Schizophrenia, Culture, and Subjectivity

The Edge of Experience

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CAMBRIDGE
UNIVERSITY PRESS

PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE
The Pitt Building, Trumpington Street, Cambridge, United Kingdom

CAMBRIDGE UNIVERSITY PRESS
The Edinburgh Building, Cambridge CB2 2RU, UK
40 West 20th Street, New York, NY 10011-4211, USA
477 Williamstown Road, Port Melbourne, VIC 3207, Australia
Ruiz de Alarcón 13, 28014 Madrid, Spain
Dock House, The Waterfront, Cape Town 8001, South Africa

http://www.cambridge.org

First published 2004

Printed in the United States of America

Typeface Plantin 10/12 pt. *System* LaTeX 2ε [TB]

A catalog record for this book is available from the British Library.

Library of Congress Cataloging in Publication Data

Schizophrenia, culture, and subjectivity : the edge of experience /
edited by Janis Hunter Jenkins, Robert John Barrett.
p. cm. – (Cambridge studies in medical anthropology ; 9)
Includes bibliographical references and index.
ISBN 0-521-82955-0 – ISBN 0-521-53641-3 (pb.)
1. Schizophrenia – Social aspects. 2. Schizophrenia – Cross-cultural
studies. 3. Subjectivity. I. Jenkins, Janis H. II. Barrett, Robert J.
III. Series.
RC514.S3349 2003
616.89′82–dc21 2003046125

ISBN 0 521 82955 0 hardback
ISBN 0 521 53641 3 paperback

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Introduction

Janis Hunter Jenkins and *Robert John Barrett*

> The fact of the psychoses is a puzzle to us. They are the unsolved problem of human life as such. The fact that they exist is the concern of everyone. Jaspers 1964 [1923].

Background to the Collection

In the fall of 1986, as postdoctoral fellows together in the Department of Social Medicine at Harvard Medical School, Janis Jenkins and Robert Barrett, the editors of this volume, began a conversation about culture and schizophrenia. By the fall of 1996 when Rob visited Janis, then a scholar-in-residence at the Russell Sage Foundation in New York City, it was time to do something about this conversation. We began by organizing a panel that developed into an invited session at the 1997 meeting of the American Anthropological Association in Washington, DC. The session was entitled, "The Edge of Experience: Schizophrenia, Culture, and Subjectivity."

After this meeting, we submitted a proposal to the Russell Sage Foundation to fund a symposium that would assemble an even larger group of scholars working at the interface of culture and schizophrenia. The foundation generously supported this project under its mandate to generate scholarship concerned with the "improvement of social and living conditions." The three-day symposium that took place brought together twenty-two scholars of diverse academic and professional backgrounds – anthropologists, psychiatrists, psychologists, and historians – to report on research that had been carried out in North America, Latin America, Africa, South and Southeast Asia, and Australia, as well as on the international studies of the World Health Organization. As our aim was to foster research in culture and schizophrenia, we deliberately invited a mix of scholars, from senior, well-established figures to young researchers reporting on their doctoral work. Students rubbed shoulders with doyens. In the 1930s, the psychiatrist, Harry Stack Sullivan lived just half a block from where the Russell Sage Foundation now stands on East 64th Street,

and it was during this era that his collaboration with the anthropologist, Edward Sapir flourished, generating a body of scholarship oriented to the dynamics of social interaction as the locus of both schizophrenia and culture. Our project continued this rich heritage of studies in culture and mental health associated with this particular New York City neighborhood.

It is from these origins that this volume emerged.

Framework for the Volume: Conceptualizing Schizophrenia, Culture, and Subjective Experience

Disorders of Schizophrenia

It has become commonplace to observe that schizophrenia is probably not a single disorder but more likely a number of disorders that are, for the time being, classified under one rubric. As Bleuler (1950) was the first to emphasize, "the Group of Schizophrenias" is fundamentally heterogeneous. The origins of this heterogeneity may be similarly biological and cultural (Lin 1996). While this volume selects cultural analysis for primary consideration, it is axiomatic that biological investigations are no less critical to an understanding of schizophrenia. This being said, the role of culture has been regarded in many quarters as secondary at best. In seeking to redress the situation, this volume is perhaps the first systematic effort to advance a cultural approach to the study of schizophrenia that takes the complex phenomenal reality of subjective experience as a starting point. We anticipate that the material presented here will therefore be of practical value to mental health professionals, not only for the insights into schizophrenia that are offered by contributing authors, but also for the interpretive approaches that are developed herein – approaches that health professionals themselves can adopt to understand their patients better.

