The cognitive and social world of schizophrenics as perceived by health care professionals and experienced by schizophrenics themselves: Autoethnography and interviews

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THE COGNITIVE AND SOCIAL WORLD OF SCHIZOPHRENICS
AS PERCEIVED BY HEALTH CARE PROFESSIONALS AND
EXPERIENCED BY SCHIZOPHRENICS THEMSELVES:
AUTOETHNOGRAPHY AND INTERVIEWS

by

Pauline Bukantz Paz

A thesis submitted in partial fulfillment
of the requirements for the degree of

Master of Arts

in

Communication Studies

Greenspun School of Communication
University of Nevada, Las Vegas
May, 1997
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ABSTRACT

This ethnographic research involved an autoethnography, and interviews of health care professionals and schizophrenic patients. The autoethnography detailed the researcher's personal experiences with schizophrenia, which were compared to other autoethnographies. Three psychiatrists, a therapist, psychiatric hospital unit manager, social worker, nurse, and psychiatric nurse's aide were interviewed, as were six schizophrenic patients, including three from the same family. The interviews were compared, and findings were correlated to the literature. Schizophrenics are individuals, not homogeneous in personality or life experience; schizophrenia is not uniform for all. Patients were dependent upon their doctors and support network. Schizophrenic family communication dynamics were examined. There was no support for the presence of a schizophrenic language. Bizarre behavior was not noted. Flatness of affect and repetitiousness were observed. A paucity of abstract ideas was seen. Divergence in philosophy and role of individual health care professionals was noted. Schizophrenia is a debilitating, presently incurable, genetic disease with diverse, but similar features that affects all aspects of life, but particularly affects communication with self and others.
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GLOSSARY

**affective flattening** - inability to experience, or at least express, emotions. Seen primarily in schizophrenia or dementia

**aphasia** - loss of the power to use or understand words

**autoethnography** - the gathering of data from various sources, including self, about some significant experiences that an individual has had

**decomp** - revert to earlier behaviors which presented a patient to the hospital

**delusion** - a false, persistent belief maintained in spite of evidence to the contrary

**double bind theory** - describes a hypothetical family in which children receive conflicting parental messages regarding their behavior, attitudes, and feelings

**electroshock treatment (Electroconvulsive Therapy)** - use of an electrical stimulus instead of a pharmacological one to elicit a convulsion of a functional nature in the brain, it is this seizure which is therapeutic

**emic approach** - internal approach taken by ethnographers that relies on interviews to learn how their subjects think about communication

**ethnography** - a written report about a group of people

**etic approach** - external approach taken by ethnographers in which attention is focused primarily on observable communication phenomena

**grounded theory method** - generalizations are inferred from data, rather than being imposed on the data from another source

**hallucination** - vivid perceptual experience that occurs in the absence of a relevant sensory stimulus. May involve any of the senses, alone or mixed

**inductive analysis** - The process whereby a researcher first gathers data, and
then develops a theory from them, often referred to as “grounded theory”

interactional approach- looking at people’s face-to-face behavior in order to describe social events and to analyze the meanings

Narcotics Anonymous (NA)- Twelve-step, self-help group that may be useful as a primary or adjunctive treatment for opioid dependence

neologisms- new words or new meanings for established words

neuroleptic drugs- dual drug actions on psychoses and motor functions. Term refers to numerous different drugs

neurotransmitter- a biochemical substance that transmits or inhibits nerve impulses at a synapse

paranoia- a mental disorder characterized by systematized delusions

phonology- the study of speech sounds

psychosis- a major mental disorder in which the personality is very seriously disorganized, and contact with reality is usually impaired

psychotropic drugs- medications that have an altering effect on the mind

Rational Emotive Behavior Therapy (RET)- a cognitive type of therapy that empowers the individual

recidivism- habitual or chronic relapse, characterized by frequent admissions to hospitals

“salad-talk”- speaking in an incomprehensible manner

schizo-affective disorder- disorder in which there is a combination of manic or major depressive along with symptoms of schizophrenia

schizophrenia- group of psychoses, the course of which is at times chronic, at other times marked by intermittent attacks and which can stop at any stage, but which does not permit a full recovery

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"swinging-door" effect - in and out of hospitals

thought disorder - a fundamental or primary symptom of schizophrenia pertaining to how a patient thinks as well as communicates with others

"voices" - auditory hallucinations
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Finally, a word or two to Dr. Robert Lynn Horne. He gave me the ability to believe in myself. It is possible to prevail over schizophrenia. His research, kindness, and fervent belief in education and the future, made me believe.
THE COGNITIVE AND SOCIAL WORLD OF SCHIZOPHRENICS AS PERCEIVED BY HEALTH CARE PROFESSIONALS AND EXPERIENCED BY SCHIZOPHRENICS THEMSELVES: AUTOETHNOGRAPHY AND INTERVIEWS

CHAPTER 1

INTRODUCTION

"No other state of abnormality, no other illness permits us to delve so deeply into what is specific to human nature. Knowledge of schizophrenia opens to our eyes and to our understanding a panorama of the human condition that includes the cardinal problems of truth and illusion, bizarreness and creativity, grandiosity and self abnegation, loneliness and capacity for communication, lasting suspiciousness and absolute faith, immobility and freedom of action, capacity for projection and self-accusation, surrender to love and hate, and indifference to these feelings" (Arieti, 1979).

Schizophrenia is one of the most chronic and disabling of the major mental illnesses. It is a complex and puzzling disorder. Clear accounts of schizophrenia have been proffered throughout history. Nigel Bark (1988) substantiated that schizophrenia has been described for 2000 or more years and was common enough to be depicted not only by physicians but by philosophers, clergy, authors and playwrights and to be recognized by their readers and audiences. The World Health Organization's (WHO) International Pilot Study on Schizophrenia (IPSS, 1966) was conducted in 20 centers in 17 countries, both developed and developing, and revealed that schizophrenia occurs in
all countries and all geographic areas; the symptoms reported were remarkably similar (Betemps & Ragiel, 1994).

Schizophrenia is characterized by cognitive, perceptual, affective, motor, and social changes. It is defined as a group of psychological disturbances or mental disorders occurring in different combinations and degrees and symptoms but generally sharing disturbances of feeling, thought, and relationship to the outside world (Haber, Leach, Schudy, & Sideleau, 1982).

No generally agreed upon objective clinical criteria for the diagnosis of schizophrenia has been discovered. No consistency in pre-psychotic personality, course, duration, outcome, has been identified. Varied opinions exist regarding whether schizophrenia is a disease or group of diseases (Laing, 1964, p. 151). While there is no single known cause, schizophrenia has been found to originate from anatomical to biochemical to psychological, from hereditary to environmental.

The justifications for the thesis are many. The National Institute of Mental Health (NIMH) sponsored Epidemiologic Catchment Area (ECA) Study reported that 1.3% of the general population is afflicted with schizophrenia (Kaplan et al., 1994). Over one in 100 will be diagnosed with the disease in their lifetime. The illness affects society as a whole. It is a financial and emotional drain on the economy. Health care funding is being cut back. Hospitalization and long term care are burdens society assumes. Society shuns schizophrenics; many of the homeless are schizophrenic. The disease presently has no cure; a large percentage of schizophrenics attempt suicide. Schizophrenics communicate differently than others and it is vital to understand that communication. With this disease, what is affected most is perhaps communication. No
one has attempted to incorporate into one paper an autoethnography coupled with interviews of health care professionals and schizophrenic patients.

Numerous theories have been generated to explain the development of schizophrenia. Biological theorists assume that the disease is caused by organic dysfunction. This explanation describes a cause and effect relationship between a specific biological factor, as yet unknown, and the development of schizophrenia (Haber et al., 1982). Biochemical theorists do not completely understand the biochemical dysfunction associated with schizophrenia. However, a number of biochemical factors that depend on the process known as neurotransmission have been identified. Neurotransmitters are substances that allow communication between nerve cells and are thought to be associated with the development of schizophrenia.

Extensive epidemiological evidence indicates that genetic factors are important for the etiology of schizophrenia (Sedvall & Farde, 1995). Genetic influences from aberrant DNA may be related to a vulnerability for developing schizophrenia. The view that mental disorders result from abnormalities of brain chemistry received its first experimental support during the 1940's. R.D. Laing formulated a theory of schizophrenia that attempted to redefine it as a social and interpersonal process. Laing defined schizophrenia as a way of dealing with a situation perceived as unresolvable. Van de Craen, De Deckers & Peuskens (1989) argued that social interaction patterns may provoke physiological effects. Their aim was to reconcile social and physiological aspects with respect to schizophrenia. Social experience may provoke feelings of anxiety; this may have physiological consequences.
Psychosocial theories relevant to the development of the disease addressed the psychological growth of the individual in relation to his or her social environment in a "complex interaction of environmental forces" (Haber et al., 1982, p. 615). Theorists agreed that the schizophrenic process began early in life, during infancy. "Inadequacies and impairment in the parent-child relationship set the stage for behavioral problems in later life" (Haber et al., 1982, p. 617). Sullivan studied the child's self-concept system and stated that satisfying experiences from a nurturing caregiver affect later life experiences and how the child comes to view the world. In family systems theory, Bowen explained schizophrenia as a systems phenomenon in which all family members participate. "The family is viewed as a single organism and the schizophrenic member is seen as the part of the family organism through which the overt symptoms of the family's dysfunction are expressed" (Haber et al., 1982, p. 616).

A communication theorist regards schizophrenia as a double bind, originally formulated by Gregory Bateson, to describe a hypothetical family in which children receive conflicting parental messages regarding their behavior, attitudes and feelings (Kaplan et al., 1994). Psychoanalytical theorists stated that schizophrenic behavior occurred when the ego could no longer withstand pressure arising from the id and from external reality. The ego of the schizophrenic is fragile and has a limited ability to cope with internal and external stress. The theories regarding the development of schizophrenia are numerous and varied. However, extensive evidence suggests the importance of genetic factors in the development of the disease (Sedvall & Farde, 1995).

Eugen Bleuler (cited in Kaplan, Sadock & Grebb, 1994) conceptualized the term "schizophrenia" to signify the presence of a schism between thought, emotion and
behavior. Bleuler described a fundamental or primary symptom of schizophrenia as being a thought disorder. Disorders of thought may in fact be the core symptoms of schizophrenia. Disorders of thought may be divided into disorders of thought content, form of thought, and thought process. Disorders of thought content reflect the patient’s ideas, beliefs, and interpretations of stimuli. Thought disorders are objectively observable in a patient’s spoken and written language. Thought process disorders concern the way ideas and language are formulated. A disorder is inferred from what and how the patient speaks, writes or draws. Thought disorder pertains to how the patient thinks as well as communicates with others (Kaplan et al., 1994). Formal thought disorder can be better conceptualized as disorders of thought, language and communication. If viewed from an empirical perspective, most of them are in fact disorders of communication (Andreasen, 1986).

The illness affects its victims, their families and friends, physicians and hospitals, and society as a whole. Because everyone is affected by this affliction of a minority, knowledge of the disease affects a broad audience. Loss of lives, loss of labor, a drain on the economy, emotional impact on individuals, group and communities, and communication impasses are consequences of schizophrenia. The speech of schizophrenia patients has been described as a hallmark of the disease since Kraeplin first described schizophrenia in 1896 (Caplan, Guthrie & Foy, 1992). A characteristic disorder of the disease is often taken to be a reduction in the capacity to experience and communicate emotion (Philip, Joseph, Sturgeon & Leff, 1992).

