People Say I'm Crazy

Unknown Fetish: Monkey Head copyright 2001 John Cadigan

A Study Guide

by

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with

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From The Filmmakers

Ira Wohl, producer
Los Angeles, CA

Speaking as a filmmaker, I would never before have considered being involved with a film which I did not write/direct/edit, as well as produce. However, when I heard about *People Say I'm Crazy* and what John and Katie Cadigan were trying to do, I asked them to allow me to see their rough footage. Right from the first minute, I recognized this film as "the real thing". Dramatic, exciting, frightening, but above all honest- in a way no film I've ever seen on a subject such as this has ever been. Speaking as a licensed, clinical social-worker/psychotherapist with fifteen years experience, what is so stunning about this film is how very unsentimentally truthful it is about schizophrenia. By the time you've finished viewing it, every single stereotype you've ever conjured up about what it's like to have schizophrenia, is blown completely out the water and is replaced by a much deeper understanding of the complexity of this illness. In addition, the film transmits vital information about how to work with, not only the person with the disorder, but with their family, their support system and within the context of their entire environment.

John Cadigan, director
Palo Alto, CA

Making this film was my idea. In the beginning I did not know what was happening with me. I thought that by filming I could explore my illness and try to understand what was going on. Later on I kept filming because I was so angry about how much misinformation there is about brain diseases like mine. I wanted to let the world know what it is really like to live with schizophrenia.

I learned that I love filming and using film as another creative outlet. Filmmaking ended up being very therapeutic for me because it forced me to explore myself and better understand my illness and its impact on my family. It helped me appreciate my family and I hope that other families respond like mine did – with love, support and understanding.

This study guide will give you a lot of background information we couldn't squeeze into my film. I really like the study questions at the end of each section and hope you will take time to reflect on them.

Katie Cadigan, producer
Los Angeles, CA

When my brother asked me to help him make a film we made one simple rule: **do no harm**.

John's recovery and stability held top priority at all times, even if it meant missing fantastic filmic moments.

Entering the world of severe mental illness was like falling through Alice In Wonderland's rabbit hole. My brother, the teddy bear, is not the ''psycho'' or violent monster people imagine when they hear the word ''schizophrenia.'' And, if horrible stereotypes weren't enough, humane and adequate treatment can still be difficult to find.

People Say I'm Crazy became the creative home for my grief, frustration and fury around dealing with John's illness and all the cultural nonsense about schizophrenia. The more we filmed, the more passionate I became about letting the world know that good treatment exists, that recovery is possible, and that people with my brother's illness can build rich and satisfying lives.

John's camera only filmed what he saw first-hand. A whole other film could be made about the things he didn't see - like how our family struggled to understand his illness and learned ways to support him. You won't see when we cried among ourselves, when we fought for decent care, or the many mistakes we made along the way. What you do see is the end result of all that thrashing – a family who ultimately decided to stand by John and help him fulfill his dream of being an artist.

Introduction

In this film, you will see the story of a young man who develops schizophrenia, then fights back to rejoin his family and community, and resumes his career as an artist. Schizophrenia is a frequently misunderstood illness. When schizophrenia is depicted in the media, it is all too often presented from the point of view of a baffled and frightened society. These depictions tend to focus on images of chronic patients who live on the street or who become involved in an acts of violence. However, such depictions of schizophrenia and of the persons who struggle with it fail to tell the human side of the story. For the person with schizophrenia and their family, the goal is to go on – to cope with the illness, to find some good in it, and to make everyone's life productive again. Many people jump to the conclusion that the person with schizophrenia must live out a wasted and lonely life. But in this film, you will see a different story. John and his family rally their resources and their love for one another to confront the reality of schizophrenia. Tangible and non-tangible problems are overcome and gradually John regains his sense of self, so that he can contribute in a new and unique way to his community. This film is the first of its kind, presenting a first-person story of recovery from schizophrenia.

