PSYCHOCULTURAL DIMENSIONS OF RECOVERY FROM FIRST EPISODE PSYCHOSIS IN JAVA

SUBANDI

A DISSERTATION SUBMITTED FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

DEPARTMENT OF PSYCHIATRY
SCHOOL OF MEDICINE, FACULTY OF HEALTH SCIENCES
THE UNIVERSITY OF ADELAIDE

AUGUST 2006

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ABSTRACT

The aim of this study was to explore psychocultural dimensions of recovery from first episode psychotic illness in a Javanese setting. A combination of ethnographic and clinical methodology was employed. During my fieldwork in Yogyakarta from August 2002 – July 2003 I followed 9 participants diagnosed as having first episode psychosis. Three of them met the ICD-10 criteria for Schizophrenia, five for Acute and Transient Psychotic Disorder (ATPD), and one for Schizoaffective Disorder.

I carried out ethnographic fieldwork among participants and their families in their home setting, as well as conducting in-depth interviews that focused on their illnesses and the recovery process. These formed the bulk of my data. In addition, I administered a number of research instruments, including the Brief Psychiatric Rating Scale (BPRS), the Global Assessment of Functioning (GAF), the Level of Expressed Emotion (LEE), and the Family Crisis Oriented Personal Evaluation Scale (F-COPES). Two projective tests were also used, the House-Tree-Person (HTP) and Sentence Completion Test (SCT). A follow up assessment was conducted in the second year.

Given my focus on psychocultural aspects of recovery, I began by outlining the cultural setting in which the study took place. Contemporary Yogyakarta, I have argued, is a place where cultural values are contested. Javanese cultural

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underpinnings exist side by side with Islam, in its many varieties, from tolerant to militant. These are challenged by modern influences: education, urban migration, wage labor, telecommunication, and tolerance of a range of sexual behavior, to name only a few. This complex interplay of values forms the backdrop within which people become ill and provides a cultural resource which they draw on in making sense of their illness.

I found that the rate of recovery among the participants in this research was high. Despite some relapses, most participants returned to normal functioning in the second year of follow-up. This finding supports those of previous studies that found a benign course of illness in developing countries. I argued that from a clinical perspective, the most significant factor associated with this high recovery rate was the acuteness of illness onset and the consequent short duration of untreated psychosis (DUP). However, I also argued throughout this thesis that psychocultural factors play a role in promoting recovery from psychosis. The most important contribution of my research lies in the rich descriptive detail that I provide on each case, which allows me to examine the process of becoming ill, family reactions to the psychosis, and participants' struggle to achieve recovery.

In this research I examined the emotional milieu of families, focusing on Expressed Emotion (EE). Despite the fact that most families in this research could be considered to have low EE, the ethnographic data I gathered provide a more complex and nuanced picture of family relationships. Through my ongoing engagement with families, I was able to gather data on the diversity of family responses to illness. I

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sought to identify responses that were specific to Javanese culture, showing how they related to changing Javanese ideas about the person and the family.

My research also addressed the issue of religion and its relationship to psychotic illness, a topic that had been relatively neglected in the literature. Given that religion plays a powerful role in Java, I explored a number of different orientations within Islam, and how they came into play—sometimes in conflict, sometimes not—within Javanese participants and their families, as they struggled to overcome psychotic illness.

A core component of this research was concerned with participants' experience of recovery. I explored the meaning of the idiom of *bangkit* (to regain awareness, to get up, to revitalize) as a central theme in recovery in Java, and described the process of recovery in its temporal and spatial dimensions. I explored a fundamental cultural dynamic, wherein recovery entails a simultaneous inward and outward movement that reconstitutes one's inner and outer world respectively. Participants also expressed their recovery in terms of a movement through physical space, from confinement in their own home to the wider spaces shared with family and community. Finally, I showed how movements in physical space parallel movements in social space, where participants accomplish a social recovery.

DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no materials previously published or written by another person, except where due to reference has been made in the text.

I give consent to this copy of my thesis, when deposited the University Library, being made available in all forms of media, now or hereafter known.

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ACKNOWLEDGEMENTS

My sincere thanks go to all participants and their family members involved in this research who allowed me to come to their houses and shared their experiences. Without their willingness and cooperation this research would never have happened. I extend my sympathy to some of them who were seriously affected by the earthquake that struck Yogyakarta when I was finalizing this dissertation.

I wish to thank to my three supervisors. Professor Robert J. Barrett (Department of Psychiatry, University of Adelaide) has trained me how to become a good researcher, from the simple matters, such as how to organize a document, to the most serious matters, such as to how to think deeply to find the underpinning cultural processes that help account for my ethnographic data. He also painstakingly read every sentence in this dissertation carefully, transforming it to a logical, analytical, and critical dissertation. More importantly, he guided and brought me to make a number of exciting 'discoveries' throughout this thesis. I thank also my co-supervisor, Dr. Rodney Lucas (Department of Anthropology, University of Adelaide) for his willingness to read this early and final draft carefully and for his inspiring comments. I learnt from him how to write simple field notes to how to finalize this dissertation. I am truly indebted to my external supervisor, Professor Byron J. Good (Department of Social Medicine, Harvard University) who has opened up the world to me. He has patiently discussed most of the material in this thesis through our previous collaborative work. But it was only after I conducted my own project that I realized

the worth of the discussion. It was also from him I learnt how to conduct ethnographic research. His psychological and financial support in time of difficulty should also be appreciated.

I wish also thank Dra. Nida Ul-Hasanat, Msi, my colleague at the Department of Psychology, Gadjah Mada University, Yogyakarta, who has assisted me to conduct the fieldwork. Dr. Anti and Dr. Krisman have provided me with the accessibility to participants' homes. I should also thank to Professor Julia Howell (Griffith University) who invited me to come to Australia the first time, especially for her willingness to comment on the chapter on Javanese culture. Professor Johana Endang Prawitasari (Department of Psychology, Gadjah Mada University) was also involved in reading the early draft of this thesis. I thank Phil Thomas and Bronwyn Norton who helped in the English editing. Dra. Ninik Supartini also helped me finding the correct translation for some crucial terms. *Matur nuwun.*

Finally, I would like to express my gratitude to Abah Anom, a Sufi Master, who taught me the way to write this dissertation.

INTRODUCTION

This dissertation reports a study of recovery from first-episode psychotic illness in Yogyakarta, Indonesia. As the main focus is on the recovery process within a Javanese cultural context, this research fills gaps that exist in three important areas of literature.

First, the research fills a gap in the literature on recovery from psychosis. Most of the literature in this area focuses on schizophrenia. There are two perspectives within this literature, a medical and a consumer perspective. From a medical perspective, the evidence of recovery from schizophrenia emerges from a number of long-term outcome studies carried out in the US and Western Europe (Harding *et al.,* 1987a & b; McGlashan, 1988; Angst, 1988). By contrast, the consumer perspective finds evidence of recovery from schizophrenia in the lived experience of psychosis (see Spaniol & Koehler, 1994; Deegan, 1996). The medical perspective tends to view recovery as an 'outcome', while the consumer perspective emphasizes that recovery is a long-term 'process' (Ridgway, 2001; Spaniol *et al.*, 2002; Andersen *et al.*, 2003). Both of these literatures, however, focus primarily on the individual's struggle to achieve recovery from schizophrenia. A central argument that I advance in this thesis is that the process of recovery not only involves individual psychological processes, but also involves social and cultural processes. Therefore, in this dissertation I refer to

the term 'psychocultural' which has been used widely in the field of psychological anthropology (see Jenkins, 1994; Lemelson, 2003).

The literature on recovery from psychosis is not limited to the study of schizophrenia. There is also a growing literature on recovery from related condition such as Acute and Transient Psychotic Disorder (ATPD), Schizoaffective Disorder, and Non Affective Remitting Psychosis (NARP). Most studies in this area concentrate on outcome, with insufficient attention paid to the process of recovery. Given that five of the participants in this research met the criteria for ATPD, and one for Schizoaffective disorder, this dissertation makes a substantive contribution to an understanding of the process of recovery in this area. It is notable that 8 of the 9 participants met criteria for NARP and, as predicted by this diagnostic concept, all made a good recovery.

Similarly, this research contributes to the literature on early psychosis, which has recently become a topic of major interest. Studies have consistently found that recovery rates among people with first-episode psychosis are high (Loebel *et al.*, 1992; Edwards *et al.*, 1998; Gitlin *et al.*, 2001). The process of the development of psychotic illness has been studied in detail and several stages have been identified (Johannessen *et al.*, 1999). However, there is an almost complete absence of research focusing on the process of recovery from first-episode psychosis. Furthermore, what studies there are tend to be clinically-oriented, disregarding the social and cultural dimensions. By focusing on psychocultural processes, this dissertation serves to address these shortcomings.

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The second major area in which this research fills a gap in the literature concerns the cross-cultural study of schizophrenia. The well-known WHO cross-cultural outcome studies have provided evidence that the course and outcome of schizophrenia is better in developing countries than in developed countries (Jablensky *et al.*, 1992; Hopper, 2004). These studies have been supported by a number of longitudinal studies conducted in local settings (Waxler, 1979; Thara & Eaton, 1996; Kua *et al.*, 2003). Following intense debate concerning the methodological problems that attend this sort of research and the validity of its findings, a number of authors have suggested a need to conduct ethnographic research to examine in more detail the process of recovery in developing countries and its relationship to the local cultural context (Cohen, 1992; Browne, 1999; Hopper & Wanderling, 2000; Hopper, 2004). Such an approach is vital since most cross-cultural studies of schizophrenia have employed hospital-based assessment and follow-up strategies. During my ethnographic fieldwork I engaged actively with participants and their family members in their local setting. In addition, I made clinical observations and psychological assessments, which allowed me to monitor the process of recovery closely over a one-year period. This was supplemented by a further follow-up assessment after two years. Thus, the methodology of this study, combining ethnographic fieldwork, clinical observation, and psychological assessment, is one of the unique strengths of this research.

Third, this dissertation fills a gap in the literature on recovery from psychotic illness in Java. Many years before the WHO conducted its cross-cultural studies, Emil Kraepelin travelled to Java. According to Zaumseil & Lessmann (1995), he was the first person to observe less severe forms of mental illness in a non-Western country.

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Unfortunately, there has not been any formal research to follow up Kraepelin's clinical observations and examine the role of culture in Java. There have been several studies conducted in Java but they have placed emphasis on the clinical dimension. For example, two doctoral dissertations conducted by local psychiatrists have examined the effect of family interventions on the outcome of affective disorder (Sudiyanto, 1998), and on schizophrenia and bipolar disorders (Sukarto, 2004). In both of these studies, the role of Javanese culture was mentioned as an important factor in the process of recovery, but the researchers provided only limited discussion of this issue.

Browne (1999), an anthropologist, addressed the issue of recovery from mental illness in Java in an ethnographic study carried out mainly in Yogyakarta. Browne has made a valuable contribution to the literature on Javanese concepts of mental illness. However, there were limitations to his clinical data. He did not establish formal diagnoses and relied entirely on medical record diagnosis; his assessment of recovery was based on his personal observations without the use of any objective instruments; finally, in most cases, he restricted himself to one follow-up visit carried out after three months. In this research I have sought to address some of the shortcomings in Browne's study. For example, using the International Classification of Diseases (ICD-10) diagnostic system, I provided formal diagnoses for each participant based on medical record data and on my clinical interviews. I also employed several objective instruments every three months over the course of a one-year period, and again at a follow-up assessment at the end of the second year. This enabled me to monitor the process of recovery with greater accuracy and reliability. While Browne provided a

brief discussion of family emotional environment—a factor that influences the course of schizophrenia—in this research I pay much greater attention to the dynamics of Javanese family life, with a special focus on the family emotional environment and, in particular, the concept of Expressed Emotion (EE) (Leff & Vaughn, 1985).

It is anticipated that the ethnographic data on Javanese family life gathered in the context of this research will provide a valuable contribution to the anthropological literature, because there has not been any intense anthropological study of the Javanese family since the work of Hildred Geertz (1961).

Overall, the focus of this research is on the process of recovery from first-episode psychotic illness in a Javanese context. It poses a number of research questions: How do the participants experience recovery from psychotic illness? How does Javanese culture shape these experiences? What are the specific cultural values which support or inhibit the process of recovery? How do the participants and family members make sense of the illness and recovery? How do family interactions and religion contribute to the process of recovery?

This dissertation is divided into 9 chapters. In this introductory section I outline the general ideas of the research, establish its goals, and identify the significant contributions that I expect it to make to the psychiatric and anthropological literature.

In Chapter 1, I review the literature on recovery from psychotic illness from two main perspectives: the objective-medical perspective and the subjective-consumer

perspective. Ethnographic and phenomenological descriptions of the process of recovery are also presented as important points of reference for this research. In the second part of this chapter I focus on the role played by the family and by religion in the recovery process.

Since this research was conducted in Java, in Chapter 2 I present an overview of Javanese culture in contemporary Yogyakarta. I outline a number of traditional ideal values and show how these values are now being contested as Yogyakarta modernizes and participates in a global culture. This chapter provides the background context that is critical to understanding the process of recovery in this setting.

Chapter 3 discusses the methodology. First, I describe the larger research project from which the present research emerged. Second, I discuss the methods applied in this research, including ethnographic research techniques and formalized clinical assessments, showing how these are combined into an integrated approach. Third, I describe the strategy I applied during the fieldwork, the data collection procedures, and the method of data analysis.

In Chapter 4, I introduce the participants' personal narratives and their clinical characteristic to prepare for the discussion in the rest of the thesis. This is followed by a discussion of the clinical aspects of the recovery. Here, I argue that the acuteness onset of participants' illness, and the short duration of untreated psychosis both contribute to the high rate of recovery in this research.

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Chapter 5 focuses on the participants' experience of psychotic illness. I begin with the narrative of one participant, focusing on her experience from a psychocultural perspective. The emergence of the illness, I argue, can be understood in terms of four phases. The discussion is then expanded and enriched by an examination of other participants' experiences.

In Chapter 6 I examine the family dimension of illness and recovery. After introducing a narrative from one participant and her family, I discuss several emerging themes. These include: diverse and changing family concept of illness, the family as a source of tension, family coping behavior, and family support for participants. My overall focus is on the family emotional milieu, with special reference to Expressed Emotion (EE), which is an active topic of debate in the literature. I also discuss the important cultural concept of *ngemong* (to care for gently) that family member strive to practice.

In Chapter 7 I discuss the religious dimension of participants' illness experiences and of their recovery. As in previous chapters, this chapter begins with one participant's narrative. Two basic themes are identified in this narrative, including the belief in *takdir* (destiny) in relation to the concept of *usaha* (effort), and the movement from *lahir* (outside) to *batin* (inside).

Chapter 8 is the culmination of the dissertation because it deals with participants' recovery experiences. The chapter explores the meaning of the idiom of *bangkit* (to get up, to revitalize) as a central theme in recovery. I then analyze the concept of

usaha batin (inner effort) which involves reconstructing one's sense of self and *usaha lahir* (outer effort) which includes seeking treatment for family members. I also emphasize the participants' experience of *terbuka batin* (inner opening) as the initial process of movement from *batin* to *lahir* as they begin to integrate with the community as the final goal of recovery.

Chapter 9 is the conclusion of the dissertation. After summarizing the overall dissertation, I present some major findings of this research, both clinical and psychocultural. I then show the link between clinical and psychocultural findings. Finally I suggest some directions for future research into the psychocultural dimensions of psychotic illness.

CHAPTER 1

RECOVERY FROM PSYCHOSIS: A LITERATURE REVIEW

In this chapter, I review the literature on recovery from psychosis. Most of the literature in this area focuses on schizophrenia and it is on this literature that I concentrate. However, there is also a literature on recovery from Acute and Transient Psychotic Disorder (ATPD), Schizoaffective Disorder, and Non Affective Remitting Psychosis (NARP) which is relevant to this research as a number of participants in this study had these diagnoses. A related literature, on first episode psychosis, is also germane to this research, and I therefore cover the main findings in this area as well.

Firstly, I trace the historical background of the current interest in recovery, which begins with a pessimistic view of the course of schizophrenia and then moves towards a more recent emphasis on recovery. Secondly, I review the literature on recovery from both a medical and a consumer perspective, these two presenting an objective and a subjective approach respectively. Phenomenological and ethnographic descriptions of the process of recovery are also presented here. Thirdly, I discuss the central issue of this research, namely the role of culture in recovery from psychotic illness. Here I focus particular attention on the role of the family and of religion.

1.1. HISTORICAL BACKGROUND

1.1.1. The Kraepelinian Pessimistic View

Emil Kraepelin (1856-1926) has been considered the most influential figure behind the pessimistic view of schizophrenia that it is a degenerative and incurable disease. In his important contribution to psychiatry, the formulation of a new class of disease he called dementia praecox, Kraepelin exaggerated the deteriorating course of this illness. He asserted that failure to recover was a key diagnostic criterion. If a patient had all the symptoms of dementia praecox and then recovered, Kraepelin would consider the patient to have been originally misdiagnosed. Harding *et al.* (1992) criticized this logic as prognosis confirming diagnosis. It is a form of tautology with the implicit premise that "the people who have schizophrenia cannot recover; therefore, if people do recover they could not have had schizophrenia" (Davidson, 2003:39).

Kraepelin's ideas about schizophrenia being incurable have cast a long shadow over psychiatry and to this day they continue to influence modern diagnostic systems and clinical practice. For example, in the Diagnostic and Statistical Manual (DSM-III), schizophrenia was delineated as a disorder such that "a complete return to premorbid levels of functioning in individuals diagnosed with schizophrenia is so rare as to cast doubt upon the accuracy of the diagnosis" (American Psychiatric Association, 1980:191). A similar description can be found in DSM-IV: "complete remission (i.e. a return to full premorbid functioning) is probably not common in this disorder. Of

those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability" (American Psychiatric Association, 1994:282).

1.1.2. The Optimistic View

This view of schizophrenia remained relatively unchanged for the first half of the twentieth century. In the second half, however, a new optimism slowly emerged, stimulated by two important developments. The first was a growing body of empirical outcome studies. The second was the emergence of the consumer movement.

1.1.2.1. Empirical Studies

A series of outcome studies began to provide empirical evidence of recovery from schizophrenia. Long-term follow-up studies in the US and Western Europe confirmed that the course of schizophrenia is heterogeneous (see McGlashan, 1988; Angst, 1988 for reviews). People with schizophrenia did not always deteriorate as Kraepelin had observed. Even individuals with a chronic condition who had experienced long periods of hospitalization were found later in life to be relatively free of psychotic symptoms, as shown in the well-known Vermont Longitudinal Study in the US (Harding *et al.,* 1987a & b). This study began in 1950 and involved 269 subjects recruited from the local mental hospital. They were described as mostly chronically ill, severely disabled, and long-stay patients. In the 32-year follow-up study the researchers found that one half to two-thirds had considerably improved or recovered. They achieved quite a high level of functioning which the research team had not

predicted: "Their achievement is even more remarkable given their original levels of chronicity" (Harding *et al.,* 1987b:723).

Evidence of recovery is even more striking in the case of ATPD. From a number of long-term follow-up studies Marneros and Pillmann (2004:155) concluded that, when compared with those who had schizophrenia, patients with ATPD show a more favorable outcome according to many different indicators. They have fewer negative and positive symptoms, less residual syndrome, less social disability, better global functioning, and better employment status. Although they may have several relapses, patients with ATPDs can achieve full remission between episodes (Singh *et al.*, 2004).

Studies examining recovery from schizoaffective disorder usually compare the outcome of this disorder with schizophrenia and ATPD. The findings show that patients with schizoaffective disorder have a more favorable outcome than those with schizophrenia but less favorable than those with ATPD (Marneros & Pillmann, 2004). As with ATPD, schizoaffective patients tend to have several relapses during the course of illness, but complete recovery is less common (Harrow *et al.* 2000).

In the study of first episode psychosis, a high rate of recovery is also evident. Loebel *et al.* (1992) conducted a one-year follow-up study with 70 patients who experienced a first episode of schizophrenia and received standard medical treatment. They found that 74% were considered to be fully remitted. Gitlin *et al.* (2001) found that 80% of individuals with a recent onset of schizophrenia achieved a clinical remission of both positive and negative symptoms during their first year of treatment. Higher rates of

recovery were found in a study by Edwards *et al.* (1998), in which 91% of people with recent onset of psychosis were in relatively complete remission after one year of assertive case management, anti-psychotic drug use, and cognitive behavior therapy. Similarly Cullberg *et al.* (2002) documented a successful treatment of first episode psychosis with fewer days of in-patient care and less neuroleptic medication when combined with psychosocial treatment.

The body of evidence of recovery in first episode psychotic illness has stimulated interest in investigating the very early stages of the development of schizophrenia. A specific field of study has emerged known as 'early psychosis' (see McGorry & Jackson, 1999; Birchwood *et al.*, 2001). A number of research centers and clinics focusing on early psychosis have been developed throughout the world, such as the Early Psychosis Prevention and Intervention Center in Melbourne, Australia (McGorry, 1996), the Nova Scotia Early Psychosis Program in Dartmouth, Canada (Whitehorn *et al.,* 2002), the Swedish Parachute project in Stockholm, Sweden (Cullberg *et al.*, 2002), and some centers in Asian countries.[1] This area of study not only focuses on the first presentation of psychotic illness, but also includes the idea of prevention. Furthermore a program of early detection for high-risk people, when the illness is in the 'prodromal' stage, has also been developed (Young *et al.*, 2004).

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[1] See the Asian Network of Early Psychosis [on-line] at http://www.asianep.net.

1.1.2.2. The Consumer Movement[2]

The consumer movement has also made a significant contribution to the recovery literature. Beginning in the 1970s in the United States, this movement had at least three different agendas (Anthony, 2000; Robert & Wolfson, 2004; Schiff, 2004). First, it fought against stigma and sought to change the public perception of mental illness. Second, since the consumer movement highlighted the potential for harm that the mental health profession could cause, it actively sought to change professional practice. Third, it played an influential role in shaping government policy on mental health.

Importantly in regard to the issue of recovery, the consumer movement tried to change psychiatric approaches to mental illness, notably by seeking to change the pessimistic view that schizophrenia is incurable. Supported by some psychiatrists who were skeptical of Kraepelin's ideas, a number of consumers wrote about their personal experiences. A large number of personal accounts have since appeared in well-respected scientific journals, such as *Schizophrenia Bulletin*, *Psychiatric Services, Psychiatric Rehabilitation Journal* and *Psychiatric Rehabilitation Skill*. Spaniol & Koehler (1994) have collected consumers' accounts into an anthology—*The Experience of Recovery.* These accounts have become the founding stories of the recovery movement. They have provided a starting point for the study of the personal experience of recovery.

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[2] Some writers on this subject use the term 'consumer', 'survivor' or 'user' to represent a person suffering from mental illness. In this dissertation I use the term 'consumer' as it is the most widely used term.

Although no consumer movement has yet formed in Indonesia, recently a patient with schizophrenia in Yogyakarta, Isvandiary (2004), published her personal account entitled *Ratu Adil: Memoar Seorang Skizopren* (*Righteous Queen: Memoir of a Schizophrenic).* This is the only personal account available in Java, and in fact in all of Indonesia. In discussing the consumer approach, therefore, I do not wish to imply that the participants in my research in Yogyakarta have been influenced by the consumer movement. It does, however, provide a model for a subjective approach to recovery which is similar to the perspective I adopt in this research. That is to say, there is a resonance between the consumer focus and the concerns of my research.

In sum, while early 20th century approaches to schizophrenia were dominated by pessimism, a rising optimism was apparent by the end of the century. Evidence to support such optimism has been provided both by empirical studies and personal accounts of consumers. It is in the context of this optimistic view that this research was carried out.

1.2. THE MEANING OF RECOVERY

The term 'recovery' may appear to be straightforward, but within the recovery literature it has a number of different meanings depending on the context in which it is used. It may refer to: the goal of treatment; an indicator for outcome research; a description of subjective experience in the context of an unfolding process; a personal narrative; a movement; or a system reform (Jacobson & Greenley, 2001; Roberts & Wolfson, 2004). Several different recovery models have been proposed, including the

medical, rehabilitative and empowerment models (Fitzpatrick, 2002), the psychological model (Andersen, *et al.*, 2003), and the public health and relational world-view models (see Ralph *et al.*, 2002). Amongst all these models and meanings, two major perspectives are evident, the medical and consumer perspectives. Since these two perspectives represent an objective and a subjective approach, in this review I refer to them as the 'objective-medical' and 'subjective-consumer' perspectives.

1.2.1. The Objective-Medical Perspective

The objective-medical perspective is best represented by the aforementioned empirical studies of outcome that I reviewed in section 1.1.2.1. From this perspective, recovery is often defined as a cure or a return to a former state of health (Fitzpatrick, 2002; Andersen, *et al.* 2003). The terms often used in medical research include 'outcome', 'remission' or 'return to premorbid functioning'. In empirical research the concept of recovery is defined with as much as rigor as possible, and employs objective outcome measures. These include the absence of, or significant decrease in, symptoms, a return to social and occupational functioning, changes in the type and amount of medication required, and the decreasing utilization of psychiatric services such as re-hospitalization (Liberman *et al.*, 2002).

From within the bio-psycho-social framework, however, a number of researchers have acknowledged the complex nature of recovery. For example, in the Vermont Longitudinal Study, Harding *et al.* (1987a & b) employed several operational criteria for recovery: not in hospital in the past year; met with friends every week or two; had one or more moderately to very close friends; was employed in past year; displayed

slight or no symptoms; able to meet basic needs; and led a moderate to very full life. These criteria addressed the multidimensional nature of recovery.

More recently, Whitehorn *et al.* (2002) applied multiple criteria in their Nova Scotia Early Psychosis Program in Canada. These researchers identified three dimensions of recovery. For each dimension there was a corresponding intervention, desired outcome, and method of measuring this outcome. The first dimension they called 'symptom control', with 'intra-psychic' as the locus of intervention, and 'mental stability' as the outcome goal, measured using the Positive and Negative Syndrome Scale (PANNS). The second dimension was 'autonomous daily living', with 'home and family' as the locus of intervention, and 'activities of daily living' as the outcome goal, measured by the Global Assessment of Functioning (GAF) scale. The third dimension was 'return to the life line', with 'community' as the locus, and 'age-appropriate roles' as the outcome goal, measured by the Social and Occupational Functioning Assessment Scale (SOFAS).

In addition to identifying such dimensions of recovery, the objective-medical perspective also concerned itself with identifying and classifying variables that correlate with recovery. For example, Liberman *et al.* (2002), in their literature search, delineated 10 factors associated with symptomatic, social, and educational or occupational recovery: (1) family or residential factors, which include the presence of supportive family members or other caregivers who encourage and positively reinforce the individual's progress, (2) absence of substance abuse, (3) shorter

Duration of Untreated Psychosis (DUP)[3], (4) good initial response to neuroleptics, (5) adherence to treatment, (6) supportive therapy with a collaborative therapeutic alliance, (7) good neuro-cognitive functioning, (8) absence of the deficit syndrome, (9) good pre-morbid history, and (10) access to comprehensive, coordinated and continuous treatment. Liberman *et al.* (2002) arranged these factors into a diagram to provide a cognitive map as follows:

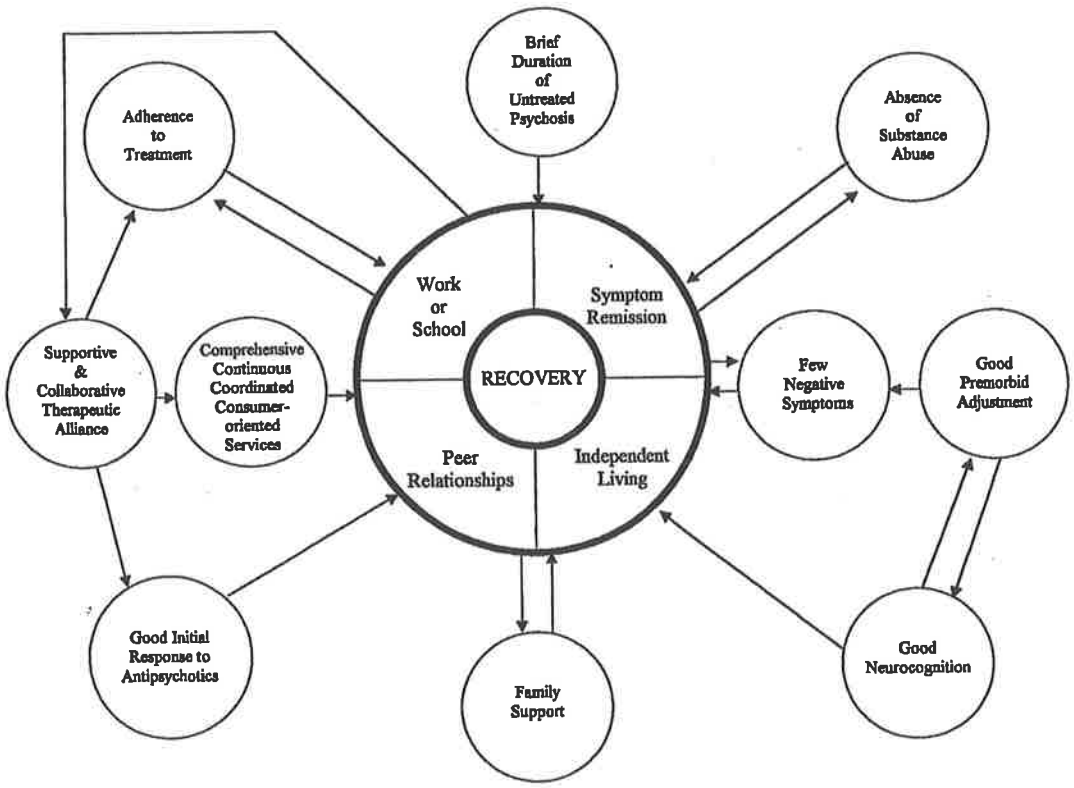

Figure 1.1. Map of factors associated with recovery (Liberman *et al.*, 2002:267)

[3] DUP refers to the length of time from the onset of overt psychosis to the first time medical treatment was given.

Thus, from the objective-medical perspective, recovery is empirically defined and measured to allow research that may be replicated, and to discern the various factors that may correlate with recovery. In order to achieve scientific rigor and reliability, there is a tendency to employ measures that depend on the assessment of an outsider. The subjective experience of recovery is often overlooked.

1.2.2. The Subjective-Consumer Perspective[4]

By contrast, the subjective-consumer perspective has viewed recovery from the insider's point of view. This perspective is mostly to be found in consumers' personal accounts, but is also represented by studies that have explored consumers' experiences and their understanding of recovery (Andersen *et al.*, 2003; Ridgway, 2001; Resnick *et al.*, 2004; Young & Ensing, 1999).

The definition of recovery within this subjective-consumer perspective varies considerably, encompassing several themes which I will discuss in turn below.

(1) Recovery is not equivalent to cure

Most consumers have rejected the concept of recovery as equivalent to cure (Davidson, 2003; Anthony, 1993). To recover does not require that all the symptoms disappear or that an individual return to full premorbid functioning. Psychiatric disability is seen as only one aspect among others that help make up a whole person. The focus is how to live well with enduring symptoms (Roberts & Wolfson, 2004).

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[4] In some sources, the consumer perspective is also known as the 'Recovery model' as opposed to the 'Medical model'.

Anthony (1993:13) defined recovery as "a way of living a satisfying, hopeful, and contributing to life even with illness-caused limitations." Thus, rather than defining recovery as a return to normality, the consumer perspective understands it as an attitude, a way of life, a feeling, or an experience. This very different perspective makes the idea of recovery an achievable goal. "The goal of recovery is not to become normal. The goal is to embrace the human vocation of becoming more deeply, more fully human" (Deegan, 1996:92).

(2) Recovery is not a linear process

The subjective-consumer literature emphasizes that recovery is not a sudden experience, a static end product, or an outcome. It is actually a slow process that requires continuous commitment. This process is described as non-linear and uniquely personal. It may be a cyclical process that sometimes moves forward to periods of positive functioning, but also includes setbacks. "At times our course is erratic and we falter, slide back, regroup and start again" (Deegan, 1994:57).

(3) Regaining and rebuilding sense of self

Regaining and rebuilding a sense of self is seen as an essential theme in recovery (Davidson & Strauss, 1992; Young & Ensing, 1999). A large number of personal accounts have documented the impact of mental illness as altering, damaging, or even destroying the core of a sense of self and identity. Therefore, the process of discovering parts of the self that people had assumed were lost is central to recovery. Several terms have been used to describe this process including 'regaining',

'rediscovering', 'rebuilding', 'redefinition', and 'renegotiating' the sense of self (Davidson, 2003; Young & Ensing, 1999; Andersen, *et al.*, 2003; Schiff, 2004).

(4) Empowerment

Within the consumer literature the terms 'empowerment', 'self-efficacy', 'will', 'control', and 'responsibility' are often used to describe a central theme of recovery. The need for empowerment may be understood as a response to a sense of helplessness, low self-esteem, and depression, often experienced by people who have achieved symptomatic recovery (Gureje *et al.*, 2004). Empowerment is characterized by increasing self-reliance, sense of personal control, and self-esteem (Young & Ensing, 1999). According to Jacobson & Greenley (2001), empowerment has three components: firstly, autonomy, which is the ability to act as an independent agent; secondly, courage, the willingness to take risks and to step outside of safe routines; and thirdly, the capacity to take responsibility for one's own life, making choices and taking risks.

(5) Hope

Having a sense of hope for the future is considered vital from the consumer's perspective. As Davidson & Strauss (1992:136) have stated: "The person's sense of hope provides the first opening to the road to recovery." More than that, hope is also considered as a source of energy which maintains the recovery process (Andersen *et al.*, 2003).

(6) Finding a meaningful life

Finally, finding a meaningful life is another important theme in the recovery process. From first person narratives Spaniol *et al.* (2002) define recovery from mental illness as the development of a new meaning and purpose in one's life that lies beyond symptoms, disability, and stigma. The sources of new meaning vary considerably. Some consumers feel employment makes life valuable and enriching. Others find purpose in life through family, through offering peer support, or creative activities. Even the work of recovery itself can be meaningful (Andersen, *et al.*, 2003).

1.2.3. Converging Perspectives

Initially, the objective-medical perspective and the subjective-consumer perspectives were competing with and critical of each other. For example, medical researchers criticized the consumer movement for using vague definitions of recovery (Liberman & Kopelowicz, 2002). Consumers, on the other hand, criticized the medical criteria of cure as impossible to achieve (Whitwell, 1999). The objective-medical perspective was often criticized for being too narrowly focused on disease and applying a form of biological reductionism that failed to take account of the broader, person-centered approach that informs consumer models (Ralph *et al.*, 2002).

Recently, however, these two perspectives have begun to converge. From the objective-medical perspective, Liberman and Kopelowicz (2002) have proposed the use of subjective indicators of recovery (hope, self control, autonomy) as complementary to objective indicators (symptom reduction, social functioning). They have attempted to combine the concept of 'outcome' and 'process'. These subjective

attributes are seen as "mediating the process leading to recovery" (Liberman and Kopelowicz, 2002:247). Similarly, from within the subjective-consumer perspective, attempts have been made to translate the personal experience of recovery into objective measures, and thereby place their research on a more solid empirical base (Resnick *et al.*, 2004).

It is clear from this review that both perspectives have their value and can be seen as complementary. Therefore, I follow the suggestion of Anthony *et al.* (2003) that these two approaches should be integrated in the study of recovery. In my research, I integrate the objective-medical and subjective-consumer perspectives by applying a combined methodology: clinical and ethnographic. While the clinical approach is more objective in nature, the ethnographic approach enables access to the subjective experience of recovery.

1.3. THE PROCESS OF RECOVERY

A number of authorities have tried to map the phases of recovery while emphasizing that recovery is not a linear process. Recovery begins when a person who is overwhelmed by mental illness develops an awareness of the very possibility of recovery. This awareness ignites the person's desire to change, to struggle and cope with the disability, to learn about mental illness, and become involved with groups and peers. This phase is variously referred to as the 'initial phase' (Young & Ensing, 1999), 'struggle with the disability' (Spaniol, *et al.*, 2002), or the 'awareness and preparation phase' (Andersen *et al.*, 2003). In the next step the individual begins to

rebuild his or her sense of self, to manage the illness, and to take responsibility for his or her own life. This phase has been called the 'middle phase' (Young & Ensing, 1999), 'living with the disability' (Spaniol, *et al.*, 2002), or the 'rebuilding phase' (Andersen *et al.*, 2003). Finally, the person grows to live beyond the disability, improving the quality and meaning of life despite the presence of ongoing symptoms. Terms for this include the 'later phase' (Young & Ensing, 1999), 'living beyond the disability' (Spaniol, *et al.*, 2002), or the 'growth phase' (Andersen *et al.*, 2003). All of these models emphasize that the process is not linear and the boundary between the several phases is not clear-cut. This non-linear characteristic has also been confirmed by Jenkins & Carpenter-Song (2006:28) whereby, following Hopper (2002) term, recovery is described as "complex and messy."

This research is complemented by the work of Davidson and his colleagues, who conducted a number of studies employing a phenomenological approach (Davidson & Strauss, 1992; Davidson, *et al.,* 2001). Importantly, they used the technique of 'follow-along' interviews in order to examine the unfolding process of recovery, as opposed to reliance on retrospective data. In summarizing his work, Davidson (2003) depicts a person with mental illness in metaphorical terms as falling into a deep hole. While the illness is described is living 'inside' the hole of schizophrenia, the recovery is described as living 'outside'. Within the framework of this metaphor, he provides the following 'map' of recovery.

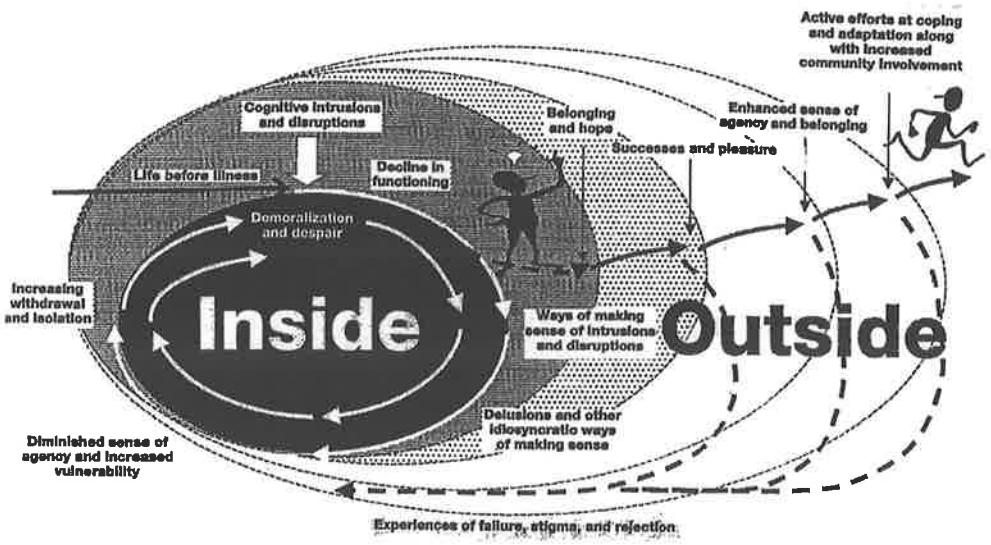

Figure 1.2. Some paths to life outside schizophrenia (Davidson, 2003:200)

Davidson conceptualizes recovery in terms of paths. The first path involves gaining a sense of 'belonging and hope'. Only once this is achieved can the person embark on the second path, which requires the achievement of a sense of 'success and pleasure.' At any point, a person can back track instead of progressing forward. The third path has as its objective to regain an 'enhanced sense of agency and belonging.' In the final path the person needs to accomplish 'active efforts at coping and adaptation along with increased community involvement.' Davidson suggests that most of the work of recovery takes place in natural community settings rather than in treatment relationships and settings.

With the exception of the consumer focus on family and peers, and Davidson's mention of community settings, most of the above literature focuses on the

individual's struggle to achieve recovery. Little systematic attention has been paid to socio-cultural processes. Only recently has research looking at both individual and social processes begun to emerge. In their ongoing research project on 'Subjective Experience and the Culture of Recovery with Atypical Antipsychotics' (SEACORE), Jenkins *et al.* (2005:224) found that "improvement and recovery from persistent and severe mental disorders occur in the complex context of interlocking personal, cultural, social, economic, and pharmacological effects." Following these authors, I argue in this dissertation that in addition to psychological processes, socio-cultural processes are integral to recovery from psychosis.

Ethnography provides a means of exploring these socio-cultural processes. One example comes from Barrett's (1996) ethnographic study of a psychiatric hospital in Australia, which depicts the everyday practices of a 'psychiatric team' (psychiatrists, nurses and social workers) in treating mentally ill patients. There are major differences between the setting of Barrett's study and my study. Nevertheless it is germane to my research, particularly in its use of the concept of the 'trajectory'. This is a dynamic concept that refers to the patient's movement through time and space. Barrett shows how it was used by the psychiatric team to describe a patient's progress and recovery.

Within the temporal framework, recovery commenced when a patient first recognized his or her role as sick person. This is similar to the stage of 'awareness' described by Andersen *et al.* (2003). In the process of adopting a sick role, patients began to comply with the staff and cooperate with the treatment regimen. Following that was a

shift toward becoming a unified person, described by the team as 'reintegrating'. Here patients demonstrated increasing rationality, indicated by their ability to make rational choices or 'reality based decisions'. Assuming responsibility and control of their illness were other characteristics of recovering patients. "At the beginning, they were described using deterministic language, but as they progress along the trajectory they were increasing described using voluntaristic terminology" (Barrett, 1996:153).

The patients' progress was also described within a spatial framework. In a literal sense, patients moved through the physical spaces of the hospital. When acutely ill, they stayed in a 'closed' ward with intensive surveillance. As they began to recover, they moved to an 'open' ward, then to a half-way house, and finally to independent living in the community. Thus, the trajectory of recovery described the patients as moving from a locked to an open ward, from acute to sub-acute ward, and from hospital to home. Metaphorically, the trajectory of recovery was also described as a movement from 'elsewhere' to 'here'. The patients who were initially described as being 'off' were later depicted as being 'settled' as they began to recover. The patients who were settled might be described as "quiet, compliant, approachable, interacting well on the ward or comfortable...Thus, 'off' referred to madness, imbalance and explosiveness, 'settled' meant sanity, stability and calmness" (Barrett, 1996:151-152).

The concept of the trajectory, with its temporal and spatial dimension, forms a template through which people assign meaning to and track the recovery process. In my research I show how this template is accorded different meanings that are culturally specific to the Javanese context.

To summarize, while studies examining the process of recovery have used differing approaches—the subjective-consumer approach, phenomenology, and ethnography—there are similarities in their findings. Firstly, all emphasize the non-linear nature of recovery. Secondly, all point to similar phases of recovery, though many different terms are used to describe these phases. The spatial and temporal dimensions of recovery are of particular interest in this regard. However, with the notable exception of the work of Jenkins and her colleagues (see Jenkins *et al.*, 2005; Jenkins & Carpenter-Song, 2006) here is a failure to address the issue of culture. Following Jenkins, the aim of this research is to elucidate the cultural dimensions of these processes by studying them in a specific Javanese cultural setting.

1.4. CULTURE AND RECOVERY

The interest in culture and mental illness in psychiatry began when Kraepelin visited Java in the early twentieth century (Ameen, 2002). In Bogor, West Java, Kraepelin interviewed 100 psychiatric patients, 39 of whom he diagnosed as exhibiting dementia praecox (Bendick, cited in Messias, 2000). Kraepelin observed that here in Java this disorder had more favorable outcomes, sometimes even complete recovery. Despite the criticism that Kraepelin's period of observation was too short and that he lacked sufficient experience of Indonesia (Browne, 1999), Zaumseil and Lessmann (1995) asserted that it was Kraepelin who first observed less severe forms of mental illness in a non-Western country.

Despite intense criticism and debate, the WHO multi-site outcome studies (Sartorius, *et al.*, 1987, 1996; Jablenski *et al.*, 1992) remain the most well-known and oft-quoted cross-cultural studies of psychotic illness. The initial WHO study, the International Pilot Study of Schizophrenia (IPSS), was conducted during the 1960s and 1970s and involved a two-year follow-up. The next study was the Determinants of Outcome of Severe Mental Disorder (DOSMED), which followed up participants for five years, using a more rigorous methodology. The International Study of Schizophrenia (ISoS), the most recent in this series, was designed to follow up participants from the previous studies over a period of fifteen to twenty-five years (Harrison *et al.*, 2001). These three studies differentiate between 'developed' and 'developing' countries. The sites in developed countries included: Aarhus, Denmark; Nottingham, UK; Dublin, Ireland; Moscow, Russia; Nagasaki, Japan; Prague, Czechoslovakia; and Honolulu and Rochester, USA. The sites in developing countries included: Agra, Chandigarh and Madras, India; Cali, Columbia; Ibadan, Nigeria; Taipei, Taiwan; and Hong Kong, China. The striking finding of all of these studies is that the course and outcome of psychotic illness is better in developing countries than in developed countries. This result is consistent across the three studies, for brief and long-term follow-up periods, and for various diagnostic groupings (Hopper, 2004).

Since their first publication, the results of the WHO cross-cultural studies have been described as 'surprising' (Sullivan, 1994; Desjarlais *et al.,* 1995), 'unexpected' (Sartorius *et al.*, 1996), 'challenging' (Edgerton & Cohen, 1994), or 'provocative' (Hopper & Wanderling, 2000). They have generated intense debate and discussion in a number of publications (Murphy, 1982; Lin & Kleinman, 1988; Cohen 1992;

Edgerton & Cohen, 1994; Jablenski, *et al.*, 1994; Hopper, 2004). For example, Cohen (1992) suggested that there were methodological problems, especially concerning hospital-based sampling strategies. Dividing developed from developing countries was another concern (Edgerton & Cohen, 1994; Hopper & Wanderling, 2000; Halliburton, 2004). In support of the WHO studies, Warner (1992:85) acknowledged the methodological problems inherent in some cross-cultural studies, but he argued that: "the difference in recovery rates in schizophrenia between the Third World and the West is so great that it must compensate for minor concerns about methodology."

The WHO results were also supported by a number of other longitudinal studies conducted in local settings. For example, Waxler (1979) conducted a 5-year follow-up study in Sri Lanka and found 45% of patients were completely functional and exhibited no symptoms of psychosis. Lo & Lo (1977) conducted a 10-year follow-up study in Hong Kong and found that 65% of the evaluated patients had full and lasting remissions or showed no or mild deterioration despite some relapses. More recently, Thara & Eaton (1996) conducted a 10-year follow-up study in Madras, India; they found evidence of a good outcome in the majority of first episode schizophrenic patients, in which clinical outcomes were good for nearly 75% of the patients. In Singapore, Kua *et al.* (2003) showed that nearly two-thirds of patients had a good or fair outcome (with only about one-third having a poor outcome), and that about 43% were rated as having superior or good functioning.

Despite the above evidence, Corin *et al.* (2004:111) raise the criticism that most of these studies only examine variables that are relevant to the course of schizophrenia in

Western countries, while "the very meaning of such variables is very often left unexamined." They suggested that the methodology of cross-cultural research into schizophrenia should allow a deeper reflection about how culture might shape the evolution of schizophrenia in a particular setting. With this goal in mind, these researchers carried out a pilot project in Chennai, India by interviewing 11 people recently diagnosed with schizophrenia. Although there was no information on whether the participants in this research have first episode psychosis, the study provides an important reference for understanding the early evolution of schizophrenia. In Chapter 5, I review some of its findings and compare them with the narrative histories provided by participants in my research.