Many researchers have studied schizophrenia. Ronald D. Laing was a psychiatrist, theoretician, and author who actively studied the disease. He was very
involved with the concept of respect for schizophrenics. He had a conviction that there was, in fact, no such clinical entity as mental illness nor did he assume the real existence of schizophrenia. Laing did make it clear that he did not deny the possibility of mental illness, even schizophrenia. What he denied was its relevance as either a characterization of life or a therapeutic tool.

Laing had a humane acceptance of persons otherwise deemed psychotic. He felt that we could not regard our norm of sanity as the measure of insanity. He believed that the behavior of the person diagnosed with schizophrenia was different because his experience was different. The statements and behavior of those deemed mentally ill are by no means irrational, but sensible when viewed from the position of the person the patient has been (Friedenberg, 1974). “The experience and behavior that gets labeled schizophrenic is a special sort of strategy that a person invents in order to live in an unlivable situation” (Laing, 1967, chap. 5).

Authenticity was a key concept in Laing’s view of healing. What was needed was understanding, acceptance and especially authenticity of response from the physician/therapist. Laing was among the pioneers in emphasizing the indispensability of the therapist’s human presence as the essential factor in whatever good he may do for his client. Laing was opposed to psychiatric diagnoses and much psychiatric practice because it was “repressive, coercive, and political rather than psychological” (Friedenberg, 1974). By 1964, Laing had concluded that a humane and liberating use of psychiatry was intrinsically impossible.

Laing thought that the standard psychiatric criteria for diagnosing schizophrenia—a split between thinking, feeling and behavior—applied to most people
he had ever met, including most psychiatrists (Evans, 1981). Erving Goffman felt as 
Laing did, that is, that no clear-cut line could be drawn between normal people and 
mental patients (Friedenberg, 1974). Laing was considered a major exponent of 
openness and spontaneity in human expression. In his “Phenomenological Approach to 
Schizophrenia” article, Laing concluded thus: “Perhaps we can still retain the now old 
name and read into its original meaning: schiz- broken; phrenos- soul or heart. The 
schizophrenic is one who is broken-hearted. But even broken hearts can mend if we have 
the heart to let them” (Laing, 1967, chap. 5).

Carl Rogers felt that real communication occurs when we listen with 
understanding (Rogers, 1961). He felt the solution to major barriers in communication 
was to create a situation in which each of the different parties came to understand the 
other from the other’s point of view. Rogers believed that psychology and psychiatry 
should be more concerned with growth and the potential in human beings. Rogers’ 
client-centered or person-centered therapy was directed to this end, striving for change in 
the client’s concept of self. Rogers claimed that good communication was essential for 
mental health and that mental illness was a breakdown of a person’s intrapersonal 
communication (Rogers, 1952).

Mental illness affects communication. How we communicate is based on our 
personal viewfinder. It is a lens through which we see the world. Schizophrenia is one 
such lens or viewfinder. When we see through the lens to the other side, we enhance our 
understanding of other people.

PURPOSE
The thesis assessed the communication process within schizophrenia from the perspective of individuals who are affected by it, both personally and professionally. Included in this group are doctors, social workers, nurses, nurse’s aides, as well as psychiatric hospital unit managers— who regularly treat schizophrenics; and, schizophrenic patients themselves. Schizophrenia is a physical pathology that has profound social and interpersonal consequences for the afflicted and those who care for the afflicted (Doubt, 1994). Since it has been established that schizophrenia is a debilitating disease affecting information-processing and therefore communication, it is important to study the communication process for schizophrenics.

Communication is how messages are exchanged and meanings are created. Human communication is a subtle set of processes through which people interact, control one another, and gain understanding (Smith, 1966). Communication occurs when humans manipulate symbols to stimulate meaning in other humans (Infante, Rancer & Womack, 1993). Listening and responding to a message “sent” by another person involves complex physiological, psychological and cognitive processes (Farley, 1992). The average person spends more time communicating than in any other activity. Communication is the art of expressing ideas, verbally and nonverbally.

Nonverbal behavior is thought to be at least as important as verbal behavior in understanding communication (Infante et al., 1993). Some researchers, such as Mehrabian (1981), argued that nonverbal behaviors typically stimulate much more meaning than the meaning created by the words used in a verbal communication context. The nonverbal code may be viewed as a language.
CHAPTER 2

REVIEW OF THE LITERATURE

This researcher used two unique methods in examining the topic. Utilizing an indirect method, scholarly books and articles on the speech and nonverbal character of schizophrenia were reviewed. The direct research involved scrutiny of studies relating to this thesis, namely, ethnographies on schizophrenia. There are only a few studies directly relating to this thesis. There are also first person accounts of an autoethnographical nature.

Two ethnographies were conducted concerning the role of psychiatric hospital health care professionals and schizophrenics. Nomura (1987) of Stanford University, in his dissertation, "Ethnography of Interaction at a Japanese Mental Hospital," addressed everyday interactions of nurses, doctors, and patients. Nomura’s purpose was to record and reproduce day-to-day interactions through the eyes of the participants. His ethnography was a result of reflective documentation in his interpretation of the people in that hospital. Nomura’s method, based on a one-year study, was to describe life mainly from the viewpoint of social interaction as he encountered it and participated in it as an ethnographic fieldworker. This was not a report on psychiatric illness, medical procedures, or hospitalization but on the people who were involved in these processes. It was an investigation in portraying such people through interactional data. He dealt with
such issues as how an ethnographer could reach the deeper cognitive world of individuals through interactional data and how one could approach the "unobservable" from observable data.

Nomura studied the entire hospital ethnographically and came to understand that the three groups of people—the patients, staff, and doctors—lived in quite different cognitive worlds of their own, even though they were constantly in contact with each other. He recorded their day-to-day performances to describe them interactionally. Nomura wrote down observations but also relied on such methods as photography, audio recording, and video recording. Interactional approaches generally look at people's face-to-face behavior in order to describe social events and to analyze the meanings. His rationale in doing the study was that it was important for anthropologists to study human interaction because through a careful analysis, even the smallest segments of people's interactions could help reveal a great deal about a social order. Nomura's primary goal was to describe life in the Hiraoka Hospital. His participant-observation interviews and hand-written portrayals of the people in the hospital illustrated the pace of life among the patients and staff and their interaction.

Robins (1994), in her dissertation, "Producing People: Industrial Ideals and Staff Experience in a State-Operated Mental Hospital," focused on participant-observation of hospital staff efforts in facilities in the Northeastern U.S. Robins' purpose was to understand the chasm that existed between the hospital's ambitious objectives and the starker reality of its day-to-day operation. She studied the reality of the hospital system, and represented the hospital to be a "factory," turning out "products."
Her method was to spend 18 months in a state-operated hospital. She also spent time in private facilities. As part of her research, she tape-recorded interviews with several staff members, interviews which focused largely on staff perceptions. She found that achieving some level of rapport with the staff was difficult. Her observations were of patient treatment, staff operations, treatment options offered, and philosophy of the facilities.

The results of her research indicated that the hospital in question was characterized by a significant number of contradictions, "all of which point to a system whose daily operation is unable to meet its lofty cultural expectations" (Robins, 1994). She argued the absence of the concept of "respect" in the hospital and concluded with an analysis of the cultural meaning of respect and the significance of its absence within the hospital system. She interpreted the gap between the ideal and the reality.

There have also been many first person accounts of affliction with schizophrenia. One of these is "Autobiography of a Schizophrenic Girl" (Sechehaye, 1979). It is the story of Renee, a schizophrenic girl and of her recovery from madness. Autobiographical accounts appear monthly in the professional publication, Schizophrenia Bulletin. One example is "Schizophrenia, Adrift in an Anchorless Reality," by Janice C. Jordan. "Maurizio Baldini's Story" of recovery from schizophrenia appeared on the Internet. In a subsequent chapter of the thesis, these will be reviewed and compared to the researcher's autoethnography.

There is much scholarly literature on schizophrenic language and thought, and the relationship between the two. Three articles that treat this subject are herein reviewed.
Elaine Chaika (1974), in “A Linguist looks at ‘Schizophrenic’ Language,” took the stance that the schizophrenic’s difficulty in thinking and his difficulty in speaking were not necessarily the same phenomenon. She stated: “If language is not necessary to abstraction and generalization and if it does not necessarily affect cognitive behavior, the misuse of language does not, in itself, prove impairment in thinking” (Chaika, 1974, p. 258). She doubted that speech and thought were inseparable, and attempted to treat language as a competence in itself.

Chaika believed that the fact of definable aberration in language suggested a disturbance in those areas of the brain concerned with linguistic production. By way of example, she said that schizophrenics who produce gibberish were suffering from a disruption in the ability to match sound strings to actual words. It was suggested that this was a disruption in the ability to apply phonological (the study of speech sounds) rules. Chaika noted schizophrenics often create neologisms (new words or new meanings for established words). These, she noted, could be caused by a failure to apply phonological rules correctly. It is crucial to an understanding of schizophrenic thought and language to ascertain whether the patient deliberately uses speech in a certain manner or is suffering from an intermittent aphasia (loss of the power to use or understand words). Further research is needed to clarify this issue; however, Chaika considered that it was just as reasonable to assume that the schizophrenic could not help his peculiar speech as it was to assume that he spoke that way deliberately.

Chaika commented on the richness of the associations employed by some schizophrenics but felt it was not surprising that the patient was able to use some rules correctly and not others. The disruptions in the ability to apply linguistic rules do not
affect all levels of speech at once nor is any level affected all the time. Chaika contended that there was such a thing as schizophrenic language, and gave six examples of the characteristics of such language; these characteristics suggested a disruption in the ability to apply those rules which organize linguistic elements. She concluded that schizophrenic language was unrelated to schizophrenic thought.

"The Thought Behind the Words: A View of Schizophrenic Speech and Thinking Disorders," (Lanin-Kettering & Harrow, 1985) was a response to Chaika’s article, which stated that schizophrenic language is unrelated to cognitive behavior. Lanin-Kettering & Harrow supported the view that the schizophrenic’s strange speech can fit into a larger view about disordered thinking. Support for this viewpoint came from four sources: the use of tests assessing disordered nonverbal behavior, evidence that schizophrenics mingle personal ideas into verbalizations, bizarre schizophrenic behavior, and the very large percentage of schizophrenics with delusions. They stated their perception of Chaika’s main thesis was that she felt that what was frequently viewed in the field as schizophrenic “thought disorder” should more precisely be regarded as schizophrenic “speech disorder.” Chaika noted that there was not good evidence that disordered schizophrenic speech was a function of disordered thinking and she maintained that speech and thought should not be automatically equated. The purpose of the article was to refute Dr. Chaika’s claims.

Lanin-Kettering & Harrow began by agreeing with Chaika that thought and speech were distinct; that speech was an observable behavior, whereas thinking was a theoretical construct. In spite of this distinction, the authors stated that inferring that schizophrenic patients’ speech disorder usually reflects a thought disorder would
facilitate advances in our knowledge about schizophrenia. There is considerable empirical evidence from many different sources to support the view of schizophrenic patients having a thought disorder as opposed to an independent speech disorder. In this article, Lanin-Kettering & Harrow considered the evidence.