1. About Schizophrenia

Schizophrenia is a brain disease that affects approximately 1 person in 100, or 1% of the population. It is found in every culture around the world and affects both men and women approximately equally. However, men who develop schizophrenia generally do so earlier in life and with more severe symptoms. The first symptoms of schizophrenia appear in late adolescence or early adulthood, although it is possible to develop schizophrenia as a young child or as an older adult. After the onset of schizophrenia, the symptoms wax and wane over time, sometimes

spontaneously and sometimes due to the effects of medication treatment and psychotherapy.

As happened to John, schizophrenia often begins with psychosis, or a ‘‘break with reality’’. When a person is psychotic, they usually cannot tell whether their perceptions, thoughts and beliefs are real or not. More recently, psychiatry has begun to use the terms ‘‘positive’’ and ‘‘negative’’ to classify the symptoms of schizophrenia. Psychotic symptoms, such as delusions (i.e., unreal beliefs) and hallucinations (i.e., unreal perceptions), are called ‘‘positive’’, in that the person with schizophrenia has experiences not common to others. Symptoms, such as avolition (i.e., lack of ability to plan behavior) and flat affect (i.e., impaired ability to express emotions and other non-verbal information), are called ‘‘negative’’, in that they represent the absence of capacity common to persons without schizophrenia. Negative symptoms often, but not always, accompany positive symptoms. While the positive symptoms of schizophrenia can wax and wane over time, the negative ones can be more persistent and disabling. Also, the negative symptoms can be misunderstood – for example, avolition can be interpreted as ‘‘laziness’’ or ‘‘lack of willpower’’ and flat affect can be interpreted as ‘‘having no concern about others." Finally, schizophrenia also affects a person’s ability to process information, learn and remember.

Schizophrenia is a complex brain disease. The causes of schizophrenia are thought to involve both genetic (inherited) and environmental (acquired, biological) factors. Schizophrenia tends to run in families and the risk of developing schizophrenia goes up when one has a close relative who also has the disorder. The environmental factors that have been associated with schizophrenia include viral infection or very poor nutrition during the fetal period. Schizophrenia affects the function of many areas of the brain. However, some areas of the brain are thought to be especially affected, such as the temporal lobe, which is involved in learning and memory, and the frontal lobe, which is involved in reasoning and planning.

Questions for discussion:

a. How do most people tell what is real from what is not?

b. Is/Does every belief that differs from one of our own a delusion?

c. How many of us have relatives with schizophrenia or other mental disorders?

2. Cultural Myths & Misunderstandings

There are many cultural myths and misunderstandings about schizophrenia, perhaps because the disease strikes at the core of what makes us human—our ability to understand the world and our relationships with fellow human beings. Schizophrenia is NOT caused by bad parenting. Also, people with schizophrenia do not have a split personality. While the word schizophrenia was coined to mean split or fractured (schizo) mind (phrenia), it was meant to describe the breaking apart of mental functions, not the splitting apart of our personality. Also, schizophrenia does not represent a sane reaction to an insane world, as some have argued in the past. Schizophrenia is a brain disease that affects thoughts, perceptions and the capacity to reason, and it can be helped by medication and psychotherapy. Although media stereotypes suggest otherwise, few persons with schizophrenia actually become violent.

Sometimes schizophrenia has been explained as exclusively a biological or psychological disease, but this kind of distinction is artificial and undermines our ability to appreciate the complex interaction of biology and psychology expressed in schizophrenia. One way to think about schizophrenia is that it is a biological illness that is experienced by a psychological being. Thus, treatment for schizophrenia must necessarily address both biological and psychological issues.

Questions for discussion:

a. How many movies have you seen where the person with schizophrenia is portrayed from a sympathetic point of view?

b. How do other common medical disorders, such as diabetes or high blood pressure, affect our psychological (mental) life?

c. Discuss any experiences you've had that prove the stereotypes of schizophrenia wrong?