Schizophrenia is one of the most severe psychiatric disorders. It carries serious implications for those who suffer from it and those who care for them because it is associated with significant disability and a substantial mortality rate. The widespread distribution of this disorder and its remarkable variability are two of its striking characteristics. It affects people from all class backgrounds, though persons of lower socioeconomic status are particularly at risk (Cohen 1993). Whether this is due to "social causation" or "downward drift," the association between schizophrenia and social class is one of the most consistent findings in psychiatric epidemiology (Fox 1990). Schizophrenia has been recognized in a wide range of cultures. Contemporary epidemiological evidence indicates that

its prevalence varies from 1.4 to 4.6 per 1,000, and incidence rates range from 0.16 to 0.42 per 1,000 population (Jablensky 2000). Germane to many of the contributions to this volume are the well-established, cross-cultural differences in the clinical features of schizophrenia, particularly in relation to its course.

With regard to the conceptualization of the disorder, we have adopted a strategy that employs contemporary research diagnostic criteria as a productive starting point for cross-cultural studies, notably those of the International Classification of Diseases (World Health Organization 1994), and the Diagnostic and Statistical Manual IV (DSM-IV) (American Psychiatric Association 1994, 2000). Given that, we are broadly concerned with a pattern of symptoms characterized by positive symptoms (disordered thinking, disorganized speech, hallucinations, and delusions), negative symptoms (such as withdrawal or blunting of emotional expression), and disorders of motor behavior that may include catatonia. And we are concerned with a pattern of illness that is of sufficient duration and severity that it leads to a loss of social function in those who suffer from it.

The DSM-IV diagnostic criteria were, for the first time, developed in consultation with a working group of anthropologists and psychiatrists charged with the task of providing cultural perspectives for particular disorders (Mezzich, Kleinman, Fabrega, and Parron 1996). One of the editors (Jenkins) served as the anthropologist charged with summarizing available cultural materials on schizophrenia and supplying text for incorporation into DSM-IV that could provide clinical guidance for an understanding of the ways in which culture should be taken into consideration in diagnostic assessments. Cultural evidence in relation to the symptom criteria for schizophrenia and related psychotic disorders are summarized in a review by Karno and Jenkins (1997). Given the depth and breadth of the ways in which culture mediates nearly every aspect of schizophrenia, it was a significant milestone when "culture" was incorporated into DSM-IV. Nevertheless, publication of DSM-IV fell considerably short of the mark by virtue of a limited representation, in light of available evidence, of the relevance of culture to diagnostic formulation (Jenkins 1998). Moreover, we are mindful that schizophrenia as a clinical concept has arisen within a European and North American intellectual milieu (Barrett 1998). For this reason alone, it is necessary to pursue the study of schizophrenia from a historically and cross-culturally informed point of view. Thus, a number of the contributions pursue a reflexive analysis of contemporary diagnostic criteria and concepts, raising questions about their western cultural underpinnings and their validity in other settings (Good 1992). It is this Janus-faced approach – working with

schizophrenia, as currently defined, while at the same time subjecting it to cultural critique – that characterizes this volume.

Cultural Orientations

The likelihood of a mutual interaction between culture and psychotic illness has been recognized since dementia praecox and its successor, schizophrenia, were first formulated as a category of illness. With the publication of this volume, we mark the centenary of Kraepelin's 1903 voyage to the psychiatric institutions of Singapore and Java, a voyage sometimes taken to be the ancestral journey that founded transcultural psychiatry. For a number of reasons, at the intersection of culture and schizophrenia, much remains to be charted nearly a century later. Anthropologists who have worked with a sophisticated and deeply contextualized approach to culture have only rarely brought clinical or research diagnostic skills to the task, while psychiatrists who have developed well-honed, operationalized definitions of schizophrenia have tended to employ lay versions of culture that look more like superficial national stereotypes than anything else. Furthermore, schizophrenia has long been regarded as the core conundrum of psychiatry, and it could well be argued that the concept of culture has occupied a similar position in anthropology, in which case it is not surprising that the question of how the two influence each other has been difficult to specify.