The WHO studies have also generated considerable speculation as to how the findings might be interpreted. Desjarlais *et al.* (1995) summarized several hypotheses. The first concerns the cultural interpretation of mental illness. It asserts that the way people interpret the cause and course of illness affects their responses to the mentally ill, and thereby influences recovery. In developed countries most people interpret mental illness as a disease with a deteriorating course, while in the developing world people often believe in possession as the cause of mental illness, which sets a framework for possible recovery. Secondly, the existence of extended families and a community-centered society in developing countries provides more support than the nuclear family and individual-cantered society that characterizes developed countries. Thirdly, the availability of non-wage labor in developing countries provides a more easily attainable source of meaningful activity compared to the more competitive situation that pertains to paid employment in developed countries. Fourth, the characteristics of

treatment settings, as well as specific treatments, and the impact these have on the experience of those for which the treatments are developed have been hypothesized to influence the development of chronicity.

An additional hypothesis, now common in the literature, is that developing countries have a greater percentage of 'acute psychoses,' which, in general, have a better prognosis than non-acute psychoses. This hypothesis can be located within the debate that surrounds the diagnosis of Acute and Transient Psychotic Disorder (ATPD). Although ATPD as an illness category has been recognized for a long time, its diagnostic validity is still being debated (Mojtabai *et al.*, 2000; Singh *et al.*, 2004). Historically, ATPD, or diagnostic entities that are very similar to it, has been categorized in the European psychiatric tradition under the rubric of 'atypical psychoses.' These diagnostic entities have included: (1) acute (undifferentiated) schizophrenia, (2) cycloid psychosis (used in contemporary German and Scandinavian practice) (3) *bouffee delirante* (proposed by Valentin Magnan in 1890 and still in use among French-speaking clinicians, especially in West Africa and the Caribbean), (4) oneirophrenia, (5) paranoid reaction, (6) reactive or psychogenic psychosis, (7), schizophrenia reaction, (8) schizophreniform attack or psychosis (introduced by the Norwegian psychiatrist, Gabriel Langfeldt, (9) remitting schizophrenia, and (11) good prognosis schizophrenia (See Susser & Wanderling, 1994; Susser *et al.*, 1995; Mojtabai *et al.*, 2003; Marneros & Pillmann, 2004; Good, 2004).

Susser *et al.* (1996) as well as Singh (2004) have criticized the diagnosis of ATPD in the ICD-10 as lacking a firm empirical grounding. These authors are particularly

critical of the division into five sub-categories under ATPD, and also question the criterion of the duration of illness. Susser *et al.* (1996) have proposed the term Non-affective Acute Remitting Psychosis (NARP) for ICD-11 and DSM-V. These authors also suggest that this type of psychosis should be considered as distinct from schizophrenia. Four characteristics of NARP include: non-affective (does not meet criteria for mood disorder), acute onset, brief duration (less than 6 months from onset with full recovery), and psychotic symptoms.

The issue of recovery from acute psychosis, whether conceptualized as ATPD or NARP, has been addressed in a number of cross-cultural studies, such as the WHO Cross-Cultural Study of Acute Psychosis (Cooper *et al.*, 1990); studies carried out in Chandigarh, India (Chavan & Kulhara, 1988); Egyptian research (Okasha *et al.*, 1993) and Scandinavian research (Jorgensen *et al.*, 1997). These studies have come to two basic findings, and they are: (1) the frequency of acute onset psychosis in developing countries is significantly higher than in developed countries; and (2) acute onset psychoses have a more benign course than insidious onset psychoses (see Susser & Wanderling, 1994; Susser *et al.*, 1995; Good, 2004). Since the concept of NARP was developed from the findings of these cross-cultural studies, the findings that I have reviewed for ATPD can be applied to NARP.

Although cross-cultural psychiatry can be said to have had its beginnings in Java, there has not been any formal longitudinal research there to follow up on Kraepelin's observations. However, several studies have been conducted by local and foreign researchers examining psychotic illness and its outcome. For example, recent studies

conducted by local psychiatrists in Java have examined the effectiveness of family interventions on the outcome of affective disorder (Sudiyanto, 1998) and on schizophrenia and bipolar disorders (Sukarto, 2004). While Sudiyanto (1998) did not specifically mention the role of culture, Sukarto (2004) examined the role of Javanese philosophy in relapse prevention. He found that families who had a high commitment to Javanese philosophical precepts in their everyday life—such as *sabar* (patience), *nrimo* (acceptance), and *teposaliro* (tolerance)—tended to have a low EE score. Relapse rates were lower than for patients whose family members were less committed to Javanese philosophy. Furthermore, two German clinical psychologists, Zaumseil & Lessmann (1995), have examined how the Javanese dealt with the mentally ill. Although they did not pay specific attention to recovery, they emphasized the importance of the concept of *ngemong* (to care for gently) which I will describe in more detail in Chapters 2 and 6. In his ethnographic study, Browne (1999, 2001a & b) provided a valuable discussion on the effect of the Javanese expression of emotions in relation to mental illness, an issue I will also take up in this dissertation.

The cross-cultural literature on psychosis thus shows a consistent pattern of a more benign course of illness in developing countries. From Kraepelin's early observations this appears to hold true for Java though there is no more recent data to substantiate this. Research into the family and its effect on outcome provides one of the most promising avenues through which to account for these differences in outcome. In the next section I review the literature on family, culture and outcome. The role of religion is a topic which has received less attention. In the last section I examine the

literature in this area as it is highly relevant to the setting in which my study was carried out.

1.5. FAMILY AND RECOVERY

To review the literature on the family dimension of recovery from psychotic illness, I begin with a discussion of the concept of Expressed Emotion (EE). I then review the literature on family burden and coping.

1.5.1. Family Expressed Emotion

The concept of Expressed Emotion (EE) and its measurement has been the subject of a great deal of scholarly attention. It is among the most widely investigated psychosocial constructs in psychiatry (Jenkins & Karno, 1992). It may be regarded as the most recent in a series of well-known approaches to the family dimension of schizophrenia. One of the earliest of these is the idea of the *schizophrenogenic mother,* developed by Fromm-Reichmann (see Falloon *et al.*, 1984). It focuses on several characteristics of the mother of the schizophrenic patient. On the one hand these mothers were perceived as cold, distant, lacking in warmth and affection, and thereby expressing rejection; on the other hand they were also domineering and seen as overprotective. Other approaches focused on family interaction. These include the *double bind* hypothesis of Bateson (1963), the concept of *pseudo mutuality* of Wynne *et al.* (1960), and work on *marital schism and skew* by Lidz *et al.* (1960). All shared a common idea that a defect in family relationships contributes to the development of schizophrenia.

The concept of EE was developed by George Browne, a sociologist at the Medical Research Council's Social Psychiatry Unit in London. Julian Leff, Christine Vaughn, and their colleagues played an important role in the further development of EE. According to this body of research, there are five types of emotion within families that play a significant role in the course of schizophrenia. They include positive emotions, such as warmth and positive remarks; and negative emotions, such as critical comments, hostility, and emotional over-involvement. In its later development, EE research focused only on negative emotions because a number of studies indicated that positive emotions had no significant correlation with outcome (Leff & Vaughn, 1985).

In preliminary work conducted during the late 1950s Brown and his colleagues found that patients were more likely to experience a relapse of symptoms if they returned to living with parents or wives, rather than if they went to live in lodgings or with siblings (Brown, 1985). Following the development of EE and its measurement, subsequent studies in the 1960s concluded that discharged patients returning to live with their family with a high EE score were more likely to relapse compared to those who returned to a low EE family (see Leff & Vaughn, 1985).

1.5.2. Cross-cultural Studies of EE

These findings have been replicated in many countries across Europe such as Denmark, Italy, France, Spain and Germany (see Kuipers, 1992 for a review) and the US (Karno *et al.*, 1987). They have also been reported in many non-Western settings,

such as India (Leff *et al.*, 1987), China (Philips & Xiong, 1995), Japan (Uehara *et al.*, 1997), Egypt (Kamal, 1995) and Iran (Mottaghipour, *et al.,* 2001). Butzlaff & Hooley (1998) conducted a meta-analysis of 27 studies of the EE-relapse relationship. The result confirmed that EE is a significant and robust predictor of relapse in schizophrenia across a range of settings.

Cross-cultural studies show that there has been a substantial cultural variation in the degree and type of EE (Hashemi & Cochrane, 1999; Bhugra & McKenzie, 2003). For example, Leff *et al.* (1987) found that in India very few (23%) households were rated as high in EE and relatives were less likely to make critical comments. Among Mexican-Americans, Jenkins *et al.* (1986) also reported that most of the key relatives tended not to be highly critical (31%), while their Anglo-American counterparts were highly critical (61%). Among Portuguese-Brazilian, Martins *et al.* (1992) found 59% of relatives were rated as high EE in the over-involvement dimension. In their review of cross-research on EE, Hashemi & Cochrane (1999) reported that Egyptian samples showed a high EE level (55%) in the criticism dimension. An even higher level of EE was observed in the families of a British Pakistani-Muslim sample compared to that found in a British Indian-Sikh sample. Meanwhile in an Iranian sample Mottaghipour, *et al.* (2001) also found 56% of family members were assigned to the high EE group.

An important criticism of EE research has been raised by Jenkins (1991) who commented that the problem of rating EE in different cultures not only concerned inter-rater reliability but, more importantly, cultural validity. The meaning and criteria of criticism and over-involvement, for example, differs from one culture to another.

Jenkins has suggested that criticism becomes valid for cross-cultural research if it is grounded on the definition of "negative response to perceived cultural rule violation" (1991:403). She has also suggested that overinvolvement should be seen as "behavioral transgression of boundaries" (1991:411).

Similarly, Hashemi & Cochrane (1999), as well as Bhugra & McKenzie (2003) have suggested that EE research should not be taken out of context. Cultural factors, family expectations, as well as internal processes within the family should be integrated into an understanding of EE. One way to address this issue of cultural validity is to use ethnography in order to gain an understanding of the family emotional environment. At Jenkins' instigation, McGruder (2004) applied ethnographic methodology in her study of madness in Zanzibar. McGruder was able to identify patterns of family EE while at the same time providing a more realistic picture of the family emotional milieu as it is played out in the everyday life of the family. In this research, I likewise apply ethnographic methods, complemented by the use of a standard instrument to measure EE.

1.5.3. Family's Burden, Coping, and Support

Whereas the literature I have just reviewed looks at effect of the family on the course of schizophrenia, there is an alternative body of literature looking at the effect of schizophrenia on the family. The first literature views families as a potential cause of relapse whereas the later is more empathic to the family, focusing on the burden of care and the struggle to cope. To adopt a balanced view, in this research I consider both of these bodies of literature.

It has been consistently reported that family caregivers experienced high levels of burden and suffering. Terms used to describe their experiences include: traumatic, catastrophic, painful, devastating, bewilderment, turmoil, and chronic sorrow (Marsh, 1992; Pejlert, 2001). The words loss, grief, and mourning also often appear in this context. Families are dealing with actual loss and symbolic loss: the loss of hopes and expectations for their sick family member (Lefley, 1987; Marsh & Johnson, 1997). The experience of suffering is not only felt by family caregivers of people with long-term schizophrenia. Caregivers of people suffering from first episode psychosis already have to cope with high levels of distress (Tennakon *et al.*, 2000).

The most common burden experienced by family members is stigmatization. Finzen (cited by Schulze & Angermeyer, 2003) called stigmatization as a 'second illness,' an additional suffering experienced not only by the sufferer but also the family members The negative effects of stigma include lowered self-esteem, damage to family relationships, social isolation, shame, and delayed help-seeking behavior (Lefley, 1996). Although stigma associated with mental illness can be found around the world, its manifestations differ across cultures. Weiss *et al.* (2001) compared the social stigma attached to mental illness in traditional society in Bangalore, India with that in a modern setting in London. These authors found that in Bangalore, the stigma experience focused on concerns about respectability, social status, and marriage; while in London stigma tended to focus on concerns about their family members being non productive.

Despite the burden they experience, families demonstrate a great deal of responsibility in caring for and supporting the ill member. This positive attitude is more evident in cross-cultural studies of family response to caring for patients with schizophrenia. Jenkins & Karno (1992), for example, found a different response between Anglo-American and Mexican-American families. While the emotional responses among Anglo-American families were characterized by anger, indignation and frustration, the Mexican-Americans families tended to display sadness, sorrow and pity. Thus, Mexican-American relatives demonstrated a greater degree of tolerance toward the schizophrenic family member. In more recent research, Garcia *et al.* (2006) found that family support among Mexican-Americans predicted higher medication usage. Ip & McKenzie (1998) reported that despite experiencing distress, Chinese caregivers developed an attitude of acceptance, taking positive actions, developing hope, and seeking religious support. Among Nigerian families, Ohaeri & Fido (2001) found that in spite of social embarrassment, families were strongly sympathetic, helpful and supportive toward the ill member

Experiencing such levels of burden, family members often use many kinds of resources to cope, including psychological, social, cultural and practical resources (Scazufca & Kuipers, 1999). Hatfield (1979) conducted an exploratory study into coping strategies. When families were asked to rate the effectiveness of their own resources, they placed a high value on their network of family and friends, as well as parents' of others who have similar illnesses. With regard to coping style, several studies indicate that problem-focused coping—where the family actively seeks care from many different resources—are especially effective in situations amenable to

change, whereas emotion-focused coping—where the family has to accept the illness—may be adaptive in situations that are chronic and unchangeable (see Ostman & Hansson, 2001). In their study of first episode psychosis, Tennakoon, *et al.*, (2000) found that families used both problem-focused and emotional-focused coping strategies.

Cross-cultural studies of family coping have suggested that families use cultural and religious resources to cope with burden and distress. Redko (2003) reported that Brazilian families often turn to religion to seek alternative therapy and for personal relief and comfort. Guarnaccia (1998) compared the family burden and source of support among Hispanic-American, African-American and European-American families. He reported that African-American and Hispanic-American families are more likely to get support from their families, religious, and other culturally based resources, than European-Americans. In an earlier study, Guarnaccia *et al.* (1992) reported that Hispanic families often used the idiom of *Si Dios quiere* (If God wishes) to express their hopes for the ill member. Ruangreangkulkij & Chesla (2001:123) found that Thai mothers understood the illness as their *karma* according to Buddhist belief, and they responded to the illness by practicing *thum-jai*: "a combination of being accepting, patient, understanding, reasonable and having a sense of obligation."

1.6. RELIGION, PSYCHOTIC ILLNESS, AND RECOVERY

1.6.1. Religion from the Objective-Medical Perspective

Historically, mental health professionals in the West have tended to have an uncomfortable relationship with issue of religion. Religion became the 'last taboo' in medicine, and it was not commonly practiced in mental hospitals or discussed in professional meetings (Foskett, 1996). If mentioned, attention tended to focus on the negative effect of religion. It was seen as contributing to the development of illness, for example, by encouraging excessive guilt and shame, or escapist thoughts and denial of life problems. Religion was also seen as part of the symptomatology, occurring for example in hallucinations and delusions, and therefore a target for treatment. Some have postulated that religious and spiritual experience are in themselves pathological, regarding them as a universal obsessional neurosis or an equivalent to irrational thinking, infantile helplessness, or regression (see Lukoff *et al.*, 1992; Fulford, 1996).

In the later decades of the twentieth century, however, there has been a growing interest in spirituality within the mental health profession. The positive aspects of religion have been increasingly acknowledged. A number of scientific studies have emerged which draw attention to the significant role of religion in the process of healing and recovery. Bergin (1983) conducted a meta-analysis of 24 studies of mental health that used one measure of religious involvement: 23% of studies showed a negative relationship between religion and mental health; 47% suggested a positive

relationship between religion and mental health; and 30% indicated that there was no relationship at all. Corrigan *et al.* (2003) found that religious involvement was positively associated with psychological well-being and diminished psychiatric symptoms in people with serious mental illness. Categorical indices of spirituality and religiosity were significantly related to recovery, social inclusion, hope and personal empowerment.

1.6.2. Religion from the Subjective-Consumer Perspective

The role of religion in the process of recovery has received much more widespread attention in the consumer literature. Young & Ensing (1999) conducted a qualitative study exploring the meaning of the recovery process from the perspective of 18 mental health consumers. The most remarkable finding of this study was that spirituality was perceived as a central aspect of the recovery process. Similarly, Fallot (2001) observed on the basis of personal accounts of mental health consumers, that spirituality is a core element in the narratives of people recovering from psychotic illness. More recently Corrigan *et al.* (2003) conducted a survey of 1,824 consumers who filled out a self-report measure of spirituality and religion. They found that nearly 90% of consumers identified themselves as being religious. The researchers also suggested that spirituality and religion have a strong therapeutic power, because they are positively associated with psychological well-being and diminished psychiatric symptoms.

Religion and spirituality have been found to contribute positively to the recovery process in different ways. First, religion provides support to cope with stress. A

number of studies have demonstrated that it was very common for psychotic patients to turn to religious resources for help (Fallot, 2001; Redko, 2003). Kirov *et al.* (1998) found that among psychotic inpatients (n=52) 61.2% used religion to cope with their disorder; 30.4% reported an increase in religiousness since the onset, and 22.4% stated that religion was the most important part of their life. Religious beliefs and practices are often sources of support at a time of crisis not only for the patient but for his/her family. Most carers have been reported to have a strong belief in God and expressed the view that religious coping had helped them reduce their distress and provide hope and solace. When psychopathology and disability in the patient worsen, the use of religious coping in carers is likely to increase (Redko, 2003; Rammohan, 2002).

Second, religion allows families and their ill members to find meaning. Young & Ensing (1999) found that religion and spirituality provides consumers with a source of inspiration and hope, as well as allowing them to find meaning and purpose in life. In a different cultural setting, Redko (2003) carried out a fieldwork with 21 first episode psychoses with their families living in poor neighborhoods of São Paulo in Brazil. She concluded that religion has the potential to provide a set of representations and meanings. Religion equips patients with a range of symbolic meanings that they can appropriate to their own quest.

Third, religion provides the possibility to reframe the illness in a more positive way, such as redefining the illness as potentially beneficial in so far as it has the effect of strengthening them spiritually. The transformative potential of psychotic illness has

been identified by a number of writers (Grof, 1998; Sodergren *et al.*, 2004). Tooth (2003) reported that nearly two-thirds of research participants found that their psychotic illness had a life-transforming experience in which the old self was let go and a new, more functional sense of self emerged. Similarly, Kirov *et al.* (1998) reported that 35% of those in a psychiatric sample experienced a distinct change in their religious faith, with the majority reporting an increase in the intensity of their faith. Rogers *et al.* (2002) reported that over 54% of participants experienced a change in religious belief and of them 66% perceived these changes to be positive.

1.7. SUMMARY

After almost a century of Western psychiatry dominated by Kraepelin's pessimistic view that schizophrenia is a degenerative and deteriorating illness, a more optimistic picture has begun to emerge. In this chapter I have proposed that the literature on recovery from schizophrenia has emerged from two perspectives, the objective-medical perspective, and the subjective-consumer perspective. Initially in conflict, there has been a convergence in recent years, and a more optimistic outlook is now supported by research conducted from both perspectives. In keeping with these recent developments, this study combines objective and subjective approaches in order to examine recovery from psychosis in the Javanese cultural context, where there is suggestive evidence that in many cases the prognosis for recovery may be favorable.

In the light of my discussion of various meanings attributed to recovery, my research pays careful attention to the distinctive meanings that recovery has for Javanese

people. Here, I aim to show how individuals and families draw on these culturally specific meanings in struggling to overcome psychotic illness. At the same time, I employ objective measures of recovery, so that my findings can be located within the broader international literature.

In examining the literature on the process of recovery the outstanding findings are that recovery is non-linear, and it proceeds in phases. However, I have demonstrated that, in the main, recovery is examined within this literature as an individual process. There is a need to explore socio-cultural dimension of recovery. The cross-cultural literature on schizophrenia that I have reviewed provides strong evidence that culture influences the process of recovery, but there is continuing debate as to how this occurs.

There are three promising directions here. The first, as Desjarlais *et al.* (1995), have pointed out, concerns the concepts of illness and recovery available to people who suffer from psychosis and those around them, a cultural repertoire on which they can draw to make sense of their illness and negotiate paths to recovery. In Chapter 6 of this dissertation I examine some concepts of illness that are specific to Javanese culture, showing how they relate to broader Javanese ideas about the person and the family.

The second concerns the role of the family in mediating cultural influences on recovery from schizophrenia. There is evidence for a wide variation in family emotional environment cross-culturally, which may contribute to differential recovery rates. It is important here to recognize that emotions themselves are culturally

constituted, that the meaning of criticism and over-involvement, for example, may itself differ from one cultural context to another. In Chapter 5 of this dissertation, I take up the issue of family emotional environment, and seek to provide an account of the varieties of emotion that occur in Javanese families in relation to psychotic illness.

The third direction concerns religion. Whereas this topic had been relatively neglected until recently, there is an emerging body of literature on the positive role that religion may play, both for those who suffer from psychotic illness, and their families. Given that religion plays such a powerful role in Java, this setting is an ideal one in which to explore the role that the diverse varieties of Islam play in patients recovering from psychosis. Chapter 6 examines a number of orientations within Islam, and how they come into play—sometimes in conflict, at other times in consensus—within Javanese families in their struggle with psychotic illness.

CHAPTER 2

CONTESTED JAVANESE CULTURAL VALUES IN CONTEMPORARY YOGYAKARTA

To study psychotic illness in its natural setting, one needs to develop a culturally appropriate understanding of the lived context. In this chapter I provide an outline of Javanese culture. Firstly, I give a general overview of Javanese culture as it is reflected in present-day Yogyakarta, the field site of this research. Secondly, I briefly outline certain aspects of Javanese family relationships and Javanese religion. Thirdly, I provide an account of Javanese understandings of mental illness. This chapter is not intended as a large-scale historical and cultural study, but a discussion that focuses on particular cultural domains that are pertinent to my ethnographic and case material, and that are available to people with psychosis and their families as they struggle with illness and recovery.

2.1. PRESENT-DAY YOGYAKARTA

Java is one of the major islands in the Indonesian archipelago and the Javanese constitute the single largest ethnic group in South East Asia. The most recent Indonesian census in 2000 recorded that Javanese population numbered

approximately 80 million, 40% percent of total Indonesian population.[5] The Javanese homelands lie in the central and eastern parts of the island. Due to migration within Indonesia as part of government transmigration projects, Javanese have spread to almost every Indonesian province.

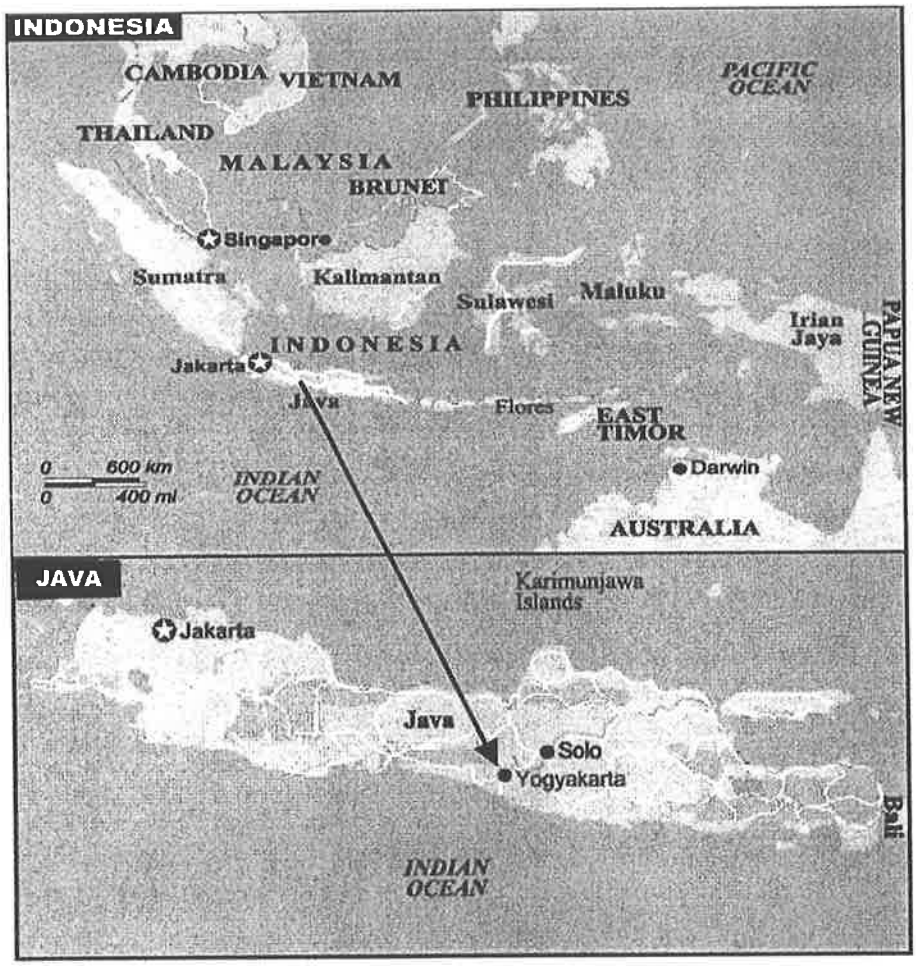

Figure 2.1. Map of Indonesia and Java
(Edited from:
http://www.lonelyplanet.com/mapshells/south_east_asia/indonesia/indonesia.htm
http://www.lonelyplanet.com/mapshells/south_east_asia/java/java.htm)

[5] See http://en.wikipedia.org/wiki/Javanese, and http://www.bps.go.id/sector/population/pop2000.htm

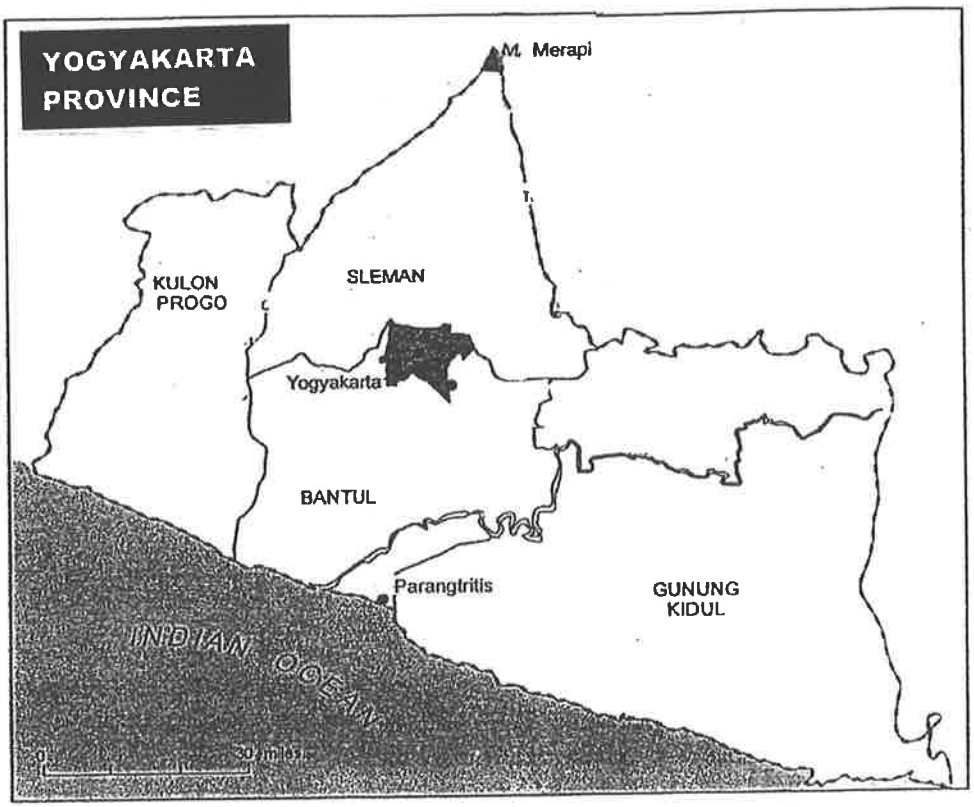

Figure 2.2. Map of the Special Province of Yogyakarta (Edited from Browne, 1999:374).

This research was conducted in what is known as the Special Province of Yogyakarta.[6] It encompasses the city of Yogyakarta (also known as Jogja) and surrounding small towns and villages. The 2000 census recorded a population of 3,120,478.[7] The region consists of five administrative districts that have different characteristics. One district comprises the city of Yogyakarta. The city, however, has grown rapidly in recent years and now extends into part of Sleman, a district stretching to Mount Merapi in the north, and into part of Bantul, a district in the south toward the sea. While Sleman and Bantul include peri-urban and rural areas, the other

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[6] Yogyakarta received its 'special region' provincial status from the Indonesian government partly due to the important role of Sultan Hamengkubuwono IX during Indonesia's struggle for independence from the Dutch. When the central government in Jakarta was not able to function normally because of Dutch attacks after 1945, the capital of Indonesia was temporarily moved to Yogyakarta.

[7] http://www.pemda-diy.go.id.

two districts, Kulonprogo in the west and Gunung Kidul in the south-east, are mostly rural.

Historically, Yogyakarta emerged in the 16th century in the context of a dispute between two princes over the succession of the Mataram kingdom. One remained in the old palace in Surakarta (also known as Solo), a city 60 kilometres to the east. The other established himself in Yogyakarta. The new Yogyakarta palace and its surrounding buildings were designed on the basis of geometric and cosmological principles (Ferzacca, 2001:28). Mount Merapi in the north, the coastal area of *Parangtritis* in the south, and the *kraton* (the Sultan's palace) in the middle, are all in a straight line. Many Javanese believe that a powerful queen spirit named *Nyai Roro Kidul* [8] resides in the south sea. It is said she and her army periodically march to Mount Merapi, a belief that continues to have strong resonance to this day. Previous research (Good & Subandi, 2000), together with the research on which this dissertation is based, both provide evidence that the myth of *Nyai Roro Kidul* frequently emerged in the experience of psychotic illness in Java.

As a city of multiple identities (Ferzacca, 2001:29), Yogyakarta is the site of cultural contestation, particularly with respect to traditional, modern, and religious values. It is known as *kota budaya* (the city of culture), *kota pariwisata* (the city of visitors) and *kota pelajar* (the student city). While the first identity links Yogyakarta to the past and to local tradition, the other two identities connect it to the future, and to modern and

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[8] Also known as *Kanjeng Ratu Kidul* (the Queen of the South).

global lifestyles. Capturing the traditional and modern nuances, Woodward (1989:16) called Yogyakarta a magical city in the modern world.

In keeping with its identity as a *kota budaya* Yogyakarta is one of the centres of 'authentic' Javanese culture along side Surakarta. Several important historical sites of ancient Hindu and Buddhist temples surround Yogyakarta. The *kraton,* in the inner city, was represented in classic Javanese texts and rituals as the imagined centre of the universe; for centuries, it was widely understood as such by the elite and continues to be so regarded among the ordinary people who live in the poorer residential neighbourhoods (*kampung*[9]) of Yogyakarta today. The present *Sultan Hamengkubuwono X,* as the King and the Governor of the Special Province of Yogyakarta, still commands immense respect. The *kraton* has also been regarded as an important source of Javanese values and traditions (Pemberton, 1994; Woodward, 1989). One example is the language hierarchy that was probably developed by the early Mataram dynasty to signify distance between the aristocracy and ordinary people (Siegel, 1986:20).

As a *kota pariwisata* Yogyakarta has become the most visited local and international tourist destination in Indonesia after Bali. Aside from the historical sites, Yogyakarta is also famous for its traditional and modern arts. Traditional forms of Javanese theatre, such as *wayang*[10] and *kethoprak,*[11] are still staged regularly not only for

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[9] See Guinnes (1986) for a detailed account of *kampung* life in Yogyakarta.
[10] *Wayang* literally means shadow. In Java, this shadow play is a popular story-telling art that uses shadow puppets. Most of the story is taken from the Hindu Ramayana and Mahabarata epics, and additional stories created by the Javanese.
[11] *Kethoprak* is a form of popular theatre that stages folk stories, accompanied by a Javanese orchestra.

tourist consumption, but also as entertainment for local people. Several well-known artists from Yogyakarta have achieved national and international reputations, such as Affandi (a painter), Emha Ainun Najib (a poet and musician), and Bagong Kussudiardjo (a choreographer and painter, who established a famous dance and art school). One of the participants in this research used to be a student in this school. Meanwhile as a *kota pelajar* Yogyakarta attracts thousands of students from many different parts of Indonesia and some from foreign countries. At present there are 4 state and 16 private universities in Yogyakarta and more than 50 other academies.[12]

These new identities, *kota pariwisata* and a *kota pelajar,* have changed Yogyakarta. No longer a local traditional centre, it now participates in the global modern world. Mulder (1994b) provides an ethnographic account of cultural change in Yogyakarta, comparing two visits he made to the city, one in the 1970s and the second in the 1990s. He writes:

> [In the 1970s] it was a laid back, sleepy town. The only public transportation available consisted of pedicabs and horse-drawn carriages...the parking business was confined to guarding bicycles, then the most normal of privately owned vehicles, and already quite prestigious...nowadays there is a lot of traffic and really nothing special about [the] motor-cycle...the mystical scene was certainly flourishing at the end of 1960s, people being attracted for a great variety of reasons...money had become available and was exerting a pull on their inward directions...ordinary people have become more mobile, physically, economically, socially (Mulder,1994b:2-8).

The influence of modernity in Yogyakarta becomes increasingly evident. A large number of housing complexes have penetrated nearby rural areas, replacing

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[12] http://www.pts.co.id/pts05.asp

agricultural land use. A global cultural lifestyle is represented by fast food, mobile phones, telecommunication cafés (*wartel)*, and internet cafés (*warnet*). Another participant in this study, as he made progress in recovering from his illness, set up a *wartel* which he ran from his house. Several Non Government Organizations (NGOs) funded by overseas foundations also operate in Yogyakarta. These organizations are concerned with social, political and health issues, particularly in village areas. When I conducted my fieldwork in 2002-2003, the penetration of global issues into Javanese villages was quite apparent. For example, during her psychotic illness, a participant believed that she was responsible for the September 11 attack in New York. Also, the global term of *setres* (stress) has become popular attribution for mental health problems in Javanese villages (Browne, 1999:110-115).

Modernity in Yogyakarta, however, has been perceived to have some negative consequences. Javanese often comment on the loss of traditional values, which they equate with modernity, as a source of many of the social ills of today's society. They cite drug abuse, pre-marital sexual relationships and pornography as issues of great concern. Some are also worried about the increase in 'modern' physical illnesses such as hypertension, heart disease, and diabetes (Ferzacca, 2001:104). Sudaryanto (2006), a Javanese teacher, has raised concerns about the diminishing use of high Javanese language (*kromo*) among students because their parents (particularly in more educated families) prefer to use the Indonesian language at home.

To counter these 'side effects' of modernisation, two trends have emerged in Yogyakarta. One is a growing religious climate in the city and the second is a series of

efforts to preserve Javanese cultural traditions. In relation to the increasing religious atmosphere in Yogyakarta Mulder (1994b) noted:

> In 1980, I was most struck by the vitality of much of the officially recognized religious life, with churches and mosques filled to overflowing, while at the same time *kraton*-oriented rituals were rapidly declining in support. Many of people who had seemed uninterested in religious matters were now going to the Friday prayers, and interest in Moslem subjects had become commonplace (1994b:8).

Meanwhile, in an attempt to preserve Javanese cultural traditions, the local Indonesian language newspaper, the *Kedaultan Rakyat*, now publishes one-page articles written in the Javanese language once a week. A monthly magazine, *Joko Lodang*, is dedicated fully to preserving Javanese language and culture. Similarly, *Jogja TV*, a new television station in Yogyakarta, has its motto: *tradisi tiada henti* (heritage never goes away). This station broadcast numerous programs to preserve Javanese indigenous traditions, such as the Javanese orchestra (*gamelan*), mystical discussions, as well as Javanese ancient and contemporary history. Finally, the traditional rituals of *labuhan*[13] and *ruwatan*[14] are becoming more popular. Thus, Browne's assertion (1999) that Javanese identity is increasingly associated with modernity and with global culture is only partly true. In addition, the revival of traditional Javanese culture and religious revival is everywhere apparent.

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[13] *Labuhan* is an offering ceremony conducted by the Sultan's family, in which *Nyai Roro Kidul* is asked for safety and prosperity. *Labuhan* is held by putting women's clothes, cosmetics, flowers, etc. into the ocean. The Sultan's clothes, nails and hair are buried in the beach (see http://www.galangbudaya.com/yogyaspcevents.htm). Ordinary people also conduct *labuhan* by throwing certain kind of foods, fruits, clothes etc. into the ocean. This similar offering of *labuhan* is also conducted at Mount Merapi.

[14] *Ruwatan* is a ritual aimed at safety and protection for individuals at risk, such as the only child in the family. It is also conducted to protect people and the earth from calamity and disaster (see Koentjaraningrat, 1985:376-377; Keeler, 1987:178; Ferzacca, 2001:190).

In sum, Yogyakarta, the site of this research, is a place where many different cultural values are being contested. As part of the global world, Yogyakarta has become more modern in many aspects of everyday life. At the same time, however, Javanese traditional values and religion are undergoing a resurgence. This dynamic of contestation over traditional life and modernity emerges in participants' illness narratives throughout this dissertation.

2.2. THE CONCEPT OF *LAHIR-BATIN*

Most ethnographic studies carried out in Java discuss the basic conceptualisation of the Javanese self as a contrast between the *lahir* (outer) and the *batin* (inner) realm (see Clifford Geertz, 1960:232, 1983:60; Mulder, 1978:13, 1994a:6; Keeler, 1987:270; Guinnes, 1986:113-114; Woodward, 1989:299; Ferzacca, 2001:79). This concept, derived from the *Sufi* mystical tradition within Islam, has been reworked into local understandings of the Javanese self. The *lahir* aspect refers to the outside world. It encompasses outward actions, external appearances, and the visible world that is apparent to the senses. *Batin* refers to the inside world, the inner realm of human experience, including inner subjective feelings and spirituality. This fundamental concept pervades Javanese everyday life.

Clifford Geertz (1983: 60) argues that *lahir-batin* contrast is connected to another set of contrasts, *kasar-halus. Kasar* refers to vulgar, rough, coarse, uncivilized; while *halus* refers to refined, smooth, subtle, civilized. Mulder (1978:18) too combines these two sets of contrast. He states "This order of existence is symbolized by man as a

microcosmos, his *lahir* representing the *kasar*, and his *batin* the *halus* qualities of existence." In the following section I discuss the concept of *lahir-batin* in relation to the concepts of *kekuatan* (power), *tentrem* (quiet, calm, peace) and *usaha* (effort).

Anderson (1972:7) suggests that the idea of power is central to Javanese culture: "It is not a theoretical postulate but an existential reality." The concept of power itself has an outer and inner dimension. *Kanuragan* refers to outer physical power. *Tenaga dalam* refers to inner power. Other relevant concepts at this deeper level include *kasekten* (magical power) and *kekuatan batin* (inner strength). All these types of power can be cultivated through a variety of practices, secular and religious. *Kanuragan* may be attained by the practice of martial arts, while *tenaga dalam* may be developed by means of breathing exercises. *Kasekten* and *kekuatan batin* are accumulated through meditation, fasting, and other ascetic practices. Some people combine all of these. Browne (1999:82) observed that the practices that aim to achieve *tenaga dalam* engage significant segments of the Javanese population. This is also reflected in my own research. All male participants in this study engaged in practices designed to accumulate power.

The concept of *lahir-batin* can also be applied to the quality of *tentrem* (quiet, calm, peaceful). The ideal of living in the world, according to Javanese, is one of being *tentrem lahir,* that is, at peace in one's outer social relationships, and *tentrem batin,* at peace in one's inner subjective world. Closely related to *tentrem lahir* is the term *rukun* (harmonious integration) which tended, by preference, to be used by most participants in this study. Both *tentrem lahir* and *tentrem batin* require suppression of

conflict and of negative emotions. Most ethnographic accounts have documented the tendency of Javanese to suppress and control negative feelings, impulses, or desires in order to be smooth outside and inside (Clifford Geertz, 1983; Keeler, 1987; Mulder, 1994a). This ideal is evident in precepts taught to children: *mikul dhuwur menjem jero*, literally means 'to carry high, bury deeply'. In order to carry high, people must maintain "the good name and moral irreproachability of their parents, by praising their parents' goodness and extolling the inner harmony of family life," whereas to bury deeply, people must hide "anything that might betray disharmony, aggressive feelings, or whatever else is felt to be negative about family life" (Mulder 1994a: 31).

Contrary to this, Browne (1999) argues that the expression of conflict and emotions should be seen as situation-dependent. Javanese people *do* seek to attain a 'flat affect' as a cultural ideal, but in reality they also give vent to powerful emotions. Browne agrees with Weiss (1977) who argues that it is often by controlling the expression of emotions that these emotions are conveyed. That is to say, not reacting in anger can be a means of subtly conveying anger. In this research I show a variety of emotional responses among participants and their family members, ranging from the control and burying of emotions, to their indirect expression, to the overt expression of anger, conflict, disappointment and sadness.

The state of *tentrem batin* can be disrupted by the experience of *kaget,* being shocked or startled. While *tentrem batin* is associated with order and control, *kaget* is associated with disorder and a sudden loss of control. Therefore, as much as possible, Javanese try to avoid the state of *kaget.* It is believed that startling experiences may

lead to illness, including fever, *latah,*[15] and being possessed by spirits (Hildred Geertz, 1961:92; Keeler, 1987:58; Browne, 2001b). In this research I identified *kaget* as one of the common triggers of psychotic illness (see Chapter 5).

The maintenance of *tentrem lahir,* peace in outer social relationships, and *rukun,* harmonious integration, is mediated through *isin*. *Isin* refers to a range of experiences and feelings that encompass shyness, shame, embarrassment and guilt. Very early in their lives, children learn how to feel *isin* (Hildred Geertz, 1961:111-113; Keeler, 1987:66-67; Mulder, 1994a:26). This feeling is normally internalised in many different social situations, particularly in the presence of authority figures and strangers. As part of the progression toward maturity, a child has to develop his or her own internal control by learning to recognise the feelings associated with *isin*, and to experience these feelings when engaging in improper behaviour. This learning process involving experience and recognition is called *ngerti isin* (to know *isin*).

However, *isin* has both negative and positive dimensions. Hildred Geertz (1961:112) described the negative aspect of *isin* as a complex anxiety reaction, involving fear and lowered self-esteem, and it is seen as a hindrance to social interaction. The positive aspect of *isin* is that it serves as a behavioural control. It may "contribute to the development of respect of others and the desire to avoid conflict and confrontation" (Mulder, 1994a:26). My recent research (Subandi, 2003) confirmed the relevance of *isin* in a contemporary Javanese setting. I identified two different dimensions of *isin*

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[15] *Latah* is a behavioural response specific to Indo-Malay culture. It is characterized by involuntary and spontaneous imitation of speech, automatic obedience, giggling, and sometimes the uttering of obscenities.

among Javanese university students, a personal and a moral dimension. The personal dimension of *isin* was perceived when someone became a focus of attention of others in a social setting. In this sense *isin* was considered by the students to be negative, since it became an obstacle to personal development. The moral dimension of *isin* referred to the violation of religious, moral or cultural norms.

Finally, *lahir-batin* is associated with the concept *usaha,*[16] meaning to make a strong effort to find solution to a problem. Believing that life is a series of hardships and misfortunes, Javanese teach their children to cultivate feelings of concern and solicitude (Koentjaraningrat, 1985). When facing difficult life problems, Javanese tend to develop an attitude of *nrimo* (accepting destiny) and *pasrah* (surrender to the will of God). They strongly believe in *takdir* (destiny) that God has destined everything. However, this does not mean that one passively waits for the problem to be solved without doing anything. It is important for a Javanese person to practice *usaha*. "No matter how burdensome and full of sufferings human existence essentially is, no matter how miserable fate has determined a man's course to be, it is his obligation to give meaning to his life by trying to make the best of it" (Koentjaraningrat, 1985:454). *Usaha* also has an outer and an inner dimension. *Usaha lahir* refers to efforts made in the outer social world, such as working hard to fulfil basic family needs, securing financial support, seeking medical treatment, or attempting to return to work. *Usaha batin* involves the practice of *tirakat* or *laku,* ascetic exercises that include fasting, praying, and meditating. It is usually performed during any critical situation such as facing a difficult task, or experiencing a crisis in

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[16] Another term often used in Javanese texts for *usaha* is *ihtiyar* (Koentjaraningrat, 1985:454)

one's family life or career. Both forms of *usaha* were commonly practiced by the participants in this study as part of their struggle for recovery.

In this section I have outlined the cultural concept of *lahir-batin* as a basic dimension of the Javanese concept of self. Following Anderson I have shown its relationship to the achievement of *kekuatan*. I have also argued that it is central to the maintenance of *tentrem. Tentrem batin* is achieved by the control of emotions, though I have argued that nowadays even this value is contested. It is an ideal not always achieved, and as Weiss and Browne have pointed out, the control of emotions can sometimes be a vehicle for their subtle expression. The maintenance of *tentrem lahir*, on the other hand, is primarily mediated through the experience of *isin,* but even *isin* does not exert the same degree of behavioural control that it formerly did. Finally, I have demonstrated that *usaha*, the effort to find a solution, also has an outer and inner dimension. All of these cultural concepts and practices are central to understanding Javanese experiences of and reactions to psychosis. In later sections of this thesis I will explore, for example, the importance to Javanese people of *kaget* as a precipitant of psychosis and the critical role of *usaha* in the struggle to recover from psychosis.

2.3. CHANGING PATTERNS OF JAVANESE FAMILY LIFE

For Javanese, the family is central to their lives. Emotionally, it provides a feeling of *tentrem* (Hildred Geertz, 1961:94), *hangat* (emotional warmth), and *kasih sayang* (unconditional love and giving) (Shiraishi, 1997:57). The importance of family is reflected in the proverb: *mangan ora mangan waton kumpul* (even if there is no food

to eat, being together is the most important thing). The value placed on being together has diminished somewhat in the face of challenges posed by modernity. Nowadays it is increasingly common for young Javanese to leave their family home in search of employment or higher education. Three participants in this research, for example, left their village to find a job. Even when living away from one's family, however, emotional closeness is still maintained as much as possible. This can be observed in the annual *lebaran*[17] celebration, where people living in large cities return to their villages to gather together with family members and relatives. On this occasion large descent groups called *trah* or *bani* usually organize an annual gathering. This extended family network provides significant support in times of crisis. Javanese also like to establish new family networks by treating unrelated people such as tenants as if they were family members. The Javanese 'family ideology' or 'family-ism' has penetrated deeply into social, cultural, and political life in modern Indonesia (Shiraishi, 1997:164).

The Javanese kinship system is bilateral, wherein both the mother's and the father's lines are treated equally (Hildred Geertz, 1961:15; Keeler, 1987:32; Mulder, 1994a:23). However, in the establishment of a new household there is a marked tendency towards matrilocal practices. A newly married couple tends to stay in the house owned by the wife's parents—uxorilocal residence. This practice is believed to minimize conflicts and tensions over household matters that often arise in the case of virilocal residence between a wife and her mother-in-law. A couple will only reside

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[17] *Lebaran* is the Javanese annual festival conducted after one month's fasting during the month on *Ramadan*. It is also known as *bodo*.

with the husband's family for special reasons such as the availability of domestic space or the proximity to the husband's place of work. Ultimately, as a young couple become established and begin to have children, they will seek to set up their own separate house. However, it is not uncommon for a second sibling, usually younger, to marry before the earlier-married sibling has moved out. Thus, a situation can arise where two or more married siblings live together in the parental dwelling. This may generate conflict over shared responsibilities or jealousy with respect to material possessions. As will be seen in the case material that I later present, such conflict can have an impact on the participants' psychotic illness.

