, Switzerland, provided a schematic for eight course types based on onset (acute versus chronic), pattern (single versus undulating), and “end state” (recovery or mild residual features), showing that the 289 persons were distributed across these types. Courtney Harding (1988) demonstrated that her study of 289 persons previously hospitalized in Vermont and New York in a study of 164 patients (mean age over seventy-five years) diagnosed with schizophrenia and hospitalized in Lausanne, Switzerland, were also well described by these types. Our cases, described earlier, are also distributed across these types.
studies look in detail at how specific social processes in local social settings may contribute to different courses of illness, and how individuals experience these very different forms of psychotic illness. We will return to this issue later.

**Effects of Type of Onset on Course: Are Acute Onset Illnesses Inevitable for Psychotic Illness?**

Nearly all clinicians and most schizophrenia researchers agree that very acute onset is associated with better prognosis for psychosis, raising questions about whether rapid onset illnesses are "reactive" or "organic" rather than "functional" or "organic." It has been difficult to define these categories, since nearly all psychoses seem to respond to stressful life events and include both psychological and organic qualities. **DSM III** (American Psychiatric Association 1980) used the category "brief reactive psychosis," indicating that the onset of psychosis occurs "immediately following a psychosocial stressor." **DSM IV** (American Psychiatric Association 1994) added the more general category "brief psychotic disorder," denoting those cases without marked stressors. Both categories assume that rapid onset and short duration go together. In general, there is little empirical evidence supporting the criteria used to define either of these disorders or the ICD's "Acute and Transient Psychosis" (Good 2005).

There is some empirical evidence that rapid onset is associated with better outcome, even in long-term psychotic disorders. For example, in the three course types reported earlier, Czompi's data show that "recovery or mild" outcomes are found in 60 percent of the cases with acute onset and only 40 percent of the cases with chronic onset. In Harding's cases, "recovery or mild" outcomes are found in 63 percent of cases with acute onset compared with 13 percent of those with chronic onset.

We of course cannot test a hypothesis with eight cases, but we can look to see whether our cases are or are not consistent with the hypothesis that rapid onset of illness is associated with better course of illness. In our cases, the three with slow onset have all led to continuous severe impairment. Of the five cases with rapid onset, one had complete recovery, two had brief episodes of psychosis with only mild residual symptoms between episodes (no positive psychotic symptoms), one (WL) developed a long-term psychotic symptom (visual and auditory hallucinations) of only moderate impairment, and one (Sur) recovered from her initial episode of illness but then had a relapse and has developed a continuous course with severe impairment. These cases thus fit the hypothesis that rapid illnesses tend to have better seven-year prognosis. It might be noted that there is little evidence of prodrome in the five rapid onset cases, and in these cases there is evidence of a significant psychosocial stressor that is considered the appearance of a terrifying spirit a stressor rather than the illness.

**Is "Expressed Emotion" on Course: Does Negative Family Interaction Predict Poorer Prognosis for Psychotic Illness?**

The literature, dating back to the seminal work of Christine Vaughan and George Brown (1985), suggests that the emotional behavior of family members places the individual suffering schizophrenic illness at risk for relapse. This literature suggests risk for relapse owing to how expressed emotion interacts with medication use, reducing the effectiveness of treatment for schizophrenia. This literature has shown that high levels of critical comments by family members place the individual suffering schizophrenic illness at risk for relapse. This literature suggests risk for relapse due to how expressed emotion interacts with medication use, reducing the effectiveness of treatment for schizophrenia. This literature has shown that high levels of critical comments by family members place the individual suffering schizophrenic illness at risk for relapse. This literature suggests risk for relapse due to how expressed emotion interacts with medication use, reducing the effectiveness of treatment for schizophrenia.
frustration in the family that this daughter was not able to attend high school and go to the university but ended up in a technical school at the same time, the mother expresses great sadness for Sari and worry about her future. Sari’s younger sister describes her as malas, a term that means “lacking in motivation.” This may have reflected not only Sari’s long history of being quiet and withdrawn but the negative symptoms that developed. It seems not unreasonable to interpret Sari’s fantasy that she is a woman, that the house is her business office, and that she maintains a crafts business as a response in part to her family’s criticism of her being unproductive.