3. Onset of John's Illness – Acute Psychosis

John first became ill in 1991 while he was in college. Initially, family members thought that his frightening beliefs and concerns might be the result of a difficult re-adjustment to college life, after a happy year studying abroad. As time went on, however, it became much clearer that John had become almost totally withdrawn and overwhelmed by paranoid thoughts. He was suffering from an acute psychosis—but psychosis alone does not make the diagnosis of schizophrenia, as many mental disorders can cause psychosis. When his family helped him into treatment, John was delusional and depressed and had great difficulty communicating. John was unable to read, understand words, or watch TV and comprehend what was happening on screen. As sometimes occurs, his doctors were slow to come to a diagnosis, in part because the features of his illness continued to evolve over time and in part because they were hesitant to devastate the family with the news that John really *did* have schizophrenia. Today doctors are usually more forthright with patients and families. His family's search for clinical expertise and appropriate treatment was disheartening at first, because no combination of medications given John yielded any significant relief for at least three years. At times, he turned to alcohol in order to self-medicate his psychosis, which further complicated his treatment.

Questions for discussion:

a. What were the early signs of John's illness?

b. If you began to experience delusions or even hear voices, how would you be able to tell those perceptions were not based in reality? How would you react?

c. How prepared would you be if a close relative developed schizophrenia? What would you do?

4. Treatments for Schizophrenia

The treatment for schizophrenia should include both medication and psychotherapy. The primary medications for schizophrenia are the anti-psychotic drugs. The first generation of such drugs, thorazine and haloperidol, were developed in the late 1950's. While these medications are effective in reducing the positive symptoms of schizophrenia, they are less effective for the negative symptoms of schizophrenia and commonly cause side-effects that affect the central nervous system. For example, in most patients, the first generation antipsychotic drugs cause temporary symptoms that mimic Parkinson's disease.

The second generation of antipsychotic drugs, such as clozapine, risperidone, olanzapine and quetiapine, were developed in the late 1980's and became widely available in the mid- to- late 1990s. These medications cause many fewer neurological side-effects, but often lead to excessive weight gain, as was the case with John. Patients who take second-generation antipsychotic drugs need counseling to reduce weight gain and should be checked for weight gain-related problems, such as diabetes. Finally, some persons with schizophrenia have unstable moods or depression, Anti-depressant medication, mood stabilizers (such as lithium), or even electroconvulsive treatment (ECT), which can have mood-elevating effects, are sometimes employed. John received ECT three years into his illness, but it did not relieve his persistent depression. John now takes both a mood-stabilizer and an anti-depressant along with his anti-psychotic drugs

The psychotherapy of schizophrenia is focused on providing support and understanding. The therapist often helps the person with schizophrenia adjust to living with their illness and dealing with the day-to-day practical problems which inevitably result. Since the schizophrenia impacts parts of the brain that control logic, language and comprehension, simple daily tasks can often be highly stressful or, at times, overwhelming. Therapy can help the person with schizophrenia learn to understand their symptoms and to sort out which experiences are real and which are unreal (i.e., related to their symptoms). Therapists can also counsel the family of the person with schizophrenia, so that family members can manage their grief, improve their understanding of the disorder and figure out how best to be supportive.

Questions for discussion:

a. What was John's attitude towards medication and treatment?

b. How did John's psychiatrist use psychotherapy to help him?

c. How would you provide support to a friend or family member with schizophrenia?

5. Initial Recovery from Psychosis

Recovering from psychosis is a difficult process that depends heavily on good treatment along with family understanding and support. People struggling with their symptoms often find it impossible to simultaneously handle most aspects of their practical lives, including employment, housing and financial issues. Even taking care of basic personal hygiene can be a challenge

when symptoms are prominent. Recovery brings the beginnings of insight and acceptance of the need for treatment. But, recovery also brings the sometimes frightening realization of how having a mental illness could change the course of one's life. In John's case, making this film was part of his process of developing insight into and understanding of his illness. Recording his story reinforced John's awareness of his need for treatment and support. It became a tool which helped him place the experience of having psychosis and schizophrenia in perspective. John was also able to develop relationships with other patients, who helped break the isolation often felt by those with this illness.

Questions for discussion:

a. What was John's initial reaction to learning he had a mental illness?

b. What was John's family's reaction to learning that he had a mental disorder, and how did they respond to John's initial needs?

c. How would you react to having schizophrenia?