Hildred Geertz (1961:94) as well as other recent researchers (Keeler, 1987:58; Shiraishi, 1997:58) emphasize the importance of *ngemong* within family context. It refers to the ideal way that Javanese should look after their children. At a physical level, Javanese babies are carried around by their mother and other adults in a *selendang*, a long shawl worn over the shoulder to form a sling. This way of carrying a child, it is said, makes the child feel *tentrem* and emotionally warm. When children are able to walk, adults keep a close eye on them to prevent them from falling or experiencing physical injury. At an emotional level, adults constantly seek to engage and amuse the child, to make them contented, and protect them from *kaget*, or shock. Javanese believe that children's contentment enhances their resistance to disease and misfortune. At night an infant sleeps next to her or his mother. This practice continues throughout early childhood, very often until school age. When a child is sick it is common for a mother to sleep next to him or her, even when the child has grown up.

Good & Subandi (2004) encountered a mother who slept next to a 40-year-old single daughter because she suffered from a mental illness.

During my field work, a participant's father explained to me that the practice of *ngemong* is not limited to taking care of a small child who might be impulsive, demanding, and unable to control his or her behaviour. The basic principle of *ngemong* is a way of dealing with any person whose behaviour is similar to that of a child. For example, a husband may *ngemong* his demanding wife, or an adult daughter may have to *ngemong* her impulsive father. This concept also applies more widely to community settings. A village leader has to *ngemong* his people so that there is no conflict between them. The concept of *ngemong* may also be applied to adult children, legitimising parents becoming involved in their affairs, such as marriage, to the extent that this can sometimes be perceived by children as interference.

Thus, the main idea underlying *ngemong* is a positive sense of tolerance and acceptance of aggressive and impulsive behaviour. In the study of how Javanese families respond to mentally ill patients, Zaumseil and Lessmann (1995) found that all of their participants emphasized the importance of *ngemong* in dealing with mental illness. They suggested that the family of a mentally ill patient should be tolerant, attentive, and caring. These researchers emphasized the absence of criticism, blame, and hostility directed towards the mentally ill in Javanese families. By way of contrast, Browne (1999) identified some families who exhibited criticism and hostility. In this research I confirmed the significance of *ngemong* in promoting the recovery process. However, I also witnessed families who expressed strong criticism

and hostility. Thus, the Javanese family is more complex and variable than the idealized image of a family in a developing country as being tolerant and supportive.

Although the focus of this research is on recovery from psychotic illness, it is anticipated that my ethnographic data will contribute to an understanding of the present-day Javanese family in Yogyakarta. It is of note that there have not been any studies focusing on the Javanese family since Hildred Geertz (1961) published her classic book, *The Javanese Family*. Due to its rich description of Javanese family life, this book has become the prime source for subsequent ethnographies that explore other aspects of Javanese culture, such as those of Siegel (1986), Keeler (1987), Mulder (1994a), and Ferzacca (2001). However, the relevance of *The Javanese Family* to present-day Yogyakarta should be questioned. Mulder (1994b) has raised the problem that much of what is known about the Javanese family concerns its ideology and its ideal values; we know much less about the lived experience of growing up in a Javanese family

With advent of modernity and the cultural changes described in the first section in this chapter, the Javanese family is also changing. In her ethnography, Hildred Geertz (1961:55-56) wrote that a marriage was often arranged for a daughter soon after her first menstruation. This might have been true in the past, but the situation is now quite different. While arranged marriages still occur these days, they are not common. Having said this, however, children tend to take their parents' advice into consideration when choosing a marriage partner. Generally, young Javanese, both men and women, tend to marry around the age of twenty, though often younger in

village communities. The obligation to marry remains strong, with daughters ideally marrying before sons, and elder siblings before younger ones. Mulder (1994a:29) provides an illustration of an old fashioned couple who were more worried about their daughter being married than in her being successful in her study. In the present research the issue of arranged marriage emerged in two young women participants, but both of them rejected this idea. Their parents did not want to force them, despite the fact that they were already in their twenties. Both preferred to continue their studies through to University level, even though they lived in a village area. Meanwhile another participant, who was 17 years of age and still in the process of recovery, received a proposal of marriage from a young man who lived in the same village. At first, her parents disagreed, because she was considered too young to get married and they wanted her to get a job in another city. After serious discussions with the parents of the man, they finally agreed. Javanese daughters clearly enjoy more freedom today.

The most important contribution of this research regarding changing patterns of family life in Java pertains to my discussion of the family emotional environment. According to Hildred Geertz (1961:149-151), the Javanese family traditionally emphasised the value of *rukun* (harmonious integration), in which there was "no intense feelings of resentment, or at least are not expressed…look for compromise solution...to minimize conflict within family." In this research I did encounter such an ideal family. However, there were also a number of other families who exhibited intense conflict, and who were highly critical and hostile (discussed in Chapter 6).

The inability of families to achieve the ideal of *rukun* parallels the diminishing hold that the ideal of *tentrem* has over modern Javanese people.

In sum, within the context of a rapidly modernizing society, the Javanese family is undergoing significant changes. Ideals of being together in physical proximity are nowadays challenged by new occupational patterns involving employment in urban centres at a distance from the village. The concept of the extended family itself is transforming to increasingly incorporate unrelated people who would not have previously been thought of as family members. Marriage practices too are changing, with increasing autonomy accorded children. In spite of these changes, core values such as *rukun,* and particularly *ngemong* are resilient, and continue to influence not only how families raise their children, but also how they look after their sick, including those who suffer from psychotic illness.

2.4. RELIGIOUS RESURGENCE AND TENSION

Javanese religious and spiritual life is highly diverse. Most noticeable is the divide between Moslems and non-Moslems. The Indonesian government officially recognizes five religions or religious denominations: Islam, Hinduism, Buddhism, Catholicism and Protestantism. Aside from these, there is another form of Javanese spiritual life known as *kebatinan* (Javanese mysticism) or *kejawen* (Javanism). Officially, *kebatinan* is acknowledged as a 'faith' (*kepercayaan*) like Confucianism and is coordinated under the Department of Education; whereas the five 'religions' (*agama*) lie under the Department of Religion. *Kebatinan* practice is generally

considered to lie outside the spectrum of proper religion, because it transcends religious denominations. Mulder (1994b:7) noted that *kebatinan* groups flourished in 1970s, but from the 1990s on they have become less prominent.

The Javanese Moslem spectrum is also diverse. Clifford Geertz (1960) in his influential book, *The Religion of Java,* divided Javanese Moslems into three variants: *santri, abangan* and *priyayi.* The word *santri* originally meant a student of an Islamic boarding school called a *pesantren*. Only later did the word *santri* come to be strongly identified with orthodox Moslems (Dean, 1999). All *santri* follow Islamic *Shariah* law that includes professing the faith, following social norms, and performing obligatory daily prayers. By contrast, the term *abangan* refers to people who are nominally Moslem. They are also known as *Islam KTP,*[18] that is to say, identity card Moslems. They may be likened to 'wedding and wake' Christians. Mostly *abangan* will limit themselves to professing the faith and performing rituals rather loosely. They tend not to fulfil Islam's other religious obligations. Finally, the term *priyayi* refers to the traditional aristocrats, whose culture retains strong Hindu and indigenous Javanese influences. The identification of the *priyayi* group as a religious category has been subject of considerable criticism, on the grounds that it is a matter of social class associated with the traditional elite, rather than a religious matter.

Dean (1999) states that over the past two decades, Javanese society has moved towards a deeper understanding and commitment to Islam of the *santri* style. Several ethnographers have observed a significant increase in the religious atmosphere in

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[18] *KTP* stands for *Kartu Tanda Penduduk,* meaning identity card.

Yogyakarta (Mulder, 1994a, b; Browne, 1999; Brenner, 1996; Howell *et al.*, 1998, 2004). This is evidenced by the flourishing of religious gatherings in mosques and the increasing availability of Islamic teachings through popular books, radio and television. Growing numbers of people now make the pilgrimage to Mecca (*hajj*). Whereas in the past only *santri*, particularly older ones, went on the *hajj*, now more *abangan* and younger people undertake the pilgrimage. More people learn and practice *Sufism* (Howell *et al.,* 1998, 2004) and more Moslem women wear the *jilbab* (veil). Pioneered by female university students, wearing the veil has been embraced by women of all social levels, including the elite and film stars (Brenner, 1996).

Within the *santri*, there are two major groups, the traditionalist and modernist-reformist Moslems. Traditional Moslems usually affiliate with the *Nahdlatul Ulama*, a religious organisation that is tolerant of traditional Javanese cultural influences. This organisation is associated with traditional *pesantren* institutions, mainly in village areas. Meanwhile modern-reformist Moslems associate with the *Muhammadiyah* organisation, which emphasises the purification of Islam and an intolerance of local influences. Clifford Geertz (1960:150-158) identified five different polarities that distinguished the traditionalist from the modern-reformist Moslem: fate versus self-determination, narrow versus totalistic religion, syncretic versus puristic Islam, religious experience versus religious behaviour, and finally customs and scholasticism versus pragmatism and rationalism. Though the contrast between traditionalist and modern reformist is less salient, these five polarities nonetheless remain relevant today.

Independent from these established organizations, some militant Moslem groups have recently emerged in Yogyakarta. These groups strive to practice Islam in a very strict way, to apply what they call 'Islamic culture', and to oppose any Javanese or Western influences. One of the groups is called *Lasykar Jihad*. It emerged in response to religious conflict in the eastern part of Indonesia.[19] The eye-catching activities of *Lasykar Jihad* members includes collecting funds in the main streets of Yogyakarta while wearing robes and turbans. Some militant groups have also responded to the global issue of *jihad*, wherein some of their members were sent to perform *jihad* in Afghanistan.

The diversity of religious denominations and variants gives rise to the potential for religious tension and conflict. In 1960s, Clifford Geertz (1960:355) identified such tension between *santri, abangan*, and *priyayi* variants, as well as conflict between the traditionalist and the modern-reformist. He suggested that tension was not only grounded in ideological differences, but it was also generated by socio-political factors. In present-day Yogyakarta, the potential for religious tension is magnified by the fact that the city is the centre of several religious movements. It is the home of a number of *kebatinan* groups, such as *Sumarah*[20] and *Subud,*[21] which have established overseas centres in Europe and the United States. *Pesantren Krapyak*, located to the south of the Sultan's palace, is one of the oldest and most important educational institutions for traditionalist Moslems. Meanwhile, Yogyakarta is the place of birth and the centre of the modern-reformist movement. For Christians, a number of

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[19] The *Lasykar Jihad* has been disbanded by their own leader following the Bali bombings (see Azra, 2005, for a discussion on militant groups in Indonesia).
[20] *Sumarah* website: http//www. Xs4all.nl/~wichm/javmys1. html
[21] *Subud* website: http//www. Xs4all.nl/~wichm/subud1. html

Catholic and Protestant theological institutions are located in Yogyakarta, where they function as a base for their broader missionary objectives. It is of note that an open religious confrontation between religious variants of Islam, or between Moslem and Christian, has never occurred in Yogyakarta. Such conflict has happened in other parts of Indonesia, both in the past and more recently.[22] Perhaps the Javanese ability to control and suppress emotion and conflict, as well as the governing idea of *rukun* (harmonious integration) may play a part in preventing the emergence of conflict into open confrontation. The presence of the Sultan, and the authority he wields within the Special Province, is also an important factor. The Sultan has exerted a direct effect in maintaining social order during the recent period of unrest within Indonesia in 1998.[23]

In sum, the various religious denominations and variants in Java, as observed by Clifford Geertz in the 1960's, still exist in present-day Yogyakarta. However, there is a striking increase in the intensity of the religious atmosphere in Yogyakarta, not only evident among Moslems, but also among Christians. The situation has changed considerably since Clifford Geertz's carried out his research, with the emergence of militant Moslem groups. Although all participants in this research were adherents to the Islamic faith, their spectrum of religiosity represented many of the varieties that exist in Java today, ranging from *abangan*, to *santri,* to modern-reformist Islam, and even to a fundamentalist-militant group.

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[22] In the 19th century the *Padri* war erupted in West Sumatra between traditional and reformist Moslems (see http://www.bookrags.com/history/worldhistory/padri-war-ema-04/). Recently there have been conflicts between Moslems and Christians in Ambon and Poso, in the eastern part of Indonesia.
[23] See Clifford Geertz (1960:365-381) for more discussion on religious conflict and integration in Java.

2.5. MENTAL ILLNESS AND MENTAL HEALTH CARE IN YOGYAKARTA

2.5.1. Javanese Understandings of Mental Illness

In the traditional Javanese literature there has not been any documentation of Javanese concepts of mental illness, perhaps because the writing tradition belonged only to representatives of the Javanese elite, who focused on more refined aspects of Javanese culture and literary expression. Rather, such knowledge of mental illness was transmitted through an oral tradition, in the form of popular folk stories.

As part of my fieldwork I identified three such popular stories relating to mental illness that are commonly put on stage in Javanese traditional theatres: *Suminten Edan* (Crazy Suminten), *Srikandi Edan* (Crazy Srikandi), and *Sumbodro Edan* (Crazy Sumbodro).[24] The story of *Suminten Edan* is the most popular of the three. It is a quasi-historical story from Ponorogo, in East Java, but it is also very popular in Yogyakarta. The story tells of a young village woman named *Suminten* who was about to marry *Radenmas Subroto*, the son of an *Adipati.*[25] The *Adipati* arranged the marriage as a gift to *Suminten*'s father, a powerful *Warok,*[26] who had successfully put down a revolt that had erupted in the *Adipati*'s area of authority. Reluctant to marry, *Radenmas Subroto* escaped from his house on the wedding day. *Suminten* was shocked, disappointed, and embarrassed. Suddenly she went mad. She wandered

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[24] The story of *Srikandi Edan* was mentioned by Dr. Rini Arianti, a psychiatrist with whom I collaborated on this research. I located the title of story of *Sumbodro Edan* at http://www.jawapalace.org/wayang.html.

[25] An *Adipati* was a local government official, usually of noble descent, during the colonial era.

[26] *Warok* is a collective term referring to powerful figures imbued with skills in the martial arts, magic and spirituality. They live in the eastern part of Java in a small town called Ponorogo. For more details see I.D. Wilson at http://wwwsshe.murdoch.edu.au/intersections/issue2/Warok.html

around the streets for some time, and exhibited bizarre behaviour, giggling and dancing in the street. It was her own uncle—another powerful *Warok*—who cured her. *Suminten* finally recovered and married *Radenmas Subroto* who, by now, had changed his mind.

The story of *Suminten Edan* is one of passion, magical power, and resolution. But there are also a number of themes that can be drawn from this story that have clinical relevance and relevance to my ethnographic data. First, family problems are represented as a trigger for mental illness. Second, the sudden onset of illness is quite striking. Third, it is important to note that *Suminten* made a rapid recovery and quickly returned to normal life. The theme of a family problem as the trigger of illness is echoed in a recent personal account by a consumer, Isvandiary (2004), who herself became ill in the context of a problematic marriage. The theme is also evident in recent empirical studies. As part of his ethnographic fieldwork, Browne (1999) conducted a community survey of perceptions of mental illness. He found that the most commonly perceived causes of mental illness were family problems. In our previous clinical survey (Good & Subandi, 2000) we also made similar findings. In this survey we collected data on people suffering from first episode psychosis in Yogyakarta in a six month period. Among the 304 cases the predominant stressors identified were family problems. Thus, sources as diverse as Javanese folk stories, a consumer account, and empirical research data suggest that family factors contribute to the emergence of mental illness. This stands in contrast to the ideal image of the Javanese family as being tolerant and supportive. I will take up this issue in chapter 6.

The theme of acuteness of onset that is clearly represented in *Suminten Edan* story also resonates with findings of our previous research (Good & Subandi, 2000). We found that 37.5% of all first episode psychoses had an onset in less than 2 weeks. In this dissertation I also found that of 9 participants, 8 had an acute onset of less than 2 weeks. Thus, acute onset psychosis, particularly acute and transient psychotic (ATPD) is very common in Yogyakarta.

The third issue that I highlighted in *Suminten Edan*, that of rapid recovery, is perhaps the most important theme of all. Suffice it to say at this point that the rest of this dissertation is an exploration of the psychocultural processes involved in such recovery.

2.5.2. The Javanese Mental Health Care System

The formal mental health system in Indonesia was established in 1882 when the Dutch colonial government promulgated a Mental Health Act, and then built a mental hospital in Bogor, West Java (Salan & Maretzki, 1983). This is the mental hospital that was visited by Emile Kraepelin in the early 20th century. A further 21 state mental hospitals were set up by the colonial administration between the end of the 19th century and the first half of the 20th century (see Subandi, 1999). Most of these hospitals served as custodial care institutions. Only after a new health care policy was introduced, through the Mental Health Law of 1966, did the mental health care system focus more on the community. Services were extended outside the confines of the hospitals and broadened to include not only treatment but also the prevention and promotion of mental health. At present there are 34 state and 16 private mental

hospitals in Indonesia with a combined capacity of approximately 10,000 beds. In order to cope with such large numbers with so limited resources, the Directorate of Mental Health introduced a new policy in mental health in the 1970s (Salan & Maretzki, 1983). This policy was intended to integrate mental health services with general hospital and community health centres at the district level.

In Yogyakarta mental health services are provided by several hospitals and private clinics. Three major hospitals offer in-patient care. The first is the psychiatric ward of *Sarjito* General Hospital, a teaching hospital of Gadjah Mada University. The second is *Puri Nirmala*, a private mental hospital located in the inner city. The third is a government mental hospital known as *Rumah Sakit Jiwa Grhasia*[27] in the town of Pakem, located in a peri-urban setting about twenty kilometers north of Yogyakarta. Most of the patients at *Grhasia* have chronic illnesses. Meanwhile first episode patients are more likely to go to *Sarjito* or *Puri Nirmala*. This is the reason for my choosing *Sarjito* and *Puri Nirmala* for recruiting participants in this research. Several small hospitals, private clinics and practices also provide psychiatric services. In total approximately 30 psychiatrists practice in the Special Region of Yogyakarta, serving a population of 3 million people. While the ratio of one psychiatrist to one hundred thousand people is low by comparison with many developed countries, it is substantial compared to the overall Indonesian ratio of one psychiatrist to five hundred thousand people.

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[27] Formerly known as *Rumah Sakit Jiwa Pakem,* this state mental hospital recently changed its name in an effort to reduce the stigma. The name *Grhasia* carries no association with mental illness (*sakit jiwa*).

In addition to the formal mental health resources, Javanese people often seek help from traditional sources to resolve psychiatric problems. These includes a wide range of traditional Javanese healers. *Dukun* is a general term for Javanese healers. They can be differentiated according to their specialty, such as *dukun pijat* (massager), *dukun beranak* (traditional midwife), *dukun sunat* (one who performs circumcision), *dukun santet* (sorcerer), *dukun manten* (one who performs marital rites), or *dukun prewangan* (spirit medium). A number of ethnographies have suggested that the term *dukun* may carry negative connotations (Clifford Geertz, 1960:95-99; Woodward, 1989:233; Keeler, 1987:114-119; and Ferzacca, 2001:172-175). This is because of its association with *dukun santet* (sorcery, witchcraft). Furthermore *dukun* healers have "the potential for trickery, scandal, and fraud, if not outright injury to those who use their service" (Ferzacca, 2001:174). Since the term *dukun* carries these negative connotations, participants in this research used more respectful terms for the healers they asked for help, such as *paranormal,*[28] *wong tuwo* (old person) or *wong pinter* (knowledgeable person). Some people also sought help from religious healers, such as *Kyai* (the leader of a *pesantren*). Browne (1999) also reported Catholic charismatic healing in Yogyakarta.

In this section, I have drawn attention to the correspondence between some of the themes that are evident in Javanese folk stories about mental illness, and the clinical characteristics of psychotic illness observed in a number of studies carried out in Java, focusing on the role of family conflict in precipitating illness, the relevance of sudden

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[28] Paranormal, though derived from English, is widely used in Java to refer to a person with the ability to cure and to foretell the future.

onset, and rapid recovery. I have also briefly surveyed the mental health care system as it exists in Yogyakarta, emphasizing the variety of resources available, both medical and traditional.

2.6. SUMMARY

This chapter has provided a sketch of contemporary Yogyakarta, one of the oldest centres of Javanese tradition, but at the same time a tourist magnet, a centre of higher education, as well as a centre of religious movements. As it expands into the surrounding countryside, Yogyakarta becomes an ever more modern city with its internet cafés, mobile phone outlets, shopping malls, and new residential complexes. At the same time there is a resurgence in religious activity and increasing efforts are being made to revive and preserve traditional Javanese culture. It is within this broader dynamic of cultural contestation that we find contested concepts of the Javanese self. The ideal values of suppressing emotions and conflicts to achieve *tentrem* and smoothness on the inside and outside, described in the early ethnographic literature, do not always hold. Javanese people do seek to attain a 'flat affect' as a cultural ideal, but in a certain circumstance may become highly emotionally expressive. Within the family context there is also contestation over patterns of marriage, residence and intra-familial communication—the value of *rukun* is itself under challenge. Finally, the mental health system reflects the same tendency. While various traditional and religious healing practices are available in Yogyakarta, the formal mental health resources offer the most modern forms of Indonesian psychiatric treatment.

Chapter 2, Contested Javanese Cultural Values

Throughout this chapter I have indicated where particular elements of Javanese culture are relevant to the experience of mental illness. These elements will be taken up in subsequent chapters to be explored in more detail. It will be argued, for example, that the experience of psychosis is mediated through the cultural dichotomy *lahir-batin,* that the principle of *ngemong* shapes the family to psychosis, and that *usaha* and *isin* are central to the process of recovery from psychosis. Most importantly, however, I will argue that mental illness in contemporary Yogyakarta, can only be understood in the light of the contested cultural values identified in this chapter.

CHAPTER 3

COMBINING ETHNOGRAPHIC AND CLINICAL METHODOLOGY

In this chapter I describe the methods I employed to achieve the goals of this research. Firstly, I describe the larger research project, the Yogyakarta Early Psychosis Project, to provide an understanding of the background from which the present research emerged. In order to examine psychosis in the Javanese context it was necessary to draw on a combination of methods, including ethnographic research techniques and clinical assessments. The second part of this chapter sets out the rationale for such an approach, describing in turn the ethnographic and clinical methodology of the fieldwork, discussing their respective merits and disadvantages, and showing how they were combined into an integrated approach. Issues of reliability and cultural validity are addressed in relation to each of the instruments used in this study. Thirdly, and finally, I will describe the strategy I applied during the fieldwork, the data collection procedures and the method of analysis.

3.1. THE BROADER RESEARCH CONTEXT

The present research is part of the Yogyakarta Early Psychosis Project. This is a programme of research focusing on the early phases of psychotic illness, and represents a collaboration between Gadjah Mada University in Yogyakarta and the

Department of Social Medicine and Harvard Medical School in the United States (represented by Professor Byron Good). I was employed as a research assistant on this project. It began in 1996 with a broad, ethnographic study of culture and mental illness in Yogyakarta. Together with Professor Good, I interviewed psychiatrists, psychologists and other professionals, as well as non-professional workers in mental health care, particularly traditional and religious healers. We also conducted a set of ethnographic case studies of people with psychotic illness, examining how themes from Javanese cultural psychology influenced the subjective experience of illness, care-seeking, and the social response to illness (see Good & Subandi, 2004). These initial findings began to focus research attention on the early phases of psychosis, particularly the non-organic non-affective psychoses or schizophrenia. More formal studies of the early phases of psychosis began in 1999 with a survey of clinicians' experiences treating first episode psychosis. All psychiatrists in Yogyakarta and the surrounding area were asked to fill out a one-page questionnaire about any patients they had treated who met the study criteria (psychotic, first episode illness, initial contact with a mental health professional). During a six-month period this study identified 391 cases of first episode psychosis. Of these cases, 70% were judged by psychiatrists to have non-organic, non-affective illness. The most striking finding of this initial survey was the prevalence of acute onset illness in this group. Based on these findings, the project team initiated a longitudinal research project to investigate the course of psychotic illness in Java.

There are strong links, therefore, between my doctoral research and the broader project. I had already established a network of connections with the mental health

services, psychiatrists, and a range of traditional healers. This helped when it came to recruiting participants for this study. I had a working familiarity with instruments that were used in this research, namely the Brief Psychiatric Rating Scale (BPRS)(Overall & Gorham, 1962; Faustman, 1994), and the Global Assessment of Functioning (GAF)(American Psychiatric Association, 1994). By virtue of my collaborative work with Professor Good I gained experience in conducting ethnographic research. The major themes of this research—first episode psychosis, experience of recovery, and the role of culture—emerged from that previous work. Finally, the larger project also provided financial support for fieldwork and analysis.

However, the research on which this dissertation is based differs sharply from my previous work in several ways. Firstly, the focus of this study—the experience of recovery and the way this is culturally mediated—differs from that of the previous studies. Secondly, the participants in this research were separate from those of the previous research. This involved recruiting a new group of people suffering from first episode psychosis. Thirdly, in the previous research the psychiatric team was responsible for the clinical dimension (diagnosis and monitoring symptoms), whereas in this research I carried out the clinical work myself. As a psychologist by training, I also employed projective psychological tests, which had not been used in the previous research. Finally, my role in the previous research was that of research assistant, while in this research project I was the principal investigator. Although two team members of the larger project assisted me to collect data during my fieldwork, I was wholly responsible for the data analysis and writing up of this dissertation.

3.2. A COMBINED ETHNOGRAPHIC AND CLINICAL APPROACH

The objective of this research was to study the experience of recovery from psychotic illness in a Javanese cultural context. It was therefore necessary to combine two methods—ethnographic and clinical—because these were deemed the best for systematically examining the cultural dimensions of experience and delineating the clinical dimensions of psychosis.

3.2.1. Ethnographic Methodology

Two rationales justify an ethnographic method for this research: firstly, the need to explore a subjective experience, and secondly, the need to examine the cultural context.

The primary goal of this research was to explore participants' subjective experience and how participants and their family members interpreted and made sense of this experience. To achieve this goal it was necessary for me to employ an *emic* perspective, that is to say, the perspective of insider, a native, or an actor-oriented perspective (De Laine, 1997). Lying "at the heart of most ethnographic research" (Fetterman, 1989:30), this perspective provides the most sympathetic means of exploring the subjective experience of recovery. It entailed developing a trusting relationship with participants over a long period of time. It also enabled me to collect first-hand data by interviewing and observing participants and their family members in their homes. It was only by engaging with them in this domestic context that I was

able to gain access to thoughts, feelings and interactions that proved crucial in understanding the experience of recovery from psychosis.

Secondly, the use of ethnographic methodology was also justified, in fact rendered essential, by my focus on the Javanese cultural context. This anthropological method is well suited to the systematic investigation of culture and its role in shaping the experience of illness and recovery. It makes possible the study of how the social processes within the participants' immediate environment—the family and local culture—influence participants' experience of recovery. Interviewing participants and family members in their domestic setting, I also observed the broader social environment where the participants lived, and sometimes visited their work place. Moreover, most of the interviews I conducted were not structured, despite being guided by a preformulated agenda. The interviews took the form of a conversation that flowed from one topic to another.

Despite the ethnographic component outlined above, my research was not ethnography in the classical style. When it comes to the study of small-scale societies it has been common practice for the ethnographer to 'live' among the participants, enabling him or her to carry out participant observation. Despite living in the same general region as the participants, in this research I did not live in the neighborhoods or villages where they lived. During my fieldwork, I visited participants at their homes, a distance of approximately 10 to 30 kilometers from my house. As a consequence there was a limit to the extent I could follow them through their day-to-day lives. Lucas (1999), however, argues that ethnography can make an important

contribution to understanding people who live in a dispersed distribution (such as people with mental illness residing in a suburban situation). The key issue is whether or not data is gathered in the context of social engagement with such people. My approach satisfied this criterion.

3.2.2. Clinical Methodology

In this section I identify the clinical instruments I used, justifying why I chose each one. In a subsequent section (3.3.2.) I will describe their properties in more detail. The rationale for applying clinical methodology in this research includes: firstly, the need to establish diagnosis; secondly, the need to assess the participants' symptoms over time; and thirdly, the need to examine psychological dimensions of the participants and their family members, particularly family emotional milieu and family coping behavior.

As the main concern of this research was to examine the experience of recovery from psychotic illness, it was necessary to recruit participants who met the diagnostic criteria for psychosis and who were not suffering from other forms of mental illness. One source of data was the diagnoses given by doctors in patients' medical records. To check the reliability of these opinions, I conducted clinical interviews and observations (see section 3.3.3.) to examine the participants' symptoms and other clinical representations such as onset and duration of illness. I made the final diagnostic assessment in the light of these data.

Chapter 3, Ethnographic and Clinical Methodology

To examine the process of recovery from psychotic illness, I could not rely just on the reports of participants or their family members. Here I needed additional clinical measures to make an objective appraisal of the status of participants' illnesses and their social functioning. Since I intended to examine the participants' changing symptoms in the process of recovery, I required standardized instruments to be administered across time to validate my observations and interviews. I employed the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962; Faustman, 1994) to assess the participants' symptoms, and Global Assessment of Functioning (GAF) (American Psychiatric Association, 1994) to assess the level of social functioning. These instruments were used because their validity and reliability in English speaking samples is well established. They are amongst the most widely used instruments in psychiatric research. Moreover, they have been translated into Indonesian, and have been used in a variety of context in this country. Issues of reliability and validity of the Indonesian version of the BPRS and GAF have also been addressed in the literature (Sudiyanto, 1998; Sukarto, 2004). However, their cultural validity and reliability did become an issue in my research and I discuss this below when I describe these instruments in more detail.

One focus of this research was the investigation of how family interactions contributed to the process of recovery. As stated above, the primary data on these issues were obtained from ethnographic interviews and observations. In addition, it was useful to employ data from standardized instruments as a point of comparison. The data from these instruments served as a second perspective to validate (or

otherwise) my observations. These instruments can be divided into two categories: objective and projective instruments.

The objective instrument I used with individual participants was the Level of Expressed Emotion (LEE), which assessed participants' perception of family expressed emotion (Gerlsma and Hale, 1997). This instrument was used because it was the only brief objective instrument (rating scale) available to assess family expressed emotion. It was much simpler compared to the standard instrument such as the Camberwell Family Interview (CFI) (Leff & Vaughn, 1985), which involved a structured interview and complex rating procedure.

The objective instrument I used with family members was the Family Crisis Oriented Personal Evaluation Scales (F-COPES), which measures family coping behavior (see McConachie & Waring, 1997). This instrument was used because it assessed a wide range of family coping strategies and it has been widely used in clinical and research contexts.

I also administered projective tests to enrich the quality of data. During interview sessions and during the administration of the abovementioned instruments, it was anticipated that participants and family members might not fully reveal their underlying thoughts and feelings. Projective tests are well suited to addressing this shortcoming. They encourage participants to express their feelings and thoughts spontaneously, without inhibition. The projective tests I used included the House Tree Person (HTP) drawing test (Handler, 1996), and the Sentence Completion Test (SCT)

(Sack & Levy, 1959; Lindzey, 1961), using a version suitable for participants. For family members I also administered the SCT using a suitably modified version. A fuller description of these instruments is provided in section 3.3.3. below.

3.2.3. The Advantage of Combining Ethnographic and Clinical Methods

The combination of different methods within a single study—ethnographic-qualitative approaches and clinical-quantitative approaches—has been suggested by Goering & Steiner (1996), Jessor (1996) and Masse (2000). This is in spite of the fundamental epistemological differences between these two approaches. The form of ethnography that I employed to gain a subjective understanding of participants' experience of recovery was based on a phenomenologically oriented paradigm. In contrast, the quantitative methods I used rested on a positivist paradigm. Rather than seeing these perspectives as conflicting, Fetterman (1989) considers them to lie on a spectrum: phenomenological at one end and positivist at the other. He argues that ethnographic research accepts the existence of multiple realities, including subjective and objective realities. In my research, subjective reality refers to the participants' perceptions revealed through inter-subjective engagement with the researcher who seeks to adopt an *emic* perspective. By contrast, objective reality refers to data derived from the use of clinical instruments. These instruments tend to be constructed from an *etic* perspective. It is this integration of perspectives that I sought to achieve. Figure 3.1 below illustrates the continuum of data gathered from this research.

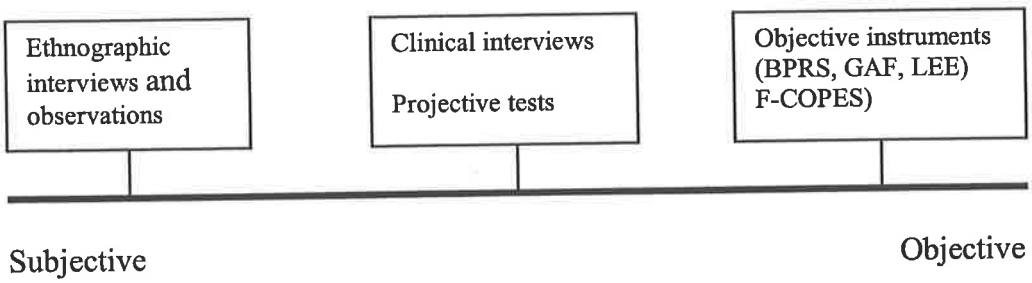

Figure 3.1: Spectrum of data

Combining several methods of data collection has a number of advantages. According to Cresswell (see Johnstone, 2004) the advantages include triangulation, complementarity and expansion. By triangulation he refers to the process of comparing, reviewing and analysing evidence from many difference sources. It aims to counteract any bias that might be inherent in one or another method. Complementarity refers to the possibility that each method provides different data to complement the data gathered using the methods. Expansion refers to the way in which combined methods add extent and breadth to a study. Thus, using a combined method is a powerful strategy for enriching the understanding of the data, and produces information that is more comprehensive (Jessor, 1996; Grbich, 1999).

Applying a combination of different methods into a single study, however, is not an easy task. The greatest challenge was how to integrate different types of data from different sources into a coherent analysis. In response to this challenge, I applied a form of triangulation in which I examined the data as a whole by comparing, contrasting and considering data from different sources.

3.3. STRATEGIES FOR DATA GATHERING

3.3.1. Immersion in Fieldwork

The fieldwork was conducted from August 2002 to July 2003. A follow-up field trip was organized in July 2004. Before conducting fieldwork I obtained ethical clearance both from the University of Adelaide Human Research Ethics Committee and the Ethics Committee of Research in Medical Health, Gadjah Mada University. I also sought permission from the Head of the Department of Psychiatry, at the Faculty of Medicine, Gadjah Mada University, and the Head of *Puri Nirmala* private mental hospital in Yogyakarta.

As previously mentioned, my involvement in the larger project meant that I had already established collaborations with psychiatrists and the mental health care system in Yogyakarta. At the beginning of the fieldwork, I approached Dr. Rini Arianti, with whom I had worked on the larger project, and Dr. Krisman, the head of *Puri Nirmala* private mental hospital, to plan the recruitment of participants who met the inclusion criteria. These criteria were:

(a) Diagnosed with a psychotic illness;

(b) First episode of psychosis and first contact with a psychiatrist;

(c) Aged 15 – 50;

(d) Length of illness no longer than 12 months;

(e) Javanese; and

(f) Living with their family.

Drs. Arianti and Krisman provided me with lists of potential participants who I could visit. From this basis, I was able to make 19 initial home visits. Of these, 10 participants met the criteria and were willing to participate in the research. However, one participant dropped out in the context of a family crisis. Thus, of 9 participants in this research, there were 7 participants from *Sarjito*, 1 from *Puri Nirmala*, and 1 from a private clinic associated with a senior psychiatrist at *Sarjito*.

Since ethnographic research relies on developing a relationship with the group of people under study, in the early phase of my fieldwork I made an effort to develop a trusting relationship both with participants and their family members. When meeting them, I introduced myself as a researcher from the Department of Psychology, Gadjah Mada University. I explained that although I had collaborated with some hospitals, I did not work for them. My intention was to establish a researcher-participant relationship, rather than a health professional-patient relationship. This introduction was important because some participants who had not continued their medication thought that the purpose of my visit was to check on their compliance. One participant even thought that my real purpose was to ensure that he paid his debt to the hospital! Another strategy I employed to build rapport was to speak in Javanese during my visits. Participants, most of whom lived in rural areas, usually became much more friendly when I used the Javanese language rather than Indonesian. However, three participants who lived in suburban Yogyakarta and had higher educational qualifications preferred to use Indonesian during interviews. Even so, I sometimes used Javanese as a mark of respect and good manners.

Another strategy I used to build up a relationship with participants and their families was to become involved in the participants' social lives. Firstly, I engaged in social exchanges with them. When I made a visit, I would bring food, such as rice, noodles, cookies, cakes, or syrup. In return, participants' families would sometimes provide me with food when I left their house. When I returned to Java from Australia, I brought some souvenirs for them. To further develop a trusting relationship I participated in participants' daily social and cultural activities. For example, I often prayed together with participants at the mosque in the village or at their houses. I also participated in important family events. For instance, one day the brother of one participant telephoned me to say that his mother had died that night. Hearing this news I went to the participant's house immediately to express my condolences to the family and participate in the funeral procession. This was also an opportunity for me to observe the family's response to the death of a family member. On another occasion I was invited to attend a participant's wedding. Since this was an important ceremony for a cultural study I visited the participant several days before the wedding ceremony. In accordance with Javanese tradition I also contributed some money for the family. On the wedding day I was able to observe the most important event in the participants' life following the recovery from her illness.

My engagement with participants was not limited to being in physical contact with them. I often telephoned them if they had access to a telephone and conversed with them in this way. As mentioned above, one family member called me to say that his mother had died. Other family members telephoned me to let me know that the participant had a relapse, or to enquire whether they could borrow books on mental

illness. Another participant also called me to welcome me back when I returned from Australia. I also used the telephone to clarify particular information I obtained from interviews. On another occasion, I asked permission to interview a participant's wife on the phone. During this interview she was able to express feelings and provide information in way that she was not able to do during the interview in the presence of her husband.

3.3.2. Ethnographic Data Gathering

In this research, the ethnographic component of fieldwork occupied the largest portion of my attention, since my primary focus was on the psychocultural dimensions of the experience of recovery. The ethnographic data were obtained by means of unstructured interviews and observations. During the course of my fieldwork, I met with each participant an average of 10 times, ranging between 7 to 11. The length of each formal interview was between one to two hours on average. Most of the interviews were conducted in the Javanese language, sometimes mixed with Indonesian. For participants who had a lower levels of education, the Javanese language was dominant, while Indonesian was generally used by those who had achieved higher levels of education. Interviews were tape-recorded when participants gave permission. For those who did not wish to have their conversations taped the data were recorded as hand-written field notes. Most interviews were conducted at participants' homes. It was very common during interviews for all family members to become involved in the conversation. Sometimes neighbours participated as well. In one interview I even witnessed a female participant arguing with her sister, her mother, and her father. In this situation I firstly assumed a passive role, but when the

argument became bitter and unproductive, I tried to mediate between them. However, not all interviews were conducted in a 'public' setting. Sometimes I interviewed them in a more 'private' setting, such as in a Mosque after performing prayer together. On one occasion I interviewed a father in the backyard, while Nida (my research assistant) interviewed his daughter (the participant) inside the house. This practice helped to protect each family member's privacy.

Conducting an ethnographic study that involves forming such intense relationships with participants always has consequences. Sometimes it may involve a breach of the research-participant boundary. The most common consequence I encountered was that the parents of participants would request that I help find employment for their son or daughter. They believed that their son or daughter would improve when he or she got a job. On another occasion, the father of a participant asked me to find someone who could buy his piece of land. He said that he needed some money to pay for his son's medication.

The most difficult problem I experienced during the fieldwork related to feelings of affection from participants. One of my participants—a 20-year-old girl and who had recovered completely—indicated that she had 'fallen in love' with me. This could be likened to transference in psychotherapy. Every time I visited and interviewed her she looked at me in a special way that conveyed her affectionate feelings. She phoned me several times for no ostensible reason. To prevent this potentially 'dangerous' situation from developing any further, I brought my little daughter to visit the family. Then I brought my male assistant who did some of the research transcription. Finally,

I decided to have a female research assistant for the rest of the fieldwork—Nida, my colleague from the Department of Psychology, Gadjah Mada University. I found that there were a number of benefits to having a female research assistant. In addition to avoiding gossip from the people in the village, she was able to interview some female participants in a more intense way. Some Javanese, especially in rural areas, consider gender separation to be important.

3.3.3. Clinical Data Gathering

The clinical component of this research started at the very early stage of my fieldwork. In the process of recruiting participants I had a list of patients diagnosed as having a first episode psychosis from both *Sarjito*'s psychiatric ward and *Puri Nirmala* private hospitals. During my initial visit I conducted brief clinical interviews to ensure the inclusion criteria were met. It turned out that for almost half of the potential participants this was not their first episode. Working on the larger research project had taught me that this was quite a common occurrence, since families were known to provide the hospital with false information to avoid social stigma.

Detailed clinical interviews were conducted during the following visits to check the diagnosis provided by the hospital medical records. Although I did not administer any formal diagnostic interview, due to the unavailability of a standardized translation of any suitable diagnostic instrument, either in Javanese and Indonesian, I conducted clinical interviews. In these interviews, I elucidated the clinical presentations from the participants themselves and from their family members. These included their symptom pattern as well as data on the onset of their illness, the duration of illness,

the length of time from first presentation of symptoms to receiving antipsychotic medication (duration of untreated psychosis—DUP); care seeking behavior, and therapy.

To confirm the diagnosis I clarified participants' symptoms in more detail by further questions in the area of their perception (to identify any evidence of hallucinations), content of thought (to identify any evidence of delusions), form of thought (to identify any formal thought disorder), affect (to identify any affective component of the illness), interpersonal functioning (for evidence of social withdrawal), and bizarre behavior. When administering the BPRS assessment I gained additional clinical information that contributed to the diagnosis. Further, I made the final diagnostic decision in discussion with Dr. Arianti, especially when there was disagreement between the medical record and the data my interviewees provided. In this research I use the ICD-10 diagnostic system because it is in accordance with the PPDGJ-3 (*Pedoman Penggolongan Diagnosa Gangguan Jiwa*) system, the system that is formally used in Indonesia. The PPDGJ system is essentially the translation and adaptation of the ICD-10.

Other important clinical data concerned the participants' symptoms and social functioning. To assess their symptom severity I employed the Indonesian version of the BPRS (see Sudiyanto, 1998; Sukarto, 2004). This instrument consists of 18 items rated on a seven-point Likert scale (0 = no symptom to 6 = extremely severe),[29] and

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[29] The earlier version of BPRS consists of 16 items (Overall & Gorham, 1962). In a recent version it consists of 24 items (Ruggeri *et al.*, 2004). In this research I used the Indonesian version used by Sukarto (2004), which consist of 18 items (Faustman, 1994).

assesses four dimensions: anxiety/depression, positive symptoms, negative symptoms and mania. To assess participants' social functioning I employed the GAF (American Psychiatric Association, 1994)..In this instrument, social functioning is measured on a continuous scale from 0, which denotes extremely severe dysfunction, to 100, which denotes extremely good function. Both of these instruments were administered every 3 months to monitor any changes in participants' symptoms and their level of social functioning over time. These data provided objective evidence of the participants' process of recovery.

As previously mentioned, issues of cultural validity and reliability did arise in my research in relation to the BPRS and the GAF because among the more educated participants the interviews were conducted in Indonesian, while the more traditional participants were interviewed in Javanese.

In the version of the BPRS I used, for example, each of the 18 items was described in a word or brief phrase. To administer the instrument it was necessary to provide an explanation of each item. For example, I would explain item 11, "*Tingkah laku halusinatorik* (hallucinatory behavior)" by giving examples such as hearing voices that no one else can hear, or seeing visions that no one else can see. Here I sought to provide consistent explanations, and to match my Javanese explanations as closely as I could to the explanations in Indonesian. It was my impression that cultural validity was not a major issue for the BPRS. Participants did not experience any significant problems in grasping the central meaning of each item. All items lay well within the scope of their cultural repertoire of understanding.

Questions of reliability were paramount in relation to the GAF, because it does not provide specific criteria for each functional category. It becomes a matter of judgment, for example, as to how to differentiate superior from good functioning in everyday life, or to distinguish mild difficulty in social and occupational functioning, and severe impairment in this area. My previous experience in administering the GAF to a wide variety of patients in Indonesia, both in clinical and research settings, was a considerable advantage here.

Another instrument used in this research was an Indonesian translation of the Level of Expressed Emotion (LEE) scale, which measures a participant's perception of family expressed emotion (Gerlsma & Hale, 1997). The LEE assesses four dimensions: lack of emotional support, intrusiveness, irritability and criticism. It consists of 38 items each with 4 options: (1) untrue, (2) more or less untrue, (3) more or less true, and (4) true. The corresponding instrument administered to family member was the Family Crisis Oriented Personal Evaluation Scales (F-COPES) which assesses family coping behaviors (see McConachie & Waring, 1997). The F-COPES is designed to identify the problem-solving attitude employed by families in difficult situations. Consisting of 30 items, this instrument assesses five coping strategies: (1) reframing, (2) passive appraisal, (3) acquiring social support, (4) seeking spiritual support, and (5) mobilizing the family to acquire and accept help. Neither of these instruments had been used in Java before and therefore an important part of this research was translating them and adapting them in a Javanese cultural setting.

Given that Jenkins (1991) has raised critical issues in regard to the cultural validity of EE, and in particular, its measurement using the Camberwell Family Interview, I was particularly attentive to the cultural validity of the LEE. Item 38, for example, asks respondents whether the family member in question expresses his or her loving feeling toward the respondent. Within a Javanese context, love can be conveyed without overt expression, and it was necessary, therefore, to take this into account when rating this response. In my use of the LEE, I found myself relying on my Javanese background and attendant knowledge of Javanese family emotions, combined with my professional training as a psychologist and attendant knowledge of the importance of reliable rating procedures.

The F-COPES, however, was more problematic. Some of the items were quite clearly inapplicable to Yogyakarta. For example, there were no family services in that city from which to seek help, and thus two items on the instrument were irrelevant. Furthermore there was no question pertaining to traditional healers in the F-COPES, whereas in Yogyakarta these form one of the most important sources of family support. It was therefore necessary for me to devise questions concerning traditional and religious healers that pertained to the local setting.

To explore the nature of family relationships, I also administered two projective tests, an adaptation of Sentence Completion Test (SCT) (Sack & Levy, 1959; Lindzey, 1961), and the HTP drawing test (Handler, 1996). In the SCT the participants and their family members were asked to make sentences from one or two words, such as : *Saya merasa ayah saya* (I feel my father)…; *Ibu saya sering* (My mother often)…;

Keluarga saya (My family)... The SCT technique has been reproduced in a large number of instruments, designed to meet specific needs of particular investigators (Lindzey, 1961). The items of the SCT used in this research are derived from the instrument developed by Sack & Levy (1959). Originally this instrument consisted of 60 items designed to elicit 11 different attitudes. I only used the items relevant to this research, particularly items which revealed participants' attitudes toward family members. The total number of items used was 17.

The use of a projective technique in ethnographic research is not new. Lindzey (1961) discusses several studies in this area, such as the work of Cora Du Bois who administered Rorschach ink-blot techniques and drawing techniques to study the personality characteristic of the people of Alor (a small island in eastern part of Indonesia). The well-known anthropologist, Ruth Benedict, also used the Rorschach ink-blot technique in her study of Japanese in a wartime relocation camp. The use of projective tests was mainly associated with the 'culture personality' school of American anthropology, where there were employed to measure personality with some degree of validity and reliability in order to test hypotheses concerning "the unique integration of the culture of a particular society and the integration of the personalities of its individuals," (Henry & Spiro, 1953:417). My purpose, however, is different. I am not proposing or testing any relationship between Javanese culture and Javanese personality. Rather, my intention, as previously stated, is to enrich my ethnographic data, particularly in sensitive areas where participants might feel reluctant to disclose feelings and thoughts. Nonetheless, in my choice of projective techniques I use similar criteria to those used in the 1950s. In particular I wished to

avoid tests that might be 'culture bound' and I favored test which were "relatively short, relatively easy to administered, and capable of analysis by persons other than anthropologist,"(Henry & Spiro, 1953:419).

