

Bangkit: The Processes of Recovery from First Episode Psychosis in Java

M. A. Subandi

Published online: 20 January 2015
© Springer Science+Business Media New York 2015

Abstract There is a growing literature on recovery from schizophrenia. Most studies, however, focused on outcome, with insufficient attention paid to the process of recovery. The aim of this study was to explore the process of recovery from first episode psychotic illness in a Javanese cultural setting. An ethnographic method was applied where researcher conducted a field work and followed seven participants in their natural setting. This study identified three phases of recovery process in the context of Javanese culture: *Bangkit*, gaining insight; *Usaha*, struggling to achieve recovery; and *Rukun*, harmonious integration with family and community integration. Recovery entails regaining insight, followed by simultaneous inward and outward efforts that reconstitute 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. Movements in physical space parallel movements in social space, where participants accomplish a social recovery. The Javanese phase of recovery found in this study is comparable to the phase of recovery identified by previous literatures in the Western context.

Keywords Recovery · Psychosis · Ethnography · Java

Introduction

A number of literatures have tried to map the phases of recovery from psychosis 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

M. A. Subandi (✉)
Faculty of Psychology, Gadjah Mada University, Jl. Humaniora, Bulaksumur, Yogyakarta,
Indonesia
e-mail: subandi@ugm.ac.id; masubandi@yahoo.com

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 and 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 and 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 and 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 and Carpenter-Song (2006) whereby, following Hopper (2002) term, recovery is described as "complex and messy."

Davidson and his colleagues conducted a number of studies employing a phenomenological approach (Davidson and Strauss 1992, and 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 as 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.

Davidson (2003) 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 backtrack 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' SEACORA, Jenkins et al. (2005, p. 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 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.

Method

The primary goal of this research was to explore participants' experience of illness and recovery, and how participants and their family members interpreted and made sense of this experience within a Javanese cultural context. To achieve this goal, it was necessary to employ an ethnographic methodology. 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.

The field work of this study was conducted in Yogyakarta, a special province in Indonesia, located in the center of Java Island. During the field work, lasted for 1 year, I recruited seven participants diagnosed as having first episode psychosis from the local mental hospitals. 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 pre-formulated agenda. The interviews took the form of a conversation that flowed from one topic to another.

To understand participants' personal experience of illness and recovery, it is important for me to use 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, p. 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.

Result

In presenting the result of this study, I begin with a recovery narrative of a participant named Bagus (42-year-old married man). My analysis moves from theme to theme, drawing on Bagus' 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 recovery. In the second part, I will present the phases of recovery which Bagus and other participants went through.

The Case of Bagus

I met Bagus for the first time in a psychiatric clinic in Yogyakarta. At that time, 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.

My first impression was that he was an educated man, and Bagus 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. He was married with three children. I did not acquire much information during this initial interview because Bagus appeared, at first, somewhat reluctant to talk about himself. The most important issue for Bagus 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 Bagus' personal background and the history of his illness in the course of my subsequent visits to his house. Bagus' wife said that her husband's illness began when one morning while he was performing morning prayer he suddenly called out God's name in a loud voice and his body spun around. Bagus 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," Bagus 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 Bagus. He also felt his heart had become 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 Bagus had tried to commit suicide by hanging himself.

Even after I had visited Bagus 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 Bagus and his wife. One morning, while speaking to Bagus' wife on the phone in order to clarify a number of points, she seemed anxious to tell me about the financial issue that Bagus 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 her opinion without her husband's interference. Bagus' 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 Bagus had misappropriated money originally earmarked for a school project fund.

Not long after this was discovered by the school authorities, Bagus fell ill and his wife took him to the home of a nurse, then taken to a private mental hospital in

Yogyakarta and finally to a private clinic where I met him for the first time. After receiving medical treatment from several different hospitals for more than 3 months, he began to recover. He was able to return to work and resumed his role as school principal. When I visited him, 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 Bagus had transferred to another school. He 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.