6. Family Education

Families, like anyone else who has only encountered schizophrenia through the media, can come to the illness filled with fearful stereotypes and misinformation. It is critical that family members have support from professionals as they react to the knowledge that one of their own has developed schizophrenia. The more accurate information the family has, the better equipped they will be to help one another and handle their loved one's illness.

The most important thing families need to understand about schizophrenia is that it is a brain disease and that those who suffer with it are not at fault. They also need to know that early intervention and good treatment can lead to recovery.

Family members who are coping with schizophrenia require education and support, in order to make their own adjustments to this lifelong illness.

Together they need to create a plan for living with schizophrenia. This plan should to include strategies for dealing with financial issues, housing, and responding to impairments in common life skills.

In John's case, his family rallied around him to offer support, coordinating with each other as to how best to be of help. Initially, John lived with his sister Katie and her husband. Once his mom relocated to California, she was able to help care for him directly. John's father and other siblings set up routines for regular visits and vacations, giving John's mother and Katie much needed breaks. As a result, relationships among John's family members grew much stronger.

Questions for discussion:

a. Where can people go to learn accurate information about schizophrenia?

b. How might a person who has developed schizophrenia react to offers of help from friends or family members?

c. What kind of help would you offer to someone who had developed schizophrenia?

7. Finding Hope

Facing a lifelong mental disorder, people need to set their own priorities and goals for recovery - even if those goals are as basic as getting up before noon each day on a regular basis. The attainment of simple goals helps to build hope, purpose and resilience.

When John first began to respond to treatment, his counselors thought he should set a goal of finishing his college degree or getting his own apartment. But John wanted to focus on his deepest passion - his artwork - which had been a source of joy and self-expression since his early childhood. Fortunately, John's treatment team supported his decision not to return to college or immediately work on living independently. John's mother and case manager helped him find studio space to rent and he began to work again as his symptoms permitted. Slowly, as John felt better, he created a growing body of woodcarvings that gave him a sense of purpose and fostered new goals, such as entering art exhibits and hosting an open studio.

It is important for every person living with schizophrenia to find goals they care enough about and to work towards, as part of their treatment.

Questions for discussion:

a. From what sources did John find hope early during his illness?

b. Was it easy or difficult for John's family members to be hopeful about his illness?

c. From what sources would you find hope if you developed schizophrenia?

8. Remission

Working with his psychiatrist, Dr. Ballinger, John learned to identify, label and understand his remaining symptoms (paranoia, unwanted thoughts, depression/dysphoria, negative symptoms). As he entered remission, he experienced steady improvements in his thinking ability and social functioning. These accomplishments permitted John to plan a daily routine that included time for working on his art.

John was fortunate to have a psychiatrist who had expertise in diagnosing and treating schizophrenia. To be able to successfully treat a person with schizophrenia, the clinician needs an excellent knowledge of psychiatric diagnosis, the medications used to treat these particular

mental disorders, and especially good communication skills.

Questions for discussion:

a. If you were a clinician offering treatment to a person with schizophrenia, how would you explain the diagnosis and make suggestions about treatment options?

b. If you were a person with schizophrenia, what would you look for in a clinician or treatment plan?

c. If you were recovering from a mental disorder, what would be the most important elements of your daily routine?

9. Building and Rebuilding Relationships

Over time John was able to build interpersonal relationships of increasing complexity and depth. These relationships included relationships with the members of his family and friendships with new people in his life. He worked through the issues that accompanied having a roommate and was able to get along with Joe, despite his discomfort sharing space with another person. John became an ''adopted son'' to his friend Anne after meeting her in a group home, and over time he developed the ability to support her when she became ill. Although a generation apart, Ed and John share the pain of developing schizophrenia during the prime of life. Both men became ill in college and though they are clearly articulate and bright, both were unable to return to full-time work. Finally, with Patrick who has obsessive-compulsive disorder, we see John develop a deep and lasting friendship with another very intelligent person living with mental illness. John and Patrick discuss their respective symptoms and learn how to support each other. They become such close friends that John applies to move into the low-income housing building where Patrick lives.

Questions for discussion:

a. Why would it be difficult for someone with schizophrenia to make new friends?

b. Would you be willing to befriend someone who had schizophrenia? Discuss any experiences you've had being close to someone with a severe mental illness.

c. What could you offer in a friendship with someone who had schizophrenia?