Outward speech is a good clue to what a person is thinking. There are at least four points that support the position that schizophrenic patients show disorders in thinking and that “their disturbed speech is often a result of disordered thinking, rather than being a consequence of a disorder only at the level of speech production and encoding” (Lanin-Kettering & Harrow, 1985, p. 2). The primary evidence was that a large proportion of patients exhibited disordered thinking rather than only disordered speech. Second, regarding verbal behavior, the speech seemed strange and inappropriate. Third, disordered speech was not the only type of strange behavior displayed by schizophrenic patients. It was, rather, part of a larger group of behaviors that could be ascribed to a more general tendency to think peculiarly and to harbor peculiar ideas. The fourth point involved the fact that a very large percentage of acute schizophrenics had delusions. The authors’ research indicated a high correlation between the presence of delusional beliefs and ideas, and disordered thinking.

Lanin-Kettering & Harrow proposed the view that a language system whose external side is speech, was also the foundation of our internalized system of concepts, and their interrelations. “Language is the basis,” they argued, “of much of thought because it provides an intricate system of concepts that is the foundation and instrument of conceptual activity” (Lanin-Kettering & Harrow, 1985, p. 4). Because language and thinking were so intricately linked, Lanin-Kettering & Harrow advanced the view that the
disturbances most frequently observed in schizophrenic verbalizations involved problems in conceptual-linguistic activity. Language and thinking cannot always be usefully separated. The authors noted that Rochester & Martin (1979) have supported a related view.

Lanin-Kettering & Harrow quoted Vygotsky (1962) who, in his classic work, "Thought and Language," said: "Thought is not merely expressed in words; it comes into existence through them" (Vygotsky, 1962, p. 125). Lanin-Kettering & Harrow concluded that one could make a good, though imperfect, inference that schizophrenics' disordered speech often reflected their disordered thinking and that this was useful as an approach to scientific inquiry and was beneficial as a way of viewing schizophrenic psychopathology.

"The Problem of Language and Thought in Schizophrenia: A Review" (Rieber & Vetter, 1994) was a scholarly study of the different philosophies and opinions of researchers regarding thought and language in schizophrenia, expressed during the 20th century.

Rieber & Vetter began by recognizing that the term "schizophrenia" referred to a group of disorders with similar features and diverse behavioral differences. "If one were to conceive of 'mental health' as a continuum," the authors stated, "schizophrenia would have to be depicted in terms of a range rather than a point on a scale" (Rieber & Vetter, 1994, p. 150). They listed the five most frequent behavioral manifestations of schizophrenia: withdrawal from the environment; disturbances of thought; increased daydreaming and autistic behavior; an alteration of overt behavior with a tendency toward excess; and, distortion or inappropriateness of affect. "The divergence between
thinking and feeling is one of the most general characteristics of schizophrenic behavior” (Rieber & Vetter, 1994, p. 150).

Rieber & Vetter noted that the linguistic phenomena of schizophrenic behavior attracted attention because of the noticeable and often bizarre forms it took. As cited in Rieber & Vetter (1994), Roger Brown denied the existence of a phenomenon of “schizophrenic language.” Brown said that he discovered plenty of “schizophrenic thought” but nothing that qualified as “schizophrenic speech”. Brown was convinced that schizophrenic speech was a myth (Brown, 1973, pp. 395-403). Lorenz (1968) also cautioned against assuming there was a schizophrenic language.

Speech itself has been regarded as a direct reflection of thought. “Schizophrenic patients whose speech is disrupted to the point of incoherence and unintelligibility are identified as showing the symptoms of “formal thought disorder” (Rieber & Vetter, 1994, p. 154). According to Rieber & Vetter (1994), Chaika had a different view, as expressed in her article, previously cited. Chaika maintained that the six characteristics of speech she studied “suggest a disruption in the ability to apply those rules which organize linguistic elements.” Chaika raised the possibility that schizophrenic speech may reflect an intermittent aphasia. As early as 1913, Arnold Pick argued that the structure of language differed from cognition, thus concurring with Chaika’s view. Pick showed that language may be illogical where the thought behind it may not be (Pick, 1913/1973).

Other philosophies were also explored. Rieber & Vetter suggested that many clinicians would probably agree with Ferreira’s (1960) notion that “the schizophrenic manipulates or disguises his or her language, in order to conceal thoughts known to be dangerous and forbidden” (Ferreira, 1960, pp. 128-138).
In review, Rieber & Vetter concluded: “The schizophrenic’s apparent flatness of affect, inappropriate expression of affect, combined with withdrawal, or loss of interest in the social and physical environment are probably the most widely cited characteristics of the disorder” (Rieber & Vetter, 1994, p. 170). In summation, this article illustrated the complex relationship between thought and language, and more importantly, between language and communication. The purpose of Rieber & Vetter’s review was to enhance understanding of the problem of language and thought in schizophrenia.

Reviewed here also are four articles from the literature that treated the nonverbal characteristics of schizophrenic communication. The articles deliberated facial expression, perception of emotions, written responses, and sign language as utilized by hearing-impaired schizophrenics.

Cramer, Weegmann & O’Neil (1989) tested the hypothesis that schizophrenic patients misjudged the emotional states of others. There was a need for this research because previous studies had not identified whether such judging or misjudging of emotional states was related to paranoid symptoms, flattened affect, formal thought disorder, general level of illness, or duration of in-patient hospital stay. Audiovisual tapes of emotional situations were shown to 34 schizophrenics and 15 controls whowere asked to rate the emotional content of the scenes. The script illustrated the following range of interactions: “concern, interfering, happy, ashamed, encouraging, angry, relaxed, worried, sad, scornful, interested, disapproving, and surprised” (Cramer et al., 1989, p. 226). Results of testing indicated that schizophrenic patients failed to detect the dominant character of the scenes. The patients even perceived the opposite emotions to those discerned by the control group.
How accurately schizophrenics judged the emotional states of others was determined to be unrelated to an impoverished social environment of the long-term hospital patient, selective inattention to psychological factors, the acute phase of the illness, flattened affect or thought disorder. The authors concluded that this suggested a global impairment in schizophrenia of the capacity to judge emotional states.

In a related article, Gaebel & Wolwer (1992) studied 23 acute schizophrenics, 21 acute cases of depression and 15 normal controls. The work was introduced by this statement: “In both schizophrenia and depression, disturbances of affect and/or mood are an important component of the clinical syndrome. Affect is defined as a pattern of observable behaviors that is the expression of a subjectively experienced feeling state (emotion), whereas mood is a pervasive and sustained emotion” (Gaebel & Wolwer, 1992, p. 46).

Reduced facial expression is one sign of affective flattening in schizophrenia (Andreasen, 1982). However, patients’ facial expressivity differs from that of normals qualitatively as well as quantitatively (Schneider et al., 1990). It is currently not known whether schizophrenic deviations in facial muscular activity are due to an emotional deficit, an intentional motor deficit, or both.

The experimental procedure involved semi-structured interviews focusing on both positive and negative experiences, and was followed by the presentation of a prerecorded video. Three parameters were tested: emotional face recognition (of six basic emotions), imitation (of displayed facial expression), and simulation (by patients, of exhibited facial expressions).
The findings indicated schizophrenics and depressives “seem to be different from each other as well as from normals in their affect-related behaviors” (Gaebel & Wolwer, 1992, p. 50). The authors’ results confirmed the work of Gessler et al., (1989) which indicated no difference between depressed and normal subjects in emotional face recognition. However, schizophrenics were characterized by reduction in “involuntary facial activity” as well as by a disturbance in voluntary facial activity. Confirming the authors’ previous findings, (Gaebel et al., 1989) facial affect recognition seemed to be unrelentingly impaired in schizophrenics. The limitation of the research was that it was based on a four-week interim between the two assessments.

Gaebel and Wolwer (1992) concluded that schizophrenics and depressives were “characterized by different quantitative, qualitative, and temporal patterns of affect-related dysfunctions” (p. 51). They noted that with schizophrenic patients, “both the processes of decoding and encoding of facial expression seem to be disturbed” (Gaebel & Wolwer, 1992, p. 51).

Manschreck, Ames, Maher & Schneyer (1987) began their scholarly work by stating that “repetition in the written language of schizophrenics and its possible relationships to other aspects of schizophrenic disorders are not well understood” (p. 164). The data on written language in schizophrenia is meager and inconclusive. The authors introduced their work by noting that there were studies, which they quoted, that substantiated the fact that one noticeable aspect of disturbed speech in schizophrenics was repetitiousness. From 1944 to 1981, the authors stated that four studies had examined written responses, but that it would be unwise to generalize about written
schizophrenic language, on the basis of those findings. The evidence is even limited that features of written language could differentiate controls from schizophrenics.

Previous studies did not entertain the connection between written and oral language characteristics. The components of speech which influence written language are unknown. The researchers felt that because excessive linguistic repetitiousness was a symptom of schizophrenia, it was plausible to study its association to other pathology. Hence, they investigated repetitiousness in schizophrenics’ written language.

In discussion, the investigators stated that their study showed that schizophrenics’ written samples were more repetitious than those of the controls. Formal thought disorder was correlated with repetitiousness in both oral and written samples. Manschreck et al. (1987) conjectured that written responses required greater capacities to utilize complex language and action sequences than did oral responses; these written responses were thus more susceptible to the disease process. Schizophrenics were more repetitious in written than oral responses. They concluded that repetitiousness in linguistic response raised the possibility that linguistic measures might be used to define the nature of the underlying deficit in schizophrenia.

A fourth article by Thacker (1994) concluded there was evidence that formal communication disorder occurred in sign language and could be elicited and described. The author contended that the nature of schizophrenic symptoms could be clarified by studying their occurrence in a non-auditory-vocal medium. This article therefore undertook to “link two traditionally separate academic disciplines, neuropsychiatry and sign linguistics, by relating findings on linearly-organized spoken language to recent data on the three-dimensional spatially organized language of deaf signers” (Thacker, 1994, p.
Thacker noted that there had been important scientific inquiry into the neurological implications of sign with brain damaged subjects; the manual language of schizophrenia had basically not been explored.

Thacker undertook a brief review of theories of the etiology of disordered communication; they are diverse and abound. Communication disorder was characterized by Kraeplin, as early as 1919, as being “marked confusion and incoherent speech.” Cutting (1990) called them disorders of “the stream and continuity of thinking as well as of certain features of language”. Thacker referred to Chaika (1982), who utilized the term “speech disorder” as opposed to “thought disorder.” In contrast, Lanin-Kettering & Harrow (1985) suggested “viewing verbal behavior as the product of interrelated conceptual linguistic activity” (pp. 1-7). This paper presented experimental findings that suggested those neuropsychological comparisons of both well deaf signers (prelingually deaf), and schizophrenic and manic signers could shed light on the nature of communication deficits in schizophrenia. The discussion centered on how levels of sign corresponded to levels of spoken language. Thacker called attention to the communication finding in hearing schizophrenics, of difficulties in recognition and identification of emotion, as seen in facial expression.

The integrity of sign as an authentic language has been amply demonstrated in neurolinguistic studies of healthy deaf individuals. There was further backing for the comparability of signed and spoken language. This was provided by studies of pathologies in sign. “There is clinical evidence that communication disorders are manifest in the sign language of deaf psychiatric patients”. (Thacker, 1994, p. 820).
In discussion, Thacker pointed out that the possibility of mere “slips of the hand” must be considered when attempting to verify true communication disorder in signing subjects. A clinical justification for depicting communication disorder, as opposed to ordinary usage, in the deaf patient’s primary language was given by Kitson & Fry (1991). They called attention to the fact that the standard diagnosis of mental illness derived primarily from analysis of form and content of verbal behavior and that this behavior (oral and written language) in deaf individuals could be misinterpreted as thought disorder, delusions, or hallucinations.