One aim of the present volume is to break this impasse, first, as we have seen, by treating contemporary definitions of schizophrenia seriously, either as research tools or as a body of knowledge deserving thoughtful cultural critique, and second, by bringing more expressly articulated and rigorously theorized concepts of culture to the equation. Whereas schizophrenia is defined from the top down – the WHO (1994) The International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD) – 10 symptom criteria or the American Psychiatric Association's (1994) DSM-IV definition – culture is defined here from the bottom up, a strategy that reflects the ethnographic spirit of this volume. It is important that the clinical definition of schizophrenia be operationalized in order to achieve agreement among researchers in diverse field sites that they are talking about more or less the same thing. In contrast, culture is an emergent property of context-bound human interaction, and cannot be operationalized in the same way. Attempts to do so reduce it to something it is not, a quantifiable "cultural factor" or a "cultural variable."

The papers in this collection are based on research carried out in a range of cultural settings. And while there are as many approaches to

culture as there are chapters, the commonalities among them lend coherence to the collection. All the authors recognize culture, in its broadest dimensions, as shared symbols and meanings that people create in the process of social interaction. They see it as shaping experience (including the experience of schizophrenia), interpretation, and action. It thereby orients people in their ways of feeling, thinking, and being in the world. Throughout the volume contributors express an interest in culture as the basic moral and ideational domain from which individuals may deviate. Schizophrenia is an instance of transgression situated at the margins of culture, at the very edge of meaningful experience. There is also agreement that while culture can be regarded as an object (a corpus of shared knowledge, a body of routine practice, a set of values), it is important to recognize that it is more fundamentally a process including the production and reification of knowledge, the transformation of practice, and the reproduction of values. This is best captured in Obeyesekere's (1990:xix) expression "the work of culture," by which he means the subjective process of formation and transformation "whereby symbolic forms existing on the cultural level get created and recreated through the minds of people." Culture theory has come to incorporate distinctions between disciplinary or discursive knowledge in relation to institutional forms of power, on the one hand, and situated, local knowledge in relation to personal forms of power and resistance, on the other. Conceptualization of the relation between these two forms of cultural knowledge and power is best formulated not as mutually exclusive, but rather as reciprocally produced (Bourgois 1995; Ortner, 1996; Floersch 2002).

It is noteworthy that much of the research for this collection has been done across cultural divides, whether it be cross-cultural research in a classical sense, or the exploration of meaning structures within the researcher's own context that are nonetheless foreign to him or her. Where this is so the authors have brought with them a strong sense of culture as a reflexive process. They have viewed their research as an interaction between cultures, that of the researcher and that of the people with whom she or he is working.

As an analytic and pragmatic strategy, all the authors work with specific concepts of culture; they toil at the microscopic level or in medium focus, not with broad brush. The collection as a whole argues that it is no longer useful in this field of research to equate culture with nation-state or society at large as pursued in much of the initial international multisite research. Instead, analytic attention must be focused in specific domains such as family interaction, gender, religion, ethnicity, or personhood, and each of these, in turn, specified ethnographically. At this analytic level, it is possible to see that culture may be contradictory, fragmented, contested, and politicized rather than necessarily

coherent or uniform. Cultural meanings attributed to schizophrenia are very often embedded in conflict between "tradition" and modernity, for example, between witchcraft and medicine, between patient advocacy groups and psychiatric orthodoxy, or between competing religions and sects. Thus, what unites the authors in this volume is an approach to culture that works between shared and conflicting meanings, between overarching structures and specific contexts, between macroscopic and microscopic.

There is a point at which the microinteractional approach to culture merges with the concept of intersubjectivity, for both are concerned with the meaning structures and interpretive processes through which individuals together make sense of each other. Working on schizophrenia demands such a merger for it is these interactions that are often so fraught for people who have the disorder, as well as for those around them. It is for these reasons that in this volume Jenkins builds a framework for research in this field from the work of social theorists like Sapir, whose concept of culture is interactional and meaning centered, and psychiatrists like Sullivan, whose concept of schizophrenia is located in the everyday details of lived experience.