In this research I chose to use the SCT for its simplicity, flexibility and efficiency. Most of the participants and their family members were able to complete the sentences easily, although the quality of the response varied. Some participants even needed assistance in writing down their responses. After they finished completing the sentences, my research assistant and I sought to clarify certain important issues arising from the test. During this clarification participants occasionally revealed new and unexpected information spontaneously. In Chapter 6, I relate how a participant suddenly disclosed details of his sexual behavior during the clarification period. It turned out that this behavior had made a significant contribution to his illness. Gaining access to information like this is one of the chief advantages of using projective techniques.

In the HTP test, all participants were given three pieces of paper. They were asked to draw a tree on one piece of paper; a person on another paper; and finally draw a house, a tree and a person on the last piece of paper. Although some participants at the first said that they were not able to draw (this is a very common response), with a little encouragement they performed the three tasks without difficulty. Only one participant refused to perform the HTP test, but he was able to fill out the SCT test. Data from the HTP test revealed participants' own personality characteristics as well as their perceptions of family relationships.

The HTP was chosen because this test has been widely used by psychologists in clinical practices in Yogyakarta. The cross-cultural validity of the test is open to serious question. However, I sought assistance in its interpretation from a psychologist, Siti Waringah, a colleague at Gadjah Mada University, who has recognized expertise in this test and who was blind to the participants. Even so, I was cautious in applying the results of the test to my analysis. As with the SCT, the HTP sometimes provided additional data in sensitive areas (such as same sex relationships) that supported hints I had picked up from family interviews, ultimately enabling me to broach these topics. Thus, I found it most useful to compare the results of the HTP with those of the SCT and, more importantly, with my ethnographically grounded understanding of the participants and their families. The HTP became useful when it corroborated or deepened the analysis from these other sources.

3.4. DATA ANALYSIS

In ethnographic work, data analysis is a continuous process starting from the fieldwork to writing the conclusions of the study (Barrett, 1996). The process of data analysis in this research began in the early stages of my fieldwork. When writing the field notes I had the opportunity to reflect on my interviews and observations. I began to identify some of the themes that were emerging and then explore them further or check them with the participants. For example, the theme of *isin* as an indicator for recovery (discussed in section 8.3.) first emerged in the early stages. I became very attentive to this issue when it appeared as a consistent theme in subsequent interviews with other participants.

To manage a large number of transcribed interviews and field notes, I used the N-6 computer software package. This software is designed to assist qualitative research data analysis (Richards, 2002). From the beginning of my fieldwork I entered all the transcribed interview data into this program. I also began to code it. However, I found that the coding process was time-consuming. I had not finished coding when I had to start writing the dissertation. I then decided to stop the coding process. However, I still found that this program was useful as a search engine to locate a specific topic and word. For example when I analyzed the theme of *usaha* in section 8.4., I used it to search for this term in all the interview texts. This enabled me to determine in what context this term was used in a particular interview and with what meaning. This procedure helped me to compare and classify themes. Therefore, the results of this search became important resources in writing the dissertation.

Several processes were involved in the development of ideas and further analysis. Firstly, reading the full transcripts of interviews provided me with the opportunity to familiarize myself with the data and to obtain a sense of the whole. More importantly, I was able to reflect, identify themes and recognize patterns of data. I could also identify key excerpts, which were important to support my argument in the process of writing the dissertation. Sometimes I needed to read my field notes again to remind me of particular information. Meanwhile, reading the results of the N-6 search allowed me to compare and contrast themes across participants' narratives. This process sometimes generated a new idea that did not emerge from reading the whole narrative.

Secondly, dialogue and consultation with my supervisors was important in elaborating and focusing my preliminary analysis of a particular topic. Several formal and informal seminars and discussions provided a critical evaluation that stimulated further reflection. I also presented my preliminary work and analysis at a number of professional meetings including: the Indonesian Psychiatric Association in Jakarta (December 2002); Workshop on Mental Health Issues, organized by the Harvard Medical School in Beijing (July 2004); and a poster presentation at a meeting of the Australasian Society for Psychiatric Research in Brisbane (September 2004). Comments and suggestions from audiences at these meetings sharpened my analysis.

The process of analysis described above is reflected in the changing title of my dissertation. When I wrote the research proposal, I intended to focus on the family's emotional milieu as an important socio-cultural factor in the process of recovery. At this stage, the title of my research was *Psychotic Patients in Interaction with Their Families: An Ethnographic Study in Java*. After conducting my fieldwork and finding that most of my participants were recovering from their illness, I changed the focus explicitly to the recovery process and emphasized family interaction: *Patients and their Families in the Process of Recovery from First Episode Psychotic Illness: An Ethnographic Study in Java*. After concentrating attention on recovery, I put the idea of recovery into a larger context. The process of recovery not only involves individual psychological processes, but also involves social and cultural processes. The title then became: *Psychocultural Dimensions of Recovery from First Episode Psychosis in Java*.

The clinical data (such as diagnoses, characteristics of symptoms, onset of illness, DUP, and course of illness) were examined using simple descriptive statistics. Clinical data derived from both objective instruments (such as the BPRS and GAF) were not analysed statistically due to the small number of participants involved, although I have represented some of these data in graph and table form. With regard to the data derived from projective tests, the SCT findings were analysed by content and integrated with the ethnographic data, and HTP findings were interpreted qualitatively following a standard procedure. These provided rich information in relation to participants' personality characteristics and their family interactions. Finally, the data on family interactions provided by objective instruments (F-COPES and LEE) were integrated into the discussion on the family in Chapter 6.

In presenting the results of my analysis I begin each chapter with a participant's narrative to provide an ethnographically grounded picture of both illness and recovery narratives. The concept of the illness narrative has been widely used in medical anthropology (Kleinman, 1988) and refers to the stories people tell of their experiences with illness and suffering. The concept of the 'recovery narrative' emerges from the consumer movement (Fallot, 1998). These two provide a solid basis for presenting the results of the present research. In each chapter I chose a narrative containing rich material relevant of the topic of that chapter. This is followed by a discussion of themes emerging from the narrative. These themes are then elaborated, enriched and expanded on, by drawing upon narratives provided by other participants.

In the next chapter I provide an outline of each of the nine participants, including their personal and clinical characteristics. This is intended to familiarize the reader with each person, and serve as an aid to identifying him or her in subsequent discussions.

3.5. SUMMARY

In this chapter I have outlined the methodology of this research, with its combination of ethnographic and clinical techniques. I have argued that the main rationale for applying an ethnographic approach is the need to explore subjective experience and its relationship to a particular cultural context. The rationale for using clinical research methods includes the need to establish accurate diagnoses, to assess participants' symptoms over time, and to examine psychological factors within the participants as well as within the family emotional milieu. It is a significant challenge to combine two different perspectives into a single research design. However, I have demonstrated several advantages to this combination, including triangulation, complementarity, and expansion. This provides a strong basis for the analysis of participants' illness and recovery narratives throughout the dissertation.

CHAPTER 4

THE PARTICIPANTS AND THEIR ILLNESSES

In this chapter I provide an outline of each of the nine participants, including personal details of their lives and clinical characteristics of their illnesses. My purpose is to familiarize the reader with each individual, providing an aid to identifying him or her in later discussions. In the second part of the chapter I discuss the participants' psychotic illnesses. I argue that acuteness of onset, a well-recognized favorable prognostic indicator, is associated in this study with a high recovery rate among the participants. I also demonstrate that the Duration of Untreated Psychosis (DUP) was short in each case, another factor favoring recovery

4.1. OUTLINE OF PARTICIPANTS' CHARACTERISTICS

Participants' personal and clinical characteristics are outlined in this section. To protect their identities, all the names used in this dissertation are pseudonyms.

Participant number 1: Wati

When I first met her Wati was a 28-year-old married woman with a ten-month-old son. She was the second daughter in her family of origin, with two brothers and two sisters. After graduating from high school she worked in a Korean glove-making

company located not far from her village. After their marriage, Wati and her husband lived with her parents. Three months after she delivered her son, her husband suddenly took her to live with his parents, his brother, his sister, and their families. Living with four families under one roof—a situation colored by tension, conflict and jealousy—proved too stressful for Wati.

The onset of her illness was abrupt. She went to work one morning and had two *kaget* (startle) experiences that triggered her illness. I describe these in detail in the next chapter, where I explore the role of *kaget* in precipitating psychotic illness. Wati's medical records documented that she had hyperactivity, incoherent speech, looseness of association, irritability, paranoid ideas of being talked about by other people, a feeling of being possessed by the spirit of her grandmother, and auditory hallucinations. I later gained additional information that although Wati's grandmother was still alive, Wati maintained a delusional belief that she had died. In fact she heard voices announcing the death. Her family took Wati to Sarjito Hospital less than a week after she first became ill.

Wati was hospitalized for six days and within weeks a good recovery ensued. She continued taking medication for only a few weeks. Several months later she returned to work. She experienced no relapse during the course of this study. Given the abrupt onset and the short duration of her illness, Wati met the ICD-10 criteria for acute and transient psychotic disorder (ATPD), specifically the sub-category of acute schizophrenia-like psychotic disorder (F.23.2). By the end of the second year of follow-up there had been no recurrence of symptoms. She exhibited excellent family

functioning (she and her husband were building a new house for themselves) and good social and occupational functioning, as a consequence of which I considered her Global Assessment of Functioning (GAF) score to be 95.

Participant number 2: Rima

Rima was a single woman, who was 18 years of age when the study began. She was the youngest daughter of four siblings. Due to family financial difficulties, she did not continue her studies after finishing secondary school at the age of 16. Instead she took sewing lessons and worked for a furniture company. However, she left this job because she said that her work mates were teasing her and she took what they said to heart.

From that time on her illness developed slowly. Her family took her to a small hospital one month after they became aware of a change in her behavior, and then to Sarjito Hospital. She was hospitalized six times in a number of different hospitals over a two-year period with partial or full remission between episodes. The Sarjito Hospital records indicated that Rima exhibited hyperactivity, irritability, incoherence and irrelevant speech, giggling, laughing, and looseness of associations. From my clinical interviews and observations I gained additional details of her symptoms. These included thought insertion; she believed that her thoughts stemmed from a spirit and from the Archangel Gabriel who lived inside her body. She also heard voices of spirits who said that they enjoyed living in her body. Rima also had manic symptoms in which she wandered around the village, talked a lot, gave speeches to people, and scribbled on the wall of her house. Her appearance was also bizarre

(attaching emblems to her shirts, and wearing a lot of necklaces and bracelets), though I was unable to determine any underlying delusions that may have accounted for this. The fact that her illness lasted more than one month indicates that Rima met the ICD-10 criteria for schizophrenia. However, the presence of manic symptoms, especially pressure of speech and hyperactivity suggest that she most likely suffered from schizoaffective disorder, manic type (F.25.0).

At the end of the first year she was in full remission. She did sewing for herself as well as working at home making *tempe*[30] and selling them, but she had not involved herself in social activities and had not secured a job outside the house. She experienced two relapses, one lasting three months and the other lasting two months, but returned to normal in the second year of follow-up, her GAF score by then being 70.

Participant number 3: Budi

Budi was a 16-year-old boy when he fell ill. He was the elder of two siblings. Budi was a 'slow learner' and could be categorized as having borderline intellectual functioning (IQ around 90).[31] The cause of this was unknown, though his father thought that it was caused by frequent falling from the bed when he was a baby. At his age he would have ordinarily progressed to the third year of secondary school, but he was still in the last year of primary school. Despite this borderline intellectual impairment his interpersonal and social functioning showed a good adjustment. He

[30] A traditional dish made of fermented beans.
[31] I use the DSM-IV here because the ICD-10 does not contain a category of borderline intellectual functioning

strived to develop *tenaga dalam* (inner power). He was also deeply committed to religion and involved in local mosque activities. His friends encouraged him to join *Lasykar Jihad*. As a result he wanted to go to Afghanistan to undertake *jihad* against the United States forces.

The onset of his illness was rapid, coming on in less than 2 weeks. The hospital record indicates that ten days before he was taken to the hospital he exhibited autistic behavior, such as daydreaming and moving around the house without purpose. He was also observed talking to himself, giggling and laughing. He refused to eat and was not able to sleep. He exhibited delusions of persecution (believing that someone wanted to kill him), as well as bizarre delusions of thought insertion and control. Sometimes he felt sad and cried without reason, but would then suddenly exhibit aggressive behavior. He destroyed household items, burned his shirt and screamed loudly. From my interview I established that Budi also experienced auditory and olfactory hallucinations. He heard music and singing that he said resembled a Javanese orchestra playing at a wedding ceremony, and he also smelt particular perfume oils.

According to his father several problems led to the development of Budi's illness. First, he felt frustrated and disappointed, because he felt his uncle had somehow removed his *tenaga dalam*. Second, his father suspected that the jihad army used a magic formula to influence his son. Third, his father had experienced conflict with another man, a former friend, and believed that this man had used black magic (sorcery) on Budi as a form of revenge.

Budi clinically recovered within weeks, but his father considered that he had not totally returned to normal functioning. Several months later his father stated that Budi was completely recovered as evidenced by the fact that he experienced *isin* (shame) for having engaged in some inappropriate behavior in the neighborhood. The acuteness of onset and short duration of illness (less than a month) indicates that Budi is most likely to have met the criteria for diagnosis of ATPD, specifically the sub-category of acute polymorphic disorder with symptoms of schizophrenia (F23.1).

Over the course of one year, Budi had no relapses, despite not complying with his medication. However, his GAF score remained at 70, because he had not returned to school and had no formal job. At the end of the second year of follow-up symptoms appeared again but at a low intensity, and there was no need for hospitalization.

Participant number 4: Sri

Sri was a 20-year-old female student undertaking a diploma course in kindergarten teaching. She was the second daughter of three children. She was an active, intelligent young woman. When she was a little girl she learned Javanese traditional dance. As a teenager she became involved in several religious and social activities. Before she fell ill Sri experienced several stressful family problems surrounding the issue of marriage. When her mother wanted her to get married to a man chosen from her extended kin, Sri refused. Meanwhile her younger brother married a girl from the same village. Feeling that she had been overstepped in the appropriate sequence of sibling marriage, Sri disagreed with her brother's marriage, but she kept silent about this.

The onset of illness was abrupt, triggered by her participation in a workshop on democratization among village people, during which she had to stay in the house where the workshop was run and was not allowed to go out. Sri's case record documented a history of auditory hallucinations, delusions of thought control, delusions of self-reference and persecutory delusions. There was also evidence of thought disorder (described as irrelevant speech) and negative symptoms of social withdrawal. Sri also experienced visual hallucinations of people carrying spears and trying to kill her. Furthermore, she had olfactory hallucinations, in her case, smelling incense. She also reported a deep sense of guilt, feelings that she was deserving of punishment, and symptoms of overwhelming anxiety, believing that she would die. She also mistook her house for a burial house, a complex form of misidentification which most likely had a delusional basis. She was sick at home for three days and treated in the psychiatric ward for five days. She recovered completely within two weeks and resumed her normal life.

Given the rapidity of onset (within days) and the short duration of illness (lasting less than a month), the diagnosis comes within the category of ATPD. Within this category Sri is most likely to fit the criteria for an acute polymorphic disorder with symptoms of schizophrenia (F23.1). She exhibited hallucinations and delusions which changed rapidly from time to time to indicate polymorphism and instability. This diagnosis is supported by her overwhelming anxiety, perplexity and misidentification.

Despite experiencing a very intense psychotic episode, Sri's course of illness was short. In less than a month she was symptom free and did not relapse in the course of

two years of follow-up. She achieved an excellent level of functioning (GAF 95). Despite her mother's death and her father's re-marriage, Sri finished her studies, developed an informal kindergarten at her house, became involved in social and religious activities in the community, and gained a part time job.

Participant number 5: Endang

Endang was a 26-year-old female university student. She was the second daughter of four siblings. Endang's narrative was full of conflict, touching on issues of sexuality, marriage, personal, and social relationships. After graduating from high school she moved to Jakarta to escape from a troubled marriage. She lived in Jakarta for five years and worked as a shop assistant. There she developed an intense emotional relationship with a woman she called *kakak* (older sister). Endang's family became somewhat suspicious when *kakak* stayed in their house and slept in the same room with Endang, the two of them spending most of their time in the bedroom. Recognizing that their relationship was unusual, Endang's family tried to separate them. However, the two of them moved away, first to Medan and then back to Jakarta, where Endang's father eventually caught up with her and forced her to come back to the village against her will. The conflict between Endang and her family was protracted, lasting from when she was 18 years of age to the present. It was still an issue of great importance to Endang when she became ill.

The onset of her illness was abrupt (within a day). It was triggered, she said, by an avocado falling from a tree and hitting her head. She was taken to the Sarjito Hospital less than two weeks later. The case records documented autistic withdrawal and

incongruous affect. She also exhibited delusions of persecution (ideas of being chased by other people), delusions of grandeur (believing that she had a special power), and bizarre delusions (believing that a spirit possessed her). My clinical interview further elucidated a history of visual and auditory hallucination (seeing *Nyai Roro Kidul* who commanded her to go to the South Sea). She also heard several voices that she said controlled her and commanded her to do things. Endang also exhibited bizarre behavior such as marching up and down in front of her house to pay tribute to the spirit who she said was leaving her house.

Due to the acuteness of onset of this illness, with its prominent symptoms of schizophrenia, Endang was diagnosed in the medical record as having acute polymorphic disorder with symptoms of schizophrenia (F23.1). However, from my observations I noted that her duration of illness was longer than one month, which meant that she was more likely to meet the criteria for schizophrenia, undifferentiated type (F.20.3).

She showed a good recovery after 6 months and returned to university, but at the end of the first year she relapsed after stopping her medication. In the second year of follow-up her functioning remained good. She returned to university and obtained good marks, despite still hearing voices. With this high level of social functioning but persistence of symptoms her GAF score was 80. She complied with her medication after the relapse.

Participant number 6: Priyo

Priyo was a 19-year-old male, a student at a technical high school. He was the third son of five siblings. Priyo was strongly committed to his religion having grown up in a religious family. His father and his father's father had both been religious leaders in his village. Prior to the illness Priyo experienced a moral conflict. He admitted that despite having strong moral and religious values, he was not able to control his strong sexual drive, engaging in masturbation and watching pornographic videos. This created a strong sense of guilt which he felt had led to his psychotic breakdown.

His onset of the illness was rapid, arising in less than two weeks. The hospital records indicated that one week before his family took him to hospital he had exhibited bizarre behavior and hyperactivity. He moved around the house without any purpose, exhibited unusual movements when praying, and became easily irritated. He also showed autistic behavior, daydreaming, difficulty in going to sleep (but sometimes falling asleep in the front yard), and he believed that he had received a revelation from God. My interview data provided the additional information that he experienced burning sensations when he immersed his head in water. He reported feelings of guilt, associated with auditory hallucinations in which he heard voices that commanded him to ask for forgiveness from his neighbors. There was evidence of visual hallucinations in which he saw a pair of eyes that he believed to be that of an angel who monitored his behavior. The clinical interview also identified that Priyo believed himself to be an especially pious person. On one occasion he placed a rosary (*tasbih*) around his neck, but he experienced this as if it had been placed there by something else, perhaps a spirit or an angel.

Priyo was hospitalized for two weeks and demonstrated a good recovery in less than a month. The short duration of the illness and its acute onset indicates that Priyo is most likely to have had diagnosis of ATPD, specifically the sub-category of acute polymorphic disorder with symptoms of schizophrenia (F.23.1). Over the course of one year Priyo showed a good level of functioning, despite not complying with his medication. He returned to his school and passed the final exam. In the second year of follow-up Priyo obtained a job in a small construction company and became involved in social and religious activities in his village. I assessed his GAF score to be 90.

Participant number 7: Wulan

Wulan was a 16-year-old female, the elder of two siblings, who was described as having been a quiet girl. Her mother often became angry with her but, according to her mother, she just tended to keep quiet. She had recently finished secondary school when she fell ill.

The onset of illness was rapid (within days), triggered, her mother said, by wearing the wrong uniform to her new high school. She suddenly felt that all of her teachers and students were teasing her. Returning home, she exhibited odd behavior such as cleaning the bathroom while still wearing her school uniform. Her family took her to the hospital less than two weeks after the sickness began. The case records documented that she exhibited autistic withdrawal, refusal to eat, crying without any reason and incoherent speech. From my interview I additionally found that she had exhibited bizarre behavior (taking her clothes off so that she was almost naked). I

found evidence of catatonic rigidity (maintaining a particular position—such as sitting or standing—for a long time). She also gave a history of visual hallucinations of people that others could not see. She refused to eat and kept her mouth shut when people tried to feed her. She also indicated the presence of delusions of persecution, believing that someone wanted to harm her, or that her mother wanted to throw her into a well. She reported having experienced a visual illusion in which her house looked to her like it was going to collapse.

Wulan was hospitalized for 2 weeks and made a rapid recovery within weeks. However, according to her mother she had not totally recovered because she had not shown *isin* (shame). Wulan continued her medication for a year. The acute onset and short duration of the illness indicate that Wulan met the criteria for ATPD, specifically the sub-category of acute schizophrenia-like psychotic disorder (F.23.2). Despite not resuming her school studies after she recovered, Wulan displayed good level of social functioning. She took up sewing lessons, then became active in a mosque-based education system where she met a boy who she later married. In the second year of follow-up she obtained a job in a tobacco company. She fully complied with her medication for the first year then stopped after getting married. Given this excellent social and symptomatic recovery her GAF score was 90.

Participant Number 8: Bambang

Bambang was a 35-year-old married man, the father of a 4-year-old girl. He worked in an aluminum company that manufactured household items. He described himself as being interested in the mystical world. He often performed spiritual and mystical

practices that derive from Islam and Javanese asceticism. Although he had a past history of drug and alcohol abuse, his mental illness was not related to substance abuse, both according to the medical records and to my own observations. Bambang himself attributed his illness to excessive ascetic practices. His mother and his wife suspected that he was ill because he wanted to build his own house quickly but without having sufficient money to accomplish this.

He reported that the onset of his illness was rapid, occurring over a period of less than two weeks. The medical record documented that he suffered from insomnia, autistic withdrawal, inappropriate affect (giggling, laughing), aggressive and bizarre behavior (burning his mattress), and delusions of persecution (being suspicious of others and saying he was threatened by them). My interviews confirmed that his paranoia (feeling of being talked about and frightened of other people) had been developing over a longer period time, but he was able to control it. When he became ill Bambang became quite frightened, believing someone was attempting to poison and kill him. He refused to eat and drink because when he wanted to drink tea, he thought it was blood, and when he wanted to eat chicken, he thought it was human flesh. He attempted suicide by throwing himself into a well. Bambang also reported experiencing auditory and visual hallucinations of spirits who he said moved around. He saw ocean waves in front of him. He reported a bizarre delusion that a dragon spirit had inserted itself into his body. Magical and mystical ideas were prominent in Bambang's illness experience.

Bambang was firstly cared for by his wife and her family. Due to financial problems, he was then sent to his brother's family and after that to his family of origin. After a month of illness Bambang started becoming aggressive, and it was at this point that he was sent to hospital by his family. The presence of positive symptoms with dominant paranoia and a duration of illness of more than a month indicate that Bambang had a diagnosis of schizophrenia, paranoid type (F.20.0). Following a week's hospitalization and a week on medication at home Bambang made a good recovery. Despite the fact that his paranoid ideas symptom would emerge from time to time he was able to return to normal family life, build his own house and return to his previous job. However, he experienced a relapse after one year and was hospitalized for a short time, subsequently returning to normal life during the second year of follow-up. Because of the persistence of symptoms, and because he was not fully engaged in social interaction his GAF score was assessed as being 75.

Participant number 9: Joko

Joko[32] was a 42-year-old married man with three children. After graduating from a state university in Yogyakarta, he became a teacher in a government junior middle school. He had subsequently been working as a principal at a private secondary school for eight years when he became ill. His wife reported that he had caused a financial scandal at the school by using school project funds for his own purposes. His behavior began to change several weeks before the illness. He had difficulty getting to sleep and became irritable.

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[32] Since the medical report concerning Joko was missing, most of the clinical data gathered from my interview with Joko and his wife.

One morning he exhibited bizarre behavior when performing prayers. He experienced a delusion of being controlled by a spirit. He screamed out the name of God in an uncontrolled way and his body spun around involuntarily, he said. He felt a special power drag at his hand. He also briefly exhibited aggressive and manic behavior, such as kicking his wife and children and talking excessively. He 'gave sermons' to people who passed his house. He reported having auditory hallucinations of voices like thunder and people whispering in his ears. There was also evidence of visual hallucination of people being tortured. He felt the unusual bodily sensation of heat in his chest. Joko experienced delusions of persecution in which he feared people were chasing him, so he isolated himself in his room. He said that sometimes he felt so sad that he cried. His wife also recounted that Joko tried to commit suicide by hanging himself. The evidence of positive symptoms of hallucinations and delusions, accompanied by bizarre behavior and thoughts, with a duration of illness of more than one month, indicated a diagnosis of schizophrenia, undifferentiated type (F.20.3). Although there was evidence of manic behavior, it was quite brief, and not sufficient to warrant a diagnosis of schizoaffective disorder.

Joko was treated in several hospitals, showing a gradual recovery over 3 months, but he relapsed in the middle of the first year. Despite stopping his medication after 10 months he then recovered steadily and reached an excellent level of functioning (GAF 95) in the second year of follow-up. He secured a job as a teacher in a government school, assisted his wife in developing a *wartel* (telecommunication café) business in his home, and became actively involved in religious, social and political activities in the community.

Summary of Participants' Personal and Clinical Characteristics

I have summarized the participants' personal and clinical characteristics, presented above, in the following two tables.

Table 4.1. Participants' personal characteristics

No.	Pseudonym	Sex	Age of onset	Marital status	Education
1	Wati	Female	20	Married	Secondary school
2.	Rima	Female	18	Single	Secondary school
3	Budi	Male	16	Single	Primary school
4	Sri	Female	28	Single	Tertiary Diploma
5	Endang	Female	26	Single	Tertiary Degree
6	Priyo	Male	19	Single	Secondary school
7	Wulan	Female	16	Single, then married	Secondary school
8	Bambang	Male	35	Married	Primary school
9	Joko	Male	42	Married	Tertiary degree

Table 4.2. Participants' clinical characteristics

No.	Pseudonym	Diagnosis	Type of onset	DUP	Hospitalization	Medical Treatment	Home Medication	Family History	Duration of illness	Relapse
1	Wati	Acute schizophrenia-like disorder (F.23.2.)	Abrupt 2 days	<2 week	Once	Thioridazine	Stopped after 2 weeks	No	2 weeks	0
2.	Rima	Schizoaffective disorder, manic Type (F.25.0)	Slow > 4 weeks	>4 weeks	Four times	Haloperidol Carbamazepine Trihexyphenidyl	Not regular, then continuous	Yes	3 months	3
3	Budi	Acute polymorphic disorder with symptoms of schizophrenia (F.23.1)	Rapid < 2 weeks	<2 weeks	Twice	Chlorpromazine Haloperidol ECT	Stopped after 1 month	No	<4 weeks	0
4	Sri	Acute polymorphic disorder with symptoms of schizophrenia (F.23.1.)	Abrupt 2 days	< 1 week	Once	Chlorpromazine Risperidone	Stopped after 1 week	No	3 weeks	0
5	Endang	Schizophrenia, undifferentiated type (F.20.3)	Rapid < 1 week	2 weeks	Twice	Thioridazine Haloperidol	Stopped after 3 months, then continuous	Yes	4 months	1
6	Priyo	Acute polymorphic disorder with symptoms of schizophrenia (F.23.1.)	Rapid < 2 weeks	2 weeks	Twice	Thioridazine Haloperidol Trihexyphenidyl	Stopped after 3 months, then continuous	No	<4 weeks	0
7	Wulan	Acute schizophrenia-like disorder (F.23.2.)	Rapid < 1 week	2 weeks	Once	Haloperidol Trihexyphenidyl Amitriptyline ECT	Continuous for the whole year	Yes	<4 weeks	0
8	Bambang	Schizophrenia, paranoid type (F.20.0.)	Rapid < 2 weeks	4 weeks	Twice	Data not available	Stopped after 2 weeks	No	2 months	1
9	Joko	Schizophrenia, undifferentiated type (F.20.3.)	Rapid <2 weeks	<4 weeks	Three times	Data not available	Stopped after 6 months	No	4 months	1

4.2. PARTICIPANTS' RECOVERY

I consider the recovery rate of participants in this research to be high. Despite some relapses, most participants returned to normal functioning in the second year of follow-up. The longitudinal course of their symptomatic recovery can be seen in the following figure representing their BPRS scores.

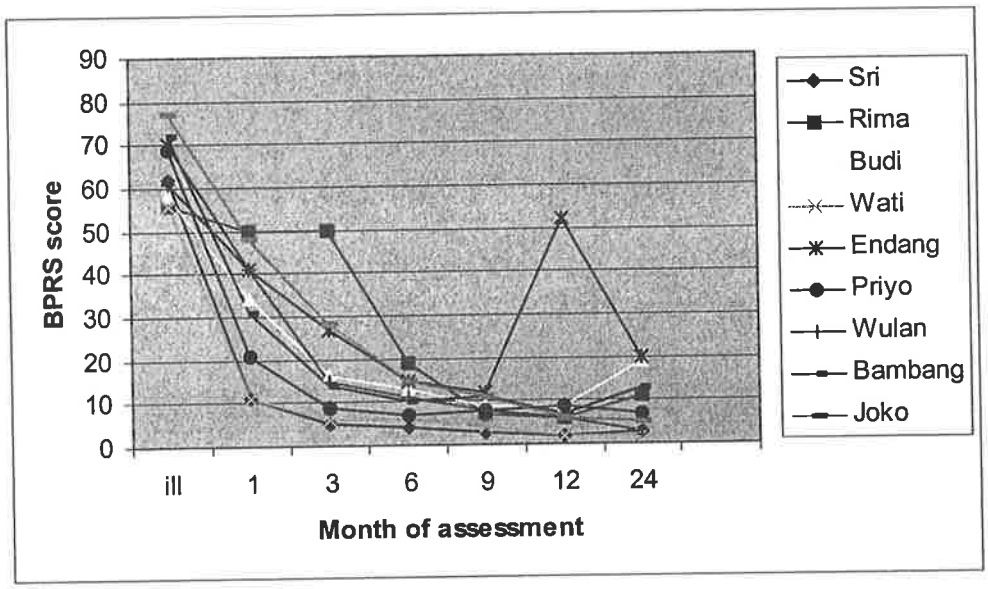

Figure 4.1. Graph of BPRS scores for all participants[33]

Figure 4.1. shows that all participants had a low BPRS score in the second year of follow-up, meaning that all of them had good symptomatic outcomes. Following initial recovery, four participants experienced a relapse of their illness. One

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[33] BPRS score for all participants during the illness episode was obtained retrospectively from the interview data and medical records.

participant, Joko, experienced relapse between months 3 and 6. This does appear in the graph because the relapse came on after my 3-month assessment and had resolved by the time of the 6-month assessment. Another, Endang, experienced a relapse at month 12. Two participants, Rima and Bambang, relapsed between months 12 and 24. The duration of relapse was in most instances short, lasting less than a month. Only one participant, Rima, experienced a relapse of more than one month. Note also that these relapses do not appear in figure 1 because, as in the case of Joko, they occurred in between assessment and had all resolved at the time of my final two-year assessment.

The participants' recovery is also reflected in their social functioning which is indicated by their GAF scores, as illustrated in the following figure.

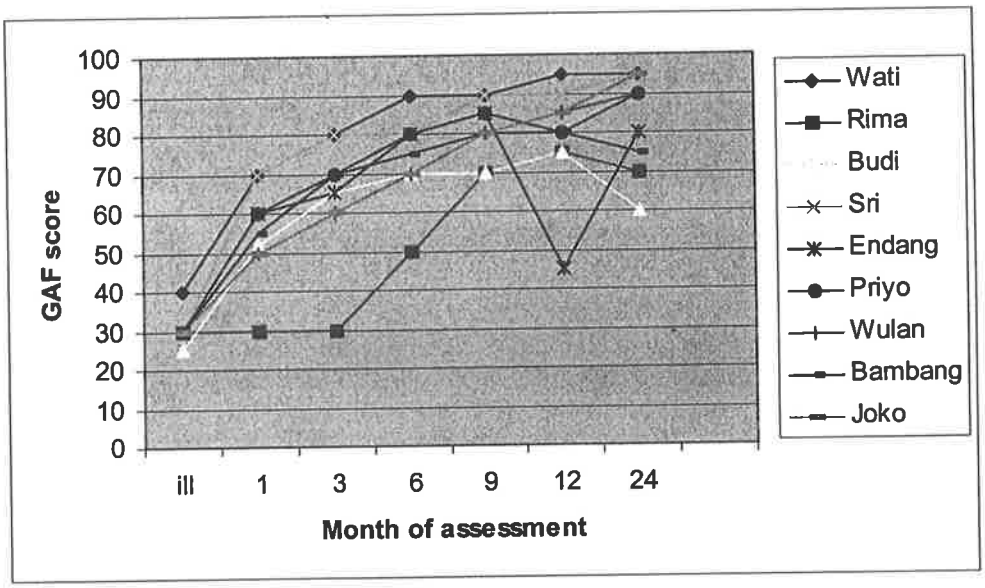

Figure 4.2. Graph of GAF scores for all participants

Figure 4.2. shows that by the end of the first year most participants had achieved a good level of social functioning except Endang who was undergoing a relapse at that stage. By the time of the follow-up assessment at the end of the second year, however, all participants were functioning well, notwithstanding relapses in the middle of the year for Bambang and Rima. Some participants even demonstrated excellent functioning (score >90 for Sri, Wati and Joko), not only because they had returned to their previous levels of functioning, but had showed a better social and occupational functioning than before the onset of their illnesses.

From a clinical perspective I would argue that the most significant factor associated with the high recovery rate among participants is the acuteness of illness onset. Table 4.2. shows that 8 of 9 participants in this series had a rapid onset of less than two weeks. This rapid onset was not only exhibited by the five participants who met the criteria for ATPD, but also those three cases with a diagnosis of schizophrenia. It is notable that these latter three cases met the diagnostic criteria for Non Affective Remitting Psychosis (NARP) because their duration of illness was longer than 1 month but less than 6 months. Taken all together, eight cases meet the criteria of NARP in this research. Based on these data, I would argue that the diagnosis of NARP has a greater utility than that of ATPD, because it more effectively captures those patients who have a good outcome.

This research is in keeping with a previous survey carried out in Yogyakarta in which we found that acute onset psychosis constitutes a large percentage of all psychotic illness (Good & Subandi, 2000). It is also in keeping with cross-cultural studies of

acute psychosis in two further respects. First, acute onset psychosis is more common in developing countries than in developed countries. Second, acute onset psychosis is well regarded as having a more benign course than insidious onset psychosis (Susser & Wanderling, 1994; Susser *et al.*, 1995; Good, 2004).

It has been argued that one factor leading to a benign course is the short duration of untreated psychosis (DUP) (Black *et al.*, 2001). Thus, it is likely that the benign course of illness observed in the participants of my study can be attributed, at least in part, to their short DUP. In the second year of follow-up, most participants in this research exhibited no symptoms of psychosis at all and had achieved a good level of social and occupational functioning. This is consistent with other studies, where two thirds of patients with ATPD have been shown to achieve a good level of social functioning at the end of the follow-up period (Marneros & Pillmann, 2004:145).

With respect to symptomatology, this research is also in keeping with previous research on acute psychosis. In an Egyptian sample, Okasha *et al.* (1993) found that the prevailing symptoms of acute psychosis were delusions, worry, irritability, mood changes, and disturbed behavior. Reviewing a number of studies Marneros & Pillmann (2004) concluded that the most specific features were the rapidly changing delusional topics, and the rapidly changing mood and anxiety symptoms. They found that delusional topics in acute psychosis varied widely, ranging from delusions of reference, delusion of persecution, religious delusions, delusion of guilt, and delusional misidentification. Religious delusions were present in more than a quarter of the sample. Also, a preoccupation with thoughts of death has been described as

typical for cycloid psychosis. Most of the cases in my research exhibited a similar pattern of symptoms. As I will show in section 5.2.3., rapidly changing delusions, rapidly changing mood symptoms and overwhelming anxiety were common. Religious delusions and hallucinations, delusions of guilt, and preoccupation with death were also frequently experienced by the participants.

Finally, prior to the onset of their illness, most participants experienced stressful life problems ranging from personal and family problems, to moral-religious conflicts, to financial difficulties. This reflects the findings of two previous studies, which identified the presence of psychosocial stressors preceding the onset of psychotic illness (Okasha *et al.*, 1993; Collins *et al.*, 1996).

4.3. SUMMARY

In this chapter I have presented an outline of the nine participants in this research. The narratives of four of them (Sri, Wati, Priyo, and Joko) will be presented in more detail in later chapters. I have also discussed the clinical features of each participant's illness and drawn attention to three salient features of this group. First, 5 of the 9 participants met the ICD-10 criteria for ATPD. Despite the small size of this sample, the findings of my research support those of cross-cultural studies of ATPD. Second, 8 of the 9 participants had an acute onset of illness and satisfied the criteria for NARP. Third, the DUP of the participants was very short, a factor likely to have contributed to the good recovery they were able to achieve. The most important contribution of my research, I believe, lies in the rich descriptive detail on each case. It is this which

allows me to proceed in subsequent chapters with a discussion of psychocultural aspects of the recovery process.

CHAPTER 5

PSYCHOCULTURAL DIMENSIONS OF PSYCHOTIC EXPERIENCE

The goal of this chapter is to discuss the experience of psychosis from a Javanese psychocultural perspective, drawing on accounts provided by nine participants. Firstly, a single case study of one female participant, here called Sri, is presented in order to understand the evolving course of her illness. The unfolding of Sri's illness can best be understood in terms of four phases: *sebelum sakit* (before the illness), *memendam di dalam* (burying inside), *hilang kontrol* (escaping control), and *penyembuhan* (recovery). Since Chapter 8 will discuss the process of recovery, the rest of this chapter will be limited to the first three phases, drawing not only on material from Sri's case, but also on the other eight cases. Several important psychocultural themes will be discussed. In relation to *sebelum sakit,* I explore the issue of contested cultural values that participants were grappling with prior to the onset of their illness. When discussing *memendam di dalam* I draw attention to the importance of *kaget* (being startled). In the *hilang kontrol* phase the central notion I address is that of *bingung* (confused) which, like some of the other 'refined' terms for mental illness in Java, is used in an effort to reduce the stigma associated with psychosis.

5.1. SRI'S ILLNESS NARRATIVE

I have chosen to begin with Sri's case for three reasons. Firstly, the content of her story clearly distinguished between normal everyday life and psychotic experience. Secondly, among all the participants, her case represented the most striking example of recovery. Thirdly, the narrative was detailed and rich because Sri proved to be very open and articulate.

I first met Sri, a 20-year-old young woman, in August 2002 at her house in a village some 30 kilometers south of the city of Yogyakarta. The village was a traditional one with lots of buffalo stalls and surrounded by paddy fields and sugar cane fields. However, it was easily accessible along the main road from Yogyakarta to Bantul Regency. It was not difficult to find Sri's house, because in such villages people know each other well.

Sri lived in a modest house with her parents and her eldest brother. After being told about the purpose of this research and agreeing to participate, Sri introduced herself by saying that her position in the family was that of middle sibling between two brothers. During this first meeting I was struck by Sri's openness in discussing her illness. Over the course of several meetings we built up an increasingly detailed picture of her illness experiences. Sri presented herself as an educated and intelligent woman. She said that she was a student of a PGTKI[34] (an Islamic college for kindergarten teachers) and was actively involved in a youth organization associated

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[34] PGTKIT stands for *Pendidikan Guru Taman Kanak-kanak Islam Terpadu*

with the *Pesantren Krapyak,* a renowned traditional Islamic boarding school in Yogyakarta. Before she became ill, she was involved in a series of social activities. As the secretary of the youth organization one of her tasks was to organize a three-day meeting to develop the program for the following year. Sri did this successfully and then began to prepare for her younger brother's wedding ceremony. Not long after this she participated in a five-day workshop on the democratization of village communities organized by a Non Government Organization (NGO). During this workshop participants had to stay within the workshop venue and were not allowed to go out.

Sri had expected the workshop participants to be in her age group and was surprised to find most of them to be much older. She said that being the youngest there she was often teased by the other older ones. This, said Sri, seemed to trigger her illness. She remarked, "They actually only made jokes, but I took it to heart." While the workshop was still in progress Sri began to experience symptoms of her illness: "On the last day of the workshop, I began to feel confused." On her way home, she noticed that the world around her had changed: "The world appeared different, I didn't know what kind of world it was," she explained. When she arrived at her village she heard birds chirping, but they sounded to her like the trumpet of an angel heralding the end of the world. When she looked at the paddy fields, they resembled the *padhang mahsyar*, a gathering place of the Day of Judgment. People on the street seemed to be going in the same direction as her and gathering there. When Sri arrived home, she thought her home was a graveyard. She was surprised when she looked in the mirror, as she could not recognize her own face.

Sri told me that during her illness, she saw a very big screen, like a cinema screen in front of her. Many things appeared on this screen. "I saw a lot of pictures, and they were so big and so vivid," she said. She was frightened by what she saw, particularly a scene where many people, looking like West Papuan tribesmen, were carrying spears pointed at her. Sri was convinced that they wanted to kill her. She also heard voices asking, "Do you want to die naturally or be killed?" It seemed to her that she was surrounded by voices. "The voices were mocking me," she said in one interview. Later she added that the voices were criticizing her and ridiculing her. "It was as if they could read my thoughts. I heard a voice saying that people were ready to put me in a large frying pan. I was about to be fried. It was as if I was in hell. I was going to be put to justice."

These experiences made Sri feel *bingung* (confused). She walked around inside the house without any purpose. She could not sleep and did not want to eat for three days because she heard voices saying, "If you eat this food, you will die." When members of her family offered her some milk she refused to drink it because she saw it as dirty water. Other hallucinatory experiences emerged. Sri suddenly smelled *kemenyan* (incense). "This room was filled with the smell of *kemenyan.* I was so afraid. It meant that I was going to die not according to the Islamic way."

Although Sri felt that she was about to die she kept struggling to stay alive. She fought the voices and the people who she believed wanted to kill her by screaming over and over the words *Allahu Akbar* (God is the Greatest). Sri then saw the people on the screen fall down and the voices suddenly stop. Soon, however, she saw them

come back and she began to hear the voices again. She kept struggling by trying to perform *shalat* (liturgical prayer) but her efforts seemed to be counteracted by a stronger power. "I didn't even know how to perform *shalat*," Sri exclaimed to me. She experienced this power as something that was controlling her behavior. When she tried to speak to other people around her she could not speak. She was convinced that the power occupied her: "I could not move my lips."

Sri also spoke of feelings of guilt, particularly the belief that she had done all the bad things in the world that it was possible to do and was therefore fit to be condemned and punished. She told me, "It was night time, I felt as if I saw a *babi ngepet.*[35] I felt that the *babi ngepet* was me." Stories she had heard when she was a little girl emerged in her consciousness. "I remembered the story of *Malin Kundang*[36]; I felt that I was the *Malin Kundang*." She mentioned these stories, interspersed with recent political issues. When the television news reported that Tommy Suharto, the son of former President Suharto, was in court being charged with corruption, Sri felt that she herself was Tommy Suharto. Her psychotic experience began to include global issues, such as the September 11 terrorist attack in the United States. Sri felt that she had to be punished because she believed it was she who had attacked the World Trade Center in New York: "It was as if the radio was talking about me. It seemed that people all around the world were talking about me, condemning me."

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[35] *Babi ngepet* is a thieving pig, a character from a mythological story from west Java, in which a thief transforms his body into a pig (*babi)* to escape from the crowd.

[36] *Malin Kundang* is a Sumatran mythological story. The story tells of a poor young man going overseas and leaving his mother alone. When he became rich and returned home, he refused to acknowledge his mother. The mother prayed and the young man suddenly turned into stone.

Sri recalled that when she was being treated in hospital, she was still afraid that she might not die according to the proper Islamic way. In particular, when she saw the sign of a cross on the wall, suddenly a big screen appeared before her eyes and she saw Jesus Christ on the cross being burnt. She interpreted this to mean that she would die as a Christian rather than as a Moslem. She therefore asked her fellow patients to teach her how to recite the *syahadat*, the Moslem decree. "I am a Moslem, I am a Moslem." She likened all this to a battle between Christian and Moslem.

I first met Sri just one month after she was discharged from Sarjito Hospital's psychiatric ward, but she showed no apparent symptoms of mental illness by then. She had recovered completely. According to her brother who joined the interview she was sick at home for three days prior to admission, treated at the psychiatric ward for five days, and then she returned home well. Within a week Sri had returned to her normal activities. She did not display any further signs of mental illness during the course of this study.

Sri's mother had a long history of asthma, kidney failure and heart disease, and her health deteriorated after Sri became ill. Both Sri and her mother attributed the deterioration to the stress of Sri's illness. Ultimately Sri's mother died in February 23, 2003. Prior to her death, however, I was able to interview her. When I asked her mother to describe Sri's childhood, she proudly stated that Sri was an intelligent child. She had been able to recite the *Qur'an* since she was a little girl. She was also a good dancer and had joined a famous Javanese dancing school. In her teenage years, Sri had also joined an Islamic youth organization associated with *Pesantren Krapyak*. Her

mother was also proud of Sri on account of her scholastic performance. Despite this success, her mother expressed disappointment that Sri was still not willing to marry. Sri's mother had arranged a marriage with a relative from her side of the family, but Sri refused.

In a much later interview with Sri during the last part of my fieldwork Sri reflected on her illness by saying, "I buried a lot of problems inside." Her biggest problem, she felt, was that her younger brother got married before she did. Sri actually disagreed with him marrying before she did, but she had to accept the reality of this situation. Sri concluded by saying that she had many kinds of emotions that she kept buried inside. "They could not be expressed, then they exploded (*meledak*)."

5.2. DISCUSSION OF SRI'S NARRATIVE

Sri's illness highlights some of the key transformations that occur in early psychosis. In this section I examine the psychocultural dimensions of these transformations with reference to the work of Corin *et al.* (2004) that I reviewed in Chapter 1. While the participants did not provide narrative histories that flowed in strict temporal sequence, in this chapter I have reorganized the material into a temporal sequence so that the experience of psychosis is understandable in terms of: firstly, the process of change within the participants themselves; and secondly, the evolution of the environmental milieu. In fact, Sri herself related the above narrative to me over eight meetings, going back and forth from the present to the past, and often repeating herself. This raises an important question. To what extent does the version below represent my voice, and to

what extent does it represent Sri's voice? Ultimately it represents both. It is the product of the interaction between researcher and participant as they seek to build an intersubjective understanding of the participant's experience. It is clear that my major contribution is to have imposed a temporal sequence. However, in doing so, I have sought to use cultural categories used by Sri and other participants as they provided me with a temporal orientation to their narratives.

As stated in the introduction, it is proposed that this longitudinal course can be best understood in terms of four phases: *sebelum sakit* (before the illness), *memendam di dalam* (burying inside), *hilang kontrol* (escaping control), and *penyembuhan* (recovery). The following section examines the first three phases and how they apply to Sri's case.

5.2.1. *Sebelum Sakit:* Living in a Milieu of Contested Values

Sebelum sakit refers to the person's life before the illness began. For Sri, her life was one in which she felt the pull of opposing personal, cultural and religious values.