Thacker concluded it appeared that communication disorder did occur in certain schizophrenics “independently of the communication modality” (Thacker, 1994, p. 822). The data from her studies of deaf signers suggested to the author that the work of Chaika (1974) and others has merit. “That which has been called communication, thought, or speech disorder may in fact involve a separate psychological function under which language is subsumed and represents dysfunctions affecting, but possibly not restricted to, language areas” (Thacker, 1994, p. 822).
CHAPTER 3

METHODOLOGY

The methodology used in this thesis was both autoethnographical as well as interviews of health care providers and schizophrenic patients. Autoethnography (Frey, Botan, Friedman, and Kreps, 1991) can be defined as the gathering of data from various sources, including self, about some significant experiences that an individual has had.

Part of the thesis concerned the researcher’s own struggles with schizophrenia (personal experience of the writer). The researcher has had schizophrenia for about 35 years and, during this period of time, was in various hospitals, given psychological counseling, neuroleptic drugs, electroshock treatment, group therapy and various other treatments. The researcher wanted to share her communication experiences: what was experienced and what was observed.

This thesis includes a section of an autobiographical nature for many reasons. It is a first person account. The person experiencing it is the best one to interpret it. The knowledge of what it is like to be schizophrenic is described. Society shuns schizophrenics. There are stigmas and stereotypes that will be confronted. Hopefully, the lack of understanding and the fear of schizophrenics that pervades can be lessened by such a personal experience. What got the investigator through it is valuable to know.
Insight can be provided, by the researcher, into the problems inherent in schizophrenia, and the communication difficulties that it presents. The personal experience of the researcher was compared to four other autoethnographies from diverse media.

The researcher used "I" only in the autoethnography chapter since she was the source of information. In all other parts of the thesis, the traditional third person was used.

The researcher interviewed three psychiatrists, a marriage and family therapist, social worker, nurse, nurse's aide, psychiatric hospital unit manager, as well as six schizophrenic patients.

The sample was selected because it represented a population advantageous to the study. Availability enabled the researcher to make contrasts between the schizophrenic patients and the health care professionals working with them. Those selected were able, willing, and available to participate in the project; the investigator was able to contact all the patients, and some of the providers through the auspices of a psychiatrist who is well-known, respected, and knowledgeable in the field of schizophrenia research and practice.

This psychiatrist selected and contacted the individual patients, discussed the researcher's project with them, and gave the patients the researcher's telephone number. Those who wished then called the investigator. The nature of the interview was discussed on the phone. When oral consent was given, interview time and location, convenient to the interviewee, was arranged. Written consent forms were signed at the time of the interview. Patients and health care providers were free to withdraw at any point before or during the interview.
The health care professionals were selected on the basis of their job title, duties, experience in treating schizophrenics, and availability. A diverse sampling of job types was sought. Two psychiatrists and the marriage and family therapist who were interviewed were not affiliated with the hospital utilized for the study. The hospital selected for the study was chosen because it was made available to the researcher, is located nearby, and is a fully accredited hospital and medical center.

Approval for the research was obtained before the investigation commenced. Application was made to Ms. Marsha Green, Sponsored Programs Coordinator of the Office of Sponsored Programs, University of Nevada, Las Vegas, to obtain permission to investigate research involving human subjects. A protocol form for research involving human subjects was completed, submitted, and is included in the Appendix. Permission was granted to interview the subjects May 23, 1996. Individual consent forms are on file with the Graduate College.

Ethnography is defined as a written report about a group of people (Philipsen, 1989). Ethnography is the use of direct observation and extended field research to produce a naturalistic description of a people and their culture (Frey et al., 1991). As an ethnographer, the investigator believes that all we comprehend and do is influenced by communication. The researcher attempted to describe, in this ethnography, how communication occurs. It is naturalistic, qualitative research as the investigator will have direct contact with those studied.

The interviews are one-on-one, and allow respondents to speak freely. The interview questions were developed in several ways. The available literature and ethnographies were studied. The author is knowledgeable about the works of Rogers,
Arieti, Laing and others well-versed in the field from earlier decades, as well as current researchers. This investigator was also a primary source. Relevant scholarly articles and books on schizophrenic speech and nonverbal communication as well as the ethnographies were utilized for questionnaire construction.

The validation for the choice of questions came from multiple sources. In order to show that the questionnaire is rooted in the literature, the researcher will give a justification for the questions that were selected. The ethnographic dissertations of Nomura (1987) and Robins (1994) were utilized. From Nomura’s work (p. 120) comes the question of what it means to be a mental patient. Nomura also discussed the roles of psychiatrists and nurses. For the question about patients looking at a doctor as almost a god, Nomura quoted a patient who states: “My illness is in the hands of my doctor” (p. 291). Mental patients tend to form protective and dependent relationships with nurses and doctors. In Japan, and quite possibly the U.S.A., patients “emphasize their handicapped position and their need for attention and guidance from the hospital staff” (p. 300).

Robins discussed the dehumanization that occurs once a person has been labeled “mental patient,” (p. 11) and also the stigmatizing belief that “once a mental patient, always a mental patient.” She noted staff members are frequently reluctant to treat their patients as human beings “much less as individuals capable of independence, choices or equality” (p. 132). The primacy of pharmacological interventions was viewed as the only real treatment option, consistent with Robins’ findings. Patients who were not on any medications were viewed by aides as “not receiving any treatment at all” (p. 150).
Staff burnout (pp. 117, 155) came from lack of remuneration, lack of appreciation by society at large, and frustration by their own "shoddy" treatment within the health care system, according to Robins. Staff at Northern State Hospital, where her study was conducted, discussed being so "used up" by the patients, to the point of physical and emotional exhaustion. Long hours, difficult patients, poor salaries, and understaffed wards were reasons given for the burnout.

Robins, like Nomura, detailed the negative load carried by the term "mental patient." "One was always either a mental patient or a former mental patient, never a person" (p. 157). She reviewed staff members' sense of futility in their work (a futility that patients shared), because the patients' illnesses transcend the limits of the knowledge of the staff (p. 161). Robins, in summary, "contended that discussions about the lack of respect at Northern State Hospital were the means by which hospital employees could safely talk about the perceived impossibility of transforming chronically mentally ill patients" (p. 197). Staff members at this hospital failed to respect their patients. Residents at the hospital were often seen as "freeloaders" and "welfare cheats" (p. 194).

The question about the value of medication is taken from the article, "Medication Effects on Referent Communication in Schizophrenic Patients: An Evaluation with a Structured Task" (Clark, Harvey & Alpert, 1994). When patients were medicated, the authors found that the patients produced more clear references and less episodes of bizarre speech.

The question, "Do you really trust and respect patients?" is taken from Carl Rogers' statement: "The major barrier to mutual interpersonal communication is our
very natural tendency to judge, to evaluate, to approve or disapprove, the statement of the other person, or the other group” (Rogers, 1961).

R.D. Laing (Friedenberg, 1973) viewed schizophrenia “as an ascribed stigma rather than an objectively pathological state.” Laing also believed that psychiatrists perpetuated the patient’s sense of isolation and helplessness. He believed schizophrenia to be a split between thinking, feeling and behavior (Evans, 1981). It is based on this statement that the question is posed: “When you hear the word ‘schizophrenic,’ what comes to mind?”

Finally, the motivation for the interviews themselves comes from Carl Rogers. He stated: “I have found it of enormous value when I can permit myself to understand another person” (Rogers, 1961).

This researcher chose to interview herself, health care providers, and schizophrenic patients. Medical professionals and health care providers were being interviewed because of their particular viewfinder. They have a professional view and experience. They have treated schizophrenics on a regular basis and are cognizant of the stigma and the stereotyping of the disease. They have the knowledge and scientific understanding necessary, and are the ones who apply the treatment and medications to help alleviate the symptoms. Their unique viewfinder puts them in a special position to augment this study.

The viewfinder of the schizophrenic patient is also unique. Patients were interviewed for some of the same reasons that an autobiographical section was chosen. Also, the patients are the other facet of the doctors, nurses and social workers. They are
the afflicted. It is their first person accounts. They can interpret their experiences and thoughts and behaviors.

Two chapters within the thesis compared and contrasted patient interviews, as well as health care provider interviews. The researcher found basic themes and perceptions in common and sought out differences. The fundamental theme is that all the participants are involved with the experience of schizophrenia. Understanding, respect, and trust are issues that affect all those involved. Stigma and stereotypes affect the health care professionals as well as the patients. Medications are part of the treatment process for both groups, also.

The thesis contains eight chapters. The first two chapters are the Introduction and the Review of the Literature. Chapter three is the Methodology. The fourth chapter is the personal experience, the autoethnography. The fifth chapter represents the patient interviews. Interviews with the doctors and health care providers comprise chapter six. Chapter seven compares the researcher's findings to the literature. The final chapter summarizes, and assesses conclusions.

An unstructured interview approach was used although, in general, the elements to be covered in the interview format were planned in advance. The interviews provided the researcher with information about communication perhaps unattainable through other research methods. The researcher encouraged the individuals to speak freely, and at length. With the permission of the informants, the interviews were audio-recorded and later transcribed. Security of tapes was maintained.

Both "emic" and "etic" approaches are utilized, by interviewing as well as observing the subjects, at the same time. The "emic" or internal approach is an approach
taken by ethnographers that relies on interviews to learn how their subjects think about communication. In the external or "etic" approach, attention is focused primarily on observable communication phenomena (Frey, Botan, Friedman and Kreps, 1992).

Individuals were encouraged to give descriptions of critical incidents to ground the context. Verbatim quotes were employed to illustrate the respondents' points of reference, and feelings about pertinent issues.

After the interviews were completed, the investigator gathered the data from the dialogues. Data were analyzed inductively. Consistent with Glaser and Strauss (1967), a grounded theory method for analyzing qualitative data was used. Generalizations were grounded or inferred from the data collected rather than being imposed on the data from another source (Frey et al., 1991). This is defined as theory that emerges from data. In the finished work, the four criteria of grounded theory are met: that the results be believable, comprehensive, grounded, and applicable (Frey et al., 1992).
CHAPTER 4

AUTOETHNOGRAPHY

We talk, we communicate. She's my best friend, my worst enemy. I trust her, yet am afraid of her. When she orders me to do something, I must obey. She is extremely difficult and recalcitrant. Sometimes I wish she was not my "friend". But I don't have a choice. She is inside me. I am the personality and she is a non-auditory voice within.

Life with her is complicated. She listens to me and gives good advice but I don't like being ordered around. I don't like being told what to do, when to talk, when to act, when to hurt myself. We are two: we consist of one personality and one voice, but we share a mind... So operated the brain of one schizophrenic.

Many people think schizophrenia is a "split personality". This is not true, in fact. Schizophrenia can be defined as a split between thinking, feeling, emotion, and relationship to the outside world. I am a schizophrenic. I think differently, I communicate differently, I relate to others differently than do non-schizophrenics.