Bagus 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 Bagus 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 alam* (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 1 km from his house and the steep, uphill, village road from his house to the mosque provided Bagus 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. Bagus 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," Bagus reflected.

Although Bagus 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 confused," she said. For example, 1 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. Bagus 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, Bagus 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 Bagus was sure that his new school provided a stimulating work atmosphere, he still felt

ashamed. The loss of his position was a heavy burden for him. He was immersed in regret for his prior unlawful behavior.

In one of my visit 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. Bagus also strove to get closer to God by performing *shalat tahajut* (night prayer) in order to ask 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. Bagus’ efforts to improve included making an effort to manage his emotions better. Bagus’ 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, Bagus’ 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. Bagus concurred that “the illness has destroyed my self-esteem, self-confidence, and self-respect.”

During my last visit, I found Bagus had made a solid improvement. He spoke more openly and now responded to my questions spontaneously. Bagus’ wife told me that they planned to open a small 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. Bagus 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. Bagus’ wife confirmed her husband now had a strict routine. More importantly, he did everything on his own. Bagus’ 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 Bagus was now more open in talking about his previous illegal behavior. “Through the illness I became aware of my faults. I now feel a deep sense of regret. In religious term, I have repented.” Bagus 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* (effort) 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 Bagus 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* (effort),” he said. He had never

thought that he would have the skill to run a telecommunications business and renovate his house. During this visit, Bagus 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.

The Process of Recovery

From the ethnographic data and participants’ narrative, I was able to identify the three phases of recovery process: (1) *Bangkit*: gaining insight, (2) *Usaha*: struggling to achieve recovery, and (3) *Rukun*: harmonious integration with family and community integration.

Bangkit: Gaining insight

The central theme of participants’ recovery is encapsulated in Bagus’ statement: “*Saya harus bangkit* (I have to get up).” I use the term *bangkit* to indicate the core idea of recovery in this study. 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.

A core meaning of *bangkit* is that of regaining awareness. In this context, Bagus 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 *sadar*.

Participants invoked many different forms of awareness. First, awareness of the present condition referred to the awareness of what was going on around them. For example, when Dian (16-year-old young woman) became aware, she realized that her mother had accompanied her in the hospital, whereupon she asked her mother to take her home. When Susi (20-year-old young mother) 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. Titi (28-year-old single woman), for example, reflected on her illness as the result of her tendency to burying many conflicts within herself. Third, there was awareness of the future, where participants looked at their future life after the illness. In Bagus’ case, this awareness sparked his motivation to struggle to achieve recovery, not only for himself but also more importantly for the future of his children. Finally, participants also referred to a further deep sense of self-awareness. Dayat (19-year-old young man) provided a good example. It was only when he became aware that he had to enact his destiny, of the illness and of his whole life, and his process of recovery had 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 and Strauss 1992). In Bagus' narrative, the active sense of self was suggested by 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.

Most participants' narratives suggested that passivity was associated with illness, whereas activity was associated with recovery. Bagus' narrative provides the best illustration. When ill, Bagus 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 and Shadily (1995) write that the term *bangkit* also means "to generate motivating force or energy." This meaning was evident in Bagus' narrative above. He invoked this term as a powerful metaphor for motivating himself to recover. In my review of the literature presented earlier, it is clear that recovery is not a linear process. This was certainly the case for Bagus. 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 setbacks, Bagus required constant motivation to reconstruct his sense of self. *Bangkit* motivated him to struggle both in the inner realm, by reconstructing his sense of self, and in the outer realm by integrating with his community to achieve harmonious integration.

Thus, by conceptualizing the recovery process in terms of *bangkit*, participants appropriated a powerful set of cultural meanings that exerted a transformative effect on their lives and their approach to their illnesses. *Bangkit* embraced 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* (inward struggle).