At a personal level the contrast was reflected in Sri's description of her character as having two opposing poles. On one hand Sri's life before the illness was characterized by her tendency to be outgoing. As a dynamic and active young woman, she was completing her diploma and was involved in many social and religious activities outside her village. Having many friends was important to Sri. On the other hand, she was strongly predisposed to keep things to herself. She preferred not to tell other people about her personal problems. She also expressed her need to have more

privacy: "Sometimes I want to have personal secrets that no one knows about. I need a time for me to be alone." Though not explicitly stating it, Sri's description of her personality was predicated on the *lahir-batin* (outside-inside) dichotomy discussed in Chapter 2. She placed importance on leading a successful life on the outside, while at the same time preserving a strong sense of inner, private self.

Sri's conflicting personal characteristics as outlined above are supported by the interpretation of the HTP test. This test indicated that she liked having social relationships and was more interested in doing things outside her house. She wanted to demonstrate her abilities and achievements. At the same time, she tended to be self-absorbed and to cling to past experiences. Sri had a tendency to be meticulous, neat, persistent and steady. The HTP test, however, also revealed that she had a tendency to be aggressive and resistant towards authority. Nonetheless, she was able to adapt to different situations and suppress her desires, needs and ambitions. And notwithstanding the tendency to aggression and resistance, she presented herself in a calm and reasonable manner. The interpretation of the HTP test suggested that suppressing her ambitions may have played a role in Sri's tendency to be anxious.

At a broader cultural level, Sri's identity was influenced by two traditions, namely the Javanese and Islamic traditions. Sri's traditional Javanese upbringing was evidenced by the fact that she learned dancing in a famous Javanese dancing school, the *Padepokan Tari Bagong Kussudiardjo*. As well as this, her involvement in the traditional Islam of the *Pesantren Krapyak* indicated a strong traditional Islamic

influence on her life. Thus, on the traditional side, Javanese and Islamic forces influenced Sri's life-world.

On the other hand, Sri's modern identity was evidenced by her involvement in activity associated with an NGO, particularly the workshop on democratization for village people, an effort to 'modernize' Javanese villagers. Sri's enrolment in a college for kindergarten teachers is another evidence of her connections to modern militant Islam, which sharply contrast with the traditional Islam of the *Pesantren Krapyak.*

All these competing influences—traditional versus modern, tolerant versus militant, religious versus secular—played a prominent role in Sri's life before the illness. They reflected the contested cultural values within Yogyakarta that I outlined in Chapter 2. Sri herself recognized this conflict as problematic. Her strategy was to bury this conflict.

5.2.2. *Memendam di Dalam:* A Psychocultural Strategy

Several months prior to her illness, Sri adopted the strategy of burying life problems within her, which she believed to have resulted in her being vulnerable to the illness. Her life problems not only centered around the abovementioned conflicts, but also around conflict within her family.

Sri's experience of religious conflict was closely linked to the tensions between the tolerant attitude of traditional Islam and the strict values of militant Islam, essayed in Chapter 2. Since she grew up within a traditional Javanese and Islamic atmosphere,

Sri's religious orientation tended toward a sense of tolerance as indicated by the way she dressed. When I met her for the first time Sri did not wear the Moslem *jilbab* (veil), leaving her long hair falling down her back like a Javanese female dancer. At other times, however, she wore a *jilbab.*[37] Even so, Sri described conflict with her fellow students at the kindergarten college. While Sri wore a Javanese style of *jilbab*, her fellow students would wear a more militant, Middle Eastern-style of dress, including a loose robe and a long, wide *jilbab*. Sri was criticized by them, she said, for not truly following strict Islamic *shariah* law.

The conflict between Sri and her mother reflected the difference in attitudes between older traditional and younger modern Javanese. Sri's mother represented a Javanese traditional culture where people were highly sensitive to the opinions of others in the village (Mulder, 1994a). In this setting people experienced a strong pressure to conform with cultural norms. Sri's mother subscribed to the idea that a girl should get married by the age of twenty. It was considered shameful and humiliating for a family to have an unmarried girl gradually becoming older and older. Sri's mother stated: "Because she is already old enough to get married and still living in the village, I wanted her to get married." As a traditional Javanese woman, Sri's mother preferred to see her daughter married than for her to have a successful career. Sri, however, was part of a modern, educated generation. Her frame of reference was oriented toward personal development, higher level education, and broader social interaction, rather than following the normative expectations of village life. On the issue of

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[37] See Brenner (1996) for a discussion of "the veil" among Javanese Moslems.

marriage, however, Sri had a dualistic attitude. On one hand she did not follow her mother's suggestion to get married to a relative. On the other hand, Sri disagreed with her younger brother marrying before she did. These problems surrounding marriage were a major concern for Sri, although Sri herself tended to play them down a little. The problems faced by Sri were in keeping with previous studies that found family problems, including marriage problems, to be the most common stressors leading to psychotic illness in Java (Browne, 1999; Good & Subandi, 2000).

The way Sri dealt with her life's problems was to become quiet and keep everything inside. This coping style corresponded not only with Sri's personality style, as revealed by the HTP test, but it was also rooted in Javanese culture. As discussed in Chapter 2, Javanese public ideals require one to conceal emotions and conflicts in order to attain *tentrem* (calmness, peace) or *rukun* (harmonious integration) in life. However, it has been pointed out that the excessive control of strong emotions can lead to behavioral disturbances such as *ngamuk* (Browne, 2001a). Sri herself perceived that the strategy of *memendam di dalam* contributed to her illness. She used a metaphor of an explosion to make sense of her illness: "Many kinds of emotions I kept inside, so they would not be expressed, then they exploded." This understanding may derive from more modern psychology popular in Yogyakarta, which advocates that emotions and conflict should be released to reduce internal pressure. However, it stood in contrast to the abovementioned cultural norms which did not permit her to express her emotions.

In sum, Sri experienced conflicts between traditional tolerant religion and strict militant religion as well as between traditional views of marriage and modern ideas that place equal or greater weight on education. She adopted the strategy of *memendam di dalam*, but even this was counterposed by modern idea of expressing feelings of conflicts. As a consequence the strategy of *memendam di dalam* did not work for Sri.

5.2.3. *Hilang Kontrol:* From Confusion to Terror

The trigger of the illness itself, according to Sri, was physical tiredness consequent on her work with the youth organization, her preparation for her brother's wedding, and her participation in the NGO workshop. She also attributed the onset of the illness to psychological distress of being the youngest participant in that workshop. These conditions resulted in her *hilang kontrol* (losing control). Although she did not exhibit any violent behavior, she said that she was not able to control her bizarre behavior. Thus, her psychotic illness was understood in terms of losing control.

Sri's experience while in the phase of *hilang kontrol* was characterized by a sense of chaotic alteration of world and self. According to her recollection, her illness began when other participants mocked her during the workshop, which led to changing perceptions about her surroundings. On her way home, she remembered everything becoming vague: the traffic looked different, the paddy field in her village she saw as the *padhang mahsyar,* and she thought her house was a graveyard. The changes in the world around her went further than this. She saw water in the well become dirty gutter water. The singing of birds sounded like a trumpet heralding the end of the world.

This was followed by the transformation of bodily experience. Sri was unable to recognize herself when she looked in the mirror. Sri's experience was that of living in a different world, akin to what Corin *et al.* (2004) refer to as the 'staggering' world. For Sri, as for Corin's participants, this world was so strange that it could scarcely be understood.

Also in keeping with Corin *et al.'s* (2004) study Sri's narrative additionally spoke to a loss of self-boundary. The loss of self-boundary was indicated by a sense of self-transparency in which she encountered a being (something or someone) who had the power to penetrate her thoughts. Sri believed that this being could read her thoughts: "So, they recognized me, they knew whatever I wanted to do." Sri's sense of time was also fundamentally altered—she experienced past and future as if they were happening now. The emergence of figures from folk stories in her symptomatology represented the past, while her experience of the end of the world—including hearing the trumpet of an angel and witnessing the Day of Judgment—represented the future.

Sri believed that she had become the central focus of the whole world, where radio and television, both national and international, talked about her. "Everything refers back to her," her mother said. She believed that she was the pig in the folk story of *babi ngepet* who stole the property in the village. She also believed she was the *Malin Kundang*, the rebel child in a Sumatran mythology; she was Tommy Suharto who was accused of being corrupt and put on trial in Jakarta; and lastly, she believed that she was responsible for the September 11 attacks on the United States. These experiences suggested that Sri was overwhelmed by guilty feelings.

Apart from feelings of guilt, *bingung* (confusion) was also prominent in Sri's narrative. This feeling initially developed as the first reaction to changing perception of the world. Later it progressively invaded every corner of her existence and manifested itself in her behavior as well. She ran back and forth inside her house, trying to perform *shalat* (daily prayer), sometimes standing, sometimes prostrating herself, but never in the correct manner. In their Indian research, Corin *et al.* (2004) found that feelings of confusion were associated with the feelings of fear. Confusion could emanate from a feeling of fear, or conversely, it could generate fear. In Sri's narrative, however, feelings of confusion and fear emerged in sequence. This is shown by the emotional terminology she used to describe her experience. Firstly, the sense of *bingung* emerged, and then it developed further to become *takut* (fear). Sri's fear was particularly associated with the vision of people holding spears who were intent on killing her. She believed that she was about to die not in the Islamic way and be burnt in hell. "I was so frightened," she said. This feeling of *takut* was followed by *serem* (being terrified). Finally, to describe the most intense fear, Sri used the term *ngeri* (being horrified). Thus, these terms (*takut, serem* and *ngeri*) indicate an increasing intensity of fear as Sri's illness unfolded.

In sum, Sri's illness narrative points to important psychocultural dimensions of early psychosis. There are striking similarities between Sri's illness experiences and the experience of people with early psychosis within an Indian cultural context. The main contribution of my research, however, lies in the temporal perspective I have applied to the material. This has enabled me to understand the cultural context of the illness,

particularly where conflicting values between Javanese traditional and modern life contribute to the development of psychotic illness.

5.3. ILLNESS EXPERIENCES OF THE OTHER PARTICIPANTS

In the following sections, I further explore the three phases I have outlined with reference to the other eight participants.

5.3.1. *Sebelum Sakit:* Contested Cultural Values

As with Sri, most of the other participants experienced growing up in an intersection between traditional and modern values. Endang (participant no. 5) provided the best example of a mixture of tradition and modernity. Similar to Sri, after graduating from high school, Endang faced the problem of arranged marriage, an old Javanese tradition. While Sri concealed the disagreement surrounding the prospect of an arranged marriage, Endang opposed her parents' suggestion openly. Endang left her village and joined her sister in Jakarta to get a job. As described in Chapter 4, she here developed an intense relationship with a woman she called *kakak* (older sister). Endang told me that, according to *kakak,* a man had fallen in love with Endang. Since Endang did not respond to his attention, the man was going to arrange for a shaman to perform sorcery on Endang. *Kakak* offered Endang protection from the sorcery provided that she stayed close to *kakak* all the time. Endang also said that *kakak* introduced her to the male spirit of a young Indonesian-American doctor who had died. This spirit could possess *kakak* and allow Endang to make love to him through *kakak*'s body. It is in this way that Endang built a physical relationship with *kakak.*

For Endang, the traditional ideas of sorcery and possession were used to legitimate the practice of a 'modern' same sex relationship.[38]

Neither Endang nor her family explicitly mentioned a same-sex relationship but the narrative they provided, particularly the above story of possession, strongly suggested this. Since it is not culturally appropriate to ask directly about same sex relationships I used projective tests to explore this issue. When Nida, my research assistant, asked her to draw a person, Endang drew a male person. After being asked to draw a female, she did so. But when she completed the third task—to draw a house, a tree and a person on one page—again she drew a male person. According to Handler (1996) most normal people (85– 90%) draw someone of the same sex, while homosexuals draw someone of the opposite sex first. The interpretation of Endang's HTP test indicates that she was not satisfied with her sexual role. She experienced conflict in the area of her sexual identity in which she was influenced by the opposite gender role. Endang's conflicted sexual role and the probability that she was engaged in a same-sex relationship was also suggested by her SCT test. She wrote: "When I was small, I often played with boys instead of girls." Extrapolating from Western-based tests (which have been normed in a Western population) to a non-Western situation (where they have not been normed) is fraught with difficulty. I have thus used the results of these tests with extreme caution. Nonetheless, the results of the HTP and the SCT in Endang's case added weight to my own interpretation, based on interview

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[38] Javanese recognize homosexual practice in the *Warok*'s tradition in east Java (see Chapter 2, section 2.5.1.). In this tradition homosexuality is a legitimate way to preserve a *Warok*'s magical power (*kasekten*). A *Warok* usually has a boy as his partner (*gemblak*). According to this tradition a *Warok* will lose his power when he has a heterosexual relationship. At present, this tradition is becoming a thing of the past. To my knowledge, there has not been any reference to lesbian relationships among traditional Javanese.

data, that there was a same sex relationship between Endang and *kakak,* and that it was an important factor in the evolution of her psychosis, especially given the negative way Endang's family reacted to the relationship.

In Bambang's case (participant no. 8) the intersection of traditional values and modern life was also evident. He practiced Javanese mysticism mixed with Islamic Sufism. He often performed ascetic exercises (*laku*) such as fasting and meditating in sacred places in remote areas to gain magical power (*kasekten*). Bambang said the most significant spiritual experience of his life, occurring many years before the illness, was one in which he felt that a dragon's spirit entered his body. However, his traditional spiritual practices were accompanied by his involvement in the use of modern drugs and other substance abuse. He disclosed to me that he often took street drugs and drank alcohol to the point of being inebriated.

For Priyo (participant no. 6), traditional religious values similarly conflicted with his desire to watch pornographic videos, and this conflict played a significant role in the evolution of his psychotic illness.

However, the intersection between traditional and modern did not always take the form of conflict. In Wati's case (participant no. 1) her father was a Javanese orchestra (*gamelan*) player, and her mother a singer (*sinden*). Wati used to sing with her mother before she got married. Yet she had no problem in reconciling this with the fact that she also worked in a modern glove-making company. Joko (participant no. 9) was a modern educated school principal, yet there was no contradiction between this and his

instructing his children to use high Javanese language (*kromo*) at home. For most participants, however, contested cultural values emerged in the symptomatology of their illness, and for some it played a direct role in the emergence of their illness.

5.3.2. *Memendam di Dalam* versus *Kaget*

Sri's strategy of burying life problems inside was also evident in most of the other participants' narratives. In this discussion I show how *kaget* (being startled) becomes a threat to the strategy of *memendam di dalam*.

Endang shared with Sri the tendency to conceal her problems inside. Her family complained that she never discussed her problems with them. This tendency to keep things to herself was seen by members of her family as a core problem; if she had not done this she might not have become ill. Endang herself asserted that she did not want to talk about her illness to her family because it was more in her character to solve problems by herself. She did not want to bother other people by telling them her problems and, more importantly, she wanted to be an independent individual. The HTP test interpretation confirmed Endang as having a tendency to focus on herself, while opposing other people, leading to feelings of alienation.

The *memendam di dalam* phase, however, was often disrupted by *kaget* (the experience of being startled), and this frequently served as the trigger for the psychotic illness. In the case of Endang the experience of *kaget* took place one afternoon when she was chatting with her neighbors and friends under an avocado tree in the back yard. Suddenly, an avocado fell from the tree and hit her on the head. She

was startled! The others laughed at her at her on account of this unusual event. That evening, Endang started to hallucinate. It is interesting to note that a subsequent relapse was triggered by an avocado falling from a tree. In this latter instance the avocado did not hit her, though it did startle her.

Another instance of the relationship between *memendam di dalam* and *kaget* can be seen in Wati's case (participant no. 1). She had been experiencing considerable family problems, having to live against her wishes with her husband's parents where there were four families living under one roof. Her reaction to this was to bury the problem inside. Wati narrated that one day, as she was about to perform prayer in her work place prayer room, someone suddenly but unintentionally threw a sandal toward her and it hit her face. "I was so startled at the time," she said. A second *kaget* experience occurred that same day. While riding her motorbike on the way home a bicycle suddenly crossed the street and collided with her. Wati again was startled. She fell off her motorbike. Although she only suffered minor injuries, when she arrived home Wati started exhibiting psychotic behavior. Both Wati and her family employed the term *kaget* to explain the trigger of her psychotic illness.

In the case of Endang and Wati, the *kaget* was occasioned by a physical event. For others, the *kaget* was more of a psychological nature. Wulan (participant no. 7) had the most striking tendency of all the participants to *memendam di dalam.* Her parents described her as always having been very quiet. "Whatever I did to her she was just quiet," her mother said. "That is so, she *is* a very quiet girl," her father added. When I tried to talk to her on several occasions her responses consisted only of a word or two.

Even when I asked my research assistant to interview her, she encountered the same problem with Wulan. At first I thought this may be a symptom of her illness, since her mother had stated that Wulan would not speak at all when she was ill (mutism). However, because she had always been like this it was more likely to be an enduring personality trait. This was supported by the HTP test. It revealed that Wulan had a very introverted personality. She experienced problems in human relationships and tended to pay little attention to other people, yet she also tended to be impulsive and aggressive. Wulan's *kaget* occurred in the context of her suddenly realizing that she was wearing the wrong uniform at a new school she was attending. She felt that others were laughing at her, and this made her feel intensely ashamed of herself. It was later that day that she became confused. Shortly after that she became psychotic.

Wulan experience bears a strong resemblance to that of Sri. Sri's *kaget* occurred when she realized that she was the youngest participant in the NGO workshop. Wulan, too, felt that people were teasing and laughing at her. The experience of intense shame was common to Sri and Wulan. And like Wulan, Sri became psychotic that day.

The idea that being startled causes illness can also be found in a number of other cultures, such as the illness of *kesambet* in Bali (Wikan, 1989), *latah* in Indo-Malay (Simons, 1996), *susto* in Latin America (Rubel *et al.,* 1984), or fright illness in Iran (Good & Delvecchio-Good, 1982). This idea is also quite common in Java (Geertz, 1961:92; Keeler, 1987:58; Browne, 2001b). Therefore, in order to prevent illnesses caused by *kaget*, Javanese seek to avoid startle experiences. A Javanese mother treats her babies gently and always holds them wherever she goes. Children should have a feeling *tentrem* and should be protected from experiencing sudden shocks. In contrast

to this child-rearing practice, one participant's father remarked that in some parts of Java there was a tradition of putting a newborn baby on a bed. Then the mother or grandmother would hit coconut sticks many times beside the baby to produce sound. The volume of sound would slowly be increased from gentle to loud. This practice is intended to make the child experience the feeling of *kaget* as early as possible so that he or she will get accustomed to loud noises. After growing up he or she will become resistant to sudden or startling shock.

Aside from causing illness, startling a person is also used for curing illnesses. Simons (1996:66) asserts that startling therapy had been applied in healing ceremonies around the world. He assumes that this is probably due to the radical changes in states of mind caused by the startling stimuli. Some Javanese also believe in this idea. In this research startling as a therapy was illustrated in Endang's case. When Endang went into a relapse and started to withdraw her family made strong efforts to get her involved in family activities. Since her family often found Endang daydreaming they tried to startle her by making loud noises or suddenly moving a chair. They believed that this technique could distract Endang's from her world of fantasy and bring her back to reality.

To summarize, *memendam di dalam* is a psychocultural strategy to deal with conflict. The goal of this strategy is to achieve a state of *tentrem lahir-batin* (inner and outer peace) that I described in Chapter 2. Sometimes the strategy is effective, but sometimes it is not successful, as in the case of Sri, Endang, Wati and Wulan. In these instances, it is very often a *kaget* experience which disrupts the state of *tentrem*.

In this context, *kaget* may serve as a trigger of psychotic illness, and it can be associated with intense shame. Equally, it could be argued that the strategy of *memendam di dalam*, by burying unresolved conflict, renders the person more susceptible to *kaget*, but a resolution of this question is beyond the scope of my thesis and the data on which it is based.

5.3.3. *Hilang kontrol: Bingung* and the Avoidance of Stigma

As they reach the stage of escaping control, most participants experience a psychotic breakdown characterized by confusion and delusional and hallucinatory experiences. In this section I discuss *bingung* (confusion) as a way of describing and naming the experience.

Bingung was a prominent feature of Sri's illness narrative. It was also evident in other participants' stories. Family members usually recognized participants' confusion through their behavior. Priyo (participant no. 6) provides a good example. In his last year at a technical high school he became ill. His father said that several days before Priyo was ill he exhibited confused behavior. When Priyo went home from his school he rode his bicycle on the right hand side of the road instead of the left. When he took public transport he went past his home. This confused behavior became more intense when he was ill. He washed his head many times and repeatedly performed *shalat* (prayer) in an unusual manner.

Similar behavior was demonstrated by Wulan during the early stages of her illness. Her mother said that one day after Wulan wore the wrong uniform to school she

began to feel confused. At first she did not want to go to school. Later on, when there was only five minutes left to go to school, she wore her uniform and told her mother that she wanted to go to school.. Ten minutes later she was back at home and now told her mother that she did not want to go to school. This inconsistent behavior made her mother lose her temper. She described her daughter has being *bingung*. Wulan became ill shortly after.

As well as describing participants' symptomatic behavior, the idiom of *bingung* was also used to name the illness. Wati—the young mother who worked in the Korean-owned factory—told her fellow workers about her illness by saying, "I was not ill, but only *bingung*." This statement was confirmed by a traditional healer from whom the family members sought help. The healer said that Wati's illness was not caused by spirits, but that she only suffered from *bingung*. In another narrative, Endang also recounted her feeling of *bingung*. "Sometimes I felt *bingung*, only *bingung*, I wasn't ill," she said. These examples indicate that both Wati and Endang rejected the notion that they experienced a mental illness, claiming that they only suffered from a state of confusion. By so doing, the idea of madness was bracketed in order to reduce the associated stigma. Note that it was widely used, not only by participants, but also their family members and traditional healers.

The use of a symptom as an *emic* diagnosis is evident in other cultures, such as that of Hispanic families. They prefer to use the term *nervios*, which carries less stigma than craziness or mental illness (Jenkins *et al.*, 1986; Jenkins, 1988; Guarnaccia, *et al.*, 1992). Here Javanese tend to use many different terms. *Bingung* is just one of them. A

modern popular term *setres* (stress) was used by some participants. Wati's father used the term *konslet* (electrical short circuit), which he reasoned had been the cause of his daughter's *sarap* (nerves). Endang's mother used her own term, *sakit kecewa* (illness from disappointment). Sri called her illness *eror* (error), a term that is usually used to refer to a computer software problem. Meanwhile Sri's mother and Wulan's mother avoided using any particular term for their daughters' predicament. When discussing the illness they applied a vague term, such as *sakit seperti itu* (an illness like that). Table 5.1. shows the terms commonly used for naming mental illness in Java.

Table 5.1. Local Terms for mental illness

	Javanese Terms	**Indonesian Terms**	**Borrowed from English / Dutch**
Kasar (crude)	*Edan* (Crazy) *Sinthing* (Crazy) *Gendeng* (Crazy) *Kenter* (Crazy) *Gemblong* (Crazy)	*Gila* (Crazy, Insane)	
Halus (refined)	*Miring* (At an angle) *Setrep* (Minus) *Ora normal* (Not normal) *Ora genep* (Not complete) *Sarap* (Nerves)	*Syaraf* (Nerves) *Sakit Jiwa* (Mental Illness) *Hilang akal* (Loss of mind) *Bingung* (Confused)	*Setres* (Stress) *Eror* (Error) *Konslet* (*short circuit)*
Ilmiah (medical)		*Gangguan Jiwa* or *Gangguan mental* (Mental Disorder)	*Psikosis* (Psychosis) *Skizophrenia* (Schizophrenia)

The columns differentiate between Javanese, Indonesian, and borrowed terms. The rows distinguish between rough terminology and refined terminology, with a separate row for medical terms. Crude *(kasar)* terms tend to imply that the illness is severe and

incurable, whereas refined (*halus*) terms provide a more optimistic idea that the illness can be cured. All terms in the central (refined) row tend to have the same effect as *bingung* in minimizing stigma. Note, however, that the medical term, *Skizophrenia*, carried the same connotations as it does in the West. As a university student, Endang learned the term 'schizophrenia' from one of the lectures she attended. When she learned that her illness could be classified as 'schizophrenia,' she also absorbed the idea that it was a degenerative and life-long illness.

5.4. SUMMARY

In this chapter I have argued that participant's illness narratives can be divided into four phases: *sebelum sakit* (before the illness), *memendam di dalam* (burying inside), *hilang kontrol* (escaping control), *penyembuhan* (recovery). It is worth reiterating that participants and their families did not neatly arrange their narratives into these phases for me by beginning at the beginning and ending at the end. Rather I discerned the phases by observing how participants would frequently make temporal references to their illnesses using the terminology that I have set out. As such, the phases I identified form a cultural template by which people organized their illness experience.

They bear some similarities to the work of Johannessen *et al.* (1999), who delineates five phases in the development of psychotic illness: premorbid phase, prodromal phase, acute (or psychotic) phase, symptom remission, and relapse or recovery. The premorbid phase is comparable to the *sebelum sakit* phase; the prodromal phase is analogous to the *memendam di dalam* phase; and the acute phase is similar to the

hilang kontrol phase. The psychocultural perspective that I have taken enriches our understanding of participants' lifeworld by using *emic* categories and relating these to participants' experience.

I was able to develop a richer understanding of the unfolding of psychotic illness by relating the phases I identified in this chapter to my analysis of Javanese culture in modern day Yogyakarta. I have argued, for example, that an understanding of the *sebelum sakit* phase is predicated on an understanding of participants' lives in Yogyakarta, where traditional and modern values are being contested. Browne (1999) suggested that sexuality is one of the prominent points of contestation. In this research the issues of same sex relationships, watching pornographic videos, and masturbation stand in opposition to traditional and religious values. Other similar issues include drug abuse, corruption, family conflict, and late marriage.

The contrast between traditional values and a modern lifestyle generates tension and conflict. The *memendam di dalam* phase is characterized by participants' effort to keep these tensions and conflict inside. This research suggests that concealing emotion and conflict not only has psychological origins, but is also grounded in cultural values. It is important to note here that a goal of *memendam di dalam* is to promote *tentrem,* a calm, quiet, and peaceful life. On the other hand, it is possible that it renders individuals vulnerable to illness, including psychotic illness. Even the strategy of *memendam di dalam* itself is now challenged by the belief fostered by popular psychology that it is better to let emotions out. I have advanced the argument

that *kaget* (being startled), both in a physical and a psychological sense, is perceived as causing one to lose control, thereby triggering psychotic illness.

In the *hilang kontrol* phase, participants describe their reaction to their hallucination and delusional experiences as being one of fear and sometimes terror. The prominent feature in this phase is *bingung* (confusion). This feature is shared in common with the experience of people with early psychosis within an Indian cultural context (Corin *et al.*, 2004). However, in this research, *bingung* is not only used by participants to describe their psychotic experiences, but also to name the illness in order to avoid stigma.

In conclusion, there is an overall theme of control and order that runs through these Javanese phasic conceptions of mental illness. In the *sebelum sakit* phase, order is threatened by conflict. In the *memendam di dalam* phase there is an effort to preserve order by burying conflict so that the person can maintain *tentrem.* The major threat in this phase is *kaget.* The third phase, *hilang kontrol,* represents the break down of order. It is characterized, par excellence, by confusion, *bingung,* the immediate precursor to, and indeed the first sign of psychosis.

CHAPTER 6

FAMILY DIMENSIONS OF PSYCHOTIC ILLNESS

In this chapter I explore some of the complexities of the family context within which psychosis is experienced. The literature I reviewed in Chapter 1 indicated that one hypothesized reason for schizophrenia having a benign course of illness in developing countries has to do with the cultural 'explanatory models' (Kleinman, 1980; Lin & Kleinman, 1988) of mental illness. In this chapter I first explore the diverse and changing family models of illness that run the gamut from supernatural to psychological to physical explanations, focusing on the extent to which families seek to minimize stigma.

A second hypothesis concerns the role of family emotional milieu in promoting or impeding recovery. I address this with reference to the concept of Expressed Emotion (EE), drawing on the work of Jenkins (1991) who has emphasized the issue of cultural validity of subcomponents of EE, especially 'criticism' and 'overinvolvement,' and who has argued strongly for ethnographic approaches to this topic. My discussion of EE is complemented by attention to the issue of support, wherein the family is perceived in a positive light as providing an atmosphere within which a person with psychosis can recover.

In addition to looking at the impact of the family on the person who suffers from psychotic illness, I also look at the effects that such an illness can have on the family. Thus, in the last section I examine the burden experienced by some families especially in relation to stigma, and the strategies they adopt to cope. In doing so, I bring together two literatures that are often separate, the EE literature and the family burden literature. By looking in fine-grained detail at one culture, and by bringing a mix of ethnographic and clinical data to bear on the topic, I aim to demonstrate the complexity of emotional responses, the apparent contradictions, and the management of contradiction, as families struggle to handle psychotic illness. In concluding my analysis, I also point to the underlying cultural values that give a sense of coherence to this fraught process.

This chapter repeats the structure of Chapter 5. First, I present the family narrative of one person, Wati (participant no. 1), addressing each of the themes outlined above, after which I further explore these themes with reference to data from the other participants.

6.1. WATI'S PROBLEM IN ITS FAMILY CONTEXT

I visited Wati (participant no. 1) and her family for the first time in August 2002. They lived in a village about twenty kilometers east of the city. Wati's mother, who was carrying a small child in a *selendang* (long shawl), greeted me for the first time. After telling her about the purpose of my visit she invited me into the house. It was typical of the old Javanese village-style dwellings with a particular kind of roof called

a *limasan.*[39] The front yard was wide, giving ample space for children to play in. In the left corner of the yard was an enclosure for chickens and goats. The house itself was large and of brick construction. The front wall was made of wood and had seven doors. Just two were open. The other five would only be opened for major occasions such as community or religious gatherings. Wati's mother told me that the child she was carrying was Wati's ten-month-old son. It was her place to *ngemong* (gently care for) this grandchild when Wati went to work and when Wati was sick. Several minutes later, Wati's father, who was in his 60s, appeared. Wati herself then joined us for the interview. Together they related their story. What follows below is a summary of Wati's family narrative which I recorded on that occasion and over six subsequent interview sessions.

Wati's mother said that Wati was the second of five surviving children (two had died when they were less than five years old). The eldest was a brother, not yet married, who lived and worked in Jakarta. The other four lived together in the family house. Of these four, two were married and two were single. Wati had married a man from a neighboring village and they had a one-year-old son. At the time of my fieldwork, her husband worked in Semarang, four hours by road from Yogyakarta, and he came home every other week to visit briefly. Wati's next younger sister was also married and she also had one son. This sister's husband, who worked in Jakarta, rarely came home. The other two, a younger sister, and her brother, the youngest of all, were not married.

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[39] A *limasan* is a distinctive roof with steep sides and a level central section. For a description of Javanese houses see Koentjaraningrat (1985:135).

Wati perceived her family relationship to be supportive. All family members provided mutual help, respected each other, and lived in *rukun* (harmonious integration) with each other. Wati's father commented, "Praise be to God, my children live together in *rukun* so that I feel *tentrem* (quiet, calm, peaceful)." When Wati was young, it was her role to *ngemong* (gently care for) her younger siblings. Now that she worked it was the role of her mother and her sisters to *ngemong* her son. As I observed over the course of my visits, Wati's mother carried Wati's son on her hip most of time. Wati's son, I was told, always cried when his grandmother left him but not when his mother went to work, which meant that the child may have become more attached to his grandmother than to his mother. In this household, cooking was conducted collectively. The extended family also shared financial responsibilities. It was this capacity to care for each other and share responsibilities with very little friction that made Wati's family an exemplar of *rukun* and *tentrem.*

Wati remarked that ever since her marriage, she and her husband had lived in her parents' house, as was customary for Javanese, and only occasionally had they visited her husband's parents. Problems began four months after she gave birth to her son. Suddenly her husband asked her to move to his parent's house. She said her husband felt that Wati needed to get closer to his family. Wati refused to move because she worried about who would take care of her son when she went to work. But her husband insisted they move. According to Wati, however, he did not provide sufficient reason to make this major change. Wati disclosed that despite her being angry with her husband, she eventually relented and moved to live with her parents-in-law.

In the household of her parents-in-law there also lived two adult married children: one, a sister-in-law with her husband and three children; the other, a brother-in-law with his wife and child. When Wati moved in, it meant that her parents-in-law plus three married couples and their children now lived under one roof. Wati said that each family unit was self-contained. They did not share their problems with each other, nor share household responsibilities. This contrasted with the situation in her family home where there was an ethos of mutual support. Cooking and eating in the new house became an issue that gave rise to conflict. The wife of her brother-in-law cooked for her own family, while the rest all cooked together. Another problem was that Wati was working while the wife of her brother-in-law stayed at home. Wati sensed that she was jealous because she and her mother-in-law had to do the household work, including taking care of Wati's son, while Wati was away from the house working. Another problem emerged when Wati's husband had to move to Semarang on account of his work. Wati felt that it was too hard for her to continue live in her in-laws' house with all these families crowded in there and without her husband being present. Therefore, when her husband left, Wati used this opportunity to return to her own parents' house, although she felt guilty about opposing her husband's will. Against this background of simmering family tension, Wati suddenly had the two *kaget* (startle) experiences that I discussed in section 5.3.2., whereby she was hit in the face by someone's sandal while she was going to pray and, later that day, when she was knocked off her motorbike. These formed the immediate precursors to her illness.

Wati's father told me that when Wati became sick everyone in the family became *bingung* (confused), Wati included. They did not know what to do. However, they did

their best to find appropriate treatment for Wati. At first they thought that she might be possessed so they sought help from a *wong pinter* (knowledgeable person, healer). Since the healer said that she was not possessed, Wati was then brought by her husband and other relatives to the community health center (*puskesmas*) and thence to Sarjito General Hospital.

Wati reported that she was hospitalized for six days. During that time her husband stayed with her while her mother looked after their son. When Wati returned from hospital her neighbors came to visit bringing food with them. Her friends in the factory collected some money to alleviate the financial burden of hospitalization. More importantly, Wati noticed that the attitude of her sister-in-law had changed: "She seemed to be aware that my illness was partly because of her jealous attitude, so now she is very kind to me."

6.2. CONCEPTS OF ILLNESS, TENSION, AND SUPPORT IN WATI'S FAMILY

Wati's family narrative illustrates the way in which family members quickly invoked a number of explanatory models comprising several conceptions of illness, each of them pragmatically oriented to seeking help for her. They perceived factors related to the family itself to be a source of tension, and thus to play a role in causing the illness. But at the same time they perceived the family as a source of support and thus central to the recovery process. In this section I will deal with these themes as they relate to Wati and her family.

6.2.1. Diverse and Changing Family Conceptions of Illness

When suddenly confronted with Wati's unusual behavior her family at first thought she was possessed. The idea of possession is very common among Javanese. Wati's father explained to me that possession could happen when a person had *pikiran kosong*, that is, empty thoughts or daydreaming. In this condition a spirit could easily enter and take control of one's body. He thought Wati might have been daydreaming, rendering her vulnerable to the experience of *kaget* (being startled) when someone had inadvertently thrown a sandal that hit her in the face. Based on the idea she was possessed, Wati's family sought help for her from a traditional healer, in this case a *wong pinter*. The healer said that there was no evidence of possession at all. Furthermore, he did not think that she was *edan* (crazy) but only *bingung* (confused), a term I have shown to be far less stigmatizing. In response to this opinion they changed to a more physical framework of interpretation.

There were three different physical explanations that Wati's family invoked, one that her illness might be inherited, another that it was a case of *sarap* (nerves), and a third, that her illness was a condition that was somehow related to the birth of her child. When discussing the cause of Wati's illness, her mother referred to two cases of mental illness in the village that she suspected as having an inherited basis, but she repeatedly emphasized that Wati's illness was not, in fact, inherited. Nevertheless, referring to these cases, Wati's mother expressed the hope that her daughter would make a full recovery, since both of these other people had recovered. "I hope Wati will recover like they did," she said.

Wati's father invoked about another physical concept, *sarap,* which refers to damaged nerves. The Javanese concept of *sarap* is similar to the concept of *nervios* that is used among Hispanic families (Guarnaccia, *et al.*, 1992). Both are less stigmatizing than the respective terms for 'crazy.' However there is a crucial difference. For Hispanic families the term *nervios* does not necessarily imply a long-term illness, while in Java the term *sarap* may have less favorable prognostic implications. It means that the person may have a physical defect and therefore that full recovery may be difficult for them. It is notable, therefore, that Wati's mother disagreed with her husband, emphasizing that Wati did not suffer from *sarap* at all.

Wati's mother also attributed her daughter's illness to her behavior following the birth of her son. Wati's mother told me that according to Javanese tradition a mother should have prolonged physical rest and be psychologically at peace after she gives birth to a baby. In Wati's case, she returned to work after three months' maternity leave. Her mother thought that Wati was still physically vulnerable at that time. Furthermore, during work breaks she had to return home and breast feed her son, rendering her even more vulnerable.

In later interviews Wati's family referred to the more psychological concept of *tentrem* (quietness, calmness, peace) and *tekanan batin* (inner pressure). As discussed in Chapter 2, Javanese place a high value on the idea of living in *tentrem* both in the *lahir* (outer) and the *batin* (inner) dimensions of life. Any disruption of *tentrem*, it is said, may lead to physical and psychological disturbance. The feeling of *tentrem* that Wati found in her family of origin evaporated when she had to move and live with her

husband's family, resulting in *tekanan batin*. Wati's family believed that she would recover when she returned to live with her family of origin and feel *tentrem* again. Her mother said, "At that time Wati experienced *tekanan batin*, now she feels *tentrem* again."

Thus, there were two characteristics of Wati's family's conceptions of illness. First, was their diversity. The illness was understood from many different perspectives, ranging from supernatural, to physical, to psychological. This diversity does not necessarily mean contradiction. They were all encompassed within a cultural framework of support and the anticipation of recovery. And the concept of *tentrem,* or loss of *tentrem,* lay underneath all of them. Second, the prevailing conception of illness changed over time in response to negotiation between family members, with a healer, and with other health care providers. For Wati herself, the most significant explanation for her illness was that of family tension.

6.2.2. Wati's Broader Family as Source of Tension

I have previously made the point that although the kinship system in Java is bilateral, there is a marked tendency for newly wedded couples to live with the wife's family of origin. In accordance with this tradition, Wati and her husband lived with Wati's family after their marriage. The problem emerged when Wati had to move to her husband's family where she experienced four family problems. First, she felt that she was being forced by her husband against her wishes to live with his parents. Second, she had to live not only with her parents-in-law but also with the other two families, Wati's husband's siblings, their spouses and children, under the one roof. Third, her

husband's move to another city for employment left her alone with his family. Fourth, she felt that she had betrayed her husband when she eventually moved back to her own family.

Having more than one household live under one roof does not always generate problems. Wati's own family was evidence of this. In contrast, however, her in-laws' family home was beset by conflict and jealousy, and it was this, she believed, that led to her illness.

As discussed in Chapter 2, family problems are commonly perceived as leading to the development of psychotic illness in Java. In our previous survey of 304 cases (Good & Subandi, 2000), the predominant stressor was considered to be related to family tension. This included marital conflict, conflict between sisters-in-law, broken homes, divorce, quarrels with husbands, infidelity, and either parent having to live apart from the family. These findings are in accord with Wati's situation. She experienced marital conflict when her husband insisted they move into his family's house, and when he subsequently went away to another city. And she experienced conflict with her sister-in-law, which she perceived to be an issue of jealousy. Thus, I should emphasize at this point that extended families in developing countries do not always provide support as previously hypothesized (see Desjarlais *et al.*, 1995). Sometimes they can become a source of tension and conflict. In Wati's case, however, the role of her immediate family in providing support was significant in her recovery.

6.2.3. Wati's Immediate Family as a Source of Support

The emotional atmosphere in Wati's family of origin was *rukun* and *tentrem*, despite the fact that her parents, her family, her sisters' family, and her unmarried sister and brother all lived there together. This is supported by the results of the SCT test which revealed that Wati's perception of her family was very positive. She described her father as being "wise in making decisions for his children." She perceived her mother as being "very helpful in dealing with work-related problems or financial matters." In regard to her siblings, Wati described them as both helpful. The result of the LEE provided similar corroborative evidence. The score indicates that she perceived her family as low on criticism, irritability, and intrusiveness.

The supportive atmosphere in Wati's family was also indicated by the rapidity of their care-seeking behavior, taking her first to a traditional healer, then to a community health center, and then to the psychiatric ward at Sarjito Hospital. Wati's husband also played a significant role. First, he was willing to accompany Wati to hospital during the illness despite the fact that his work place was so far away. Second, he was willing to back down over the issue of where they lived, by agreeing that Wati should return to live with her own family. For Wati, returning to her family of origin meant she could regain the *tentrem* and *rukun* that she had lost.

Wati also received great support from her social network, her neighbors and her fellow workers. It is customary when one member of a community falls ill for others to feel a social obligation to visit, whether at home or at hospital. They usually bring food or fruit or donate a small amount of money. For Wati, her wider support network

played a positive role both in the process of symptomatic recovery and in the task of returning to the community.

In sum, I have shown that there are diverse views of illness within the family. Sometimes this led to a difference of opinion, as when her father and mother disagreed over whether she was suffering from *sarap*. For the most part, however, these differing conceptualizations of the illness were not inherently contradictory. By examining Wati's family narrative in some detail, I have also shown how her broader family constituted a source of tension that could only be understood within the context of Javanese kinship and marriage patterns. At the same time, her immediate family was perceived as a source of *tentrem,* which was considered therapeutic in and of itself. This apparent contradiction was embodied in the person of the husband who, in wanting her to live with his family, was perceived as playing a role in precipitating the illness, but who then behaved in a very sympathetic way when she became ill, supporting the move back to her family.

I now explore these themes in relation to the narratives provided by the other participants' families.

6.3. DIVERSE AND CHANGING FAMILY EXPLANATORY MODELS

As with Wati's family, other participants' families employed diverse and changing explanatory models which were linked to the pragmatic purpose of seeking treatment

for their sick family member, but which also served to make sense of and thereby shape the experience of illness.

6.3.1. Supernatural Explanations: *Kemasukan* and *Guna-guna*

Kemasukan (possession) was the most common concept used by family members in relation to psychosis. This echoes broader cultural beliefs in Java. Traditional Javanese tend to adopt the explanation of *kemasukan* when exposed to any strange and unusual behavior. Many believe that spirits directly possess a person because he or she has disturbed the life of the spirits, for example by cutting a tree where the spirit is believed to reside. The father of Rima (participant no. 2) explained that his daughter's illness was caused by a spirit who previously lived in a *keris* (dagger) belonging to Rima's grandfather. After her grandfather died no one took a proper care of the *keris*. The spirit became angry and entered Rima's body. Rima's father adopted this explanation from a traditional healer, in this case a *paranormal*, who then helped him to perform a ritual on the *keris* to care for its spirit.

Other participants believed that a spirit was intentionally inserted by some one into their body through certain practices, such as cultivating *tenaga dalam* (inner power) or *kasekten* (magical power). An example of this is found in the case of Joko (participant no. 9). He told me that during an inauguration ceremony in a *tenaga dalam* school he had just joined, the members were being 'opened' by the instructors. He suspected that during that time spirits were inserted into the members' bodies to provide strength, including into his body. After quitting the practice of *tenaga dalam*, Joko later received a spiritual instruction from an Islamic leader to recite particular

Qur'anic verses. Joko and his wife believed that his illness was partly caused by the 'clash of power' between the power of the spirit inside his body (derived from his practice of *tenaga dalam*) and divine power (consequent on reciting the Qur'an).

In Joko's case, the practice of *tenaga dalam* was perceived to lead indirectly to psychotic illness. Browne (1999:88) has noted that this practice may in some cases directly initiate psychotic illness. The idea that spiritual practice may initiate psychotic illness is to be found in Bambang's narrative (participant no. 8). He believed that his illness was caused by his excessive *laku* (ascetic exercise). He was instructed by his spiritual guide to repeatedly recite a short prayer. Instead of following the prescribed number of repetitions, he recited it more often than instructed. According to Bambang this is what led directly to his illness.

Other supernatural explanations include *guna-guna* (sorcery). For example, the family of Endang (participant no. 5) believed that her illness was caused by *guna-guna* arranged by someone who had wanted to marry her but who had been rejected by her. In Rima's case, her father also employed this explanation. He believed that his daughter's illness was caused by a neighbor who hated him and consequently used *guna-guna* against him. The neighbor had wanted to harm Rima's father but the *guna-guna* inadvertently affected Rima instead.

The most complicated use of *guna-guna* can be found in the narrative provided by the family of Budi (participant no. 3). As discussed in Chapter 4, before he was sick, he became involved in the activities of an Islamic militant group the *Lasykar Jihad* and

wanted to go to Afghanistan. His father suspected that the *Lasykar Jihad* had used a *guna-guna* to influence his son. His suspicion was confirmed by Budi himself, who said that he was asked to drink something while at a *Lasykar Jihad* meeting. After returning from the meeting Budi exhibited psychotic behavior and so the family took him to Sarjito Hospital. His father was convinced that the drink contained *guna-guna.*

Returning from the hospital, Budi was not totally cured and his father then sought help from a friend who he considered to have expertise in removing the influence of *guna-guna*. The friend came to their house and carried out the treatment in Budi's room. While Budi was being treated in his room the door was locked and Budi's father did not know what his friend was doing to his son. Several days later Budi became very aggressive, ran amok (*ngamuk*) and hurt himself. Budi's father then sought help from another healer, a *paranormal*. He was told by the *paranormal* that instead of healing his son, his so-called friend had used this opportunity to make the illness worse by performing *guna-guna* on his son. The reason he did so was because he deeply resented Budi's father. As Budi failed to improve his father sought help from several other *paranormal*. Finally one of them was able to remove three spirits (*jin*) from Budi's body. Only then, said his father, did Budi recover completely.

Thus, participants and their family members employed supernatural concepts of two principal types of *kemasukan*, and *guna-guna*. Almost every family in this study used one or other of these ideas as the first way of making sense of the illness before considering other explanations. For some families the idea of possession remained

unchanged, whereas in other families the idea of possession was replaced by more psychological explanations as the illness evolved.

6.3.2. Psychological Explanations: *Kagol, Tertekan*, and *Setres*

The Javanese term *kagol*—which literally means frustration or disappointment—is usually used in reference to children. According to Javanese tradition, a child has not yet developed the ability to tolerate frustration and disappointment. Children usually feel *kagol* when they do not get what they want. Wati's parents said, "As far as possible children should be amused all the time so they do not feel *kagol.*" The term can also be used in relation to mental illness. Zaumseil & Lessmann (1995) as well as Good & Subandi (2004) have found that *kagol* is perceived as a possible cause of mental illness. Both sets of researchers identified several cases in which young people were said to have developed a mental illness because they did not get the motorbike of their choice. In the present study, the mother of Sri (participant no. 4) attributed her daughter's illness to *kagol* because she (her mother) had pressed Sri to get married while Sri wanted to continue her studies. Mental health professionals working in Yogyakarta also consider that *kagol* plays a significant role in mental illness. Rima's mother told me that her doctor warned her not to let her daughter feel *kagol*, in order to prevent relapse. Therefore when Rima wanted a motorbike her father had to sell his cow to buy it!

Figure 6.1. Graffiti tag: *Kagol*

Another psychological explanation is conveyed by the Indonesian term *tertekan* (under pressure). This term derives from the word *tekan* meaning to inhibit, restrain, or apply pressure. The mother of Wulan (participant no. 7), for instance, thought that prior to the incident of wearing a wrong uniform Wulan might have felt *tertekan*. This was because Wulan had wanted to go to a vocational school, but her father insisted she go to a general school where the standards were much higher and the work much harder. Wulan thus felt the pressure of having to perform at a level that was above her capacity. In Sri's case, her mother said that Sri might have felt *tertekan* because she was afraid to say that she did not agree with her younger brother's marriage.