10. Achieving Major Goals

Like most professional artists, John has an urgent and ongoing need to create. John discovered, however, that when his symptoms flared, he had difficulty working. He expresses himself through his artwork and gets frustrated when his illness impairs his concentration. John takes advantage of the times when he feels good to work in his studio. He learned how to carefully structure his days and his studio time so that he could work towards his goals without triggering

a relapse.

John felt the acute need for meaningful work to feel whole again. John was honored to participate in an art show at the Capitol where he was a spokesperson for artists struggling with mental illness. He prepared for an open artist studio by printing and framing many works of art and inviting the public to come and see his art. It was a turning point for John to interact as a professional artist with the public and to integrate the commercial side of art (i.e., selling his pieces) into his creative life.

Questions for discussion:

a. What thoughts and feelings did you have watching John work?

b. What thoughts and feelings did John's artwork bring up in you?

c. Is John a good spokesperson for those recovering from schizophrenia?

11. Maintaining Remission from Psychosis in Schizophrenia

During the remission phase of schizophrenia, symptom management is an ongoing process. John's psychiatrist helped him learn techniques to test reality - as we see when he asks Katie whether he was given the evil eye. Later we hear John repeating the mantra "It's not true. It's not true. It's not true.", when he is battling paranoid thoughts about Katie. John's family learned how to provide reality checks for him, telling him their feelings and perceptions whenever he asked. Over time, John and his family learned to accept that there will always be good days and bad days and that his symptoms will continue to wax and wane.

Learning to recognize and have insight into one's psychosis is also critical to maintaining remission. John gradually gained recognition of the violent imagery in some of his experiences, as well as an understanding of the feelings this imagery produced in him. Understanding how distressing the imagery is to him, shows great insight. John lives with the risk of relapse, tries to identify symptoms of an impending relapse and attempts to manage any such relapses so that they do not bring his recovery to a halt.

Questions for discussion:
a. How does John react to increases in the severity of his symptoms?

b. How does John's family respond to increases in the severity of his symptoms?

c. How is John's life with schizophrenia similar to and different from your own?

12. Substance Abuse and Schizophrenia

John's conversation with Ed at the restaurant touches on the issue of the use and abuse of drugs and alcohol in persons with schizophrenia. People with schizophrenia often turn to alcohol and

drugs for relief from their symptoms and they often rely heavily on caffeine and nicotine to improve concentration. This type of self-medication is common in many mental disorders, but the use of these substances complicates treatment and impairs the efficacy of medications. Drug and alcohol abuse can add to the confusion produced by positive symptoms, and can also be associated with treatment non-compliance, both of which, in turn, can greatly increase the risk of relapse. In the treatment community people who struggle with both substance abuse and mental illness are referred to as having a "dual diagnosis." Recovery is dependent upon both problems being treated. In the film there is a stark contrast between the choices that Ed is making and the power of John's choice to be sober.

Questions for discussion:

a. How does John maintain sobriety during his struggle with schizophrenia? How does John react to Ed's stories about the use of alcohol?

b. How could you tell whether someone abusing drugs or alcohol might also have schizophrenia or another disorder?

c. If you were a clinician treating a person with schizophrenia, would the person's use of drugs make you less sympathetic?

13. Reintegrating into Family and Community

As John rebuilds his life and relationships, he begins to take part in more family and community activities. He serves as an usher at his brother's wedding and helps at a community food bank with Patrick. John develops a new perspective on life and can tell himself to "just lighten up." He rediscovers his sense of humor and can sometimes laugh at his own predicament -- even accept gentle teasing by his sister about his appearance. He gains confidence by hosting an open studio and spends time helping his friends to understand how he creates his art. John also takes pleasure in recreation and vacations—he goes bowling with his father and enjoys hiking with Patrick.

Questions for discussion:

a. What role does recreation play in John's recovery from schizophrenia?

b. What strengths does John discover in himself?

c. What kind of support does someone with schizophrenia need to be able to begin reintegrating into society?