A number of the chapters raise important theoretical issues for debate. The so-called pathoplastic model has provided a conventional framework to understand the relationship between culture and mental illness. It proposes that symptoms are invariant in form, but that their content is shaped by culture (McHugh and Slavney 1986). Several chapters (Jenkins, Barrett, Hopper, Corin and colleagues, Good and Subandi, and Sadowsky) critique this model, raising questions about the validity of distinguishing between form and content that has been identified by Kleinman (1988). Alternative models are examined that accord a more fundamental role to cultural processes in constructing the experience of illness. Culture may provide stable frameworks of meaning that enable a person to make sense of experiences that may be bizarre and anomalous. They may enable that person to build intersubjective understandings of the illness with others. Alternatively, some people with schizophrenia may draw on cultural resources to obfuscate and conceal experience from themselves and others, creating a barrier to understanding which serves to establishing social distance.

In sum, what we know about culture and schizophrenia at the outset of the twenty-first century is the following: Culture is critical in nearly *every* aspect of schizophrenic illness experience: the identification, definition and meaning of the illness during the prodromal, acute, and residual phases; the timing and type of onset; symptom formation in terms of content, form, and constellation; clinical diagnosis; gender and ethnic

differences; the personal experience of schizophrenic illness; social response, support, and stigma; and, perhaps most important, the course and outcome of disorders with respect to symptomatology, work, and social functioning (Jenkins 1998:357).

Subjective Experience

Clinical psychiatry has long been intrigued by the subjective dimension of psychotic experience. It has been a particular focus of attention for psychiatrists who work from a phenomenological perspective, or those who practice within a psychoanalytic framework. Yet with few exceptions (Chapman 1966; Cutting and Dunne 1989; Strauss 1994; Jenkins 1997), the subjective experience of schizophrenia has been a neglected area of research in the latter part of the twentieth century. Some people with schizophrenia say that it affects their sense of who they are, their body, their thoughts and feelings, their day-to-day activities, and the people around them. The illness seems to pervade their world. Yet this is by no means the only pathway leading from a psychotic episode. Many of those with schizophrenia experience periods of recovery between episodes, with or without residual symptoms, while still others enjoy sustained improvement. Substantial recovery is possible in relation to favorable living conditions and medication response (particularly for many patients taking the newer, atypical antipsychotic drugs); moreover, such patients are not likely to characterize their lives as dominated by the illness (Jenkins and Miller 2002).

Conventional approaches to subjective experience flowing from descriptive psychopathology and classificatory psychiatry have not provided an adequate basis to understand the pervasive, alternating, or transformative aspects of schizophrenia. A number of studies in this volume break new ground in this area. Grounded in an empirical tradition of ethnographic research and a theoretical tradition of social phenomenology, they investigate the triadic relationship between an illness, a person, and that person's lived world. By these means, they provide new insights into the subjective experience of schizophrenia, how the illness may influence a person's sense of self, its impact on immediate social relationships, and the distinctive ways in which it may shape that person's lifeworld.

A theoretical move toward *subjectivity* has taken hold in anthropology at a time when retreat from this domain of inquiry has largely taken place in psychiatry and psychology. As this volume is guided by the rise of anthropological thinking about subjective experience, it is useful to provide a brief summation of recent ideas in culture theory that have led to this development: (1) the primacy of lived experience over analytic

categories imposed by anthropological theory (Kleinman 1988); (2) the active engagement of subjects in processes of cultural construction; and (3) the irrepressibility of subjectivity as embedded in intersubjectively created realms of meaning and significance.