The symptoms started when I was about fifteen. It began with little things—indecision about small matters, troubling thoughts over trivia. After a while, the illness actually came on rather quickly—within a period of less than one year. Fears began to crop up, and time hung heavy. There were hang-ups about time; about whether I was truly deserving of things; of overwhelming guilt; of badly concealed anger at everyone. I
developed fears of traveling from place to place and of being close to and physically touching others. I was afraid to be with people and more afraid to be alone. There were feelings of worthlessness and despair which led to thoughts and later obsessions about hurting myself. I didn’t deserve good in life. Eventually, thoughts of suicide followed me everywhere.

It all began when I was in high school. I was a successful, well-liked young woman. I was editor-in-chief of the high school yearbook, and ran for “Miss Personality” of the school. I graduated with honors, in spite of the onset of the disease. After high school, I settled into a local city college in New York, which I attended from September, 1963-October, 1965. Life was not good to me there. I was depressed and frightened of everything. I particularly remember riding the subway. The noise was terrifying and overwhelmed me. The movement of the train was maddening. I felt I was going crazy. I was afraid of bumping into people. I would panic at the thought of touching anyone or being touched. Busses were just as frightening to me.

I was trying to harm myself in various ways. I would dig my nails into my arm and legs until I drew blood, and then revel in what I had created. I knew about the fact that aspirin enhances the body’s ability to bruise. I would take overdoses of aspirin, and then throw my body repeatedly against a wall to bruise myself. Subsequently, I would be afraid that people would notice the bruises and be angry at me. You see, they wouldn’t understand that I was “no good” and did not deserve to live in peace with myself. I was very afraid that the ground might give way beneath me when I walked, so I would avoid all the cracks on the sidewalk, and would focus on counting number sequences, over and over, trying to make order of the chaos inside. By then, things had pretty much gotten
out of control. I entered counseling in college, but didn’t trust the counselor. I wandered through days and nights, unaware of hours and troubled by minutes.

By October of ’65, things were unbearable. I couldn’t communicate with others. I felt, I knew, they just didn’t understand me, how bad I was. I was fooling all of them. It was all a joke, a horrible joke, and everyone else was on the receiving end. I was in control, but, I was losing control, and “it” was taking over. “It” referred to the commands. The commands were not the auditory hallucinations which so many schizophrenics experience. The commands were inner voices that actually commanded me to do negative things to myself. They effectively put me down, tempered any positive feelings, quelled any resolve to make things better for myself. They were very negative. They were always present and affected my ability to communicate with others as I was constantly putting myself down to myself while I was conversing with other people. I was totally distracted in my ability to communicate with the outside world, and everyone was a threat.

My psychiatrist had started me on Thorazine; I had graduated from Librium and Valium. I was no better on Thorazine: drugged, very frightened, a danger to myself, and appearing very abnormal. My doctor recommended hospitalization. My parents were horrified. They did not know or understand what I was going through. I don’t know what diagnosis, if any, they were given of my condition. As far as I know, it wasn’t until years later that I was actually given a diagnosis of schizophrenia. Anyway, hospitalization it was to be: at a live-in facility, for a period of what would be ten months. I was put on heavy-duty drugs at very high doses. I became a zombie, wandering drugged through the halls, feeling a need to pace for hours, and follow that by
staring vacantly into space for equally long periods. Once the drugs had begun to take
hold, a period of I do not know how long, I began, once again, to be interested in the
world around me, although still quite fearful. The hospital routine—shop, occupational
therapy, group therapy, private counseling, medications, talking to other patients—all
enthused me. I wanted to get better, but not to leave the hospital. I had to try. The
commands quelled. They became backdrop rather than center stage.

I remember the suicide that occurred while I was in the hospital. I remember
even his name. He was quite ill and he confided in me that he was going to commit
suicide, but he made me promise not to tell anyone. I didn't. He did. He ran in front of a
moving train and was killed. It taught me a bitter lesson about the sanctity of life, and
how fleeting life can be.

I was getting better and better in the hospital as time went on. My father was
quite ill, my sister was heavy into drugs, my mother went back to work. None of that
phased me; my life centered on me. I looked forward to seeing family and was interested
in others, but meds, sleeping, and getting through the days were paramount. Sleep was
an issue; the medications drugged me and the staff would not let us sleep during the day.
So it became a question of going to sleep, being awakened, and seeing how fast you
could sneak back to bed: over and over, each day. The exhaustion was overwhelming
and ever-present. Sleep was peace and quiet, of body and mind.

I developed a fear of leaving the hospital. The hospital was safe; outside was
dark, vast, and extremely threatening. We would periodically leave the hospital on
excursions, and it was quite fearful for me. I was elected president of my unit several
times, and led various activities and groups. I was popular among the staff, and my drive
to get better was contagious to some. The feeling among staff was that I had the stuff to
make it. For once, the commands didn't contradict them.

Finally, it was time to leave the hospital. It was October of '66. I was better, but
scared. I had lost everything except my life. Miraculously, I had a few friends left, but
my real life as I knew it before, was gone. I had been hospitalized so long that my ability
to cope, on a daily basis with life, was absent. I was frightened of going out into the
world, although my fears of other matters had been greatly reduced. I went home. I
don't remember much of what happened next, but by 1968 I was teaching part time at a
daycare center, and by 1969, working full time as a receptionist. During this time, I was
doing so well that my doctor had me counsel and reassure other patients of his. He
always had faith in me, and encouraged me. Everyone thought I had it in me to make it.
By 1970, although I had been on medication all this time, all was as bleak as it had been
in '65. The fears, depression, suicidal thoughts, terrible commands, the despair—had
overwhelmed me once again. It had come on gradually, then quickly escalated; my
pattern had repeated itself. I was hospitalized for a short period, released, and
immediately hospitalized again, suffering from acute depression. I voluntarily underwent
shock treatment. The doctors actually told my parents they had exhausted all other
options. Shock treatment was an experience that haunted me for years and still does. I
remember the experience vividly. Sitting in a hall and moving down a line of waiting
patients. When it was my turn, somewhat dazed and drugged, I was strapped down onto
a table, given an injection, and forced to count down from 100. That's what I remember.
The counting. Then you were out. Or almost out, and then the shock. Then, no memory.
My memory, which used to be so clear, has been damaged ever since. Both my short
term and long term memory are impaired. I remember so well waking up after my first shock treatment and trying desperately to remember my name. It starts with a "P", I thought. But, what is it? I puzzled, in a drugged and confused state. I do credit shock treatment with rattling me out of my depression. It didn’t lift, it subsided. After a series of shock treatments, I was discharged and taken to a long term care, live-in, rehabilitation facility. It was a working farm in Massachusetts.

The ethic at the farm was work, rest, care. And work I did—farming, kitchen, and later giving tours of the farm to visiting professionals and prospective guests (as we were known). I grew on the farm. My life force regenerated. I developed a sense of pride in self. I instituted Jewish holiday celebrations and started the Farm Yarn newspaper, and various activities. These were good, growing times for me. While I was on the farm, my psychiatrist in New York started me on Clozapine. I was one of the first in the U.S. to be on this medication, and I remained so for 23 years, until 1993. I used to get the medicine illegally from Europe, as it was unavailable in this country. A courier, who was a priest, would make the trip every six months for his nephew and a small group of us, transporting the very expensive medication, in quantity. I left the farm after a year-and-a-half, relaxed, stronger, and more confident of my strengths and abilities.

I moved back to New York and in 1971, got a job in a retail store, which I enjoyed. Later, I worked for a publisher, full time, again doing well. I was productive, more relaxed, dating, and making friends. The commands were few. I was one person again. I did retain compulsions; one was to shop, and I would obsess about all I had acquired. It was later that I learned I also suffer from obsessive-compulsive disorder. To date, I still obsess about numbers, time, and events.
I met my husband in '76, the same year my Mom died. It is a shame she did not get to see me as I am today. We got married that same year, and I returned to college, obtaining a bachelor's degree seven years later. It was a struggle. We gave birth to a son, miraculously normal though conceived and carried while I was on Clozapine.

In 1981, I did a television interview with Dick Cavett, relating to my illness and Clozapine. It was fascinating to see his reaction to my world. I remained on Clozapine, and matured in my marriage and motherhood. There were no thoughts of hurting myself, although I remained insecure and not a confident individual. Therapy was very helpful. It was in '89 that we moved out west, and I began a masters program at the university there. I am currently writing my thesis, on schizophrenia and communication.

In 1993, my psychiatrist suggested I try Risperdal, a new medication. I agreed, having suffered many side effects from Clozapine, such as drooling, excessive sleeping, bedwetting, weight gain, and, needing weekly blood draws. Risperdal did not work out. It did bring a new sense of freedom and life that I did not have before, but it did not hold me. Depression, anxiety, and fears once again began to take hold of me. My doctor suggested returning to Clozapine but I could not, having felt so alive and undrugged on Risperdal. The only alternative was to join an experimental drug study in order to get Sertindole, a new schizophrenia medication as yet unapproved by the FDA. I entered the hospital and was put on the triple blind study, which means that you are randomly assigned one of three drugs, which may not be the one you hope for. I got one of the alternative drugs and developed hallucinations and delusions. After over twenty years of relative stability, I was down there again. This is an insidious disease. My roommate, a quiet, lovely girl, later stabbed her father to death with an ice pick. The voices
commanded her to do it. Finally, after two months, I was given Sertindole and, in conjunction with another drug, Zoloft, have been on this regime ever since.

I am doing well. I would describe my thought process as tolerably normal. Some schizophrenic thinking remains. I often catch myself singing words from various songs, and when I finally realize I am singing to myself, I am startled to find that the words of the particular song correspond to my feelings about a thought I am having, at that same moment. I remain insecure, with a tendency to be negative. On the other hand, I am fully functional, productive, actively involved in life, and completing my masters. I harbor no bitterness or resentment to this affliction. It is just one more thing to overcome, one day at a time. When times get tough, I say to myself: just get through the next few minutes; calm yourself, and regroup your forces. It seems to work. I often get anxiety attacks and am fearful, but continue on, somehow. Two articles on my treatment success have appeared in city newspapers. I believe I am a good person, wife and mother, and a responsible human being. Am I happy? It is relative, I guess. I am often content, but my main peace comes from my thoughts. There are no commands, and I can spend hours by myself, enjoying myself and my thoughts.

Great doctors and the support of family and friends are the network that helped me through this, and continue to sustain me. I could not have come this far without my special husband and son. I feel the value of medication in treating schizophrenia is unquestionable. God was not there for my illness, but has helped me find the way back from it.

Schizophrenia has changed my life, but I have prevailed. It remains with me, but it under control. I can communicate with others, smile, laugh, pet my dog, go marketing,
or take a walk. These things were not possible, before. No more voices, no more commands. I wish the prejudice and fear the world has of schizophrenia and schizophrenics were not. I wish I could command it to go away. However, the commands are gone. And I hope that the prejudice and fear will soon be gone, as well.

**COMPARISON OF THE RESEARCHER'S AUTOETHNOGRAPHY TO OTHER AUTOETHNOGRAPHIES**

Autoethnography (Frey, Botan, Friedman, and Kreps, 1991) can be defined as the gathering of data from various sources, including self, about some significant experiences that an individual has had. Autoethnographies of schizophrenia have appeared in all media. The researcher has selected just four from completely unique sources, to review and compare to her autoethnography.