15. Spirituality

John becomes reconnected with his spiritual life. He attends a healing service regularly at church with Katie and finds a spiritual community that accepts and supports him. He discovers that his

art helps him explore the mystery of God and understand his own journey to find meaning in his life. This is reflected in his woodcuts, which become more expressive of his inner life.

Historically, some spiritual communities rejected people with severe mental illness and their families by accusing them of harboring "demons" or having incurred the wrath of God. Today, parishes like John's are learning how to embrace people with severe mental illness and their families in the same way faith communities have embraced people with other diseases. John and his family discovered that active spiritual lives (especially prayer and meditation) helped guide them and sustain them through the many years of dealing with his illness.

Questions for discussion:

a. How is John's inner life reflected in his artwork?

b. How does John's view of his inner self change as his symptoms wax and wane?

b. What role can spirituality play in a person's recovery from mental illness?

16. Independence and Resilience

As John recovers, he assumes the ordinary responsibilities of everyday life. When relapses occur, he recognizes the symptoms and calls for help. He takes the initiative to correct problems and to handle situations which previously would have baffled him. When John's application for housing is at first denied, he recognizes that he needs help and reaches out to his family. Despite experiencing paranoia, fear and sleeplessness, he sets up a meeting to work through the issues that blocked his move into the new apartment. After more than a decade of coping with schizophrenia, John achieves a major milestone of adulthood – independent living.

John's ability to live independently was a gradual process requiring a lot of small-steps, before taking the big leap. Those small steps built his resilience, as well as his ability to handle setbacks and relapses. Now in his early thirties, John handles everyday tasks most adults take for granted- cooking, cleaning, laundry, bill paying, even making coffee - tasks that are meaningful to him as significant markers of his recovery.

Questions for discussion:

a. What happens to John's symptoms when he encounters the common and not-so-common frustrations of daily life?

b. How well would you cope with being refused housing?

c. How do John's relationships with his family members change as he becomes more independent?

Postscript from John Cadigan- An update on how he is doing since the film ended.

I'm still living in my apartment and it is working out well for me. It's nice to have my own space. I've met a great friend named Michele who lives on my floor. I joined Weight Watchers in March 2003 . My blood sugar was really high and I was on the verge of getting diabetes. I'm happy to say I've lost over 130lbs and in June 2005 I reached my goal weight. My skin is loose, which bothers me, but I'm not huge anymore. Since I've lost all this weight I am no longer at risk for diabetes - unless I gain it back. A few months ago I shaved my beard and cut my hair. I'm not sure you'd recognize me now.

I'm still sober and have been so since 1995.

The response to my film has been amazing. I have been surprised at how many people relate to my symptoms. I have been traveling all over the world to speak at film festivals and events. For some reason, that I don't quite understand, I have not had trouble with paranoia when I'm up in front of large audiences. I actually enjoy talking with people about my artwork and my illness.

I have decided to keep filming my life and am having fun learning more about cinematography.

I continue to do my artwork. I still have my great studio. I've done two more giant 2 foot by 4 foot woodcuts. One is called "Dread: The Ogre of Consciousness" which features a six-headed beast. The other is based on the temptation of St. Anthony. I also did a large mushroom-shaped woodcut called "Enlightenment: One Big Doodle." Right now I'm working on a series combining the book of Genesis with my dream life.

I just finished my first commission of two vertical woodblocks based on gospel stories for the Church of the Epiphany in San Carlos, CA. They are mounted at the front of their Healing Chapel - on either side of the cross. You can look at my woodcuts online at www.johncadigan.com. And yes, they are for sale.

Further Reading

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About the Authors

- **Cynthia Csernansky** received her doctorate in Pharmacology from Stanford University, and has worked on the biochemistry of the central nervous system. She is currently working on developing an international database to facilitate collaborative research on dementia and other

brain disorders.

- **John Csernansky** received his medical degree from New York University School of Medicine, and his training in psychiatry from Stanford University. He currently serves as the Gregory B. Couch Professor of Psychiatry at Washington University School of Medicine. He has devoted his career to caring for patients with schizophrenia, and to conducting research on the underlying biology of schizophrenia.