Usaha: Struggling to Achieve Recovery

In Java, the word *usaha* means ‘effort’ to achieve a particular goal. The strongest degree of effort can be expressed as a form of a struggle. A number of participant narrated that they had to take a strong effort in the process of recovery. They differentiated between *usaha batin* (inner effort) and *usaha lahir* (outer effort).

Participants’ inner struggle can be seen in two different levels, spiritual and psychological levels.

One of the principal ways of participants’ effort in spiritual level was through the performance of religious practices, such as prayers, fasting, and reading the Quran. There were several types of prayers that participants employed. First, it was the obligatory prayer which must be performed five times a day. As stated by Dayat, prayer 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, it was a non-obligatory prayer, which usually performed in the middle of the night. Most participants and their families suggested that the night prayer 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. For example, in the case of Laras (18-year-old young woman), her father emphasized that the practice of night prayer, and other religious practices, was part of his *usaha batin*, the effort to find solution to a problem in the inner 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. Bagus’ 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 Bagus’ 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.”

Although there are no formal obligations to read the *Qur’an* for Moslem, yet in my research, all the participants referred to reading the *Qur’an* as important to the process of recovery. During her psychotic breakdown, Titi 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. Titi’s recitations, for example, failed to achieve their purposes.

Participants’ inner effort in psychological level is more complicated. It includes the change in three different aspects: cognitive, affective, and behavioral aspects.

Bagus’ inner struggle is the best example of a struggle in psychological level. First, he strove to develop a sense of self-control, notably by especially controlling his anger. When he was ill, Bagus could not control his outbursts; he hit his wife and his children. His wife noticed, however, that in the process of recovery, Bagus would often look tense, as if trying to control himself, and then express his anger by hitting a wall with his fists. Second, Bagus had also to struggle hard to conquer negative thoughts and feelings, particularly those concerning the loss of his position

as a school principal before he got ill. Third, Bagus has 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, Bagus strove to get closer to God by performing non-obligatory religious practices, particularly night prayer and reading the *Qur'an*.

Participants' inner struggle in psychological level is also indicated by their effort to change attitude from close off to openness. In Bagus case, there was evidence of increasing openness in the way he 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, Bagus 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 opened out. This was evident in the case of Yati (26-year-old single woman). When ill, she maintained a closed-off 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 closed off 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.

Dayat 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 one of my visit, Dayat stated that he believed that through the illness God had opened his heart, enabling him to become aware of his wrongdoings and accept his experience of God "opening his heart" enabled him to accept 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 Yati'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, Yati would go into the kitchen and help her cook, as well as joining her family to watch television with them.

The change in Dian 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.

The concept of *usaha lahir* the outward struggle 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. In this study, participants used many different activities to reflect the outer struggle, including family effort to seek treatment and participants’ effort to arrange their physical space.

It was usually family members who initiated the process of seeking treatment for their ill family member, and they characteristically demonstrated their outer effort by seeking treatment from several sources. The inherent pluralism of the health system in Yogyakarta, I would argue, facilitates the expression of outer effort.

In Bagus’ 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 mental hospital. 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 Bagus 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 Susi and Titi 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.

For the family, outer effort was not limited to taking an ill family member to a hospital. It extended to taking responsibility for monitoring the medication at home. 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 Dian 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 Titi, somnolence Dayat, or irregular menstrual cycle Dian. Bagus 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 effort in encouraging participants to comply with their medication. For example, Laras' father stated that he used many different methods to get Laras to take her medication, such as putting it in her food or drinks. Dayat's father used a religious framework of authority to encourage his son to take his medicine.

While the outer effort for the family is seeking treatment, for the participant, it is arranging their physical space. Participants' effort to reconstruct their physical space is an important step in their recovery process. When I first visited Laras' 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 Laras had scribbled on the front wall, although it had just been painted by her father to celebrate the annual festival. When Laras began to recover, the change in her house was noticeable. Laras' 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. Laras was making her own dresses using this machine.