“Schizophrenia – Adrift in an Anchorless Reality,” by Janice C. Jordan, appeared in *Schizophrenia Bulletin* (1995), as part of the magazine’s First Person Account series. Her story begins thus: “The schizophrenic experience can be a terrifying journey through a world of madness no one can understand, particularly the person traveling through it. It is a journey through a world that is deranged, empty, and devoid of anchors to reality”.

Jordan, like the researcher, holds a college degree and is working toward a masters. She has suffered with schizophrenia for 25 years. She writes: “I had one particular friend. I called him the “Controller.” He was my secret friend. He took on all of my bad feelings. He was the sum total of my negative feelings and my paranoia. I could see and hear him, but no one else could.” The researchers has lived with “commands” of her own.
Jordan's problems, too, exacerbated and compounded when she started college. Like the researcher, she “withdrew from society and reality.” It was Clozaril that for her, too, turned the tide. She calls it “a true miracle drug.”

Her story is tenderly written, filled with hope. It concludes: “It is up to us, people with schizophrenia, to be patient and to be trusting. We must believe that tomorrow is another day, perhaps one day closer to fully understanding schizophrenia, to knowing its cause, and to finding a cure” Jordan, 1995). She communicates her feelings beautifully and effectively. When she voices the following, “Thank you very much for listening to me. It is my hope that I have been one more voice in the darkness—a darkness with a candle glimmering faintly, yet undying,” she echoes the sentiments and motivation of the researcher for the writing of her thesis.

“Maurizio Baldini’s Story” of recovery from schizophrenia appeared on the Internet-Mental Health, in August, 1995. He has had schizophrenia for 18 years and, like Jordan and the researcher, became quite ill while attending college. His disease came on suddenly, and he describes his psychosis: delusions, depression, and demonic voices. He graphically states: “These grotesque distortions tormented me day and night until I could no longer distinguish between reality and nightmares.”

Baldini was in law school, but was having trouble coping with an episode of schizophrenia. He writes: “An interesting note about the stigma of mental illness and the legal profession at the time. My psychiatrist had to write a letter for me to the Dean of the law school in order for me to postpone my exams. He decided not to write the word “schizophrenia” as my illness but rather said I suffered from “emotional illness.” My doctor said that if the Law Society should one day find out I had schizophrenia, I would
be disqualified from practicing law. However, the strategy almost backfired when the
Dean at first would not postpone my exams because an emotional illness was not serious
enough, he thought. Eventually, I did get my exams deferred and was able to write them
later as I said” (Baldini, 1995). Baldini did complete law school but was recurrently ill
over the years. He was off medication for a number of years and did do well, but
relapsed.

He agrees with the researcher and patients interviewed, “that successful
relationships are a key factor in overcoming serious illnesses, such as schizophrenia.”
He ends his story thus: “In conclusion, my experiences with schizophrenia were initially
very devastating, derailing my career and almost destroying my future. Since those
difficult times, I now use my experiences in a positive way to educate others and
advocate for better services for all consumers of mental health services” (Baldini, 1995).

An Editor’s Update that also appeared on the Internet (2/14/96) stated that Baldini is
married, working fulltime as a legal research assistant for the British-Columbian
government, and is on the Board of Directors of the largest provincial psychiatric facility
in Victoria. His story is inspirational, as is Jordan’s.

Perhaps the most poignant, moving, violent, and unsettling autoethnography the
researcher has seen is “Out of Darkness,” a made-for-TV movie that appeared on HBO.
Diana Ross portrays a paranoid schizophrenic who, interesting to note, has the same first
name as the researcher. Like Jordan and the investigator, when, in the story, all else has
failed, the patient is given Clozaril and makes a slow but remarkable recovery. There are
many similarities in her story to that of the researcher. Her fears of transportation, how
terrified she was, her wanting to sleep all the time on Clozaril, not caring for her appearance, talking in “salad talk” (not making sense).

Nothing worked for her before Clozaril, and there was no hope for her. She was also extremely violent and paranoid; she communicated her feelings physically. The story vividly portrays her recovery. She shares the researcher’s sentiment that she lost years of her life, but has begun to get them back. Diana Ross’ acting is excellent, exhibiting suddenly changing emotions, depression, anger, and the slow development of hope in her life and future. It is extremely well-done, and a moving experience.

The researcher could not relate to a book entitled “Autobiography of a Schizophrenic Girl,” with analytic interpretation, by Marguerite Sechehaye, who was the therapist of a schizophrenic young woman. The book jacket reads, “Reality Lost and Regained.” The analyst compares childhood and schizophrenic thinking, and discusses “the dynamics of regression, of ego destruction... and of ego reconstruction” (Sechehaye, 1951). The narrator of the story, Renee, relives fantasies, delusions, and psychoses which she experienced during her illness, and speaks of her recovery to normal mature adulthood. Mme. Sechehaye treats the subject matter in a technical and professional manner that did not have the warmth, simplicity, and clarity of the other autoethnographies reviewed.
CHAPTER 5

PATIENT INTERVIEWS

PATIENT I

Patient I was interviewed on 6/17/96. The patient was a 26-year old female of small build, with blond, very curly hair who was dressed casually and neatly. She was interviewed at her nicely furnished apartment, where she lived with her mother and her cat.

She appeared to be very honest and sincere, and spoke softly, thoughtfully, and haltingly during the entire interview, the duration of which was 21 minutes. Patient I thought before she answered each question. She possessed a sharp mind and was very bright. She had bachelor’s and master’s degrees and commuted part time to California where she was undertaking a Ph.D. The patient worked 40 hours a week in a bookstore. In addition to schizophrenia, she suffered from a severe eating disorder, for which she was in a support group. She was hospitalized in the past, and had relapsed several times. Patient I was on a new drug study, but she maintained it did not seem to help. She has heard suicidal voices continually, and has lived with the auditory hallucinations since she was five years old. The voices, she felt, were devastating. They told her to kill herself or to take laxatives; they told her she was fat, and also told her to drive her car into on-coming traffic. She would visit her doctor once a month, took her medication regularly, and
stated that a miracle cure or drug that works 100% is what kept her going. Her family was supportive but did not understand, and they felt blame and disgrace, which the patient said were the stigmas of the disease.

Patient 1 defined a “schizophrenic” as “someone who suffers from a mental illness... someone who has trouble coping with the world,” but she added, “Sometimes I think that we’re all kind of crazy.” To her, the connotation of being schizophrenic was being “crazy,” and she has kept her schizophrenia a secret. She felt people would look at her differently if they knew, and that “they might think that I’m not all there.” She explained that she meant that “there would definitely be less respect and definitely less trust”. Co-workers have given patient 1 a lot of support at her workplace. Her support network was important to her.

Patient 1 was very bland during the interview, in both affect and speech. She utilized simple language and gave short, concise answers that directly responded only to the question asked. She did not, at any time, show any display of emotion. Her voice, however, was telling of her emotions. It was often high-pitched and strained as she spoke, as if the words were an effort to articulate. It seemed as if depression was a feature of her situation.

She felt cared about by her medical support team but did remark that of the nurses she’s had, “they have to deal with you on a daily basis... and it’s more of a routine and it’s more of a job for them, instead of being personally invested in your well-being. They see to the daily chores of taking care of a schizophrenic...” She has, however, experienced some nurses who were very supportive. The patient related that her social
worker was very supportive of her. He listened when she needed to talk, and was there for her. She said also that her doctor "has been beyond wonderful."

In answer to the question, "To what extent are you dependent upon your doctor?,” patient I replied, "very dependent on him. My whole sense of self is wrapped up in Dr... He has become the center of my health... My whole sense of identity is wrapped up in Dr... now.” She depended upon him for emotional support and relied on him for decision-making. She affirmed that he was one of the few people who didn't judge her. She did not explain what she meant by that, if she was referring to being judged because she was a schizophrenic or because she had an eating disorder, or for some other reason. Lack of understanding about the disease by people was a problem for her. The patient added that her mother thought there was a stigma associated with schizophrenia, and she felt it, also. Here again, she was not specific.

The voices were the worst thing, this patient verbalized, because they were so destructive. "...Things like that make it difficult to survive...But there’s that little piece of me that won’t give up. So I keep going and dealing with the voices.” Without the medication, she claimed she would be dead. It has been a lifeline. But during the interview, she also maintained that the medication did not help her that much. She suffered side effects but dealt with them effectively.

In answer to the question, "How important is communication to you in your treatment?”, patient I answered that it varied because she didn’t talk about it much with her family. However, communication and honesty of communication were extremely important to her in her relationship with her doctor. She asserted that it was also extremely vital to be 100% honest about her schizophrenia with anyone she chose to tell
about the disease. Her definition of communication was "verbally talking about any problem." She felt honesty was a large component of communication. At the conclusion of the interview, patient 1 exclaimed: "Well, that was painless!"

PATIENT 2

The researcher interviewed patient 2, a 22-year old female, at the researcher’s home on 6/21/96. This young patient had short hair bleached very light blond, and was somewhat heavy-set. She was quite fashionably dressed, wearing makeup and jewelry. She had requested that the interview be held at the researcher’s home. She seemed a little confused, forgetful, and nervous. She joked around, and laughed at herself. She appeared very insecure and tended to agree with the researcher on most of what was said, before, during, and after the interview. She dropped items and spilled a beverage during the interview.

The patient had schizophrenia since age 17. She had her own apartment, which she shared with her new husband. Her marriage to this Russian man was arranged by her father, for monetary gain. She ambiguously explained that her father was looking out for her future, financially; she said she hoped the researcher would not think less of her because of the arrangement. She also had a boyfriend.

Patient 2 participated in a narcotics anonymous (NA) program for a drug use problem, and has been drug-free for some years. The patient did not attend school, but stated she "cleans a couple of houses a couple of days a week." She was on disability and explained that she slept a lot. She seemed to have very few interests and relied on a telephone support network of friends and family. Her father, a physician, and her
mother, were divorced. Her vocabulary was very limited, the subject matter she discussed was extremely basic.

Her level of concentration was minimal. She was unable to be at all abstract, and she seemed immature. She laughed at herself several times during the interview. She never experienced auditory hallucinations; she was hospitalized in the past. The duration of the interview was approximately 14 minutes. Patient 2 hesitated often when answering questions and forgot the question or her answer to it, more than once. She utilized very short answers, and did not stray from the question. She showed a range of emotions, however, and visibly reacted to the quieries. Her voice was more expressive than patient 1 in that she varied her tone and pitch and modulation.

She reported that she suffered a lack of self-worth and remained in bed a lot. The patient felt better when she talked to people and she needed her support system. At the onset of the interview, the researcher asked the patient what came to her mind when she heard the word “schizophrenic.” The patient replied that it meant being “totally out of reality... someone who doesn’t have it all together... a break with reality.”

Patient 2 called herself “crazy”; she utilized the word, however, in a lighthearted manner. When queried, “What does crazy mean to you?”, the patient responded: “But crazy means, you usually think of somebody who just doesn’t have a job, can’t get it together, is in mental institutions, has no idea of what’s going around them, and is just so much self-absorbed.” People responded to her “jokingly” as a schizophrenic and accepted her “behavior that isn’t so normal.” Patient 2 told just some people she was schizophrenic because she felt she might be judged on being schizophrenic. The patient mentioned there were stigmas and stereotypes to the disease.
She said that she “feels pretty loved as far as the medical profession goes,” and that she is cared about by her doctor and nurses. She had negative emotions about a social worker she had, and asserted: “But normal people don’t understand, like my mother, she just, I don’t think she really accepts it.” Patient 2 reported that she was an individual, not just another patient, to her doctor, and that she was very dependent upon him for medication and his opinions. Her doctor was there for her, on the phone in emergencies, giving her a hug at the end of a session. He made her feel comfortable.