Interestingly, participants' family members used different loci of *tertekan*, including *tertekan pikirane* (pressure on the mind) and *tertekan atine* (pressure on the heart). Both were conceived as *tekanan batin* (inner pressure). The meanings connoted by *tertekan* overlap with those associated with *setres,* a word borrowed from English that

has come into more prominent use in the past two decades. It is notable here that Sri herself used the term *setres* interchangeably with *tertekan.*

Psychological explanations thus range from traditional Javanese ideas of *kagol* to Indonesian ideas of *tertekan* which overlap with the borrowed term *setres.* We see here an amalgum of traditional and modern concepts conveying slightly different nuances of meaning, but used without any apparent contradiction. Furthermore, I found that the psychological concepts I have described were also used in conjunction with supernatural explanations. For example, Joko's wife thought that her husband's illness was caused by *kemasukan* but at the same time she believed he had also suffered from *tertekan* due to problems he had encountered at work.

6.3.3. Changing Explanatory Models

A characteristic feature of family explanatory models was that they changed through time as the illness unfolded, one concept replaced by another, depending mainly on the treatment context. Such change was best illustrated in Rima's narrative.

In the first interview Rima's father sought a psychological explanation because he regarded her to be a highly sensitive person and thought this personality trait may have contributed to her psychotic illness by rendering her vulnerable to *tertekan.* He said, for example, that when her friends at work teased her, Rima took this very seriously because she was so sensitive. Later, when Rima's psychotic illness persisted for several months, her father started to believe that she was possessed by the spirit that lived in her grandfather's *keris* (dagger). This idea of *kemasukan* was confirmed,

for Rima's father, by her rude behavior. He said, "If she was my real daughter, she would have paid respect to me, because all my children pay respect to me, but she talked harshly to me." Rima's unwillingness to take the medicine he also attributed to the influence of the spirit. The belief in *kemasukan* was also confirmed for him when a powerful healer was finally able to chase the spirit away. As a consequence, he said, Rima displayed no psychotic symptoms for several months. Her father, however, explicitly stated that his understanding of her illness might change in the future. In fact, when Rima relapsed and was taken to hospital her father sought yet another explanation. This time, he proposed that his spiteful neighbor used *guna-guna*.

The ethnographic data I have presented thus far indicate that the understandings of psychotic illness developed by family members are complex. They tend to employ several different concepts. Sometimes these concepts are contradictory and reflect the contested cultural values in Yogyakarta, where traditional beliefs in possession and sorcery are challenged by more psychological explanations that include notions of *kaget, kagol, tertekan,* and *setres.* However, I have shown how sometimes apparently contradictory concepts of illness are applied at the same time. More commonly they occur one after the other within shifting illness and treatment contexts. What might seem to be contradictory views are thereby incorporated into a dynamic and changing family response to illness. Corin *et al.* (2004:124) similarly found 'fluid and shifting' explanatory models among her Indian participants. Thus, a cross-sectional assessment, at a single point in time that has been applied by a number of researchers (Phillips, *et al.*, 2000; Ohaeri & Fido, 2001) does not provide an adequate picture of family responses to psychosis.

6.4. FAMILY EXPRESSED EMOTION (EE) IN CULTURAL CONTEXT

In this section, I discuss the family emotional environment and its influence on the participants by drawing on data from three sources, the Level of Expressed Emotion (LEE) scale, the Sentence Completion Test (SCT), and ethnographic data.

Table 6.1. The LEE score

No.	Pseudonym	LEE Score
1	Wati	48
2	Rima	85
3	Budi	68
4	Sri	104
5	Endang	102
6	Priyo	40
7	Wulan	70
8	Bambang	59
9	Joko	55

Table 6.1 presents the results of the LEE scores. There are two caveats to the following analysis. First, due to the small size of the sample, and the fact that this instrument has not yet been normed on an Indonesian sample, it is not possible to establish an appropriate cut-off point to distinguish between low and high scoring families. However, on visual inspection of Table 6.1. it is evident that Sri and Endang obtained the highest and second highest scores and that they were well separated from the rest, the third highest, that of Rima, being 17 below that of Endang. Both the result

of the SCT and ethnographic data support these findings. Second, Jenkins (1991) has cautioned against drawing conclusions from family EE in individual cases.

> The predictive value of EE, like any statistical analysis, is limited and must be confined to discussion of large group differences. It tells us nothing about how given individuals might intend their communications or how these might be interpreted by persons to whom they are directed (1991:418).

With these caveats in mind, I examine the two highest scoring families because these are the families that if they formed part of a larger sample, would have EE scores likely to be associated with relapse. Rima's family also needs to be considered because their situation carries significant implications for EE in relation to the idea of boundary transgression.

6.4.1. Sri and the Interpretation of EE

Sri's LEE score was the highest among the participants, which is to say that Sri perceived her mother to exhibit a high level of EE. Ethnographic observation also revealed that her mother was often highly critical of her and overtly hostile toward her. These are two sub components of EE. Sri described her mother as being 'fierce.' In the SCT test she wrote: "My mother often loses her temper." When Sri came home late one evening from an organizational meeting her mother became furious. Sri also told a story that after she had a hair cut and returned home with her friends, her mother suddenly lost her temper and hit her with a wooden stick in front of these friends. In addition, Sri's mother also showed a high degree of overinvolvement, another component of EE. In one of my interviews Sri's mother disclosed that she

thought deeply about the family problems, including the problem of Sri's marriage and her illness. She would often bring up these problems in discussion with Sri. Furthermore, Sri's mother said that these leave as worries went round and round in her head so much so that she became depressed and wanted to die. She lost weight dramatically, and her health deteriorated. When I interviewed Sri's mother before she died she still showed her annoyance at Sri for refusing to get married.

The criticism exhibited by Sri's mother can be examined in the light of Jenkins' (1991) idea of cultural rule violation. Jenkins has proposed that the critical comment component of EE should be define in terms of cultural rule violation rather than personality-based criticism. In Sri's case, her mother's criticism and hostile behavior occurred in the context of Sri's violation of cultural norms. By traditional Javanese values it would be considered inappropriate behavior for a girl to return home late at night. Therefore when Sri did this her mother became furious. Also, her mother became annoyed when Sri refused to get married. From her mother's perspective Sri had violated the cultural norms of age appropriate marriage. At the same time it could be argued that Sri's mother's style of criticism itself violated a cultural rule insofar as she punished Sri physically in front of her friends. Given that hostility is so closely linked to criticism, the same argument could be mounted that the overt expression of anger by Sri's mother is best evaluated in terms of cultural rule violation.

Yet despite her mother's strong criticism, open hostility, and overinvolvement, Sri interpreted her mother's behavior in a *positive* way. She said that it was the way her mother expressed love for her. In the SCT Sri's wrote: "My mother is very kind and

very close to me." Thus, it could be argued, the high EE evidenced by Sri's mother, and the criticism and hostility in particular, may not have had a major negative effect on Sri. Although Sri returned to live with her mother, she recovered well. This raises the issue of the importance of considering the meaning of EE according to participants' interpretation. It bears out Jenkins (1991:418) point, cited above, that it is critical to understand "how given individuals might intend their communication," as well as to understand "how these might be interpreted by persons to whom they are directed." To the best of my knowledge, the issue of meaning of EE from the ill member's interpretation has not been addressed in EE studies. It goes beyond the issue of 'perceived' EE that has been discussed in some of the literature (see Bachmann *et al.*, 2006; Cutting *et al.*, 2006).

The LEE, like the CFI, takes account of the level of EE of one or two key family members. An advantage of ethnographic observation is that a more rounded picture can be developed of the emotional atmosphere within the whole family. In Sri's case it was only her mother who exhibited high EE. Sri perceived her father to be a distant figure, always busy with his work outside the home. But her elder brother emerged as a key figure and he had a warm and supportive attitude. During Sri's recovery it was her brother who accompanied her to attend a class at the kindergarten college for the first time. He also helped Sri to change the house to a kindergarten class at her later stage of recovery.

Sri's case thus highlights the fact that a participant's interpretation of criticism, hostility, and overinvolvement may play a role in mitigating the effects of EE.

Furthermore it suggests that there may be more than one or two key family members that contribute to EE, and that taking account of the whole family may provide a more accurate view of the family emotional atmosphere.

6.4.2. Endang and the Coexistence of Criticism and Warmth

In Endang's family the LEE score, the results of the SCT and my ethnographic observations all suggested high levels of criticism. Her mother, her father and her sister were all highly critical. In fact, they often criticized each other to the extent that her father asked in anguish: "Why is our family not united?" In one interview Endang's father criticized her mother for controlling Endang too much, for example by not allowing her to ride a motorbike. He wrote in one answer on the SCT test: "I feel my wife is quite good but she is still not able to be a good parent." He also criticized Endang's attitude of wanting to solve all her problems by herself. In return, Endang criticized her father, writing: "I feel my father is a quiet person; he prefers to hear the opinions of other people instead of his family; when there is a problem, he does not want to share it with us." Endang also criticized her mother, writing in the SCT test: "My mother often loses her temper; when she has an opinion, no one can change her mind." Later she added, "My mother and I often quarrel, we have incompatible ideas." On several occasions her mother defended herself by saying that she did not want to be blamed for causing the illness. In fact, she blamed Endang herself for the illness. Further to all this, Endang disclosed that she often quarreled with her sister because her sister insisted that Endang follow her opinions and satisfy her demands. The following is an excerpt from field notes that I recorded on 22

January 2003. I was able to interview the whole family and record the tense emotional atmosphere that pervaded the home:

> Firstly, I interviewed Endang and then her mother joined in, followed soon after by her sister. Endang said that when she was sick, she felt her family did not pay enough attention to her. Suddenly, her elder sister interrupted sharply:
>
> "That means you were not sick! You were obviously aware of what was going on around you."
>
> "It was half aware and half not," Endang replied.
>
> "So you are just pretending!" her sister said in a confrontational tone of voice.
>
> "No, I wasn't!" Endang shouted. "I was being ordered by voices to do this and that."
>
> This argument continued to the point where Endang remarked that when she graduated from high school, she wanted to go to university.
>
> "I wanted to have a part-time job and go to the university," Endang said.
>
> "We did not stop you," her sister interjected, "but it depended on whether you could do it or not. If you were able to do it you could have gone."
>
> Her mother interrupted, turning to me and saying,
>
> "It was her own fault. I don't want to be blamed. When she graduated from high school, I said to her, 'Do you want to go to the university or not?' "
>
> "No, that was not so!" said Endang, raising her voice.
>
> Here they argued about the issue of a man from the same village who was willing to marry Endang. Endang felt that her parents were trying to force her to get married. Her mother said that they did not want to force her. Her mother tried to explain the problem to me from her point of view. Endang interrupted, "Wait, wait! Daddy told me about that man!"
>
> "We did not force you," her mother said defensively.
>
> Her father who had just joined the interview denied this:
>
> "I didn't tell Endang about the man," he said to me.
>
> "Yes, you did!" Endang shouted.
>
> Endang's father kept trying to say that he did not tell Endang about him.
>
> "I am sure you told me!" Endang interrupted. "I swear I felt hurt!"

Notwithstanding this open hostility and criss-crossing criticism, Endang's family still exuded warmth and maintained a supportive attitude. For example, Endang's sister and mother would always accompany her when she was hospitalized. When she was

at home they would all three work together in the kitchen, teasing each other, or sometimes watching TV together in the living room. They were able to achieve this by virtue of their capacity to express conflict and then resolve it quite quickly, so as to return to a state of *rukun* (harmony) again. The ability to resolve conflict was also partly due to the role played by a psychology student who I refer to in this dissertation as Nia. Nia rented a room in Endang's house and was now regarded as one of Endang's family members. Her involvement in and influence on family matters was significant, especially in regard to Endang's illness. It became Nia's role to act as a mediator in family communication.

Thus, the complexity of family EE in this case is shown by the coexistence of high levels of criticism with high levels of warmth. This apparently contradictory finding within one family is not uncommon. It was first observed by Leff *et al.* (1987) in Chandigarh in Indian families of patients with schizophrenia. Among Mexican decent families Jenkins (1991) found a father who was very critical toward his ill daughter, but simultaneously he expressed warmth and affection.

6.4.3. Rima and the Interpretation of Boundary Transgression

Rima's family provides further evidence that family EE may be shown to be subject to competing interpretations when it is examined in greater detail. In Rima's case I concentrate on the issue of overinvolvement. The LEE score, at 85, was moderately high. Rima perceived her mother to be intrusive. In her response to the SCT test, Rima wrote: "My mother treats me like a small child," and then, "My mother often pays too much attention to me." These sentences were repeated twice in the test with

slightly different wording. In a followed-up interview, she suggested that she did not like the fact that her mother paid too much attention to her. Later interviews with Rima's father also suggested that he exhibited overinvolvement, though to a lesser degree. He seemed to be preoccupied with his daughter's illness and often expressed the suffering and burden that her illness had brought on him.

During the course of my fieldwork, however, I met her mother only twice because she was usually busy working outside the home doing farm labor. My interviews with her suggested that Rima's mother did not exhibit any significant overinvolvement, yet Rima interpreted her mother's attention as being 'too much' and she said she felt she was being treated 'like a child.' From my observations, Rima's mother was a little under-involved if anything. In a collective society like Java the boundary between self, family, and community is often blurred. As indicated in Chapter 2, parents often remain involved in their adult children's affairs, particularly marriage. When an adult daughter is sick a mother will often sleep beside her. When she is hospitalized the mother, or another family member, will usually visit almost every day. These behaviors might easily serve as indicators of overinvolvement in another setting, but not in Java. From a Javanese cultural perspective Rima's mother definitely did not exhibit overinvolvement. In fact she may have showing her capacity to *ngemong* Rime, caring for her gently as one would a child.

The disparity between my opinion and Rima's interpretation raises the question of how to recognize the threshold above which parental involvement is regarded as overinvolvement. Here, Jenkins' (1991) idea of emotional overinvolvement as the

transgression of boundaries is helpful. It is possible to conclude that a culturally acceptable level of involvement was 'interpreted' as overinvolvement because, for Rima, her mother's behavior transgressed her self-boundary.

In sum, although most families in this research indicated a low level of EE as measured by the LEE instrument, the emotional atmosphere within these families was complex. I have demonstrated this in my discussion of the family of Wati, Sri, Endang, and Rima, as they best exemplified the complexity of emotional interactions that were also present, though to a lesser extent, in all the families investigated in this study. Following the suggestion of Jenkins (1991) as well as Hashemi & Cochrane (1999) I have argued that EE must be understood within a cultural understanding of the family. Like McGruder (2004), I employed ethnographic methodology, but in addition I used the SCT test. On this basis I have been able to provide an exploration of the nuances of family emotions that is not usually provided in the EE literature. I have also emphasized the importance of participants' interpretations of family members' emotions. From the data gathered in this research I postulate that a high level of EE may not necessarily have a negative effect on participants if it is interpreted in a positive way. Contrariwise, the behavior of a family member that is culturally acceptable may be interpreted by the ill member as an indication of high EE. Finally, I have demonstrated that the SCT provides a useful complementary data of the EE family. This test may need to be considered as an additional instrument to assess EE.

6.5. SUPPORT IN CONTEXT: THE CONCEPT OF *NGEMONG*

6.5.1. Complexity of Family and Social Support

Similar to family EE, family support, too, is multidimensional. This becomes especially evident when the extended family and the neighborhood are taken into consideration. Table 6.2. sets out levels of support estimated on the basis of ethnographic data, taking into account support from the nuclear family, extended family, and from the neighborhood. The latter includes support from members of participants' rural hamlets and suburban *kampung* (see section 2.1).

Table 6.2. Family and social support systems

No.	Pseudonym	Nuclear Family	Extended Family	Neighborhood Support
1	Wati	High	High	High
2	Rima	High	Medium	High
3	Budi	High	High	Medium
4	Sri	Medium	Medium	Medium
5	Endang	High	Medium	Medium
6	Priyo	High	Low	Medium
7	Wulan	High	Medium	High
8	Bambang	High	High	High
9	Joko	High	Medium	Medium

The above table indicates that apart from Wati, only Bambang received high levels of support in all three categories. When Bambang fell ill he was firstly cared for by his wife's family, then his brother's family, and finally his mother and father. They all

took good care of him until he became so aggressive that it was necessary to send him to hospital. Neighbors from his *kampung* played an important role in taking him to hospital. As he began to recover Bambang built his own house next to his in-laws' house. It was his brother-in-law who helped Bambang with the building. He also returned to his previous job in the aluminum factory—located in his parent's *kampung*—without encountering difficulties and this was, at least in part, due to the support given to him by the factory owner and his fellow workers.

Table 6.2. also shows that only in Sri's case was there a moderate level of support from nuclear family. Most of the other participants received high levels of support from members of their nuclear families. For example Joko fully and gratefully acknowledged the significant role of his wife. He expressed this in his response to the SCT test: "I am happy when my wife supports me in a difficult situation, she always gives me advice and suggestions."

A more varied picture was evident in relation to extended families and neighborhoods. For example Priyo felt that his parents, who both worked in their own rice field, were very supportive. In the SCT test he wrote: "I feel my father likes helping me in school lessons and guides me in religious matters, and my mother often helps me with household matters." However, his uncle was unsupportive, despite the fact that he lived nearby. Priyo's father told me that when Priyo was sick the family preferred to ask for help from neighbors instead of from Priyo's uncle.

In Joko's case his nuclear family was highly supportive (even though his wife often made critical comments toward him). Joko's extended family, however, only provided moderate levels of support. This was because only his wife's extended family provided support, while his family of origin remained indifferent. Meanwhile, his neighbors displayed a variety of attitudes. According to Joko's wife, some of his neighbors were quite unsupportive, but Joko himself received a remarkable level of support from the Mosque congregation as he began to recover.

The above discussion suggests that taken together, nuclear and extended families and neighbors provide moderate to high levels of support. This is in line with the findings of several previous studies that the families in developing countries tend to be more tolerant and supportive toward the mentally ill (Waxler, 1976; Guarnaccia, 1992). My findings bear out the suggestions made by previous researchers (Cohen, 1992; Browne, 1999; Hopper & Wanderling, 2000; Hopper, 2004) that more ethnographic work should be conducted to provide a more nuanced picture of family emotional milieu and support in developing countries.

6.5.2. Three Aspects of the Practice of *Ngemong*

Most participants' families emphasized the importance of practicing *ngemong* in providing support. As discussed in Chapter 2, *ngemong* is a special way of treating a child that aims to foster a feeling of *tentrem* (quiet, calm, peace). Zaumseil & Lessmann (1995) have pointed to the relevance of *ngemong* in dealing with a family member who suffers from mental illness. However, these authors only focused on the ideal value of *ngemong*. In this research I identify three important characteristics of

ngemong as they are practiced by family members, and as I observed them in my fieldwork.

The first characteristic of *ngemong* is displaying a tolerant and uncritical attitude. Rima's father said that during her illness he would treat her gently. He and other family members did not want to make Rima feel irritated or place her under pressure. I observed that Rima's elder brother tried particularly hard to treat her gently and with warmth. For example, when Rima exhibited strange behavior during an interview, her brother put his hand on her shoulder to gently quieten her down. Rima's family also let her put up on the wall a number of pictures she had bought from village market. Moreover, her father was also tolerant enough to let her draw pictures on the wall, even though the wall had only just recently been painted. In the same vein Joko's wife said that Joko often hit her and the children in the early stages of his illness. Her response was one of tolerance and, although it was hard to endure, she learnt to be patient. Similarly, Bambang's wife related how difficult it was to *ngemong* her husband when he exhibited such unusual behavior.

The second characteristic of *ngemong* is a non-demanding attitude. This was most clearly evident in Priyo's family. Priyo's father told me that he did not insist that his son help him in the rice field or do the household work. Even when Priyo had finished his high school education his father did not demand that he get a job like other young people in the village. In Wulan's case, her parents also did not demand that she return to school when she recovered. They did not want Wulan to feel *kagol* (disappointed) again, as she was before she became ill.

The third characteristic of *ngemong* is the practice of fulfilling participants' needs. This was evident in Rima's family. On one of my visits I observed that Rima's brother took her to the village market to buy a necklace that she wanted. On another visit Rima's father told me that he had to sell his cow to buy an old motorbike to satisfy Rima's request. Similarly, with regard to Wulan, her parents acquiesced to her request to get married, even though she was still just 17 years of age. According to her mother, Wulan was too young to get married. She wanted Wulan to get a job first. Wulan's father told me that after a serious discussion with the father of Wulan's prospective husband they agreed to the marriage, provided that both families *ngemong* the newly-married couple.

In sum, I explored in this section the varying degrees of family and social support. While high levels of support came from nuclear families, the degree to which extended families and neighborhoods provided support was variable. The concept of *ngemong* was highly significant in regard to the cultural context of family support. Derived from Javanese child rearing practices it was here invoked by families in the way they responded to psychotic illness. My data strongly suggest that the principle of *ngemong* is pivotal to relapse-prevention, since tolerant, uncritical and non-demanding behavior is very much in line with the criteria associated with low EE.

6.6. STIGMA AND COPING IN CULTURAL CONTEXT

In this section I argue that families also experience considerable levels of burden as a consequence of psychotic illness, particularly social stigma. Two important points will be emphasized. Firstly, the family experience of stigma changes over time. Secondly, in contrast to previous ethnographic studies that emphasize the Javanese tendency to maintain a flattened emotional response, in this research I found that family members often gave vent to their emotions.

6.6.1. The Family Experience of Stigma

The adverse effect of psychotic illness is mainly reflected in families' experience of stigma. As discussed in Chapter 1, the experience of stigma is often characterized with reference to cultural norms and values.

As in other traditional societies, the most common focus of stigma in Java related to problems regarding marriage, especially for the families of unmarried female participants. This can be understood in the light of its connection with the Javanese cultural idea of *bibit, bebet, bobot* for choosing a partner in marriage. *Bibit* literally means 'seed.' It refers to inherited factors and thus biological worth (which includes the hereditary diseases). *Bebet* refers to social status or wealth, while *bobot* refers to moral character. It is widely accepted that psychosis is an hereditary illness. Thus, having a mentally ill patient in the family can imply that the family does not have a good *bibit*, leading to social embarrassment and loss of respect. For an un-married female participant, this may have quite a negative effect on her.

Sri's mother, for example, was very concerned about the issue of marriage. Before Sri became ill, Sri's mother felt that she had a problem in this regard because her younger brother married before she did. With the occurrence of her psychotic illness, this problem magnified. Her mother's worries about Sri's marriage, Sri felt, may have contributed to her illness and death.

Families would go out of their way to avoid their family member being publicly identified as mentally ill. Endang's family resisted the hospital rule that Endang must wear a uniform, worrying that it would affect Endang's self-image in the future. In Wulan's case, the stigma was indicated by her family's care-seeking behavior. When they were already on the way to Gracia 'Mental' Hospital, Wulan's mother changed her mind and took her daughter to Sarjito 'General' Hospital instead because she was ashamed of the stigma attached to admission to the mental hospital. She also took pains to prevent her neighbors from visiting her daughter in hospital.

The family experience of stigma changed over time. When firstly confronted with the illness most family members experienced feelings of embarrassment. The mothers of both Wulan and Endang, as well as Joko's wife, expressed these feelings. However, this changed slowly as the families began to cope and also began to encounter positive social responses. For example, the intense worry felt by Wulan's mother diminished after a man from the same village, who was aware of Wulan's illness, married her daughter. In the later stages of my fieldwork I asked a number of family members whether they felt embarrassed. Most of them said they did not feel it any more.

Among participants in this research, work-related stigmas were the least problematic. Wati and Bambang returned to their previous jobs without difficulty, while Wulan and Priyo found new jobs. Priyo narrated that he disclosed the problems he had had to his manager and he received ample support from him. Only Sri maintained that her illness led to a negative response at work. She suspected that her friend, who did not have a job, told the other teachers at the kindergarten where Sri worked that Sri had experienced a psychotic illness. Sri was concerned with the strain this had on her social relationships. Therefore, when her teaching contract at that school finished she did not want to continue. Not long after, however, Sri was able to get a job in a better school without difficulty.

6.6.2. Coping Behaviors

To deal with the burden of looking after an ill member, families employed several methods of coping. For a start they expressed their suffering verbally. Terms often used to indicate burden and suffering were *sedih* (sadness), *bingung* (confusion), and *cobaan berat* (a difficult test from God). Crying was another form of expression of emotional burden and suffering. Endang's mother, for example, said that all she could do was cry: "I felt so sad, how come I have a daughter suffering from illness like this." Similarly, Joko's wife also expressed her suffering through crying. "When I cried, my children also cried," she said. When she performed her nightly prayers she often cried, expressing her burden to God. The outward and inner expression of emotion were widely perceived by the families in this study to be helpful—in short, they were one way of coping.

Thus, I agree with Browne (1999) who suggested that Javanese do not always hide their emotions. In particular situations they also express their emotions openly. As discussed in section 6.4.2. Endang's family members expressed their internal family conflict in my presence. Similarly, Joko's wife disclosed her conflict with her husband and she cried when I spoke to her on the telephone. Thus, the expression of emotion was not only culturally sanctioned, it was positively valued as a means of coping.

To further explore family coping methods, I also administered the F-COPES instrument. The F-COPES scores indicate that they used different kinds of active coping strategies, as shown in the following table.

Table 6.3. Family coping strategy

No.	Coping strategy	Mean score
1	Seeking spiritual support	4.67
2	Mobilizing the family	4.41
3	Acquiring social support	4.35
4	Reframing	4.33
5	Passive appraisal	1.44

Table 6.3. shows that the most common strategy that families used was to seek spiritual support, including the use of prayer, performing religious obligations seriously, and seeking help from religious leaders. The ethnographic data confirmed these results (see section 7.4. in which I discuss religious coping in more detail). The second strategy was one of mobilizing the family to seek help from broader

community resources, such as seeking help from *wong pinter, paranormal* or formal health institutions. This illustrates the active role of the family in finding solutions to the problems that link to the idea of *usaha* (to be discussed in Chapter 8). The third strategy is one of seeking support from members of the extended family, friends, and neighbors. This indicates that the role of social networks in providing support is significant. The fourth strategy is one of reframing events to make them more manageable. Passive appraisal or minimization of response to the problem recorded the lowest score since it contradicted the ethos of *usaha* that most participants referred to.

In sum, this research supports previous findings that the experience of suffering is not only felt by family caregivers of people with long-term schizophrenia. Caregivers of people suffering from first episode psychosis already have to cope with high levels of distress (Tennakon *et al.*, 2000). One of the most distressing effects of psychotic illness for family members is social stigma, particularly in relation to the issue of marriage. I have discussed here the variety of coping strategies employed by families to deal with this distress.

6.7. SUMMARY

In this chapter I have explored what happens in a family when one of their members develops a psychotic illness. I have looked at this in two ways, firstly in terms of the influence that families may have on the patient and the illness, and secondly, in terms of the influence that the illness may have on the family. With respect to the influence

that families exert, at a cognitive level, they invoke explanatory models in order to make sense of the illness. These models are usually oriented to seeking treatment and they characteristically change as the illness and its treatment evolve. I have explored the influence that families exert at an emotional level by examining family EE in all its complexity. I have also looked at how families may affect the patient and the illness by means of the support they provide. Here I have suggested that it is important to look beyond the immediate family to the extended family and the neighborhood to gain an accurate picture of this support. Secondly, in order to understand the effect that psychotic illness can have on families, I have looked at the influence of stigma on family members and examined the various ways they cope with this. The initial exploration, in each instance, took place in relation to one participant, Wati, but was then extended in relation to the other participants.

I have looked at families from these various perspectives to provide a multidimensional understanding of the mutual interaction between a person with a psychotic illness and his or her family, taking into account the changes that occur over time. This comprehensive and dynamic understanding which I have sought to develop is a product of the methodology of my research, which not only looked at family processes from several angles, but also involved following these families closely over a period of two years.

Throughout, I have sought to understand the family processes involved in relation to the Javanese cultural context in which this study took place. Explanatory models, I have argued, cannot be understood without setting them in the context of

contemporary Yogyakarta, which I have shown to be a place of contested cultural values. Thus, traditional ideas of possession and sorcery are invoked in conjunction with more modern notions of pressure and stress. When examining EE, I have emphasized the extent to which, as Jenkins first pointed out, criticism must be understood in terms of cultural rule violation. Likewise, I have emphasized the extent to which overinvolvement can best be understood in terms of transgression of the self-boundary. I have also shown how stigma is acutely felt by Javanese families, particularly in relation to the way in which mental illness may affect the marriage prospects of a sick family member. Finally, in coping with illness, Javanese turn to traditional sources of help, particularly the Islamic religion. But I have argued that the expression of emotion, scarcely a traditional response, is just as important for the families I studied.

The different perspectives that I have adopted—explanatory models, EE, support, stigma and coping—may give the appearance of a piecemeal approach. However, by examining them in relation to their cultural context, a more coherent picture of the relationship between family processes and illness processes emerges. I would argue that the overall theme of *tentrem* (peace) underpins the family dimensions of psychotic illness in Java. Explanatory models of illness are couched in terms of loosing *tentrem*. The loss of *tentrem* can be conceptualized at a family level as a loss of *rukun* (harmonious integration)—Wati's in-laws exemplified this. At an individual level the loss of *tentrem* emerges as *tekanan batin* (inner pressure) or *setres* (stress)—Wati's inner state after the birth of her child, when the maintenance of *tentrem* is most critical, exemplified this. Whether it involves the individual or the whole family, the

absence of *tentrem* may render a person vulnerable to illness, particularly through *kaget* (startle) experiences. Ideas of *kemasukan* (possession) or *guna-guna* (sorcery) may be invoked, but the illness is usually explained in terms of *bingung* (confusion), thereby minimizing stigma, as far as it is possible to do this.

High levels of EE, particularly high levels of critical comments as seen in Sri's and Endang's family, are also understood as the antithesis of *tentrem*, here conceptualized at the family level as an absence of *rukun.* Javanese families see this as impeding recovery from illness. What aids recovery is to *ngemong* the family member, much as one would a child, the associated gentleness and tolerance preventing the emergence of *kagol* (frustration) that might lead to relapse.

Working against recovery are concerns about the longer-term consequences of psychotic illness for a family member. These may be expressed in terms of *sarap* (nerves), a term that implies that full recovery is impossible. Or they may be expressed in terms of concerns about *bibit*, that is, about whether he or particularly she will ever be able to get married.

In pulling these cultural threads together, I do not wish to imply that Javanese culture provides a coherent framework through which to understand psychosis and its effect on families. But it does provide for a range of possibilities. I have emphasized throughout the diversity of explanatory models, of family emotional responses, and of coping mechanisms. The open expression of emotion, for example, is hardly compatible with *tentrem* or *rukun.* Yet these days it appears to be a valued means of

coping, both for family members and patients, an indication of the rapidly changing cultural value system that is seen in modern day Yogyakarta.

CHAPTER 7

ENACTING DESTINY: RELIGIOUS DIMENSIONS OF PSYCHOTIC ILLNESS

There are three reasons for discussing religion in this dissertation. First, as mentioned in Chapter 4, religion is prominent in the symptomatology of Acute and Transient Psychotic Disorders (ATPD) and this was born out by the participants in this study who had a diagnosis of ATPD. Second, I have shown in Chapter 6 that for my participants, religion formed an important basis for coping with psychosis. Third, religious themes are conspicuous in participants who are recovering. This chapter therefore anticipates the next chapter where I explore participants' process of recovery.

While there is an extensive literature on the relationship between religion and psychotic illness that I reviewed in Chapter 1, the methodology I have applied in this study is unique because my engagement with participants as ethnographer led to my becoming involved with them in their practice of religion. Thus, the data that I bring to this literature is unique. First, my active involvement has led to me developing a dynamic understanding of the relationship between religion and psychosis—one that focuses on cultural and religious processes. Second it gives cultural specificity to the relationship between religion and psychotic illness by examining the distinctive forms

of Islam to be found in Java and the influence they have on the lives of people who suffer from psychosis.

As in previous chapters, I look first at one participant in detail, in this case Priyo (participant no. 6), looking at the *lahir* (outside) and *batin* (inside) dimensions of his illness experience, as well as the way he 'enacts' his destiny. These two themes are subsequently explored in the light of other participants' narratives.

7.1. PRIYO'S NARRATIVE

Priyo was 19 years of age when I met him for the first time in August 2002 at his house in a village approximately 20 km outside Yogyakarta. In the village I observed several traditional Javanese houses located alongside a modern housing complex. Looking for Priyo's house I came to four old Javanese-styles houses facing each other, two on the left side of the front yard and two on the right. They shared a frontage some five meters wide. One of these houses was Priyo's. Members of his extended family inhabited the other three. When I knocked on the door I could hear the loud sounds of a western song coming from inside. Priyo's father greeted me and introduced me to Priyo, who was repairing an old tape deck.

During this initial visit I learnt about Priyo's family background. He had been raised in a deeply religious environment. Priyo's grandfather, his father's father, used to be a religious leader in the village. He had built a small prayer hall (*musholla*) at the far end of the four houses. The village people used to pray in this prayer hall before the

mosque was built. When Priyo's grandfather died, Priyo's father was chosen as a religious leader in the village. The religious intensity of this family became apparent when, in the middle of the first interview, Priyo asked permission to go the mosque to perform noonday prayer. Driven by my ethnographic curiosity, I went to the mosque to pray together with Priyo. It presented an opportunity to develop a closer relationship with him and observe his activities in the community. On the way to the mosque located just 200 meters or so from his home, Priyo greeted several people. He appeared to have good social relationships with his neighbors and community members. Before performing noonday prayer it was Priyo himself who recited the *adzan*, the call for prayer. I gained the impression that Priyo was a well behaved youth, committed to his faith.

Despite these efforts to develop a close relationship with Priyo, details of his illness emerged only very slowly. In the early meetings both Priyo and his father seemed to be avoiding any discussion of problems that might be related to the illness. They preferred to focus on Priyo's schooling. His father told me that Priyo was in the third year of technical high school and was about to do his final exam when the mental illness struck.

The onset of the illness was rapid. Several days before he became ill Priyo complained that he had frequent headaches and could not concentrate on his school lessons. The next day he sensed his body becoming very hot. He began to feel confused. The following day, on the way home from school, he rode his bicycle on the right side of the road instead of the left. One day after that he went to school

despite the fact that it was a holiday. Priyo's father said, "That night, O God, he could not sleep inside the house. He went in and out of the house and then slept on the ground outside the house. He rolled around on the ground." Priyo's behavior became quite bizarre. Whenever he was about to eat something he would recite prayers and move his hands in a strange way. When he performed his daily prayers he faced the wrong direction. After praying he usually recited *istighfar*, a short prayer to ask forgiveness to God. On a later visit Priyo told me that he saw lights inside his house when he was ill. The lights appeared to be two eyes looking directly at him. He interpreted this to be an angel from God. Priyo also reported that he heard voices that ordered him to ask forgiveness of all the people in the village. He followed this voice's instruction and proceeded to go around the village from door to door and ask everyone for forgiveness. The voice also admonished him that if he wanted to follow the lifestyle of a pious man it would be difficult indeed for him to do this.

Up to my third visit the story of Priyo's illness was still not clear to me. Priyo always said that it was his *takdir* (destiny), God's will, which he had to accept. The turning point occurred when my female research assistant, Nida, accompanied me on a visit. While I interviewed Priyo's father, Nida administered the SCT test to Priyo in the same room. At first, Priyo was able to finish the sentences easily. When he arrived at the last sentence, however, he complained that he was not able to complete the sentence. Nida encouraged him to write whatever he could. He said, "I can't, I feel *isin* (ashamed)." After further gentle encouragement Priyo then wrote: "I will not say something shameful." When Nida probed a little further, Priyo answered that he was *isin* because he had done something he considered immoral.

It was at that point that Priyo made a surprising confession in front of us and his father. He said that he had watched pornographic videos several times together with his friends. He said he had also.often masturbated and watched some women taking a bath. Hearing Priyo's confession, I observed that his father felt uneasy. After that he always tried to downplay the importance of Priyo's confessions. For example, he would say that it meant something different or change the topic slightly to discuss religious teachings in this matter, thereby diverting attention from Priyo's confessions. He told Nida and me that Priyo's sexual behavior was only a dream and therefore morally acceptable.

By contrast with his father, after making this confession, Priyo became more open in talking about his personal and sexual life in subsequent visits. He disclosed that he had a very strong sexual drive. He said, "It is a gift from God; I could not refuse it." He told me that in order to control his sexual desire he performed *puasa* (fasting), but he was still not able prevent his desire to masturbate. Priyo repeatedly said that every time he masturbated he felt like he had committed a sin. "It make me feel not *tentrem.*" According to him, masturbation was sinful because it was against Islamic law. "I don't know for other people, but for me, it was a great sin," he remarked.

Priyo likened his illness experience to the experience of receiving special knowledge from God. He did not have the ability to handle his behavior, he said, and this is why he became sick. Priyo believed that the voice he heard was from God: "It was not from Satan, because I had recited a particular prayer." He also explained the experience by likening it to another experience which he felt as if someone was

putting a rosary on his neck, even though it was he himself who had done this. "Although it was my own hand," he explained, "my hand moved by itself; I made no movement myself." He felt that the movement was directed by God.

He also believed that his illness reflected his sinful deeds. He felt that God had opened his heart through the illness and had made him *sadar* (become aware) of his bad deeds, including watching pornographic videos and masturbating, stealing his neighbor's mangoes and taking some building materials from the modern housing complex nearby. "For other young people it might be a small matter, but for me it was a big issue," he said. "God opened my heart so that I could put a stop to the bad behavior." Summarizing the illness as a whole he said, "My belief in God is stronger now than before because God has paid attention to me."

Priyo was sent to the hospital after several days of displaying unusual behavior. He returned home following a week's hospitalization. But his symptoms reappeared several days later. He was then rehospitalized for another week and showed a good recovery after that. He continued his medication after discharge. When I met him for the first time he had been discharged for about three weeks. I did not observe any evidence of mental illness. He looked normal like other young people in the village and was no longer taking his medication.

According to Priyo, everything had been destined by God, including his illness. "If someone is destined to fall down, he will fall down. So I follow my *takdir* (destiny)." His father shared this belief and emphasized that as long as Priyo continued to ask for

God's forgiveness then God would forgive him. His father said that he could accept his son's illness: "For a believer the illness should be accepted happily. There is no need to complain, be patient. The most important thing is making every *usaha* (effort) to find a remedy." His father believed that God would cure him. He said, "God sent the illness," he said, and "God also provides the remedy. I should return everything to Him. That's all."

Priyo recovered rapidly. Following his discharge he continued at school although he had to repeat the same level. Though he stopped taking his medication from time to time, for the most part he persisted with it. He complained that the medicine was so strong that it made him sleepy at school which made it hard to concentrate on his work. Nonetheless he did well in his grades. His father told me that Priyo had several activities at home. His main hobby was working with electronic appliances such as repairing old tape recorders. He also built a stall to breed chickens. Priyo was also actively involved in mosque-based activities. Every time I visited him he always asked me to pray together with him at the mosque. He performed the *adzan* (the call for prayer) and participated in the congregational prayer. After praying, he always recited several *wirid* (invocations) for quite a length of time. In the afternoon he taught children to read the *Qur'an*. He told me that he also attend monthly religious gathering in other villages.

With much support from his family, Priyo finally graduated from technical high school in 2004. He planned to go to Malaysia or Hong Kong to obtain employment.

However, when I made a follow-up visit in July 2004, Priyo told me that he had already gained a job with a local construction company.

7.2. DISCUSSION OF PRIYO'S NARRATIVE

In chapter 1, I reviewed the literature on the relationship between religion and mental illness. In that review I made the point that early writings focused on negative aspects of religion as contributing to the development of illness. Only recently were the more positive aspect of religion as a therapy considered. These two sides of religion were well presented in Priyo's narrative. But the most striking idea emerging from Priyo's narrative was the reciprocal movement that occurred between *lahir* (outside) and *batin* (inside).

7.2.1. From *Lahir* to *Batin* and *Batin* to *Lahir*

The above narrative suggested that, for Priyo, conflict between his religious values and his behavior was central to the illness experience. The strong religious milieu of his family had shaped his sense of self. Being a good Moslem meant that he had to lead a pious life. He was not supposed to watch pornographic videos and he was not supposed to masturbate. Because it involved a social activity (watching videos with friends) and a physical activity (masturbating) this conflict was, at first, firmly located in the *lahir* (outer) realm.

In the lead up to the illness, however, he became increasingly oriented to his *batin* (inner) realm. For example, he mobilized Islamic religious practices in the form of

periodic fasting in order to gain inner control over his sexual desire. This strategy did not work, however. As a consequence he found the dissonance between his image of himself as a good Moslem and his desire to masturbate led to inner feelings of sinfulness and guilt. He became unsettled. He did not feel *tentrem* (peaceful) in his *batin* self.

Excessive guilt has been identified as one of the major negative influences that religion may have on people's mental health. However, Al Issa (2000) has made the point that it is important to distinguish between the irrational guilt that is associated with illness and feelings of sinfulness anyone might feel on breaching a religious precept. In Priyo's narrative the feelings of guilt are more likely to be a rational consequence of breaking religious injunctions concerning sexual behavior. Rather than seeing the guilt and the illness as pathological, Priyo understood them within a religious framework of expiation. For him, the illness was a way of *nglebur dosa* (removing sins through purification).

Priyo's purification took place principally at a spiritual level, and thus within the *batin* realm. This was evident when he recited the *istighfar*, a short prayer asking forgiveness of God. Also within this realm, Priyo had the experience of seeing a pair of eyes constantly watching him. He interpreted this as the eyes of an angel who monitored his behavior to prevent him from doing bad things. The culmination of Priyo's purification was the experience wherein he believed someone had put a rosary around his neck, which he interpreted as receiving the gift of grace from God.

Thus far, I have traced a movement from *lahir* to *batin* as Priyo became more inwardly focused on feelings of sin and guilt and sought to purify his inner self through fasting and prayer. I do not wish, however, to suggest that there is an absolute separation between *lahir* and *batin*, for these two are closely linked. In fact Priyo did not ignore religious practices that operated in the *lahir* realm. For example, he had experienced a sensation of heat when he first became ill, so to rid himself of this he immersed his head repeatedly in water and slept outside the house at night, rolling himself on the ground to cool and purify himself. These physical attempts to cleanse away his sin operated within the *lahir* realm. Further evidence of the close connection between *lahir* and *batin* was his inner experience of hearing the voice of God ordering him to ask forgiveness of people in the village for his past wrongful deeds. He acted on this and went out around the village seeking forgiveness from one household to the next.

Notwithstanding the interconnection between *lahir* and *batin*, we can see an increasing preoccupation with the inner world that accompanied the onset of Priyo's illness. The problem was at first external, but then became internalized. The remedies worked at an external and internal level, but shifted increasingly to the latter, a shift of emphasis from *lahir* to *batin.*

Later, when he looked back over the whole experience, Priyo mentioned several times his belief that through the illness he was opened up by God. By means of his illness God had opened his heart, the *batin* dimension of his life. This led him to a new sense of self. The effect of this was that he was now *sadar* (becoming aware) of his

wrongdoings in the past. Thus, before the illness, his *batin* was *tertutup* (closed off) and after the illness his *batin* was *terbuka* (open).

The opening of his *batin* suggests a transformative process affecting his inner self, such that he not only became aware of his past sins, but also became aware that he had to *nrimo* (accept) his illness. The state of *nrimo* (acceptance) is highly prized in Javanese mysticism as part of "the cultivation of one's inner being and deep self" (Mulder, 1994a:17). In this sense, for Priyo, his illness facilitated a spiritual development, which involved attaining the state of *pasrah* (surrender to the will of God) thereby enabling the resolution of inner moral conflict, so he could aim toward a more consistent life. As his illness developed and he began to recover, Priyo experienced a movement from *batin* to *lahir*.

The opening out into the *lahir* realm was obvious in his increasing involvement in everyday activities. As I observed when I visited his house at the first time he was repairing an old tape deck recorder. On another occasion I saw him fixing the stall beside his house where he bred chickens. Within the village, Priyo also began to engage more actively in productive social relationships. He returned to school, despite having to repeat the same level. Ultimately he was able to achieve reasonable school grades and finally graduated and got a job. A most important experience of opening outward for Priyo was his willingness to openly discuss his illness experiences with me, particularly those concerning his sexuality.

I would argue that a most significant contribution of Priyo's religion to his recovery was its transformative effect. As discussed in Chapter 1, a number of authorities have pointed to the transformative role of religion and spirituality in recovery from psychotic illness. This analysis of Priyo's narrative elucidates the culturally specific ways in which Islam helps to effect this transformation among Javanese. For Priyo, the underlying transformation was from *lahir* inward to *batin* and from *batin* outward to *lahir*. As emphasized above, this is not a simple processual sequence, for *lahir* and *batin* are intimately interconnected. It would be more accurate to depict the process as a simultaneous double transformation from outer to inner and inner to outer.

7.2.2. Enacting One's Destiny: *Ngelakoni* in *Lahir* and *Batin*

A critical feature of the transformation that I have described above is that in Islam, as practiced in Java, there is a strong expectation that the person must play an active role in the process. This is best expressed in the concept of *ngelakoni* or enacting one's destiny. Priyo put this well when he said: "This illness is given by God, it is my destiny, and I have to *ngelakoni* (enact) it." The root of the word *ngelakoni* is *laku*, meaning enactment or behavior. Thus, *ngelakoni* means an intentional act or intentional behavior. In Javanese *kebatinan* (mysticism), *ngelakoni* in the *batin* realm refers to ascetic exercises (see Keeler, 1987:41-44), while in the *lahir* realm it refers to correct ethical behavior (Mulder, 1978:23).

As discussed in Chapter 2, the root of *ngelakoni, laku*, has a parallel in the idea of *tirakat*, that is, ascetic exercises performed in order to strengthen the power of one's inner life. Javanese usually practice *tirakat* when facing difficult situations, such as

illness, a family crisis, a natural disaster, or social unrest. The practice involves various different types of fasting, prayer, abstinence from sleep and sex, bathing with cold water, or even immersing oneself in a river at night, or meditating on a mountains or in a cave (Ferzacca, 2001:156-157). Koentjaraningrat (1985:372) has described the benefit of *tirakat* being that, "these efforts will make a person mentally strong and resistant to discomfort, dissatisfaction, and disappointment which may be experienced in life."

For Priyo, *ngelakoni* in the *batin* realm was evident in the performance of religious practices. These included not only daily prayer, *shalat*, but also the performance of *wirid* (invocation) and *doa* (supplication). When I prayed together with Priyo I observed that after the congregational prayer was over he spent additional time performing *wirid* and *doa* by himself. He said that he added the recitation of *istighfar,* asking forgiveness from God. He also continuously practiced fasting on Mondays and Thursdays in his effort to be abstinent from masturbation.

For Priyo, *ngelakoni* in the *batin* realm had an immediate impact on the *lahir* realm. For a start, the routine of these religious practices had a positive influence on Priyo, providing him with a structured, stable and predictable everyday routine. This enabled him to achieve a sense of *tentrem* in the *lahir* aspects of his life. Since he also performed daily prayers in the mosque, he remained engaged with his social network. In performing the *adzan* he maintained an important role in the community. Teaching children to read the *Qur'an* provided an ongoing connection with members of his

community, not only the children but their parents as well, and mitigated any feelings of alienation or isolation.

Further evidence of *ngelakoni* in the *lahir* realm was Priyo's effort to behave according to an Islamic code of behavior. For example, he told me that at first he was reluctant to take the medication for a while. He even intended to throw it away because he felt that he had recovered. However, he soon began taking the medication again as he felt that it was his duty to obey his father in accordance with Islamic teaching. More than just a matter of obedience to his father, he believed that God commanded him to find a remedy for his illness. Such religious understandings may be significant in the process of recovery as suggested by Kirov *et al.* (1998). These researchers reported that psychotic patients who used their religious faith to cope with psychotic illness ultimately had more insight into their illness and were more compliant with their medication regimen than those who did not. For Priyo, religion played an important role in his adherence to medication. There was a direct meaningful connection between his religious faith and his attitude toward his medication. He understood that taking medication was part of his *ngelakoni*, the enactment of his faith, in the *lahir* realm.