For Titi, her recovery was marked by 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 that had been put back against one wall, which gave the living room more space. Titi 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 Titi 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 Bagus 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 losing his position. In the end of this study, 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. Susi took a larger step. 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 were 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 community.

Rukun: Harmonious Integration with Community

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 peaceful state and, thus, significant for recovery. Very often, to achieve integration, one needs to sacrifice one's interest to avoid conflict. This was best illustrated in Bagus' narrative. As I have indicated, Bagus 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, Bagus wanted her to go to a religious school, but his wife and daughter disagreed. Bagus decided not to impose his own views on them so he arranged for his daughter to enter a state secondary school.

Participants in this research exerted much effort to achieve integration at community level. In Bagus' 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. He also became involved in community social life such as attending a wedding ceremony and meeting in his neighborhood. 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.

Increasing social engagement was also evident in other participants. In Dian'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 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 integration. Susi 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. Laras' narrative provides a unique illustration of the achievement of community reconciliation leading to a state of *rukun*. Her father mentioned that, when ill, Laras 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, Laras 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 whereby the neighbor was invited to pray and had meals together. He disclosed that the ritual was not only intended to

achieve reconciliation with their neighbor, but also with the spirit who may have been offended by Laras' 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 harmonious integration.

Discussion

The ethnographic data of this research showed that 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. However, after a series of medical treatment and intensive family care at home in their community natural settings, participants experienced recovery. This research identified three phases of recovery process in the context of Javanese culture: *Bangkit*: gaining insight, *Usaha*: struggling to achieve recovery, and *Rukun*: harmonious integration with family and community integration.

The phase of *Bangkit* used by participants in this research is comparable to the phase of gaining insight as the basic idea of recovery, which has been noted frequently in studies of recovery from schizophrenia. Young and Ensing (1999) called this phase as the 'initial phase' (Young and Ensing 1999), while Spaniol et al. (2002) called as 'struggle with the disability,' and Andersen et al. (2003) called this phase as the 'awareness and preparation phase.' In a meta-analysis of the psychopathology, meaning that the more severe the illness, the less the 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.

Bangkit became the primary cultural motivating force for participants to become active and to achieve the goal of recovery. It motivated them to perform *usaha* and *rukun* in the later phases. This ethnographic analysis strongly supports the work of Jenkins and Carpenter-Song (2006, p. 29) whose work on recovery emphasizes the importance of people "engaging as active participants in the process." Active participation in Javanese terms is by *bangkit*, and then *usaha*.

The second phase identified in this study is called *Usaha*, where participants performed many kinds of effort both in inner and outer realm. The phase of *Usaha* is similar to the phase of the 'middle phase' (Young and Ensing 1999), 'living with the disability' (Spaniol et al. 2002), and the 'rebuilding phase' (Andersen et al. 2003) where mentally ill patients begin to rebuild his or her sense of self, to manage the illness, and to take responsibility for his or her own life, empowerment, self-reliance, and personal control.

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). A number of literatures on recovery therefore emphasized the importance of the patient regaining a sense agency, or gaining an enhanced sense of

agency (Davidson 2003). Essential components of recovery include self-reconstruction (Davidson and Strauss 1992), self-renewal and transformation (Mead and Copeland 2000), and self-empowerment (Young and Ensing 1999). One of participant's narrative (Bagus) aptly illustrates the main feature highlighted in the literature. He felt that the illness had destroyed his self-esteem, self-confidence, and self-respect. For Bagus, the process of self-reconstruction was encapsulated in the concept of *usaha batin* (inner struggle).

Barrett's (1996) discussed how recovering patients were depicted by mental health workers using increasingly voluntaristic terminology. In 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*, *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*, and 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.