The patient described an intense feeling of helplessness and futility: “I feel like I can’t hold down a regular job. I feel that I’m going to have this for the rest of my life. I feel I’m not going to be a success because of this. Well, you know, it is hindering...so it’s like you, like a lot of the time, I feel helpless.” When she experienced feelings of futility, patient 2 called people, usually her parents; or, she slept.

She asserted she was “paranoid” about her medication, musing: “If I take it, it makes me worse than if I don’t take it.” She has taken it anyway, to “stable me out a little bit.” What made her feel more full as a person was helping other people and getting out and doing things for herself. Cleaning the house was helpful. She has tried to occupy herself, but she has been laying in bed a lot lately. The patient suffered severe side effects from medication in the past, and her current complaint was forgetfulness, which she believed might have been caused by medication or by schizophrenia itself.

Communication and honesty of communication were very, very important to this patient. When she talked to people, she felt better. She uttered the following: “You know, because if you have nobody and you’re schizophrenic, I mean, it’s not too good. You need a support system.” The interview wrapped up with her definition of
communication: “Talking with people, sharing your feelings, sharing what’s going on in your life, talking, of course, but keeping a close little niche there, I don’t know.”

PATIENT 3

The researcher’s interview with patient 3 was approximately 17 minutes in duration, and took place on 6/26/96 at the patient’s home. The patient, a 32-year old male, has had schizophrenia since age 18. He was big, tall, heavy-set, and good-looking. He was dressed very plainly and simply. His living conditions were simple and spare. Patient 3 lived with his extended family in a house; his mother and brother were also schizophrenic. All three were interviewed by this researcher for this thesis.

The patient was an unpretentious individual, not of strongly developed intellect. He was very pleasant, friendly, calm, and spoke in a melodious voice. He said he was a little nervous about the interview, but did not appear so. He was in very good spirits and, throughout the interview, rambled on and on. He used the researcher’s name many times during the interview, and also referred to her as “ma’am”. He wanted very much to be helpful and candid, and he mixed up the meaning and usage of words as he spoke.

Patient 3 neither worked nor attended school, and was on disability. He was committed to a hospital in the past, had attempted suicide, was violent, and was placed in restraints. For the past six weeks, he had been on experimental medication, and heralded the praises of his new medication repeatedly during the course of the interview. The answers given to almost every question asked pertained either to his medication or to the importance of communication. The patient appeared uneducated and was clearly impressed by the education and status of the researcher. Patient 3 was very congenial during the interview. His new medication required weekly monitoring and blood work,
which occupied some of his time, he stated. In addition to weekly visits to the lab, he said: “I occupy my time play catch, baseball catch, out in the backyard and we’ll play maybe Yahtzee, or Monopoly, or uh, Stratego to fill to fulfill the time and believe it or not, doing dishes and doing laundry and stuff really fulfills my time.”

At a subsequent follow-up interview, the patient confided that he had heard voices in the past that were extremely troubling; however, on his new medication, he did not hear voices. Patient 3 divulged: “When one doesn’t take his medication, I tend to feel lost or, like in another world. I use another world again because you’re really not in touch with, uh, you know, quote, um, reality, you tend to stray off or, or maybe go against the laws of our natures and that’ll tend to get you in trouble, so it’s really unpredictable and I think, then again, taking your medication is really, really important to people that have schizophrenia.”

This patient perceived schizophrenia as “an inhabited genetic disease that I’ve gotten from a family member.” Schizophrenia is something the patient didn’t discuss openly to a lot of strangers; he tried to avoid telling people about his disease “because it might tend to think, you know, they might think, like, uh, well it’s catchy, when it’s genetic.”

Patient 3, in answer to the question, “To what extent do you feel your doctor, nurses, and social worker care about you?”, responded: “…the doctor that I have, he is very concerning.” He praised his nurse as well. He said he was treated like any other patient and was dependent upon his doctor for medication and for friendship. He thought that the friendship of others was important.
He answered a query about what "crazy" means to him with a convoluted, unclear response, in part, about "crazy is diving after a half-mile long net... on a fishing boat." He concluded that "crazy" was not being on his medication.

He affirmed "it works out pretty good" having both a brother and mother who were also schizophrenic, because they all took medication. Interestingly, he advised the researcher not to interview his brother and mother, patients 5 and 6, because they were "paranoid".

Patient 3 concluded that "the communication between me and my doctor, um, my family and friends and people that you meet around the... communities is really important." His definition of communication was "to talk, or to discuss, or to figure out problems and situations, or just kidding around, like goofing around, so communication is really important." His closing remarks once again concerned the fact that the most important thing with schizophrenia is communication and that medication also played a big role in schizophrenia. The patient’s experimental medicine, Olanzapine, has just been approved by the FDA.

PATIENT 4

The interview with patient 4 was unique. Patient 4 was a 45-year old female who was fully functional and productive, and seemed content with her lifestyle. She was interviewed in the corridor of her doctor’s office on 6/29/96; the interview lasted just 12 minutes. She arrived at the interview stylishly and neatly attired and coordinated; she was an attractive looking woman with dark hair. The patient was married, and had two teen age children. She had a daughter, mother, grandfather, and great aunt who were all schizophrenic.
She and her 14 year old daughter were both on medication. The patient stated that she has had schizo-affective disorder (disorder in which there is a combination of mania or major depression along with symptoms of schizophrenia) for 28 years. She explained that this disorder was characterized by an inability to talk or relate to others. She would stare at the wall. Her husband had to relate her symptoms to her doctor. She said she was currently in complete control of her life. She seemed to enjoy a full life, working full time in juvenile court. Patient 4 liked to read, cook, and crochet, as well as care for her home and family. She spoke of how proud she was of herself and how supportive her doctor had been. However, she experienced a lot of prejudice on the part of the health care community.

Ten years ago, the patient was psychotic, hospitalized, unable to function and barely able to communicate, suffering auditory hallucinations and seeing visions. She was completely non-communicative. She has become aware that she must be on medication for the rest of her life and adapted to this fact, and to the side effects she endured. She mentioned side effects such as weight gain and dry mouth. She spoke highly of the value of medication. She told the researcher she thought of it in terms of a diabetic who needed a chemical the body didn't produce. She was cognizant of the fact that she had a chemical imbalance.

The patient answered all questions in detail, utilizing good vocabulary and command of language. Her voice was well-modulated and expressive and she spoke clearly and effectively. She seemed to very much want to assure the researcher that she was content with her life, and thoroughly understood her situation.
She defined schizophrenia as a difficult disease, biologically based, characterized by hearing voices and having difficulty staying in reality. The patient has suffered “abuse and betrayals” from friends and her children’s teachers who didn’t understand what it meant.

“Crazy”, to patient 4, meant a person with a biological, mental illness who “doesn’t react to stimuli the way other people do.” There were, she affirmed, stereotypes about schizophrenia, such as “that you can control it, that you need to snap out of it, that, uh, it’s some type of a personal weakness.”

This patient felt her doctor was an exception to the health care professionals she had experienced. Her doctor took her concerns seriously, dealt effectively with her medication, and was concerned about “social life, my family life, my career, that I can function the best that I am able to do.” She asserted that she was a person to her doctor and that he saw his patients as individuals. She felt dependent upon her doctor for medication and support.

The patient has absolutely no feelings of helplessness or futility. Communication was very important to patient 4. She stated: “I communicate verbally and with eye contact and gestures and a hug, or a lot of different ways.” For ten years, she has not heard voices or seen visions, since she was stabilized on her medication.

Patient 4 said her job in juvenile court was a very versatile one that required a lot of independent thinking. She was very pleased she was able to handle it so successfully. The patient seemed content with her life and had adapted to her situation.
In a follow-up telephone conversation with patient 4, the researcher called her to thank her for the interview. The patient had no recollection of the interview or the researcher, and needed to be reminded several times before she recalled.

**PATIENT 5**

Patients 5 and 6 were son and mother, both related to patient 3. The interviews of these two patients also took place at their house, a simple dwelling, sparsely furnished, very neat and clean. Patients 5 and 6 lived with an extended family which included patient 3, and they all depended on disability.

Patient 5 appeared dressed very simply, in a green tank top and shorts. He was 31-years old, blond, very big and heavy-set, clean-shaven with short hair. He looked exactly like patient 3. The researcher, in fact, mistook patient 5 for patient 3. He was friendly and pleasant. The interview took place on 7/31/96 and lasted only 11 minutes.

The patient was a very simple individual, apparently uneducated. He was not very verbal. He answered all questions directly, in just a few short, basic sentences. He was very honest and candid, but explained nothing in depth. He smiled frequently, showed expression and reactions. His sentences tended to trail off.

The patient has had schizophrenia since 1984. To this patient, "schizophrenia" meant being "really crazy, a mental illness". His definition of "crazy" was "someone that can't handle day to day life. You know, stuff like that." People treated him like a normal person. He felt normal, and did not think people would know he was schizophrenic unless he told them. The patient told only some people he had schizophrenia. He related the following: "Some people I will tell, some people I won't tell 'cause I don't want them to...um, I feel like it takes away your credibility when you
tell somebody and that's because of the lack of their understanding about the disease. So that's life.”

When asked what he did with his time (the patient neither worked nor attended school), he replied: “Clean house, clean house, do running around, just day to day things, you know. Mow the lawn, take care of the yard. Just stuff around the house to keep me busy.” The patient was also physically disabled, having broken his back in 1984.

In the past, the patient was psychotic, had a nervous breakdown, and heard voices which were “like living a nightmare, 24 hours a day.” He felt stabilized on his current medication and did not complain of any auditory hallucinations.

Patient 5 felt his medical support team cared about him, but that it went no further than a “medical person/patient type relationship.” He thought his doctors cared about their patients, that he was a person to them, and that they were really good doctors. The patient was very dependent upon his doctor for his medication only. Without his medication, he said: “I would be crazy.” He suffered no side effects from his medication. He appeared to state he did not need emotional support from his doctor, just recognition that he was doing fine. The patient harbored no feelings of helplessness.

The researcher interviewed three patients from the same family (patients 3, 5, and 6), two sons and their mother. The researcher asked patient 5 how life was with three schizophrenic members of the same family sharing a household. He responded that they had all come to terms with their illnesses but that, in the beginning, it was a little hectic. They were well-equipped, he claimed, to take care of problems that arose because they had been dealing with it for so long. “But, we all get along great and we’re the closest family you’d ever want to meet, in your life.” Patient 5 affirmed his family did a good
job of supporting each other emotionally. “We’re really supportive of each other. You know, if somebody’s having a low day, when you’re real depressed or something, we all try to cheer each other up and get each other through the day. So… to me, we’re a normal family, you know. This has just been our life, you know.” There were things patients 3, 5, and 6 discussed among themselves, according to patient 5, that they never discussed with doctors, like their paranoid thoughts. He conveyed that they were very much in sync with each other. The illness had brought them closer. “We can’t survive without each other.”