In summary, I have shown in this section that religion was integral to Priyo's illness and recovery. First it provided him with a powerful set of transformative experiences that entailed the movement between *lahir* and *batin* and vice versa. It was quite clear that he was no mere passenger in this transformation. By definition, it involved *ngelakoni,* that is to say, being fully engaged in the process of enacting his destiny

both in the *lahir* and *batin* realm. Only then could he make the final transition from *tertutup* to *terbuka*, from closed to open.

7.3. DESTINY AND ACTIVE EFFORT IN THE *BATIN* REALM

In this section I further explore the theme of *ngelakoni* by examining a constellation of concepts and practices that are closely related to it, as they emerge in the narratives of the other participants, opening my discussion with the key concept of *takdir*.

7.3.1. *Takdir:* Destiny

If *ngelakoni* means enactment, what is primarily enacted is *takdir*, one's destiny. *Takdir* could be translated as fate, for it carries the same meaning of a predetermined course of events. However, I have avoided this translation because it can connote a certain passivity that is best expressed in the cognate word fatalism, "a submissive attitude to events as being inevitable" (Allen, 1990:426). It is this connotation of fate that I wish to explicitly avoid in my analysis.

As with Priyo, most participants and their family members invoked *takdir* to find meaning in the illness. For example, Sri made sense of her illness through her belief that everything had been arranged by God. For Joko and his wife the illness was a test or reprimand from God. "If I were able to choose, I would not choose this test, but it is my *takdir,*" Joko's wife remarked. Through their belief in God and *takdir,* participants transcended the illness, enabling them to see the problem from a wider perspective and within a longer-term context.

As I have already pointed out in relation to Priyo, destiny is something that has to be *ngelakoni*, or enacted. The sense of doing something about one's destiny was even more forcefully expressed by some of the other participants. For example, they employed the term *usaha*, which I defined in Chapter 2 as making a strong effort to find solution to a problem. Joko put this very succinctly: "God has arranged our *takdir*, but we have to make our own *usaha*." Mulder (1994a:12) encapsulated the logic as follows: "One can only know the results of one's lot by the outcome of one's actions." This approach was taken by Rima's father who said, "Since we do not know what is the will of God, we have to take every *usaha* to find a solution, for when all of the *usaha* has been expended done and nothing changes, that is the *takdir* that we should accept."

The imperative to act can further be appreciated by recognizing that *takdir* strongly connotes *harapan,* or hope. It does not in any way imply despair. That is to say, whatever one's destiny is, one should always hope for the best and work towards it. To express this sense of *harapan* that accompanies *takdir* many participants used the specific Islamic idiom: *Insya Allah* (God willing). This expression is comparable to the idiom *Si Dios quiere,* which is used by Hispanic families of mentally ill people (Guarnaccia *et al.,* 1992). In Java, according to Bousfield (see Dean, 1999), the expression *Insya Allah* is used widely in everyday life in a number of contexts. Firstly, it is used as a positive intent or agreement to do something. Javanese tend to avoid any expression of certainty about the future, lest this be taken as evidence of personal arrogance. Secondly, *Insya Allah* is used as a polite way to reject an

invitation by providing an ambiguous response. Thirdly, *Insya Allah* is also used to avoid personal responsibility for not doing something at some future point in time.

The ethnographic data I gathered suggested that *Insya Allah* tended to carry the double meaning of an intent to do something about one's difficult situation and the hope that God will intercede to help in this struggle. Budi's father, for example, expressed his hope: "I believe that my effort, *Insya Allah,* will be successful." Endang's father expressed his hope that his daughter could change her behavior "*Insya Allah* everything will be alright." Similarly, Rima's father, who was struggling to get help for his daughter's illness, remarked, "*Insya Allah* I will find a solution, there must be a way to find it." Joko's wife also had a similar experience. When she woke up at night and performed *shalat tahajut*, sometimes her eldest daughter would sometimes accompany her and ask why she did all of this. She told me she would answer her daughter, "*Insya Allah* your father would be recovered, for everything comes from God and we return it to God."

Another attitude closely tied to *takdir* is *nrimo* (accepting one's destiny) and it is commonly invoked by Javanese to deal with life problems. Mulder (1994a:12) writes: "Accepting (*nrimo*) means knowing one's place, means trust in one's fate and gratefulness to 'God,' because there is satisfaction in fulfilling one's lot in the consciousness that all has been destined." Thus, in my research, I found that the attitude of *nrimo* was commonly adopted by family members. Wulan's mother said, "I am *nrimo* because illness, wealth, marriage—all has been arranged by God." *Nrimo*, in turn, was associated with *sabar* (patience). It meant that one needed to accept the

fate without any complaint. *Sabar* was not regarded as a state of mind that comes easily. It has to be actively cultivated all the time. Budi's father said that a healer suggested that he should learn *sabar* in dealing with his son. Similarly, Endang's family learnt from his daughter's illness that he had to be *sabar*. Rima's father reasoned that when one is not trained to feel *sabar,* one cannot respond to life's crises properly. The illness, for him, was thus understood as part of his training to be *sabar*.

Just as the belief in *takdir* is not a matter of passive acceptance, so *nrimo* involved an active effort. It would best be described as a matter of acceptance combined with an active struggle. Endang's father, for example, considered that passive acceptance of one's fate without doing anything was the wrong attitude to take. *Nrimo* should thus be considered as part of participants' *usaha batin* (effort in the inner realm), as well as *usaha lahir* (effort in outer realm). Here my findings are in agreement with those of Ferzacca (2001:102) who defined *nrimo* as "acceptance as working with one's set of circumstances and conditions, rather than fatalistic passivity."

Similarly, *sabar* does not mean patiently waiting for God to help. Rather, it means persistence and endurance in making *usaha*—patiently making an effort. Rima's father said, "*Usaha* should be accompanied by *sabar,* prayer and belief in God." Joko's wife told me that in the initial phase of her husband's illness she often cried and felt sorry for herself and her bad fate. When she started to *pasrah* (surrender to the will of God) and *sabar,* she gained resilience and strength in making efforts to find solutions to her husband's illness.

7.3.2. *Usaha Batin* by means of *Shalat, Puasa,* and Reading the *Qur'an*

One of the principal ways of *usaha batin*, or making an active effort in the inner realm, was through the performance of religious practices. In their study of religious coping among the mentally ill, Tepper *et al.* (2001) found that participants used up to half of their time performing religious practices, with prayer being the most common of these. Similarly, most participants and family members in my research engaged in such practices in order to help cope with the crisis that confronted them and to facilitate recovery. As with the findings of Tepper's group, the most common practice among my participants was prayer, including *shalat* (liturgical prayer) and *doa* (supplication). While *shalat* is governed by strict rules concerning the timing and mode of its performance, *doa* is more flexible in that it can be performed anywhere and at anytime. Furthermore, *doa* allows people to use their mother tongue.

There were several types of *shalat* that participants employed. First was the obligatory *shalat* which must be performed five times a day. As discussed in relation to Priyo, this provided an important source of structure for participants in their daily activities and it also facilitated social support when performed in a congregation at a mosque. Second was *shalat tahajud*, a *non-obligatory* prayer, mostly performed in the middle of the night. Most participants and their families suggested that *shalat tahajut* was a way of communicating directly with God and it was of great help in finding solutions to problems and coping in times of crisis.

Although the way to perform *shalat tahajut* has been laid down by Islamic *shariah* law, participants frequently used additional methods to attain the particular state of

mind that they sought to achieve. For example, Joko's wife always took a cold bath before performing *shalat tahajut.* She reported that after performing *shalat tahajut* she felt physically fresh and *tenang*, an Indonesian synonym of the Javanese *tentrem.* The practice of night bathing is a common practice among Sufi and *kebatinan* groups in Java that I mentioned earlier in this chapter.

Rima's father reported that he performed *shalat tahajut* almost every night and sometimes did this in his front yard. He believed that it was more likely that God would respond to his prayer. Praying or meditating outside the house is typical of a *kebatinan* practice. Rima's father emphasized that the practice of *shalat tahajud*, and other religious practices, was part of his *usaha batin,* the effort to find solution to a problem in the *batin* realm.

Aside from prayer, fasting was the most common practice used by participants and their families. As with obligatory prayer, obligatory fasting, which must be performed in the month of *Ramadan*, is not directly associated with coping or problem solving. It is the *non-obligatory* fasting that participants and their family members turned to for these purposes. Fasting on Monday and Thursday every week is a popular practice among Javanese Moslems (Mulder, 1994a:27). Bambang told me that he usually performed fasting on Monday and Thursday as part of his ascetic practices. Joko's wife told me that she performed many kinds of fasting, including on Mondays and Thursdays, on the 13th, 14th and 15th of the lunar month, and on her Javanese day of birth, a typical Javanese tradition. For Joko's wife this fasting promoted a sense of

inner strength in times of crisis. As she commented, "I do it to feel strong, to endure, to face the crisis, and without it, I would not be able to bear this burden."

Reading the holy book is also a common coping method among mentally ill people (Tapper *et al.*, 2001). There are no formal obligations to read the *Qur'an*, although many people do so, especially during the month of *Ramadan.* It could be said therefore that reading the *Qur'an* is not obligatory. Yet in my research all the participants referred to reading the *Qur'an* as important to the process of recovery. During her psychotic breakdown Sri tried to fight her visions and voices by reading the *Qur'an*. She believed that *Qur'anic* recitation would chase away the spirit who was disturbing her. At times this way of coping failed. Sri's recitations, for example, failed to achieve their purposes. For Budi, although he was intellectually borderline he was still able to read the *Qur'an* and recite *adzan* at the appropriate time. Joko, meanwhile, disclosed that sometimes he still regretted the loss of his position as school principal. To ward off these thoughts, he recited the *Qur'an* on many occasions, especially in the afternoon. By reciting at this time he ensured that there was no time for daydreaming. Thus, when troubled with regret and guilt, the *Qur'an* provided him with some certainty of relief and comfort.

Thus far, I have extended the analysis of *ngelakoni* (enactment) by showing how it belongs to a broader cultural configuration of concepts that include *nrimo* (acceptance) and *sabar* (patience). Underpinning this configuration is the more pervasive concept of *takdir* (destiny). Throughout I have emphasized how all these ideas carry the implication that one should be actively engaged—one should actively

participate in one's destiny. The principal forms of being actively engaged were religious: prayer, fasting, and reading the *Qur'an.* Performing these three was a way of *usaha*, or making a struggle. With regard to prayer and fasting it was the *non-obligatory* forms, *par excellence*, that the participants and their families talked most about. That is to say, they were not just passively conforming to the routine obligation to pray and fast, they were going out of their way to perform additional prayers and undertake additional fasts, thereby demonstrating the extent to which they were participating in their destiny. Reading the *Qur'an* was similar in this regard because there was no obligation to read it at all, yet all participants placed great emphasis on this. Obligatory Islamic practices are similar throughout the Muslim world, but the non-obligatory practices may vary. It is these non-obligatory practices, I would argue, that are specific to the Javanese context, and that the participants in this study found most helpful.

7.4. MOVEMENT BETWEEN *LAHIR* AND *BATIN* IN OTHER PARTICIPANTS

The dynamic relationship between *lahir* and *batin* that I examined in relation to Priyo was evident in all participants. In the following analysis I further analyze this dynamic by relating it to the current religious context in Yogyakarta.

In Chapter 2, I explored the tensions that exist between various forms of Islam, traditional and modern, tolerant and militant, as well as between Islam and Javanese traditions and, finally, between Islam and Christianity. As religious tension in Indonesia and in Java in particular is considered a highly sensitive issue, communities

and neighborhoods tend to *memendam* (bury) this problem as much as is possible, in order to maintain *tentrem* (peace) at a community level. Yet the recent religious riots between Moslem and Christian communities in the eastern parts of Indonesia such as Ambon and Poso are a reminder of the serious consequences of open, violent conflict. In Java, religious tensions run just as deep but are more subtly expressed. For example, everyone recognizes that a person's religious affiliation will have a bearing on his or her election to positions of neighborhood or community leadership, yet this is rarely talked about openly.

The theme of religious tension was clearly evident in many of the participants' illness experiences. As in Priyo's case, the tension was almost always first experienced as lying at a *lahir* (outer) or social level, but quickly internalized to become part of the participant's *batin* (inner) self. To examine this dynamic I turn again to Sri (participant no. 4), who found herself becoming affected by differences between traditional Javanese culture and a modern-reformist version of Islam. At first this affected her behavior in the *lahir* realm. She quit her traditional Javanese dancing, arguing that according to Islamic *shariah* law it is not permissible for a girl to make the sensual movements required in this form of dance. Then the conflict entered her *batin* experiences. She experienced an hallucination in which she saw some primitive people bearing spears and using these to try and kill her. She also experienced olfactory hallucinations, smelling *kemenyan*—the incense used by traditional Javanese to pray. The visions of primitive people, as well as the smell of *kemenyan* are highly suggestive of Javanese traditions that have been shaped by Hinduism and even earlier animist influences. Since Sri was very much afraid of dying not in the Islamic way,

she fought her hallucinated voice by reciting *Allahu akbar* (God is great) the phrase often used by Moslems on the battle field. The conflict between Javanese traditions and militant Islam had become internalized.

Conflict between Islam and Christianity was even more obvious in Sri's hallucinatory experiences. Firstly, she hallucinated that she saw Jesus on a cross being set on fire in the streets. Secondly, while she was receiving treatment in Sarjito Hospital she perceived that every cross in the room was the symbol of Christianity. She felt that she was in the middle of a Christian environment that was attempting to convert her. This crisis deepened when suddenly a big screen appeared before her and she saw Jesus Christ on the cross. She interpreted this as meaning that she would die as a Christian and not as a Moslem. She resisted this by reciting the *syahadat*, the Moslem decree, and repeatedly saying "I am Moslem, I am a Moslem, I don't want to be a nun."

Religious tensions and conflict are part of the cultural milieu of Yogyakarta and can become appropriated and internalized by people as they become psychotic and become part of the symptomatology. This is not surprising because *memendam di dalam* (burying inside) is a model for dealing with conflict that is widespread, at a social level, in Java. As I indicated in Chapter 5, *memendam di dalam* also operates at a personal level; it was a common prelude to psychosis in many of the participants.

I do not wish to argue, however, that religious conflict is always internalized. For example, in the case of Endang, the confrontation between Islamic and Javanese

traditions remained at the *lahir* level of interpersonal relationships. This was evident in her clashes with her father over the practice of holding *slametan* (community meals) to commemorate the death of family members. Being more oriented to modern-reformist Islam, Endang opposed her family in this traditional practice. She criticized *slametan* as not being in line with Islam. But this conflict did not form a prominent part of her psychotic illness. Similarly, Joko and his wife, who were also associated with a modern-reformist Moslem organization, told me that they avoided seeking help from *dukun* (Javanese healer) or *paranormal*, because they considered their practices as *shirk,* that is to say, an act that diametrically opposed the Islamic principle of *tawhid* (the oneness of God). In this case, it was not internalized to form an inner conflict, but it did influence his care-seeking behavior. Likewise for Wulan, the tension between Christianity and Islam had a strong bearing on the family care-seeking behavior. Her mother remarked that during Wulan's psychotic breakdown, they took her to a hospital in a neighboring village. Wulan promptly refused to take her medication because she knew that it was prescribed from a Christian hospital. It was only when her parents moved Wulan to Sarjito Public Hospital that she agreed to take medication.

As I emphasized in relation to Priyo, at the same time that there was a movement from *lahir* to *batin* there was also a movement from *batin* to *lahir*, and this, too, was evident in other participant's narratives. Here religion facilitated an external movement through their relationship with local mosques, either by participating in congregational daily prayer or other mosque-based activities. Sri was the best example of this. Having a formal education in an Islamic college for kindergarten

teachers, she became a teacher in a TPA (*Taman Pendidikan Al-Qur'an*), a *Qur'anic* learning kindergarten before she opened an informal kindergarten in her house. Wulan too became actively involved in TPA activities in the mosque at her village. All of these activities promoted a sense of competence and meaningful contribution to the community.

Equally importantly the movement from *batin* to *lahir* facilitated community integration in the process of recovery. It encouraged the movement outward to wider social space that included returning to schools and universities or reintegrating in the work place. Even at this stage, however, participants also moved back and forth from *lahir* to *batin.* This enabled them to adopt a stance of simultaneously relating to and distancing themselves from the world around them. For example, while enjoy a good social relationship with her friends, Sri suggested that she needed time to be alone to examine her personal life. Joko's narrative provides a more obvious example of distancing. While he ran a telecommunication business and secured a job as a teacher, he emphasized that he did not want to be too much attached to material possessions. He had learnt that his desire for material possessions had made him worry and this, he said, was what had brought him to the illness.

7.5. SUMMARY

Much of the literature on the relationship between religion and psychosis that I reviewed in Chapter 1 has a static quality. It largely seeks to evaluate by statistical correlation whether religion has a positive effect or a negative effect on psychosis. In

this chapter I have demonstrated, by ethnographically exploring Javanese native categories and Muslim religious precepts, a more dynamic relationship between psychosis and religion. There are two overriding themes that I have identified in the relationship between religion and psychosis. One is the *lahir-batin* (outside-inside) dynamic, the other is the *takdir-usaha* (destiny-effort) dynamic.

Islamic religion in Java provides a cultural dynamic of movement from *lahir* to *batin.* External conflict can become internalized such that it emerges in the symptomatology of psychotic illness, whether it be in the form of guilt, as in Priyo's case, or hallucinations, as in Sri's case. This is facilitated by the cultural logic of *memendam di dalam* that operates both at a social and personal level. I have argued that there is an opposite movement facilitated by religious practice that takes participants from *batin* to *lahir*, enabling them to reengage with their family members and more widely with the community. Although in some cases the movement is sequential—from *lahir* to *batin* to *lahir* again, in many cases I found that these two movements occurred at the same time.

This simultaneous movement from outside to inside and from inside to outside, relating to and distancing from the world, has parallels with Corin's work on 'positive withdrawal' (see Corin, 1990; Corin & Lauzon, 1992). Positive withdrawal refers to a strategy adopted by schizophrenic patients that Corin first observed in a Western cultural setting whereby they establish a distance from their social world but at the same time relate to it. Sells *et al.* (2004) suggests that positive withdrawal is critical to

recovery from schizophrenia. Corin underscores the marginal position of the psychotic people:

> Their strategies of relating to the world and to themselves remain a mere "bricolage," always fragile and vulnerable. This reflects the absence of cultural processes allowing people to go back and forth between marginal and normal positions (Corin, 1990: 184).

In Yogyakarta, I would argue, we find precisely the sort of cultural processes that Corin finds lacking in a Canadian context but present, for example, in Central Africa. Throughout this chapter I have placed much emphasis on *lahir-batin* as a cultural *dynamic.* The Islamic religion inflected by Javanese culture thereby provides people who have a psychotic illness with the possibility of moving back and forth between withdrawal and engagement. I would argue that this powerful dynamic provides a strong yet flexible basis for recovery from psychosis in Java.

The second theme of this chapter is the *takdir-usaha* (destiny-effort) dynamic. I would argue that it is not possible to conceive of destiny without, in the same breath, thinking of the active role one must play in realizing this destiny. Thus *nrimo* (accepting destiny) goes hand in hand with *ngelakoni* (enactment). So too *sabar* (patience) goes hand in hand with *usaha* (making an effort). So closely linked are these dyads that it is not possible to conceive of one in the absence of the other. Thus *takdir* implicitly invokes *harapan* (hope) and stimulates action oriented *usaha* to achieve recovery.

These two dynamics, *lahir-batin* and *takdir-usaha* strongly influence the way people experience psychosis and recovery from psychosis in Java. They are closely related in so far as both collapse a structure-agency dualism into a single dynamic. *Lahir-batin* brings the outer world of Javanese culture and Islamic religion into conjunction with the inner self of individuals. *Takdir-usaha* similarly brings together the social structure in which they are situated and the human agency that is essential to living in this structure. As the patient and family members, through their Javanese religion, move from outside to inside and from inside to outside, there is a powerful injunction to be active participants in this process, not mere passengers.

In the following chapter, I continue my exploration of these fundamental cultural themes as they influence the process of recovery.

CHAPTER 8

THE PSYCHOCULTURAL DYNAMICS OF RECOVERY

As the culmination of this dissertation, this chapter focuses on the struggle by participants and their families to overcome psychosis. In line with the work of Jenkins and her colleagues on recovery (see Jenkins *et al.*, 2005; Jenkins & Carpenter-Song, 2006), the basic goal of this chapter—and of this research—is to examine the complex, interlocking effects of individual psychological factors and broader sociocultural factors that are involved in and influence the process of recovery.[40] Several issues I have discussed in previous chapters provide a starting point for my analysis.

In Chapter 7 I explored the way participants moved from *lahir* to *batin* and from *batin* to *lahir*. Because chapter 7 was concerned with religion, I gave special emphasis there to the *batin* or inner realm. This present chapter, however, places more emphasis on the *lahir* or outer realm. Nonetheless, I have already made the point that *batin* and *lahir* cannot be separated. To reinforce this point, I include here a short discussion of *usaha batin*, the inward struggle for self-awareness, thereby demonstrating that recovery in the outer *lahir* world is predicted on recovery within the inner *batin* self.

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[40] Analysis of the pharmacological factors that are also involved in the recovery process is beyond the scope of this dissertation.

The main thrust of my ethnographic analysis, however, is devoted to the various ways in which individuals and families struggle in the *lahir* realm, including the efforts they make to seek treatment, the emphasis they place on 'opening up,' and the goal of harmonious integration that they strive for, including family and social engagement as well as occupational reinvolvement.

I emphasize the idea of struggle throughout this chapter. The very movement from *batin* to *lahir* itself involves a struggle, and once engaged in the *lahir* world, the struggle continues. The notion of struggle is captured in the term *usaha*, but *usaha* is motivated by an underlying energy known as *bangkit*—a regaining of awareness, motivation, vitality and agency—that underscores the recovery process.

I conclude this chapter by comparing my findings with those of the literature on recovery that I reviewed in Chapter 1, identifying points of correspondence with these studies, but also drawing attention to certain differences which make my findings unique.

In previous chapters I have first presented one narrative and analyzed it before proceeding to further discussing the themes of my analysis in relation to other participants. In this chapter I likewise begin with the narrative of one person, Joko (participant no. 9). My analysis, however, is structured in a slightly different way. Here I move from theme to theme, drawing on Joko's narrative and the narratives of other participants at the same time. This strategy enables me to bring a sharper focus to the relevant dimensions of the outward struggle for recovery.

8.1. THE RECOVERY NARRATIVE OF JOKO

I met Joko for the first time in mid-August 2002, during which time he was hospitalized in a psychiatric clinic in Yogyakarta. He no longer showed evidence of any positive symptoms, but had developed negative symptoms such as a feeling of flatness, difficulty in focusing his attention, and slowness in responding to questions. However, he understood all my questions and had developed partial insight. I had some difficulty in establishing rapport with him at first because he remained reserved. It was only after several visits that I was able to establish any warmth of rapport.

My first impression was that he was an educated man and Joko confirmed this when he said he worked as the principal of a private secondary school. He had graduated with a teaching diploma from a Teachers' Training College in Bandung, West Java in 1983 and received a Bachelor of Education degree in 1995. He was married with three children. I did not acquire much information during this initial interview because Joko appeared, at first, somewhat reluctant to talk about himself. The most important issue for Joko was that before he fell ill there were financial problems at his school. These problems seemed to be connected in some ways to his illness but he did not enlarge on them at all.

I obtained further details about Joko's personal background and the history of his illness in the course of my subsequent visits to his house. He lived with his family in a small modern housing complex mainly occupied by middle-class people. In contrast to Joko's reserved attitude in the initial interview, Joko and his wife were very

cooperative during these subsequent interviews, and related the story of his illness together.

Joko's wife said that her husband's illness began in mid-May 2002. One morning while he was praying he suddenly called out God's name in a loud voice and his body spun around. Joko added that he felt vibrations throughout his body and sensed the presence of a power, which he interpreted as coming from a spiritual being. "I was controlled by a spirit," Joko said. At that point, he could not control his behavior. He suddenly punched his wife and kicked his children. Then he called out to people passing by his house and lectured them. "It was totally outside my conscious awareness, like I was being controlled by someone, as if someone had occupied me," explained Joko. He also felt his heart had became hot and noticed he was sweating profusely. He could see images of people being tortured. He heard voices. Some of the voices sounded like thunder whereas others sounded like people whispering in his ears. He began to think people were chasing or following him and this made him feel frightened, so he isolated himself in his room. "Sometimes he cried," his wife remarked. His wife also recounted that Joko had tried to commit suicide by hanging himself.

Even after I had visited Joko several times it remained unclear to me exactly what he meant by financial problems at his school. My curiosity was rewarded later in the course of my fieldwork, after I had consolidated my relationship with Joko and his wife. One morning, while speaking to Joko's wife on the phone in order to clarify a number of points, she seemed anxious to tell me about the financial issue that Joko

had alluded to in the first interview. Her desire to talk about it then was because we were talking by phone and she was therefore able to express he opinion without her husband's interference. Joko's wife whispered when she told me, "He used the money for his own purposes." She disclosed how shocked and angered she felt when she had received a telephone call from the school telling her that Joko had misappropriated money originally earmarked for a school project fund.

Not long after this was discovered by the school authorities, Joko fell ill and his wife took him to the home of a nurse in Magelang.[41] He was treated twice in Magelang with little success. He was then taken to a private mental hospital in Yogyakarta and then to a private clinic where I met him for the first time. After receiving medical treatment from several different hospitals for more than three months he began to recover. He was able to return to work and resumed his role as school principal. However, he soon relapsed and was hospitalized again in the same private clinic for a week in December 2002.

When I visited Joko in March 2003 I noted that his appearance and behavior had changed considerably. During previous visits he had looked tense and was unable to answer my questions spontaneously. Now, however, he looked much more relaxed, and he laughed openly and spontaneously. His wife's opinion was that he began to improve, although she noted he was "still not one hundred percent." His improvement was possibly related to the fact that Joko had transferred to another school. He

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[41] Magelang is a neighboring city of Yogyakarta, where a colonial style mental hospital is located. Due to the policy of deinstitutionalisation, some nurses working at this hospital were asked by family members to take care of patients who had been discharged. Though this practice is illegal, it became a popular alternative to hospitalization.

explained that he had previously been a state school teacher prior to securing the position as the principal of a private school. Due to his illness, however, and the shadow of the financial scandal, he resigned from the private school and returned to a state school to work as an ordinary teacher. This change of employment and the new atmosphere of the state school gave him a renewed sense of optimism.

During this visit Joko told me that he had stopped taking his medication for a week after having taken it regularly for almost a year. I asked him whether he had consulted his doctor about this. He said that his doctor had continued prescribing the medication although the dosage had been decreased. The main reason Joko gave for stopping his medication was that he did not want to become addicted to drugs and he felt this was more likely to occur if he had to take them for a long time. Thus, he decided to stop the medication and replace it with what he called *terapi alami* (natural therapy). He explained the therapy to me. Every morning at 3.30 a.m. he got up, took a bath and then performed *shalat tahajut* (night prayer) at home, together with his wife. At 4 a.m. he walked to the mosque to perform morning congregational prayer, accompanied by a neighbor. The mosque was located approximately one kilometer from his house and the steep, uphill, village road from his house to the mosque provided Joko with the opportunity for regular physical exercise. Besides this, he could also mix with other people, not only with his neighbors from his housing complex, but also with people in the village. Joko told me that he started to give sermons during Friday congregational prayer in the mosque. "This is a natural therapy—to integrate with the community," Joko reflected.

Although Joko felt a sense of relief because he was able to leave the school environment and the financial scandal that had triggered his illness, his wife insisted that her husband had not completely recovered. "He still felt tense and *bingung* (confused)," she said. For example, one day he received a telephone call from the aforementioned private school and suddenly his body became hot as it had done during his illness. She also observed that he would often sit on a chair and quietly daydream. Joko disagreed, saying he did not daydream, contending instead that he was "thinking hard." He became preoccupied with his children's education since it was very expensive to fund a university education and his salary as a regular teacher was low. "What will be the future of my children?" he would murmur to himself. Besides worrying about the future, Joko was full of regrets about what had happened in the past. "I often ask myself," he said, "Why did I have to suffer from this illness that ended up with me losing my position as school principal?" Although Joko was sure that his new school provided a stimulating work atmosphere, he still felt *isin* (ashamed) because he often met the school principal, a man who used to be his colleague. "We used to go together to school principals' meetings," Joko remarked. The loss of his position was a heavy burden for him. He was immersed in regret for his prior unlawful behavior.

In May 2003 I visited Joko again. This time he told me, "I am making a strong *usaha* (effort) to return to my previous condition." Regular exercise was a major component of his effort. Joko also strove to get closer to God by performing *shalat tahajut* in order to asked God's forgiveness for his wrongdoings. He would also read psychology books and religious books, "as a form of self-therapy," he said. However, he

continued to experience the burden and shame of losing his position as a principal. "I try to stop thinking these thoughts for the sake of my family and children, but I find myself thinking about them all the time," he said. Joko's efforts to improve included making an effort to manage his emotions better. Joko's wife related that sometimes he looked extremely tense, as if he was trying to control his anger, and then he would bang the walls with his fists to express this anger.

According to his wife, Joko's problem at that time was that he was unable to accept the reality of the situation—that he was sick and had lost his status as a principal. "As well as that he is also always worrying about money," she said. Joko concurred that "the illness has destroyed my self-esteem, self-confidence, and self-respect."

During my last visit of the first year in July 2003 I found Joko had made a solid improvement. He spoke more openly and now responded to my questions spontaneously. Joko's wife told me that they planned to open a small *wartel* (telecommunications café) in their house. I noted a telephone booth in his garage that was part of the plan. I also saw a mirror and some hairdressing equipment that they had bought for his wife to operate a small beauty salon. Joko remarked, "I tried to keep myself busy." His routine activities included going to the mosque and doing physical exercise in the morning and reading the *Qur'an* in the afternoon. "I have no time to daydream," he said. Joko's wife confirmed her husband now had a strict routine. More importantly, he did everything on his own. Joko's wife no longer had to remind him and direct him to do things as she previously had to.

When conversing with him I felt that Joko was now more open in talking about his previous illegal behaviour. "Through the illness I became aware of my faults. I now feel a deep sense of regret. In religious term, I have repented." Joko asserted that he was also able to accept the reality of his new situation and had begun to find a sense of self-confidence again. He emphasized that he had to *bangkit* (regain awareness, get up, revitalize himself): "I strive to *bangkit* because I am still young and my children are still small. I feel pity for my children. I really do try to *bangkit*. I make every *usaha* to overcome the previous wound I inflicted on myself, and I try to think positively." From his perspective it was a good thing that he had had this illness. It was a reminder from God of his wrongdoing. "If I had not been reminded, my sin would have become much greater."

At my follow-up visit a year later I met Joko together with his wife again. They both looked contented. His telecommunications business was doing well. As I interviewed them, I saw people coming in to make telephone calls from his garage. I could also see that he was adding a second floor onto his house. He disclosed that he had been able to completely eradicate all his old worries about material possessions. "God has arranged, but we have to make *usaha,*" he said. He had never thought that he would have the skill to run a telecommunications business and renovate his house. During this visit Joko talked about the happiness he now experienced: "Behind all of this is happiness." He called this happiness "a spiritual experience." Every morning, he said, when he got up early and walked to the mosque he was able to feel the fresh air and appreciate the beauty of nature: "It is deeply enjoyable, it is a happiness that cannot be measured in material terms, it is an inner contentment." He reinforced the point that

his spiritual experience had had a significant impact on his own life, on his wife, children, and on the community.

8.2. *BANGKIT* : TO REGAIN AWARENESS, TO GET UP, AND TO REVITALIZE

The central theme of Joko's recovery is encapsulated in his statement: "*Saya harus bangkit* (I have to get up)." I use the term *bangkit* to indicate the core idea of recovery in this thesis, since it underpins and embraces the entire process of recovery. In this section, my strategy is to carry out a semantic analysis of this term in order to facilitate our understanding of the layers of meanings that pervade the many different contexts of recovery from psychosis. I argue that *bangkit* carries meanings of such motivational force that it can exert a transformative effect on individuals faced with illness and seeking to recover.

Bangkit is used in a variety of personal and socio-political contexts, particularly in the period following a crisis, upheaval, or catastrophe. For example, the concept of *bangkit* was appropriated by Indonesians to their struggle for independence from Dutch colonial rule. The term was also repeatedly used during the period that Indonesia struggled to recover from the severe economic crisis which bedeviled its economy in 1997, and which ultimately led to the collapse of the Suharto regime. More recently the term found widespread use following the 2002 Bali bombings and again following the 2004 tsunami which devastated Aceh. On television one would hear the term repeated over and over as government officials, politicians, media personalities and others sought to motivate the populace to rise up and overcome the

crisis. When I was finalizing this dissertation, a strong earthquake struck Yogyakarta on 27th of May 2006, the Bantul regency being the most seriously affected area. Shortly afterward, a leading religious figure in Bantul, Emha Ainun Nadjib, declared: *"Bantul Bangkit,"* to motivate people to struggle in the face of this very difficult situation.[42]

A core meaning of *bangkit* is that of regaining awareness. In this context Joko and other participants used the cognate term *sadar* (becoming aware) to indicate what, from a psychological perspective, might be called gaining insight. Most participants said that when they were ill they were *tidak sadar* (not aware), or half aware and half not. The initial process of recovery began only when they had become became *sadar*.

Participants invoked many different forms of awareness. First, awareness of the present referred to the awareness of what was going on around them. For example, When Wulan (participant no. 7) became *sadar,* she realized that her mother had accompanied her in the hospital, whereupon she asked her mother to take her home. When Wati regained her sense of awareness, the first thing she did was to look for her ten-month-old son. The second type of awareness was awareness of the past which participants were able to examine their life prior to the illness. Sri (participant no. 4), for example, reflected on her illness as the result of her tendency to *memendam,* burying many conflicts within herself. Third, there was awareness of the future, where participants looked at their future life after the illness. In Joko's case, this awareness sparked his motivation to perform *usaha,* to struggle to achieve recovery, not only for

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[42] http://www.padhangmbulan.com/index.php

himself but more importantly for the future of his children. Finally, participants also referred to a further deep sense of self-awareness. Priyo (participant no. 6) provided a good example. It was only when he became *sadar* that he felt he had to *ngelakoni*, to enact his *takdir*, destiny, of the illness and of his whole life.

Gaining insight as the basic idea of recovery has been noted frequently in studies of recovery from schizophrenia (Young & Ensing, 1999). In a meta-analysis of the role of insight, Mintz (2003) found that insight was inversely related to psychopathology, meaning that the more severe the illness, the less insight. Translated to a Javanese context, this indicates that in the process of becoming ill individuals lose their sense of awareness and regaining awareness is the first sign that the recovery process has begun.

The second meaning of *bangkit* refers to change from a passive to a much more active disposition. This is captured in the idea of revitalizing one's self and coming alive again. In physical terms, the concept of *bangkit* indicates a change from a static posture to a more dynamic one, such as moving from lying down to standing up. At a more abstract level, the term implies that the person rediscovers his or her 'active sense of self' (Davidson & Strauss, 1992). Joko's narrative suggested that keeping active and busy was integral to the process of recovery. I refer here to his involvement in socio-political and religious interaction, as well as his regular physical exercise. He reasoned that by doing these activities he could dispel negative thoughts, fantasies and daydreaming. The latter, in particular, epitomizes inactivity, and it is widely regarded as a form of empty idleness that can predispose an individual to *kaget* (shock) and

thence mental illness. As discussed in Chapter 7 other participants involved themselves in many different activities including performing religious practices, as their way of active coping. I emphasized there that they understood the concept of *takdir* (destiny), *nrimo* (accepting destiny), and *sabar* (patience) in a highly active way to incorporate the idea of *usaha* (effort).

Most participants' narratives suggested that passivity was associated with illness, whereas activity was associated with recovery. Joko's narrative provides the best illustration. When ill, Joko led a passive life. At first he felt that he was under the influence of spirits. Although still aware of what was going on, he was not able to control his aggressive behavior. During this time it was his wife who played the more active role in seeking care and treatment. When he underwent medical treatment it was his doctor who took control of his life by virtue of the authority bestowed on the medical profession. When discharged, his wife took control of him again and directed him in what he could do and what he could not do. He exercised no sense of autonomy and independence. The first indication of his recovery occurred when he began to play an active role in his own life again.

The third meaning of *bangkit* is acquiring motivation to change. In their *Indonesia-English Dictionary*, Echols & Shadily (1995:49) write that the term *bangkit* also means "to generate motivating force or energy." This meaning was evident in Joko's narrative above. He invoked this term as a powerful metaphor for motivating himself to recover. I emphasized in my review of the literature in Chapter 1 that recovery is not a linear process. This was certainly the case for Joko. There was always

something that seemed to hinder him in achieving his goal of returning to his previous state of health. For example, when he regained a sense of self-awareness, regret over losing his position as school principal immediately surfaced. This generated further worries concerning his children's future and their education. These feelings reactivated his previous symptoms, particularly daydreaming. Therefore, in order to continue the process of recovery in the face of such set backs Joko required constant motivation to reconstruct his sense of self. *Bangkit* motivated him to perform *usaha,* to struggle both in the *batin* realm, by reconstructing his sense of self, and in the *lahir,* by integrating with his community to achieve *rukun,* harmonious integration.

Thus, by conceptualizing the recovery process in terms of *bangkit*, Joko and other participants appropriated a powerful set of cultural meanings that exerted a transformative effect on their lives and their approach to their illnesses. *Bangkit* embraced *sadar* or regaining awareness, changing to a more active orientation to the world, and self-motivation in initiating the recovery process. Pivotal to this was the performance of *usaha batin*.

8.3. *USAHA BATIN*: THE INWARD STRUGGLE FOR SELF-AWARENESS

This section focuses on Joko's internal struggle to reconstruct his sense of self to achieve self-awareness. It extends my earlier discussion of this theme in Chapter 7 where I explored how participants and their family members coped with illness by the performance of religious practices.

Chapter 8, The Psychocultural Dynamics of Recovery

In my review of the process of recovery in Chapter 1 I showed how people who have achieved symptomatic recovery from psychosis often experience adverse effects of the illness such as low self-esteem and depression (Gureje *et al.*, 2004). Essential components of recovery therefore include self-reconstruction (Davidson & Strauss, 1992), self-renewal and transformation (Mead & Copeland, 2000), and self-empowerment (Young & Ensing, 1999). Joko's narrative aptly illustrates the main feature I highlighted in the literature. He felt that the illness had destroyed his self-esteem, self-confidence, and self-respect. For Joko, the process of self-reconstruction was encapsulated in the concept of *usaha batin* (inner struggle).

Joko *usaha batin* included several tasks. Firstly, he strove to develop a sense of self-control, notably by especially controlling his anger. When he was ill Joko could not control his outbursts; he hit his wife and his children. His wife noticed, however, that in the process of recovery, Joko would often look tense, as if trying to control himself, and then express his anger by hitting a wall with his fists.

Secondly, Joko had to struggle hard to conquer negative thoughts and feelings, particularly those concerning the loss of his position. Regretful that he had lost his status, he described to me the power of being a school principal: "As a principal, I could give an order, set the direction and control or monitor the other teachers. A principal is an authoritative figure at a school." When he started working at the state school, a completely different environment, he was able at first to forget the past and build a new life. However, the sense of loss surfaced, particularly when he encountered the school principal who used to be his colleague on the school principals

forum. Joko became *isin* (ashamed) that he was no longer a school principal. According to Joko's wife, her husband's feeling of *isin* indicated that he had not accepted this reality, and it became an obstacle for him in his pursuit of a better future. In fact Joko's wife was instrumental in helping him to accept the reality of the situation that he was no longer a school principal. He also felt he learnt from psychology books he read to overcome his negative thoughts and feelings.

The third task for Joko in the process of self-reconstruction was to overcome his worry about his children's future. Since he and his wife had only one source of income, and since he was now an ordinary teacher on a relatively low salary, he would not have enough money to pay the expenses for his children's higher education. In order to come to terms with this, Joko strove to get closer to God by performing non-obligatory religious practices, particularly *shalat tahajud* (night prayer) and reading the *Qur'an*. It was the non-obligatory nature of these practices, I argued in the previous chapter that were so important, for they were a manifestation of the active effort he was making. It was through this active struggle, I would add, that he was able to adopt an attitude of *nrimo,* accepting his destiny.

Joko successfully accomplished the task of self-reconstruction. On the last visit of my fieldwork, he appeared as if a new person. He had become more positive in his thinking. There was no evidence I could elicit of his former negativity. Slowly, his sense of self-worth had consolidated. He said he felt more confidence, more accepting of his previous life, and also his current position. He also believed he could now control his worries about the future. My own observations suggested that Joko had

changed from being closed-off to being more open with his emotions, attitudes and feelings. In particular, he openly admitted his guilt regarding the financial illegalities at his former school. By reconstructing himself, guided by the cultural principles of *usaha batin*, Joko was able to attain a deeper state of *sadar,* or self-awareness that was, it would be argued, more insightful than before he became ill.

Joko's *usaha batin* to reconstruct his sense of self can be located within the Javanese mystical idea of struggling to a find the true self. This has been depicted in the *wayang* (shadow play) performance regarding a well-known story called *Dewa Ruci* or *Bima Suci* (Clifford Geertz, 1960:273-274; Mulder, 1978:22; Woodward, 1989:193-194).[43] The hero of this story, *Bima,* is a larger than life character, an enormous man of great strength and a famous warrior. In short, the story tells of *Bima*'s struggle to find his true self, metaphorically described as finding the 'water of life.' He is asked by his spiritual teacher to go to dangerous places to find the water. He has to go to a mountain where two giants live. *Bima* kills the giants but he finds no water there. Then he has to plunge into the ocean where he has to fight with a giant *naga* (a mythological dragon). Upon killing the *naga*, *Bima* encounters *Dewa Ruci*, a god who looks exactly like himself, but who is as small as his little finger. *Bima*, with his enormous size is asked to enter *Dewa Ruci*'s body. Inside the minuscule *Dewa Ruci, Bima* finds that *Dewa Ruci,* in fact, contains the entire world. *Bima* receives

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[43] According to Woodward (1989:193) this story might have been written during the period of transition from Hinduism to Islam. The main character of this is *Bima*, one of the major heroes in the Mahabharata epic from India, but the core message is derived from Sufi theory about the mystical path. The story of *Dewa Ruci* occupies a prominent position in the court literature, and is very popular among the *priyayi* elite as well as lay village people. The complete Javanese text with English translation is available from http://www.xs4all.nl/~wichm/dewaruci.html.

secret knowledge from him about the wisdom of life. Inside the body of *Dewa Ruci, Bima* feels immense joy and happiness. He does not want to leave but *Dewa Ruci* insists that he should return to the outside world and enact his duty of life in the world.

Figure 8.1. Bima fighting the *naga* in a shadow puppet play (http://www.stsi-ska.ac.id/pedalangan/index.htm)

The inward and outward movement that I first described in Chapter 7 is rendered explicit in the story of *Bima Suci*, in fact exaggerated to magical proportions and laid out in an ordered processual sequence. *Bima* first struggles in the upper mountainous regions and fails to find his true self. Then he plunges down into the depths of the ocean, where he undergoes a life-or-death struggle, and finally encounters himself in the form of a tiny replica, *Dewa Ruci*. It is only when he makes the movement inward into that tiny self that he achieves full knowledge and awareness, and with these, happiness. And it is only then, as a new person, that he is ready to goes out again into the external world to fulfill his duty.

The sequence of Joko's recovery does not neatly fit the processual sequence outlined in this story, nor should it, because the story is an archetypal culturally available version in which all the elements are set out with exaggerated clarity. We can nonetheless see in his progress through some of the phases that *Bima* undergoes. We see Joko struggle with his guilt over the financial misappropriation, his uncontrolled anger that causes him to lash out at his family, and his shame at anticipated failure to educate his children. It is only when he goes into himself through *usaha batin* that he gains full awareness of himself and his illness. Here he finds his deeper self and is able to feel joy and happiness which he referred to as a spiritual experiences: "It is deeply enjoyable, a happiness, that cannot be measured in material terms, it is an inner contentment." It is after experiencing this contentment that Joko becomes able to open himself to the outer world to engage there in *usaha lahir*.

8.4. FROM *TERTUTUP* (CLOSED OFF) TO *TERBUKA* (OPENNESS)

There was evidence of increasing openness in the way Joko became able to discuss his feelings about the money he had misappropriated, first with his wife, then with me, and then later again in company with my research assistant. I noted from one visit to the next that he was able to talk about this in a way that showed growing self-acceptance. Though he did not discuss this with his children, Joko became much more interactive with them, playing with them and taking an interest in their schooling again. This was followed by a return to community involvement which I discuss in the next section.

The theme of increasing openness was also echoed in other participants' narratives. There was a tendency, when ill, to keep their illness experiences to themselves—they remained closed off. As time went by, however, the illness frequently became *terbuka,* or opened out. This was evident in Endang's case. When ill, she maintained a *tertutup* posture. She confined herself to her own room, talking mainly to herself. When her family would ask what she was doing, she would deny that there was anything wrong with her behavior, acting as if everything was normal. But as she started to recover she began to share her illness experiences, first with Nia—the psychology student who rented a room in her house and who was considered a part of the family—and then with other family members. She also disclosed details of her private illness experiences to me, including the fact that she continued to have auditory hallucinations, despite her having made considerable progress in her social functioning by returning to university. She told me that when she was doing her final exam she heard several voices telling her how to respond to multiple-choice items. When she relapsed, however, she again became *tertutup* again. When I met her in this condition, she denied all of her hallucinatory experiences she had so freely told me about before. With the second recovery, she was again able to talk about them with me.

Priyo provides another example. At first he tried to cover up what he had done that troubled him so much, but after three visits he was able to discuss his feelings of sinfulness for having watched pornographic videos, first with my research assistant, and then with me and his father. It then became an open family matter. In my more extended discussion of Priyo in Chapter 7 I emphasized that Priyo's belief that

through the illness God had opened his heart, enabling him to become *sadar* or aware of his wrongdoings and accept his experience of God "opening his heart" enabled him to *nrimo* himself and his destiny.

Growing openness at a psychological and family interactional level was mirrored by an opening out in the physical space that the participants inhabited. This was most clearly evident in Endang's case. When ill, she confined herself to her bedroom. She even ate her meals there. As she slowly recovered, she began to move out into the family rooms within the house and began to eat with them again. Her father said, "She came out from her room like she used to, and chatted with other family members as per usual." Her mother added that when she had recovered even more, Endang would go into the kitchen and help her cook, as well as joining her family to watch television with them.

The change in Wulan was just as dramatic. When ill she sat motionless in a chair in her room for hours, confined, as it were, to this sitting position. When she recovered she came out and started helping her parents prepare the food that her father sold at the local school. Before long she joined in with the activities of the village mosque.

Thus, the process of recovery was characterized by a movement from *tertutup* (closed off) to *terbuka* (openness). The state of *tertutup* was associated with illness and relapse—a separation from the world around them. The state of *terbuka*, by contrast, was associated with recovery, and signified their connectedness to the outer world. The transition from *tertutup* to *terbuka* in Javanese culture has parallels with the

cultural logic of Western psychotherapy, especially the notion of disclosing previously hidden and often guilty secrets to the therapist as a pathway to self-discovery. However, the closed to open transition has a distinctive cultural inflection in Java which distinguishes it from Western psychotherapy, and this has to do with its relationship to *batin* and *lahir*.