The third phase of recovery identified in this study is called *Rukun*, where participants integrated harmoniously with their family and community. The *Rukun* phase is comparable to the 'later phase' (Young and Ensing 1999), 'living beyond the disability' (Spaniol et al. 2002), and the 'growth phase' (Andersen et al. 2003).

The term *rukun* has been used much more widely in Java across a variety of social contexts. Geertz (1960) defined *rukun* as 'traditionalized cooperation' in the sphere of labor and capital exchange. 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.

This research showed how recovery processes were affected not only in terms of the self, but also in terms of participants' physical space. Here, participants demonstrated how at a later stage of recovery some of the participants literally reconstructed their living space. Young and 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.

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 and Strauss 1992), my ethnography demonstrates the importance of rebuilding social relationships. The act of reconstruction of physical space (re-arranging rooms and rebuilding houses) perhaps symbolizes this more outward sense of social reconstruction.

Although I have traced a culturally inscribed illness trajectory, I have to emphasize that this is by no means a single linear trajectory. Some participants recover in line with this model, others backtrack several times, yet others recover without proceeding through the steps I have outlined. My findings are very much in keeping with those of Jenkins and 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.

Conclusion

This study explored a fundamental cultural dynamic of recovery from psychotic illness, wherein recovery entails regaining insight, followed by simultaneous inward and outward efforts that reconstitute 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.

References

- Andersen, R., L. Oades, and P. Caputi
2003 The experience of recovery from schizophrenia: toward empirically validated stage model. *Australian and New Zealand Journal of Psychiatry* 37: 586–594.
- Barrett, R.
1996 *The Psychiatric Team and the Social Definition of Schizophrenia*. Cambridge: Cambridge University Press.
- Bou-young, R.
1995 The health care seeking behaviour of schizophrenic patients in east Asian areas. *International Journal of Social Psychiatry* 413: 190–209.
- Davidson, L.
2003 *Living Outside Mental Illness*. New York: New York University Press.
- Davidson, L., D. Stayner, C. Nickou, T.H. Styron, M. Rowe, and M.J. Chinman
2001 "Simply to be let in": inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal* 244: 375–388.
- Davidson, L., and J. Strauss
1992 Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology* 65: 131–145.
- De Laine, M.
1997 *Ethnography: Theory and Applications in Health Research*. Sydney: MacLennan & Petty.
- Echols, J.M., and H. Shadily
1995 *Kamus Indonesia Inggris: An Indonesian-English Dictionary*. Jakarta: Penerbit PT Gramedia.

- Fetterman, D.M.
1989 *Ethnography: Step by Step*. Newbury Park, CA: Sage.
- Geertz, C.
1960 *The Religion of Java*. Glencoe, IL: The Free Press.
- Gureje, O., C. Harvey, and H. Herrman
2004 Self-esteem in patients who have recovered from psychosis: profile and relationship to quality of life. *Australian and New Zealand Journal of Psychiatry* 38: 334–338.
- Jenkins, J.H., and E. Carpenter-Song
2006 The new paradigm of recovery from schizophrenia: cultural conundrums of improvement without cure. *Culture, Medicine and Psychiatry* 29: 379.
- Jenkins, J.H., M.E. Strauss, E.A. Carpenter, D. Miller, J. Floersch, and M. Sajatovic
2005 Subjective experience of recovery from schizophrenia-related disorders and atypical antipsychotics. *International Journal of Social Psychiatry* 513: 211–227.
- Mead, S., and M.E. Copeland
2000 What recovery means to us: a consumer perspective. *Community Mental Health Journal* 36: 315–328.
- Mintz, A.R., K.S. Dobson, and D.M. Romney
2003 Insight in schizophrenia: a meta-analysis. *Schizophrenia Research* 611: 75–88.
- Spaniol, L., N.J. Wewiorski, C. Gagne, and W.A. Anthony
2002 The process of recovery from schizophrenia. *International Review of Psychiatry* 14: 327–336.
- Young, S.L., and D.S. Ensing
1999 Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal* 22: 219.