First is the primacy of lived experience. This is reflected in the movement away from what Geertz (1984:124), borrowing from Kohut, has called "experience-distant" concepts and toward "experience-near" concepts. As applied to anthropology, the differentiation is as follows:

> An experience-near concept is, roughly, one which someone – a patient, a subject, in our case an informant – might himself naturally and effortlessly use to define what he or his fellows see, feel, think, imagine, and so on, and which he would readily understand when similarly applied by others. An experience-distant concept is one which specialists of one sort or another – an analyst, an experimenter, an ethnographer, even a priest or an ideologist – employ to forward their scientific, philosophical, or practical aims. 'Love' is an experience-near concept, 'object cathexis' is an experience-distant one. 'Social stratification,' or perhaps for most peoples in the world even 'religion' (and certainly 'religious system'), are experience-distant; 'caste' or 'nirvana' are experience-near, at least for Hindus and Buddhists. (Geertz 1984:124)

The theoretical movement in anthropology toward experience has led to person-centered ethnographies and the development of culture theory to incorporate subjectivity (Devereux 1980; Rosaldo 1984; Estroff 1989; Desjarlais 1992; Csordas 1994a; Good 1994; Pandolfo 1999, 2000; Scheper-Hughes 2001). Evidence from such ethnographies called into question the generalizabilty of European-derived categories for experience. Thus, what is "medicine" in one cultural context may be indistinguishable from "religion" in other contexts, as LeVine (1984) has shown, for example, among the Gusi of East Africa.

Exemplary among contemporary studies of experience is Lovell's (1997) narrative analysis of schizophrenia and homelessness in New York City. Her work provides an ethnographic cautionary tale for the consequences of the denial of subjectivity of persons experiencing schizophrenia that diminishes the "range of communication in clinical settings as well as everyday relations" (356). Likewise, an incisive ethnographic analysis of personal experience, narrative, and institutional structures in Ireland has been elegantly set forth by A. Jamie Saris (1995).

No one has raised these questions with more perspicacity than Desjarlais (1997:10–27), who dissects layer upon layer of assumptions (most of them stemming from romantic and postromantic thought) that attach to contemporary anthropological uses of the term "experience" – its so-called primacy, supreme authenticity, facticity, fundamental constancy, interiority and reflexivity, and proximity to the sensate. His argument, that experience itself is historically and culturally constituted, is

by no means new, but what is remarkable about *Shelter Blues* is the way it is worked out ethnographically, in this instance among Boston shelter residents, for whom experience was a matter of "'struggling along,' a journey, a series of movements through a landscape at once physical and metaphoric" (20).

One cannot follow Desjarlais' injunction to take history and culture seriously without assigning a critical role to linguistic processes in constituting lived experience, a central concern of this volume. As Gergen (1990:576) has observed, "when we use language of other peoples to access their subjectivities, it is essentially their category or conceptual systems that are at stake." Sapir (1924) summarized this vital issue of language with his statement that "the worlds in which different societies live are distinct worlds, not merely the same world with different labels attached." Sapir was no less tenacious in his insistence on the importance of individual variability in the creation of psychocultural dimensions of subjectivity. Such variability, really what we can call a "constrained idiosyncrasy," defies neat classification on the basis of the psychological and cultural categories for experience.

Second, an emphasis on experience has meant an emphasis on the active engagement of subjects in processes of cultural construction. This has been premised to a great extent on philosophical notions of agency and intentionality, with the intended subject moving toward, as Kleinman and Kleinman (1995) would have it, whatever is "at stake" for an individual. As Ortner (1996:2) argues, contemporary ethnographies that "omit, exclude, or bid farewell to the intentional subject" are no longer viable in light of recent developments in culture theory. These developments include the cultural "making" of forms of subjectivity "from the actor's point of view" – where the "question is how actors 'enact,' 'resist,' or 'negotiate' the world as given, and in so doing, 'make' the world."

Third, the notion of intersubjectivity is increasingly important as a bridge between individual experience and social reality, between a subjectivity too often criticized as implicitly isolated and solipsistic and the material conditions of life that are generated in collective processes of production and reproduction. Indeed, part of the discomfort with granting the notion of experience a central place in social theory has been failure on the part of its proponents to theorize experience as thoroughly interpersonal and intersubjective. This step has been decisively and eloquently taken by Arthur Kleinman:

> Experience is thoroughly *intersubjective*. It involves practices, negotiations, and contestations among others with whom we are connected. It is a medium in which collective and subjective processes interfuse. We are born into the flow of palpable experience. Within its symbolic meanings and social interactions our

senses form into a patterned sensibility, our movements meet resistance and find directions, and our subjectivity emerges, takes shape, and reflexively shapes our local world. (Kleinman 1999:358–9)

Kleinman shows that such a conception allows a theoretical and empirical appreciation of the "interpenetration of the moral and the emotional, the social and the subjective" (1999:378), and consequently a more precise understanding of the interactions among cultural representations, collective processes, and subjectivity. Such an approach is essential for understanding schizophrenia, not only as the biologically conditioned affliction of an isolated individual, but, in Kleinman's term, as a form of *social suffering* conditioned by the moral coloring of practical activity that occurs "under the impress of large-scale transformations in politics and economics that define an era or a place" (1999:381). To borrow a contrast framed by Kleinman, it is essential to regard schizophrenia not as a disordered modulation of "human nature," but as a function of a particular configuration (not excluding the biological) of "human conditions."

Introduction to the Three Parts: Themes and Cross-Currents

This volume is intended to bring the puzzle of schizophrenia under scrutiny from the standpoint of the social sciences; that is, those disciplines that take as their central concern the problem of human life as such. And while the chapters represent perspectives that combine social and medical sciences broadly, the overarching conceptual framework for the volume hinges largely on culture theory from contemporary anthropology. The volume is organized in three parts that elaborate cultural analyses of the problem, each of which constitutes a piece of the puzzle of the psychoses. In the first part, authors outline state-of-the-art understandings of culture, self, and experience that are critical to a cross-culturally comparative and global understanding. Each of the four chapters in the second part sets out a methodological strategy, in turn developing the ethnographic, sociolinguistic, clinical, and historical dimensions of schizophrenia and related psychotic disorders. The third part plumbs the depths of subjectivity and emotion, without an understanding of which the daily lived experience of schizophrenia must remain unnecessarily incomprehensible.

We will summarize each of the parts in turn, and conclude our introduction by reflecting on the clinical implications of the work collected here.

Culture, Self, and Experience

The first part deals with a number of critical issues that confront all studies of human experience, and culture and schizophrenia in particular. One is the relationship between the ordinary and the extraordinary; another is the nexus between subjectivity and culture; and a third is the tension between general and specific concepts of culture. These problematics, elaborated through studies of schizophrenia, define the broader terms for analysis that are developed more fully in the ensuing parts. Jenkins (Chapter 1) argues that schizophrenia itself offers a paradigm case for understandings of culturally fundamental and ordinary processes and capacities of the self, the emotions, and social engagement. She also shows how the experiences of people with schizophrenia can be quintessentially extraordinary just as they can be exquisitely ordinary. As a consequence, people who suffer from the disorder have a unique capacity to teach us about human processes that are fundamental to living in a world shared with others. A single-minded focus on the similarities between those who have schizophrenia and those who do not carries the risk of negating what is so extraordinary about this illness, underestimating the intensity of suffering it entails, and overlooking the resilience of those who grapple with it. But if the focus is restricted to understanding differences between abnormal and normal, the risk is one of devaluing the person with schizophrenia. Difference may lead to diminution and decomposition of the person into an object. Jenkins embraces the extraordinary and the ordinary in schizophrenia, the abnormal and the normal, and gives no quarter to those who would play down the insights that people with the illness offer, nor to those who would characterize them as flawed or emotionally empty humans.

Lucas (Chapter 5), in exploring some of the cultural processes at work around this ordinary/extraordinary interface, carries this analysis further. Drawing on ethnographic work in Australia among people with schizophrenia and juxtaposing these data with classical formulations of the disorder within the psychiatric literature, he locates schizophrenia both outside and inside the bounds of culture. Psychiatric discourse identifies the source of this illness in the body and in nature, thereby placing it beyond culture. On the other hand, schizophrenia itself is a cultural category, replete with cultural tropes. It is sometimes construed as a primitive state in which archaic sources of violent energy erupt through surface layers of control; or a state of confusion and alienation that mirrors the complex modern society in which we live; or a form of creative power akin to artistic genius. Such images are not only invoked by psychiatrists, but also by people so diagnosed when representing schizophrenia to themselves.