Sur, the young woman who grew up with her grandparents, now has her father and mother. Her mother is very authoritarian, and both are critical of their daughter. Both speak mockingly of her in front of our letters, calling her too stupid to answer questions and openly suggesting that she is only pretending to be sick, even though she is obviously deeply ill. Her mother apparently sometimes strikes the daughter, and once cut her hair off while she was asleep. She often intrudes and asks personal questions we address to Sur. And the parents only buy the medications for their daughter sporadically, complaining of the cost and her not really being sick.

The two cases in which the family is highly critical both have psychotic illness. Sur was in apparent recovery for nearly one year before there was a severe relapse. Of the six cases in which family members are aggressive and supportive, three have continuous psychotic symptoms, and the other three recovered or have only rare psychotic episodes.

The work on the family emotional climate and its influence on illness points in another direction as well. It has become clear, as we proceeded, that the concepts of stigma and negative expressed emotion are related. Critical comments within the family are a kind of internalized stigma within the most intimate of social relationships. However, comments within other important social environments, often seen as having a similar effect as negative expressed emotion. Thus, a comment by a friend of Mas Tri’s intimate religious community, questioning whether he still leads prayers, triggered a strong emotional reaction and relapse of his psychotic symptoms. Obviously stigma extends beyond interpersonal relations and institutional structures, but the two are interrelated concepts, and our data suggest that the general argument that negative social environments can place individuals at risk for relapse and more severe and continuous illness.

WHAT IS THE RELATIONSHIP BETWEEN CLINICAL COURSE AND IMPAIRMENT? It may seem obvious that social impairment is closely related to levels and types of psychotic symptoms, with increased levels of psychosis producing increased levels of disability. It should be equally clear that the extent of pathological symptoms in itself is insufficient to account for variability in levels of disability and occupational functioning. Our data are consistent with the findings of previous research on variables such as quality of family relationships, disability, and occupational functioning; all in addition to symptoms. And psychosocial interventions are critical determinants of improvement. If we are to understand recovery from psychotic illness and in different social environments, we will need to understand how we now do the interaction between social and cultural processes associated with schizophrenia, particularly those that produce resilience as well as disability.
interpretations of her illness was that the spirits were sending her illness, and they wanted her to take up the healing mission of her father. She, initially, insisted that her symptoms were a mental illness, not a calling to be a healer, and has been strongly supported by her family, particularly her mother, who monitors her health and her medications, and who supports her efforts at work but tries to prevent her from pursuing unrealistic goals. Her personality is obsessive and perfectionistic; one result is her ability to focus very narrowly on her schooling, screening out attention to the hallucinations. Over the past year, her impairment has increased modestly. She is still quite young, and it is not clear whether she will be able to complete her schooling, develop ongoing relationships, get married, and follow a normal Japanese life course. However, she has been remarkably resilient in the face of continuous illness.

Conclusions

We began this chapter questioning the model of schizophrenia and schizophrenia-spectrum psychotic illnesses as inevitably chronic and degenerative, inherited from Kraepelin and reinforced by the "clinician's fallacy," which describes the sense view of clinicians that schizophrenia is inevitably chronic because of their patients are those who return over and over again (Cohen and 1984; Harding et al. 1987a: 481). We reviewed the emergence of a novel hopeful focus on the potential for recovery. And we asked how social research can contribute to understanding what social factors may contribute to recovery.

Our primary argument has been that the classic, inherited model of schizophrenia provides a far too unitary model, one that is often reproduced by anthropological research by describing the experience of psychosis as an illness in terms of psychotic experience rather than examining how individuals and families live with the fluctuating qualities of psychotic illnesses over time. We have argued that only by attending closely to the heterogeneity of illness, by understanding the nature and sources of that heterogeneity, can anthropologists, social scientists, and researchers contribute to the development of mental health services more focused on recovery rather than managing psychotic symptoms.