Moving from *tertutup* to *terbuka* has features in common from *batin* to *lahir* in so far as both imply a transition from inside to outside. It is important to note, however, that *tertutup* is not synonymous with *batin*, nor is *terbuka* synonymous with *lahir*. In fact the shift from *tertutup* to *terbuka* can occur in the *batin* realm and separately in the *lahir* realm. I have shown how Joko and Priyo changed from *tertutup* to *terbuka* can occur in their *batin* inner selves. I have also shown how Endang and Wulan changed from *tertutup* to *terbuka* can occur in their *lahir* space and in their *lahir* social relationships.

8.5. *USAHA LAHIR*: THE OUTWARD STRUGGLE

In the previous chapter I analyzed in detail *usaha batin,* the active effort in the inner realm. In this chapter, I focus on *usaha lahir*, one's efforts in the every day world. The concept is used in many different aspects of Javanese daily life. It can refer to the effort one might make in the world of business, politics, or education. It is especially applicable to matters of health, illness, and recovery.

Figure 8.2. *Usaha* in everyday life in Yogyakarta

8.5.1. The Effort to Seek Treatment

It was usually family members who initiated the process of seeking treatment for their ill family member (c.f. Janzen, 1978) and they characteristically demonstrated their *usaha lahir* by seeking treatment from several sources. The inherent pluralism of the health system in Yogyakarta, I would argue, facilitates the expression of *usaha lahir.*

In Joko's case, it was his wife who organized him first to see a nurse in a neighboring town, then to be admitted to a private hospital, and ultimately to be admitted to a private clinic. She also arranged for him to see a religious leader. This literally involved enormous effort, especially taking him to Magelang. Even when he was admitted to the private clinic in Yogyakarta, she had to make a one and a half hour journey by motorcycle to visit him several times a week. While all this was going on,

she also had to take care of their three children, bring them to school and then pick them up in the afternoon. On top of this she had to find a way to return the money that her husband had stolen from the school project and spent on himself.

Although Joko and his wife did not seek help from traditional healers, all the other participants sought care from both the medical and the traditional or religious sectors of the Javanese mental health care system. Generally speaking, they firstly sought care from the latter sources before seeking recourse to hospital. Even in cases of acute severe illness, for example the illnesses of Wati and Sri which lasted only a few days, their families sought help from traditional healers or took them to religious leaders for advice before presenting to hospital. However, the hospital was not always the final place from which care was sought. This has been confirmed by several hospital-based studies on care-seeking behavior (Bou-young, 1995; Subandi & Utami, 1995; Skeate, 2002). In my study participants' families commonly continued to seek care from healers after being discharged from hospital. Thus, they were able to switch with facility from modern medical health professionals to traditional healers and back again. In several cases both medical and traditional therapies are used at the same time. Both, in fact, are avenues through which *usaha lahir* can be expressed.

In Table 4.2. (see Chapter 4, section 4.1), I presented data on participants' DUP (Duration of Untreated Psychosis), that is to say, the length of time from first presentation of symptoms to receiving anti-psychotic medication. The table showed that overall the DUP was very short, ranging from 2 to 4 weeks. Family members clearly responded very quickly to the illness by seeking medical care, notwithstanding

the fact that they first sought non-medical treatment earlier. I would hypothesize that the Javanese cultural injunction to *usaha lahir* plays a role in bringing participants rapidly to treatment. I argued in Chapter 4 that the short DUP, in turn, may contribute to the participants' recovery (see also Black *et al.*, 2001).

For the family, *usaha lahir* was not limited to taking an ill family member to a hospital. It extended to taking responsibility for monitoring the medication at home. Table 4.2 showed that most participants were not compliant with their medication, either stopping after less than one month, or taking medication on an irregular basis. Only one participant (Wulan) took the prescribed medication for a whole year. The principal reason for participants not continuing their medication was that they felt that they had already recovered. Some indicated that unwanted side effects influenced their decision to stop. These included dizziness (Sri), somnolence (Priyo), or irregular menstrual cycle (Wulan). Joko feared becoming dependent on his medication so he turned to what he called natural therapy. My ethnographic data, however, showed that most family members made a great *usaha* in encouraging participants to comply with their medication. For example, Rima's father stated that he used many different methods to get Rima to take her medication, such as putting it in her food or drinks. Priyo's father used a religious framework of authority to encourage his son to take his medicine.

The practices of traditional healers as discussed in this research varied considerably. They ranged from physical to spiritual treatments. Physical treatments included massage, the use of particular powders and herbal medicine (*jamu*). The spiritual

treatments were more varied, including magical power to repel spirits (*jin*) and other unwanted objects from Budi's body (see Chapter 6, section 6.5.1.). One healer suggested that Bambang's wife should walk in a circle around the house, akin to performing circumambulation at an Islamic religious ritual. Rima's father, who took Rima to twelve healers in all, talked of the various rituals performed by different healers. One performed a ritual to cleanse a family *keris* (dagger), because the healer believed that the *keris* had not been taken care of properly so that the spirit who dwelled inside it had possessed Rima. Another healer suggested that the family should perform a ritual offering at Rima's home for her spiritual sisters,[44] and again at the graveyard to ask forgiveness from Rima's ancestors. Another healer performed a ritual to remove spirits who lived in Rima's house, followed by a second ritual to protect the house with a magical power.

In summary, families' *usaha lahir* was evident in their effort to seek treatment from different sectors of the Javanese mental health care system. This is comparable with the study conducted by Halliburton (2004). In his research on psychiatric pluralism in southern India Halliburton found that participants who were treated with three forms of therapy for mental illness—ayuverdic (indigenous), allopathic (Western) and religious healing—showed improvement in the follow-up assessment. He argued that the availability of different forms of therapies provided more possibilities for participants to find a therapy which suited them. Halliburton (2004) hypothesized that using different models of therapy may contribute to recovery from psychotic illness in

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[44] Traditional Javanese believe that when one is born, he or she is accompanied by four spiritual siblings (*sedulur*) who always take care of him or her in the spiritual world.

the developing world. This idea is interesting, but must be considered with caution in this research. Although the three models of therapies in India do exist in Java, it is too early to conclude that psychiatric pluralism is a factor associated with recovery for the participants in this study. Further research still needs to be done.

However, it is clear from my ethnographic data presented here that the search for multiple forms of therapy has a special set of meanings that give medical pluralism, so commonly found around the world, a special accent in the Javanese cultural setting. The variety of treatment options enables participants and families to demonstrate *usaha lahir* by utilizing many options, often simultaneously. This expression of *usaha lahir*, I would argue, is in itself therapeutic, in so far as it constitutes one of the chief ways in which they can *ngelakoni takdir* or enact their destiny.

8.5.2. Achieving *Rukun,* or Harmonious Integration

As discussed in Chapter 6, the term *rukun* was frequently used by participants to indicate harmonious integration at a family level. As I will demonstrate, it also applies to harmonious integration at a broader social level.

Participants strove to achieve a state of *rukun* (harmonious integration) because it was regarded as an important factor to attain a *tentrem* (calm, peaceful) state and, thus, significant for recovery. Very often, to achieve *rukun* one needs to sacrifice one's interest to avoid conflict. This was best illustrated in Joko's narrative. As I have indicated, Joko became more involved with matters of everyday family life as he recovered. For example, he had to deal with finding a new middle school for his

oldest daughter after she graduated from her primary school. At first Joko wanted her to go to a religious school, but his wife and daughter disagreed. Joko decided not to impose his own views on them so he arranged for his daughter to enter a state secondary school. Also, when his wife proposed the idea of opening a *wartel* (telecommunication café) at his house, Joko firstly disagreed because there was already a *wartel* near his house. After much discussion, he finally agreed and assisted his wife in operating this small home business, not only a *wartel* but also a beauty salon. This is indicative of his integration with his family in a way which shows a degree of maturity, vastly different from his prior approach.

The term *rukun* has also come to be been used much more widely in Java across a variety of social contexts. Clifford Geertz (1960:61) defined *rukun* as 'traditionalized cooperation' in the sphere of labor and capital exchange. Analyzing the concept at a more abstract level, Koentjaraningrat (1985:251) suggests that *rukun* represents 'harmonious integration,' a particularly important value among the *priyayi* elite, who invoke it to maintain a sense of in-group solidarity and to maintain their superior social status and identity. The term *rukun* has been applied to the modern Indonesian social system. It may designate neighborhood structure. The smallest neighborhood is called a *Rukun Tetangga* (RT), which, literally translated, means harmonious integration with neighbors. One RT usually consists of around thirty households. Six to ten RTs make up a *Rukun Warga* (RW), literally, harmonious integration with all members of the community.

Participants in this research exerted much effort to achieve *rukun* at community level. In Joko's case, he strove hard to participate in social-religious activities. He told me that every morning he participated in congregational prayer at the mosque. In fact, he said to me that one reason for him going to the mosque was so that he could socialize with people in the housing complex and with people in the village. During the *idul adha*[45] celebration, Joko actively participated in the proceedings as a committee member and organized the sacrifice of animals. He also became involved in community social life such as attending a wedding ceremony and meeting in his RT group. These activities provided him with a feeling of being valued by the community, and a sense of reconnection because he had re-established a substantial role in the community. Further to this, Joko's reintegration into social life in Yogyakarta was evident in his involvement in political activities. During the 2004 Indonesian presidential election he organized supporters for Amin Rais,[46] one of the candidates. Although Amin Rais was not successful, Joko learnt much about party politics in Indonesia and, more importantly, he said he learnt from Amin Rais' example how he should lead his own life.

Increasing social engagement was also evident in other participants. In Wulan's case the progression toward increasing social engagement was quite obvious. When I met her for the first time, during the initial phase of recovery, she was able to help her mother make food that her father sold. Later she became involved in mosque activities where she taught village children to read the *Qur'an*. This not only gave her a sense of

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[45] *Idul adha* is the annual Moslem celebration during which goats or cows are sacrificed.
[46] A leading figure in the Muhammadiyah movement who had previously been the chief of the Indonesian Consultative Assembly *(Majelis Permusyawaratan Rakyat)*.

self-worth but it was also through this activity she struck up a personal relationship with a man with whom she was later married. Her marriage ultimately symbolized her reintegration into the community.

Part of the process of social engagement involved an effort to achieve reconciliation with members of the community and to rebuild social networks which had been fractured by illness. This was critical to the achievement of *rukun*. Wati and Bambang sought to improve their social relationships with their fellow workers, trying to convince them that nothing was wrong with them now as they had fully recovered. Rima's narrative provides a unique illustration of the achievement of community reconciliation leading to a state of *rukun*. Her father mentioned that, when ill, Rima often wandered around the village, and on one occasion drew the symbol of a political party and a political figure on the wall of her neighbor's house. When she recovered Rima felt ashamed about going out. Her father asked her brother to go to her neighbor's house to ask forgiveness for her inappropriate behavior. Her father also performed the ritual of *slametan,* whereby the neighbor was invited to pray and had meals together. He disclosed that the *slametan* was not only intended to achieve reconciliation with their neighbor, but also with the spirit who may have been offended by Rima's behavior.

Thus, participants moved from a focus on themselves to increasing involvement first with family members and then more broadly with members of their neighborhood and community, resolving their damaged relationships at each level, in pursuit of *rukun*.

8.5.3. Increasing Occupational Engagement

Participants' integration with the community also occurred in their working life. In Joko's case this was evident when he move to the new school to take up duties as a regular teacher. The initial struggle to accept his altered circumstances, in the long run, proved psychologically beneficial because it opened the possibility of him developing a new life.

Just as Joko returned to his work as a teacher, other participants also engaged in productive occupations as they recovered. Two of them returned to their previous jobs. Wati recommenced her job in the glove-making factory without any difficulty. Her fellow workers provided support during her illness and when she returned to work. Similarly, Bambang returned to his previous work in the aluminium factory. I had an opportunity to visit this factory, located not far from his father's house. Although I was unable to meet with his supervisor, I was informed that Bambang had done very well, notwithstanding the fact that he had been ill. His brother, who also worked in the same factory, assisted him in his negotiations with the factory owner. Bambang did not experience any discrimination even though his fellow workers were well aware of his illness.

Two other participants, Sri and Endang, returned to university and Priyo returned to school. Before graduating, Sri secured a temporary job at a kindergarten. In the second year of follow-up, Sri told me that she had graduated and now worked at another kindergarten in a more permanent position. Endang was still continuing her studies when I made the last visit. Priyo, who had also graduated from school, was

able to get a job with a building contractor. He remarked that during his first month in the job, he still took his medication. By contrast, Wulan decided not to continue her schooling and instead took up sewing lessons and teaching children to read the *Qur'an* in the village mosque. Here she met a boy who later married her. After her marriage, Wulan worked in another city for three months and then returned to her village, where she took up work in a cigarette company located not far from her village home.

8.5.4. Reconstructing Physical Space

In an earlier section I discussed the transition from closed to open, and showed how this was effected not only in terms of the self, but also in terms of participants' physical space. Here I extend that discussion to demonstrate how at a later stage of recovery, some of the participants literally reconstructed their living space. Young & Ensing (1999) underline the importance of taking care of the living environment as an important part of recovery from mental illness. It provides evidence to others that the recovering patient is a capable human being who can survive and function in the world. In this research I was impressed by the extent to which participants expressed their recovery by reconfiguring their living space.

When I first visited Rima's house while she was still ill there were only two chairs in the living room. I could see a broken mirror in the dining room; she had smashed it. She had also bought some stickers and posters from the market and attached them on the wall more or less randomly, which gave the impression of a disorganized and

messy room. During the next visit I observed that Rima had scribbled on the front wall, although it had just been painted by her father to celebrate the annual *lebaran* festival. When Rima began to recover, the change in her house was noticeable. Rima's father had put new ceramic tiles over the old, bare, cement floor. New chairs in the room made it look tidier, and it now had a small television set in the corner and sewing machine against the window. Rima was making her own dresses using this machine.

For Sri, her recovery was marked by her re-arranging her living room. When I visited her for the first time the living room was partitioned with a large cupboard. She received guests in the front part while the back part was used as a dining room. During a later visit, after her mother died, I found the cupboard had been put back against one wall, which gave the living room more space. Sri told me that some children from the neighboring area often came to play and learned to read the *Qur'an*. The next time I visited I was surprised by how different her house looked. The living room had been transformed into a classroom for an informal kindergarten. With the help of her brother the wall was brightly painted in green, yellow and red, and Sri had drawn some pictures of flowers, and houses, as well as writing the names of angels. The room now exuded a sense of cheerfulness, order, and openness.

Some participants also reconstructed their living spaces by engaging in major building projects. In a follow-up visit I observed that Joko was building a second floor onto his house. This activity strengthened his self-confidence further enhancing the recovery process. He disclosed to me that he had never thought he would be able to renovate

his house so soon, after being so ill and loosing his position. In January 2006 I visited him and he had finished building the second floor of his house, and he proudly showed me how he had successfully initiated the building of a new mosque near his house.

Bambang took a larger step. When I first met him Bambang lived in a small temporary bamboo house where his wife operated a small food stall. Once he began to recover he built a more permanent house behind the bamboo house. His brother-in-law helped him on this project. In my follow-up visit Bambang and his wife were clearly very happy because they had just moved into the new brick house. Wati had a similar story. When I visited her for the last time she told me that her husband was building a house for them to live in independently. They would soon move in when the house was ready.

The arranging and reconstruction of living space was both a manifestation of recovery and a factor that further strengthened the recovery process. Building new houses, I would argue, represented participants' development of a new sense of self and purpose and confirmed their place in the community.

In the next section I explore the theme of *isin* (shame) and its role in mediating participants' community integration.

8.6. *ISIN:* THE SOCIAL DIMENSION OF AWARENESS

As discussed in Chapter 2 section 2.2, *isin* has both negative and positive connotations. In negative terms it encompasses feelings of anxiety, fear, and lowered self-esteem, which may become a hindrance to personal development (Hildred Geertz, 1959). Seen more positively *isin* serves as a behavioral control, contributing to the development of respect for others and involving the desire to avoid conflict and confrontation (Mulder, 1994a). A number of participants in my research invoked these more positive meanings associated with *isin* as an indication of social awareness and self-control. The loss of *isin* to them was regarded as an indication of illness and relapse; and the presence of *isin* indicated recovery.

The importance of *isin* as a cultural index of illness and recovery was evident in Budi's narrative. Budi's father told me that before Budi fell ill he felt *isin* if he was asked to eat in his relatives' house. But when he fell ill, Budi did not feel *isin*. He ate the food that his neighbor offered him. A similar story was narrated by Endang's mother. When ill, Endang ate food in her uncle's house without showing any form of politeness or attention to proper Javanese manners. Rima's father similarly described his daughter as not being able to conform to, or even understand, etiquette when she was ill. She often shouted, talked rudely, stared insolently at her father, or lectured people in the village. This was in stark contrast to her previous pattern of behavior, which her father described as polite and highly respectful.

While illness is associated with loss of *isin*, recovery is linked to the re-emergence of *isin*. Wulan's mother told me at the six-month follow-up interview that she believed her daughter had not completely recovered: "She has recovered ninety percent, but she still has no *isin*." During one of my visits to Budi, I asked his father if Budi had recovered. He said no, because he still felt no sense of *isin*. On a later visit, Budi's father described the emergence of *isin* in Budi and associated it with his recovery. He told me that Budi now felt *isin* to eat food at a neighbor's house. It is culturally prescribed to feel some degree of *isin* when eating outside the family home, say, with neighbor, and especially with strangers. His father concluded, "This means that he has returned to his previous condition." In Rima's case, she wandered around the village, shouted, scribbled on walls, and assaulted people. In contrast, once she had recovered, she stayed at home feeling *isin* for what she now saw as shameful deeds.

In Chapter 2 section 2.5.1, I discussed the play *Suminten Edan* (Crazy Suminten) as an important cultural representation of madness. I emphasized there the theme of rapid and complete recovery. Here I would further add that in this play the recovery of *isin* is dramatically represented as symbolizing recovery itself. When Suminten regained consciousness from her madness the first sentence she uttered was, "I am *isin*."

Returning to the data from my research, *isin*, or loss of it, was used as a sign of relapse. Bambang's wife told me that her husband, after a period of recovery, suddenly began to display suspicious behavior. He said he had the feeling that someone was going to harm him. That night he secreted a sword in his bedroom and

told his wife not to go out. The next morning, Bambang's wife asked her brother to take her husband to the hospital again. She told me, "When my brother asked my husband to ride on a motorcycle with him, I gave my husband a bottle of tea and I put it inside a plastic bag, but then suddenly he opened the plastic bag and drank it without feeling *isin* of the presence of others, so I concluded that he must have become ill again." This inappropriate behavior convinced Bambang's wife that he had relapsed and needed medication again.

There are two reasons why *isin* is used as a cultural index of illness and recovery. Firstly, *isin* is associated with moral-behavioral control. According to Hildred Geertz (1961:114), "to know *isin* is simply to know the basic social properties of self-control and avoidance of disapproval." In Chapter 5 section 5.4.3. I emphasized that psychotic illness is interpreted as *hilang kontrol* (escaping control). Since the role of *isin* is to control behavior, losing control can also mean losing *isin*. Thus, the emergence of *isin* means the re-establishment of self-control and this, in turn, indicates recovery.

Secondly, feeling *isin* may be regarded as a kind of consciousness (Mulder, 1994a:26). It is in this context that, on a personal level, *isin* is associated with the emergence of self-awareness and insight. It is in this sense that *isin* is closely linked to *sadar*. It is then understandable that most participants also understood psychotic illness as losing consciousness. In popular terminology, mental illness was called *hilang akal* (losing one's mind). On a social level, gaining consciousness was

associated with participants' awareness as a social being living in a community, where he or she had to consider social rules, norms, and the presence of others.

Thus far, I have explored *isin* in its positive dimension. In two cases, those of Rima and Joko, however, *isin* had negative implications. Not only did it serve as an index of failure to recover, but also it appeared to play a role in preventing recovery. Rima remained somewhat socially isolated, even at the time of the two-year follow-up assessment. In seeking to account for this, Rima told me that her weakness was that she closed herself off to the outer world because she felt *isin* about her behavior when she was ill. Rima's brother also felt that her feeling of *isin* inhibited her ability to reintegrate with the community or return to work, notwithstanding her strong motivation to accomplish these goals. Joko provides a similar example. His feeling of *isin* when he firstly took his duty as a regular teacher at first prevented him from fully engaging in his work and relating to his colleagues. However, with the support of his wife he was able to overcome this inhibition and successfully integrate into his work place.

In summary, family members understood psychotic illness as losing *isin* while recovery was understood as gaining *isin.* The reason *isin* served as such a critical index of illness and recovery was its association with control and social awareness. When ill, participants' awareness was *tertutup,* closed off, so that they were not able to feel *isin.* When their awareness was *terbuka,* opened up, *isin* emerged again. *Isin,* however, could carry negative implications and in some cases impede recovery. Nonetheless, this analysis of the role of *isin* in its positive sense as an indicator of

illness, relapse, and recovery, represents a significant contribution to the literature in this area.

8.7. SUMMARY

This chapter has been complementary to the previous chapter because both have examined the dynamic and inseparable relationship between *batin* and *lahir*, with *batin* the centre of gravity of the last chapter and *lahir* of this. The ethnographic material of the present chapter began with an analysis of *bangkit.* This overarching concept encompasses both *batin* and *lahir* and therefore, as I said earlier, it embraces the whole process of recovery.

I have argued that *bangkit* conveys a strong sense of self-awareness. In the *batin* realm, this refers to an awareness of the inner self of thoughts and emotions, and even deeper than this, an existential awareness of one's *takdir* or destiny. But it also encompasses awareness in the *lahir* realm, where it means an awareness of self in relation to others, and this is primarily experienced through *isin* (or lack thereof).

Secondly, I argued that *bangkit* implies a strong sense of active engagement. It relates closely to ideas of *ngelakoni* (enactment) and *usaha* (struggle). In this regard, too, *bangkit* is encompassing, for we see participants enacting their struggle on the inside and on the outside.

Most importantly *bangkit* conveys the idea of a spark, a force, or an energy that motivates change. I have previously emphasized the movement from *batin* to *lahir* and simultaneously from *lahir* to *batin*. It is possible, at this stage, to give ethnographic specificity to the term "movement." In the context of recovery, the notion of *bangkit* gives the idea of movement a sense of dynamism and force that involves a true transformation. With its encompassing, transformative force, the experience of *bangkit* is pivotal to the process of recovery—it is the engine of recovery.

In Chapter 1 I reviewed the literature on recovery. There are multiple points of correspondence between my findings and the findings of this literature. In both, phases of recovery can be identified. The initial phase of awareness and preparation in the literature (Anderson, 2003) bears a strong resemblance to *sadar* in the Javanese context. The emphasis in the literature on struggle has its corresponding emphasis in my material on *usaha.* Rebuilding the self that the literature identifies with the middle phase of recovery may be likened to *usaha batin* which entails self-reconstruction. Davidson's (2003) work also implies a movement from inside to outside which resonates with my observations on the shift from *batin* to *lahir.* And his emphasis on the active effort involved in recovery is clearly akin to the Javanese notion of *usaha*, suggesting the importance of personal agency.

However, it would be mistaken to attempt to map my Javanese material directly onto the findings of this literature, as there is not a one-to-one correspondence between the

two. And it would be a mistake to impose a linear format on either. Both in the literature and in my material there is a strong sense of recovery being non-linear.

Perhaps of greater importance are the differences between the findings in the literature and my findings. One way of approaching these differences is to start with the underlying template of a trajectory, suggested by Barrett (1996), and examines how this is culturally signified in Java in comparison to the psychiatric literature. In the literature the trajectory of recovery is very often seen as a trajectory of progress. The organizing metaphor is one of growth (Andersen, 2003). The trajectory I identified was a reciprocating one of movement from outside to inside and from inside to outside, driven by the transformative cultural force of *bangkit.*

Further to this, in the literature I reviewed the *progress to* recovery is often viewed in personalized or individualized terms. By contrast, I have shown how the *transformation of* recovery is couched in terms of integration with the participant's social group. This is encapsulated by the goal of *rukun*, or harmonious integration. Tellingly, where the notion of integration does come into play in the literature it focuses on reintegration of the self (Barrett, 1996). My ethnography focuses on integration with the participants' family, neighborhood and community. And where the literature lays great store on self-reconstruction (Davidson & Strauss, 1992) my ethnography demonstrates the importance of rebuilding social relationships. The act of reconstruction of physical space (rearranging rooms and rebuilding houses) perhaps symbolizes this more outward sense of social reconstruction.

In sum, most literature on the process of recovery that is derived from research conducted in Western settings focuses on individual psychological processes. My research gives equal weight to socio-cultural processes. In doing so it responds to the challenge laid down by Jenkins to give social and cultural specificity to the process of recovery. The most dramatic instance of this is *isin*, the quintessential Javanese measure of recovery.

CHAPTER 9

CONCLUSION

This thesis has examined recovery from psychosis in the context of Javanese culture. The research questions I have addressed emerge from a literature on recovery that lays emphasis on the meaning of recovery as well as the role of culture, family and religion in the recovery process. My study was located in modern-day Yogyakarta and grounded in a cultural analysis in which I argued that the traditional cultural values identified by an older generation of anthropologists such as Clifford and Hildred Geertz are nowadays highly contested. The methodology that I used in this study combined ethnographic and clinical research techniques, involving intensive analysis of a small sample of 9 patients. I found that this group, as a whole, demonstrated high levels of recovery. The subsequent analysis sought to account for this finding, both from a clinical and a psychocultural perspective. The latter began with an analysis of the process of becoming ill and recovering wherein I identified four culturally defined phases. They were concerned firstly with personal and family conflict prior to the onset of illness; secondly, a phase in which such conflict was buried within the person; thirdly, a phase of losing control; and finally the phase of recovery. In the subsequent chapters of this dissertation I further explored the recovery phase, examining the role of family relationships in promoting or hindering recovery, and then looking at the influence of religion on the recovery process. This

material on religion and the family was then drawn together in order to focus on the principal psychocultural factors that influenced the recovery process.

In this conclusion I present some main findings of this research. I begin with clinical findings followed by psychocultural findings. I then draw some links between the clinical and the psychocultural. Finally I propose some suggestions for future research.

9.1. CLINICAL FINDINGS

The clinical data gathered in this research suggest that participants in this study showed evidence of a good recovery. Despite relapses most participants were functioning well in the second year of follow-up. I have argued that, from a clinical perspective, the acuteness of onset is a primary factor that accounts for this good outcome. Eight of the nine participants had a rapid onset within 2 weeks or less. This is consistent with our previous survey data suggesting that acute onset psychosis is very common in Java. These findings also support the hypothesis that psychosis in developing countries has a distinct characteristic, wherein acute onset is more common than insidious onset.

Another way of looking at the same issue is to consider the diagnosis in each of the participants. Five participants met the ICD-10 criteria for ATPD (where the onset, by definition, is less than two weeks) and they all demonstrated a full recovery within two years. Even the three cases of schizophrenia had an onset within two weeks and

they also showed a good recovery despite short relapses. One case of schizoaffective disorder had an onset over a period of more than a month. It is notable that this person had more frequent and longer relapses.

I have shown that the category of NARP proposed by Susser *et al.* (1996) best captures the clinical features and course of illness of the participants in this study. First, the diagnosis of NARP describes not only the cases that meet the criteria for ATPD, but also the cases of schizophrenia with acute onset. Second, NARP is associated with a good prognosis and this born out by the outcome of most of participants in this research.

I have argued that another clinical factor that may contribute to good recovery among the participants of this study is the short Duration of Untreated Psychosis (DUP). Most of the participants received hospital care in less than one month, notwithstanding the fact that they received alternative treatments prior to that. This short DUP itself may be linked to the acuteness of onset. Family members quickly noticed the sudden breakdown and made a rapid response.

9.2. PSYCHOCULTURAL FINDINGS

By drawing together the ethnographic analyses of becoming ill (Chapter 5), family processes (Chapter 6), the role of religion (Chapter 7), and the recovery process (Chapter 8), there emerge two major findings concerning the psychocultural dimensions of psychosis and recovery in Java.

Chapter 9, Conclusion

Firstly I have stressed the cardinal importance of *tentrem* (calm), whereby illness is conceptualized as a loss of *tentrem* and recovery is understood in terms of achieving *tentrem* again. Secondly I have identified two cultural dyads that are critical to the process of recovery, one being the *lahir-batin* (inside-outside) dyad, the other being the *takdir-usaha* (destiny-effort) dyad.

I have shown that most ethnographic studies in Java have emphasized the *lahir-batin* dyad as central to the concept of the Javanese self. These studies, however, differ slightly in the way they understanding this concept. For example, Clifford Geertz (1983) writes of the *contrast* between *lahir* and *batin,* thereby emphasizing that these two realms are independent of each other. He states, "These two sets of phenomena—inward feelings and outward actions—are then regarded not as functions of one another but as independent realms of being to be put in proper order independently" (1983:61). Mulder (1978:20), however, emphasizes the connectedness between *lahir* and *batin.* According to him, the relationship between *lahir* and *batin* is hierarchical and co-ordinated. The ethnographic data presented in this dissertation supports Mulder's position. Becoming ill and recovering from psychosis, I have shown, is signified in terms of a dynamic movement back and forth within the *lahir-batin* dyad.

In identifying *tentrem* as a core cultural concept around which Javanese construct a sense of personhood and self, emotions and social relationships, health and illness, I follow a long tradition of ethnographic studies of Javanese culture. What I add to this literature is an emphasis on the importance of *batin* and *lahir* in achieving such a state

of *tentrem*. The state of *tentrem* in the *batin* realm is experienced as an inner feeling of calmness and peace. *Tentrem* in the *lahir* realm encompasses the condition of *rukun* (harmonious integration) with family members as well as with the broader community. The process of becoming ill begins when these ideals (*tentrem batin* or *rukun*) are threatened. The ideal of *tentrem* may be perturbed by internal, sexual, moral, or religious conflicts, whereas *rukun* may be disturbed by family problems and conflicts.

In my analysis of family interactions, I showed that most Javanese families exhibited low levels of EE. However, in my introductory analysis of Javanese culture I suggested that well-established traditions which placed a high value on the flattening of emotional expression are now contested in modern-day Yogyakarta. It was not surprising therefore that I found a number of families where there were high levels of critical comments, hostility, and overinvolvement. It is in these families that I observed a loss of *rukun* within the family and a parallel loss of *tentrem batin* within the participant. This bears out the importance of ethnographic work in the study of EE, enabling the researcher to take into account the whole family in assessing the family emotional environment. More importantly, I have argued for the importance of understanding the meaning of EE from the ill member's perspective.

This is not the first study to take the perspective of the ill member seriously. However, to my knowledge, it is the first to distinguish between the perception of EE and the meaning that the person attributes to EE. Thus, I have argued that it is possible for a participant to perceive their family members as demonstrating a high

level of EE while at the same time positively valuing this high EE as an expression of family caring.

To maintain the ideal of *tentrem* and *rukun* when they are challenged by personal conflicts or family problems, participants in this research employed the strategy of *memendam di dalam* (burying inside), a strategy that is psychologically as well as culturally grounded. This strategy involves a movement from *lahir* to *batin*; external conflicts are internalized. It is when this strategy does not work that participants experienced feelings of *tekanan batin* (inner pressure), *setres* (stress) and *kagol* (frustration), thereby becoming vulnerable to mental illness. It was precisely in this situation that they were vulnerable to the experience of *kaget* (startle) and this served as the trigger for the illness, leading to the person *hilang control* (escaping control). *Hilang kontrol* was closely associated with the stage of *bingung* (confusion) and in fact the term *bingung* was the principal designation for mental illness, a term that was quintessentially de-stigmatizing.

In dealing with an illness that was already established, the second dyad of *takdir-usaha* (destiny-effort) became pivotal. The understanding that the illness had been destined by God generated a feeling of *nrimo* (acceptance) and *pasrah* (surrender to the will of God). I repeatedly emphasized, however, that adhering to *takdir* did not mean that participants had to wait passively for God's help. Rather, they were expected to motivate themselves to actively make an *usaha* (effort). *Usaha* was understood as part of the process of *ngelakoni* (enacting) of one's destiny.

Chapter 9, Conclusion

In my review in Chapter 1 of the recovery literature, I gave attention to writers who emphasized the importance of the patient regaining a sense agency, be it expressed in terms of empowerment, self-reliance, personal control, taking responsibility for one's life (Young & Ensing, 1999), or gaining an enhanced sense of agency (Davidson, 2003) or in Barrett's (1996:153) discussion of how recovering patients were depicted by mental health workers using increasingly voluntaristic terminology. In this Western-based literature, the importance of recapturing agency comes across as a *desideratum*—something that is often lacking but sorely needed if one is to recover. In my ethnographic material there is a constellation of cultural concepts—*usaha, ngelakoni, bangkit*—that similarly speak to agency, or even more than that, to active effort. By contrast with the Western literature, my analysis suggests that this configuration is not just a *desideratum*, it takes the form of a powerful cultural injunction among Javanese, patients and families alike, to regain agency, to take the initiative, to enact one's destiny, to make an effort, to get up, and to revitalize one's self. This constellation of ideas and practices, I argue, gives cultural specificity in this Javanese setting to the more generic idea of agency. I would hypothesize that it plays an important role in the process of recovery.

Similarly, the recovery literature places emphasis on hope (Davidson & Strauss 1992; Andersen, *et al.,* 2003), very often casting this within a religious context (Corrigan *et al.*, 2003; Kirov *et al.*, 1998; Young & Ensing, 1999). My ethnographic material confirms the importance of *harapan* (hope) and similarly places it within a religious context, wherein hope was chiefly expressed through the idiom of *Insya Allah* (God willing). But here, too, there is a difference between my findings and those reported

in Western settings. In Javanese culture, the expression of *harapan* was strongly predicated on *usaha*—participants avowed their *harapan* that God would help them while at the same time engaging in *usaha*, a deliberate and determined effort to recover, to ensure that this hope would be fulfilled.

I have referred to *lahir-batin* and *takdir-usaha* as twin dyads because it is not possible to understand one in the absence of the other. *Usaha,* I argued, takes place in the *batin* realm and the *lahir* realm. For family members, *usaha batin* embraced the performance of religious practices and *tirakat* (ascetic practices), the critical ones being *non-obligatory* practices such as night bathing followed by *shalat tahajud* (night prayer), *doa* (supplication), *wirid* (invocation), different kinds of fasting, and reading the *Qur'an*. The significance of non-obligatory practices was that they entailed additional *usaha* compared to obligatory practices which everyone was routinely expected to perform. These practices aimed to enhance the family members' inner strength and resilience in dealing with the difficult situation they faced.

In the *lahir* realm, family members accomplished *usaha lahir* by seeking treatment for their ill family member from many different types of mental health resource that included the medical and the traditional-religious sectors. It was also in the spirit of *usaha* that family members practiced *ngemong*, treating their ill family member gently —as they would treat a small child—displaying a tolerant, acceptance, and a non-demanding attitude. The practice of *ngemong* suggested a high level of family support and tolerance toward the ill member, notwithstanding the considerable level of family burden. It provided an important buffer that served the cause of relapse prevention.

Chapter 9, Conclusion

Given the importance of the practice of *ngemong* for Javanese families it is not surprising that the majority of the families I studied exhibited low levels of EE. In this regard, their tolerance resembles that of Mexican American families (Jenkins & Karno, 1992), Chinese families (Ip & McKenzie, 1998), and Nigerian families (Ohaeri & Fido (2001).

Participants' responses to their illness can also be understood in terms of *usaha batin* and *usaha lahir.* Like their family members, participants practiced *usaha batin* by performing *non-obligatory* religious practices. The aim was to enhance inner strength and the effect was to reconstruct their sense of self, while at the same time resolving inner conflict. Through these practices participants experienced the state of *terbuka* (inner openness) wherein they became *sadar* (aware) of previous mistakes that contributed to the cause of the illness. *Sadar* also implied an acceptance of the illness as part of their destiny, and furthermore, an acknowledgement that they had to struggle to recover.

This experience of inner openness established the fundamental preconditions for a movement from *batin* to *lahir,* from inner personal space to outer social space in furtherance of the recovery process. Participants were then ready to *usaha lahir,* that is to make an effort in the outer world to achieve the goal of recovery. This chiefly involved integrating with family and community. One of the important cultural indices of recovery that I observed in this study was the emergence of *isin* (shame), a sign that the participant had developed both personal control and social awareness. Another observation from this study was that a number of participants, in the final

stages of their recovery, reorganized their living space, either by rearranging furniture or by making building additions, indicative of their changed stance *vis-à-vis* the outside world.

I earlier suggested that the movement between *lahir* and *batin,* in the process of becoming ill, was mediated by the mechanism of *memendam di dalam.* In the process of recovery the corresponding concept was that of *bangkit* (to regain awareness, get up, revitalize). Driven by the *takdir-usaha* dyad, whereby one has to accept one's destiny but at the same time make an effort to fulfill this destiny, *bangkit* became the primary cultural motivating force for participants to become active and to achieve the goal of recovery. It motivated the shift from *batin* to *lahir* that I have described above. This ethnographic analysis strongly supports the work of Jenkins & Carpenter-Song (2006:29) whose work on recovery emphasizes the importance of people "engaging as active participants in the process." Active participation in Javanese terms is by *usaha* and *bangkit.*

Although I have traced a culturally inscribed illness trajectory from *tentrem* to loss of *tentrem,* with all the culturally mediated steps in between, I have emphasized in my analysis that this is by no means a single linear trajectory. Some participants recover in line with this model, others back-track several times, yet others recover without proceeding through the steps I have outlined. Indeed the movement between *batin* and *lahir* is reciprocating, not linear. My findings are very much in keeping with those of Jenkins & Carpenter-Song (2006) as well as Hopper (2002) that recovery is "non-

linear" and "messy." Nonetheless, what I have outlined in this work is a powerful cultural template for becoming ill and recovering.

It is important to note that the cultural principles that I have identified by this ethnographic analysis are not merely cultural concepts or ideals. They are also cultural practices that require personal effort to enact. Furthermore, they signify a way of interacting with self and others to achieve a way of being-in-the-world that constitutes a recovered self.

The cultural concept of *bangkit* is pivotal to recovery, I argue, because it mediates between the two dyads I have identified in my analysis. *Bangkit* mediates between *takdir-usaha* and *batin-lahir*. It is through the complex inter-relationship between these two dyads that *transformation* of recovery from psychosis may occur and the state of *tentrem* can be achieved again.

Similar ideas of transformation within everyday Javanese have been essayed by Clifford Geertz (1960, 1983). He points to the centrality of *lahir-batin* dyad, but works this out ethnographically in terms of the distinction between *kasar* and *halus* (vulgar and refined). This latter distinction was not salient to the participants in my study. As I have shown, *lahir-batin* was connected, for them, to *takdir-usaha* through *bangkit*. Nonetheless, my data indicate a similar transformative power that Geertz has identified. The goal, Geertz writes, is to effect a transformation from *kasar* to *halus* in both *batin* and *lahir* realms of the self. For my participants, the goal was to both accept their fate and make an effort in both the *batin* and *lahir* realms, thereby

becoming more open inwardly and outwardly, to achieve transformation back to inner *tentrem* and outer *rukun.*

Mulder (1978), in support of Clifford Geertz's idea of transformation, explores its religious dimension by examining Javanese *kebatinan* (mysticism), with emphasis on the importance of movement between *lahir* and *batin* in the process of achieving mystical union with God. Mulder sees this in the form of a journey, "moving from the outside to the inside" (1978:22). In a previous study (Subandi, 1993) I observed the transformational experience that occurs when Javanese practice Sufi-like meditation known as *dhikr* (remembrance).

There are important parallels between the process of recovery from psychosis and the development of mystical experience. First, both suggest the importance of struggling to combat the negative side of the self that has been so evident in the material provided by the participants in this research. Second, the non-obligatory prayers, fasting, and other ascetic techniques performed by these participants is basically derived from mystical practices. Third, the story of *Bima Suci* I employed in this dissertation to analyze the process of *usaha batin* is likewise used by Javanese mystical groups as a basic form of teaching to describe the importance of the internal journey, the necessity to overcome the passions and desires, and finally the accomplishment of eternal unity with God, symbolized by the unity of *Bima* with *Dewa Ruci.* Fourth, the state of *terbuka,* opening up in the *batin* realm, experienced by participants in this research parallels the inner opening and revelation of inner knowledge in mysticism. Those who undertake these mystical practices experience

an inner openness, attain a state of total surrender to the will of God, and finally experience a self-transformation characterized by a sense of selflessness.

Finally, Javanese mysticism, according to Mulder (1978:18), involves the practitioner "maintaining distance from the *kasar* world and his own *lahir* aspects." One *kebatinan* ethic that has become a popular saying is *"Sepi ing pamrih rame ing gawe,"* literally, "inwardly quiet, outwardly active" (Ferzacca, 2003:25). Within Javanese Sufi teaching the concept of distancing is symbolized by a metaphor of a fish living in the sea. Although its surrounding is salty, the fish is not (Subandi, 1997). In my analysis of recovery from psychosis I found a similar need, for some participants, to reintegrate with their family and their community while at the same time maintaining a degree of distance, so that they could preserve a sense of *tentrem batin* or inner peace. Javanese religion provides a template for this balance between involvement and distance.

Corin (1990) has emphasized the importance of religion in maintaining such a balance between involvement and distancing. She writes:

> ...religious idioms help to protect, to reinforce and to positively value an inner space of withdrawal. Religious idioms can also justify the normative distance taken toward culturally valued social roles such as work (Corin, 1990: 181).

However, in her analysis of the Montreal data she asserts that there is an "absence of cultural processes allowing people to go back and forth between marginal and normal positions" (Corin, 1990: 184). By contrast, I have shown that there are powerful

cultural dynamics that enable just this. The dynamics of *batin-lahir, takdir-usaha* and *bangkit* actively promote the transformation from sickness to health, and encourage social involvement while at the same time permitting inner withdrawal and peace. I would hypothesize that these are the core Javanese cultural dynamics that play a role in promoting recovery from acute psychosis in Java.

9.3. THE LINK BETWEEN CLINICAL AND PSYCHOCULTURAL FINDINGS

There are several points of connection between the clinical and psychocultural findings in this research. The first relates to the acuteness of onset of psychotic illness, evident not only among the nine participants to this study but also in my previous work in Yogyakarta. It could be hypothesized from my data that cultural conceptions of *becoming ill* encourage the sudden onset of illness. Psychosis is perceived as a response to stress or family conflict which, if it cannot be contained by *memendam di dalam,* leads to a sudden *hilang kontrol,* frequently sparked by *kaget.* This model of becoming ill is deeply inscribed in Javanese culture, nowhere more evident than in the story of *Suminten Edan* within Javanese popular theatre, whereby *Suminten* became suddenly mad when she was stood up by her prospective husband, *Radenmas Subroto.* While there are no doubt cases of insidious onset psychosis, there is no salient cultural model for this pattern of illness.

The second connection between the clinical and psychocultural finding is also evident in the relationship between DUP and family *usaha.* The clinical data suggest that participants' DUP is short, suggesting that family members make a quick response to

the illness by seeking both traditional religious and medical care. This rapid response is driven by the ethos of *usaha.*

Finally, the main thrust of this thesis is that there are powerful psychocultural forces that encourage recovery from psychosis. The model of recovery that I have demonstrated in my research is equally deeply inscribed in Javanese culture. Again I point to a popular representation in Javanese traditional theatre whereby *Suminten* recovers rapidly and completely and with her successful marriage to *Radenmas Subroto* regains a state of *tentrem.*

9.4. SOME SUGGESTIONS FOR FUTURE RESEARCH

Based on my analysis throughout this dissertation and the findings of this research I make several suggestions for future research.

First, I have demonstrated the usefulness of the SCT test in providing data on family EE. Not only is this test simple and flexible, but it also provided significant information that supported my ethnographic data. Thus, I propose that this test be considered as a complementary instrument for assessing EE. More than that, I have shown the usefulness of projective techniques (the SCT and the HTP) to reveal sensitive issues such as sexual behavior. Therefore, I would suggest that projective tests be brought back into the field of ethnographic research.

Chapter 9, Conclusion

I have shown that Javanese practice of *ngemong* is essential in providing support for ill family members. I recommend that this concept should be explored further in future research within a Javanese context. It may be also useful to compare the concept of *ngemong* with similar concepts from different cultures. For example, the practice of *ngemong* maybe parallel to *thum-jai*, practiced by Thai families as "a combination of being accepting, patient, understanding, reasonable and having a sense of obligation" (Ruangreangkulkij & Chesla, 2001:123).

Finally, this research is mainly concerned with recovery from early psychosis. To extend this study, I would suggest further ethnographic study looking at the process of recovery from long-term schizophrenia. This is in line with suggestions from other researchers that more ethnographic study on recovery from schizophrenia in developing countries settings is still needed in response to the WHO outcome studies. Based on the general finding of this research I would suggest that particular attention be paid to the role of family, religion, and spirituality.

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GLOSSARY

abangan	nominal Moslem.
Adipati	a local government official during the colonial era
adzan	a call for prayer
bangkit	to regain awareness, to get up, to revitalize
batin	inner realm of the self
bibit	seed, inherited factor
bingung	being confused, confusion
bebet	social status or wealth
bobot	moral character
doa	supplication
dukun	a general term for traditional healers
edan	crazy
guna-guna	sorcery
halus	refined, smooth
hangat	emotional warmth
hilang kontrol	escaping control
Insya Allah	God willing
isin	being ashamed, shame
istighfar	a short prayer to ask forgiveness to God
jilbab	veil
kaget	being shocked or startled, startle
kagol	frustration, disappointment
kakak	older sister or brother
kampung	residential neighborhood in the city
kanuragan	outer physical power
kasar	rough, coarse
kasih sayang	unconditional love and giving

Glossary

kasekten	magical power
kebatinan	Javanese mysticism
keris	dagger
kejawen	Javanism
kemasukan	possession
kekuatan	power
kemenyan	incense
kethoprak	a traditional popular theatre
kota budaya	the city of culture
kota pariwisata	the city of visitors
kota pelajar	the city of students
kraton	the Sultan's palace
kromo	high Javanese language
Kyai	the leader of a *pesantren*
labuhan	offering ceremony in the South sea and Mount Merapi
lahir	outer realm of the self
laku	action, ascetic exercise
Lasykar Jihad	a militant Moslem group
lebaran	annual festival conducted after *Ramadan* fasting, also known as *bodo*
memendam di dalam	burying inside
ngelakoni	to enact
ngemong	to gently care for like one would care for a child
ngeri	being horrified
nrimo	to accept one's destiny
Nyai Roro Kidul	a powerful queen spirit, believed to reside in the South sea
orang pintar	a knowledgeable person, other term for a healer
padhang mahsyar	a gathering place of the Day of Judgment
pasrah	to surrender to the will of God
penyembuhan	recovery
pesantren	an Islamic boarding school
pikiran kosong	empty of thought

Glossary

priyayi	traditional aristocrats
puasa	fast
rukun	harmony, harmonious integration
ruwatan	a ritual for safety and protection
sabar	being patient, patience
sadar	becoming aware
santri	orthodox Moslems
sarap	nerves
sebelum sakit	before the illness
sembuh	recover
selendang	a long shawl worn to carry a child
serem	being terrified
setres	stress
shalat	daily liturgical prayer
shalat tahajud	night non-obligatory prayer
shirk	associating other being with God
slametan	community meals
Sufism	Islamic mysticism
syahadat	the Moslem decree
takut	fear
takdir	destiny
tawhid	the oneness of God
tekanan batin	inner pressure
tenaga dalam	inner power.
tentrem	quiet, calm, peaceful
tentrem batin	at peace in one's inner subjective world
tentrem lahir	at peace in one's outer social relationships
terbuka	opening up, open
tertutup	closing off, closed
tertekan	under pressure
tirakat	ascetic exercises
trah	a large descent group

Glossary

usaha	effort, struggle
warnet	an internet café
Warok	a powerful figure imbued with skills in the martial arts, magic and spirituality
wartel	a telecommunication café
wirid	invocation
wayang	shadow play
wong pinter	knowledgeable person, other term for traditional healer
wong tuwo	old person, other term for traditional healer