In the conclusion to this chapter, we indicate some critical dimensions of heterogeneity that deserve attention if we are to understand potential of resilience and ways that mental health services can build on natural processes of resilience and contribute to improving the lives of persons with psychotic illness.

Clinical and Biological Heterogeneity

Although there is a long-standing hypothesis that "the schizophrenia is a genetically heterogeneous family of disorders, contemporary psychiatric research is just beginning to empirically distinguish the various forms of the illness, including paranoid schizophrenia, affective (bipolar) schizophrenia, and schizoaffective disorder. The emerging model of the illness has made only modest progress in unraveling specific phenotypes of schizophrenia. What is clear is that schizophrenia is a complex psychiatric disorder with multiple clinical dimensions: reality distortion (including positive and negative symptoms), thought disturbance, and affective and cognitive pathology, with the possibility that depression is a core dimension of schizophrenia rather than a secondary illness. If anthropologists are going to contribute to serious rethinking of the heterogeneity of psychotic illness, they will need to understand very different dimensions of illness may vary for individuals with schizophrenia, producing very different patterns of illness and recovery.

Consequently, describing illness in clinical language minimizes or deflects from social and cultural processes that produce heterogeneity of illness. There is no alternative to rich ethnographic description that understands the local worlds of psychotic illness and sources of both vulnerability and resilience within these worlds. Linking of clinical research and ethnographic research is an important research challenge.

In conclusion, we suggest the importance of long-term longitudinal research that combines ethnographic, clinical, and epidemiological methods. Any effort to disentangle of experience of psychotic illness, to address such factors improve long-term outcomes, requires longitudinal research. Harding's work suggests that following persons with a psychotic illness over their lives provides surprising evidence of unexpected recovery. We suggest that we should substitute the term "prolonged schizophrenia" for "chronic schizophrenia" and "brief or short-term schizophrenia" for "brief or short-term schizophrenia" (Harding et al. 1987: 483). Finding ways with other research to represent "clinical course" of such illness with better "clinical course" are of particular importance.

Conclusion

The empirical research movement within psychiatry, focused on understanding of the very earliest phases of psychotic illness, provides an opportunity for anthropologists (e.g., McGorry et al. 1999; McGorry et al. 2000). There is virtually no research on the cultural heterogeneity in the early phases of psychotic illness, social responses to the illness, and care-seeking for psychotic illness. Much remains relatively obscure and largely unproblematic that much psychiatric research depends on identifying cultural and social factors that influence illness and recovery.
precisely when a psychotic illness began. Rich ethnographic analysis to complement ongoing clinical and epidemiological research.

**Psychological Heterogeneity**

So powerful have neurobiological understandings of psychotic illness become that real person-oriented understandings of the nature of psychoses are increasingly neglected. Anthropologists need to resist the tendency to view schizophrenia, particularly given our experience that many people suffering from psychotic illness are not psychotic much of the time, that persons with different personalities and personal lives suffer psychotic illness. Understanding how individuals and families cope with psychosis requires a new understanding of psychological, even when they suffer psychosis.

Anthropologists need a far more nuanced understanding of the diversity of psychotic illness if we are to contribute to efforts to intervene to support individuals and families struggling to live with and heal from psychotic illness.

NOTES

Special thanks to the Javanese families who have met us many times over with great grace, allowing us to enter their intimate spaces to talk about these issues. Thanks to Ken Vickery for great help in editing this chapter.

1. This study identified 392 cases of first episode first contact psychosis in the period, a treated incidence rate of 2.5 cases/10,000 population.

2. All research has been carried out following human studies procedures approved by the Institutional Review Boards of Harvard Medical School, Gadjah Mada Faculty of Medicine, and the Indonesian hospitals whose patients participated in the study.

3. Mas is a term of address in Java for young or unmarried men or men with a particularly intimate relationship. Mbak is the similar term of address for women who have been altered to hide the identity of the individuals and families who participated in this study.

4. The province of Yogyakarta has approximately thirty psychiatrists and the population of three million people, lower than Jakarta but much higher than Indonesia.