Communication was important to this patient, although he sometimes hesitated to communicate if he has “a couple paranoid episodes and stuff where I go off by myself.” He suffered from panic attacks and hardly went anywhere alone. When asked if honesty of communication was important to him, he replied: “Honesty is the best policy… and being honest is important.”

In concluding this interview, patient 5’s definition of communication was: “being able to speak to people well, in a fair manner, get your point across, have them understand what you’re saying, nothing wrong with it. So I would say that’s about it.”

PATIENT 6

Patient 6, the mother of patients 5 and 3, is a 52-year old female who had schizophrenia since 1980. The 15 minute interview took place at her home, described previously. She had the two adult sons the researcher interviewed, as well as an 11 year-old boy. She was dressed very simply for the interview, her hair long, straight, blond, and somewhat messy. The patient had a ruddy complexion and was very plain. Her
voice had a raspy quality. She spent her time at home with her family and was on disability.

This patient felt her divorce was the cause of her schizophrenia and that, if she could “have a face-to-face with (her) family and ex-husband,” the schizophrenia might “clear up” and go away. She realized she lived in the past and that this was the cause of some of her problems. The patient was devoted to her family and, because she had a youngster, would not try any of the newer experimental medicines her doctor suggested. She asserted she “wants to keep things stable,” and couldn’t afford to “get on some medicine that’s not going to work and I can’t take a chance.”

Patient 6 heard voices, perhaps frequently, and wanted to know if the researcher heard voices, also. When asked what “schizophrenic” meant to her, she replied: “Well, it’s a selfish disease where you think everything centers around you. And you think that people can read your thoughts and you hear voices, and you think they know what you’re thinking and you think things, you think they can take thoughts out of your mind.” When people would hear she was schizophrenic, the patient assumed they thought she was crazy. “Crazy”, to her, was “somebody who can’t cope with society... who’s more or less a raving maniac...”

The patient confided in people that she was schizophrenic “because of the income that I have and in some cases I think I’ve ran into a lot of people that I think need help... (They) could be on medication and they might be helped. I find a lot of people that I think need help.” She told others she had schizophrenia in order to help them, and she suggested to them that they see a doctor. She felt her doctor really cared about her “because he’s always concerned about whether I’m hearing voices or not... I’ve been
telling the doctor I don't hear voices, but I still really do hear voices occasionally."

Patient 6 has been on medication but felt it was not doing anything for her, "but it, I think it must be keeping me from hearing more voices."

The patient "had doctors where I didn't feel that they were any help at all." She sensed that her current doctor "tries to help." She affirmed that she was a person to her doctor, not merely another patient. This patient stated she was dependent upon her doctor for nothing other than her prescription, and she sometimes wondered if she could go off her medication. Medication was important to patient 6 only in that, when she stopped her medication in the past, "the voices just hit me so hard, I-I-I just really got sick, you know. I'd have to take it." The patient did not get any help until 1983. Her son (patient 5) then had her hospitalized and placed on medication; eventually she became stabilized. She claimed she was, however, bedridden, and didn't talk for three years.

Lack of understanding about the disease was not a problem for her. Everyone in her home understood the disease. This patient felt she and her two sons did a good job of supporting each other, "because we can talk to each other, we can understand each other's problems. And because we have the disease ourselves, we know what they're going through. Where if it's somebody who doesn't understand the disease, has never heard voices, or had paranoid thoughts about people getting us, or thinking things like that, uh, you know it just seems that we understand better." They were in sync with each other. Their family "revolves around each other...because we basically all stay home all the time or we go out together." When asked what she did with her time, patient 6
declared: "We just clean house. When we have a little extra money, we go play video poker or bingo."

The patient answered the question, "How important is communication to you in your treatment?" by indicating that it was important, but that everything could be straightened out if she could resolve her divorce. She believed, utilizing the same words as patient 5, "that honesty is the best policy" in communication. Patient 6 hesitated to communicate with others because she would think about the past. She defined communication as: "so that you can, everybody can understand each other. A good understanding of what you're saying and what's going on... And if you have a clear understanding of what's going on, is there something really going on, then you would have the answer to your problem..."

This patient was torn by voices, the past, her divorce, and ambivalent feelings about medication. Patient 6 mused, "You know, sometimes I think I'd like to try it without medication."

**COMPARISON OF PATIENT INTERVIEWS**

Six schizophrenic patients were interviewed and many common themes emerged. All six had schizophrenia for years; all were hospitalized in the past; were on medication, and had tried other medications, previously. Patients were interviewed in different settings at various locations. Age and sex of patients varied. The same or similar questions were asked of all. Follow-up questions (probes) to each reflected previous answers given. The patients were attired in different manners.

Personality, behavior, expression, and attitude were observed and recorded by the researcher. Stark honesty and use of limited vocabulary and phraseology were
pervasive. Patients reflected a fear of being crazy. A bland affect was common in most. All except patient 4 appeared very insecure. Five out of six were reticent to give detailed answers and examples, and were not particularly forthcoming of more than basic explanations; little information was actually conveyed to the researcher.

The researcher found a lack of self-confidence to be common in five patients, as was rambling. A paucity of ideas was reflected in responses given. The content of the responses was directly limited to the questions asked, in all but patient 4. Information was not volunteered. None of the six showed any great emotion when discussing their experiences with schizophrenia, or at any other time during their interviews. No bizarre behavior or inappropriate gestures or mannerisms were observed. Patients 1, 2, and 6 exhibited very little facial activity. None of the patients smoked during the interview. The six patients all related stories of greatly disturbed thinking processes over long periods of time. Patients 3 and 6 made unclear references. Several patients used stock phrases. All patients were cooperative and curious about the researcher.

Except patient 4, all patients exhibited no ambition or enterprise in what they said, yet were talkative.

Schizophrenia ran in the families of all but patients 1 and 2. Patients 2, 3, 5, and 6 were on disability. Patients 2 and 4 were married, patients 4 and 6 had children. All patients came from differing social, economic, and educational backgrounds.

Signs of depression were visible in patients 1 and 6, and possibly in patient 2. They exhibited hopelessness, sadness, gloominess, and feelings of inadequacy. A wide range of moods was seen during the interviews. Repetitiveness was apparent in the speech of most. None of the six seemed to have the ability to utilize complex language.
or form abstract ideas. All but patient 2 stressed concern over auditory hallucinations (voices), either present or in the past.

Patients 1 and 4 worked full time; patient 2 worked part time; patient 1 was also in graduate school. Patients 3, 5, and 6 neither worked nor attended school. All patients expressed the need to care for their homes, and patients 2, 3, 5, and 6 referred directly to cleaning as an important facet of their lives. To patient 2, sleeping excessively was a problem. Patients 3, 5, and 6 (of the same family) spoke of cleaning the house and yard, playing video poker and table games.

Personal thoughts on specific issues were repeated over and over by practically all patients. Perhaps because of knowing about the researcher's thesis, some patients were obsessed with discussing the importance of communication, and also of medication.

Only one patient, patient 4, felt her life is wonderful. All thought communication was important. Definitions of communication were vastly different. A support network was considered very important to each.

Some equated the term "crazy" to mental illness. Patient 6 is the only patient who felt there was no lack of understanding about the disease; perhaps she meant no lack of understanding by patients 3 and 5, who are her family members, and schizophrenics themselves. She felt comfortable with her family; they shared knowledge of the disease and compassion for each other. The other patients felt there was a lack of understanding about the disease by non-schizophrenics. Patients 3, 5, and 6 all expressed support of and for each other. Only patient 6 would tell everyone she was schizophrenic. The others believed that different people had differing reactions to schizophrenia, but that not
everyone accepted it. The general feeling was that there were stigmas and stereotypes to schizophrenia.

Most patients thought schizophrenia was genetic. Patient 3 feared people might think it was “catchy.” Patient 6 said it was “a selfish disease.” Losing contact with reality and being out of control were themes that were conceptualized by each patient, individually.

Interestingly, each patient felt his or her doctor cared about them and saw them as individual. They were each dependent upon their doctor for different needs, that include medication (important for all); support, friendship, decision-making, and feedback (important to some).

The value of medication received a mixed response. Half the patients felt they were not being helped, either partially or completely, by their medication. Patient 2 didn’t know why she remained on her medication. Patient 1 hoped for a cure, patients 1, 3, 4, and 5 felt it was a lifeline, and patient 6 wistfully mused about managing without her medication.

The patient interviews were relatively short in duration, and seemingly not of great depth. The health care provider interviews that followed were richer, fuller, longer, and more detailed in scope of responses. However, many common themes emerged from the patient interviews and the responses given seemed very genuine.
CHAPTER 6

HEALTH CARE PROVIDER INTERVIEWS

From June-August, 1996, eight health care provider interviews were conducted, including interviews with three psychiatrists, a marriage and family therapist, social worker, psychiatric unit manager, nurse, and nurse's aide. The opinions and responses of each subject were unique. Detailed accounts of these interviews follow:

**PSYCHIATRIST 1**

Three psychiatrists were interviewed. The first, a 45-year old male, was interviewed on 6/24/96, for 18 minutes. He was of slim build, very fair, blond, and had fine features. He possessed a calm, serious, and analytical countenance, was dressed in business attire, and was well-groomed. He was professional, warm, very candid, and patient during the interview.

Psychiatrist 1 had practiced since 1979, and attained his MD in 1975 at Washington University. He was on the medical staff of all the major local hospitals, and was medical director, department of psychiatry, at a major hospital and medical center. The doctor maintained a busy, full time private practice, and was on the cutting edge of much research into new treatments for schizophrenia and other diseases.

He defined the word 'schizophrenic' as "an illness that is genetic, that involves a malfunction of the brain in which individuals have psychosis, usually involving both
hallucinations and delusions... One of the connotations is having a chronic, treatable, but not curable illness.” This doctor professed that schizophrenia had been around thousands of years, but was not, until recently, designated as such. He conveyed, “We have much more knowledge of schizophrenia today than we did 100 years ago... The progress we have made in the past 100 years has been phenomenal... It may be that we make far more progress in the next ten years than we’ve made in the past 100 years... But I’d like to see the day when we can prevent anyone from being born with schizophrenia. And, I think they’re coming.”

As a doctor, he stated his role with patients is “as being first a person to evaluate, to diagnose or confirm a diagnosis, to describe to the patient and patient’s family the treatment alternatives and options that are available today, and to implement, with the patient’s consent, a treatment plan to attempt to get a complete remission of all symptoms of the illness.” His role was usually as team leader and, as the person who actually prescribed medication. Each patient was an individual and unique. It was impossible to know what patient would respond best to which medication. “There is an intersection between what I would call the, the psycho-social factors and the biochemical factors and the genetic factors and the environment, and all these things intersect. Each person is unique.”

Psychiatrist 1 believed himself to be “an instrument of God... to help (his patients) as best as I possibly can.” He did not believe his patients viewed him as a god. He respected his patients completely and trusted his patients “yes, but understanding that the nature of the illness may interfere a great deal with a person’s insight and understanding.” This physician was thoughtful before he spoke, during the course of the
interview, and chose his words carefully. He was patient with the researcher’s questions and responded directly and candidly, in detail, to questions asked.

Medication generally improved communication a great deal, “if they’ve been on medication long enough. It restores their ability to communicate to that of an individual without schizophrenia.” The doctor conveyed that “the treatments that we can prescribe and do prescribe frequently make dramatic differences in a person’s life... And the person, who may not have been able to even get out of their house, is able to mildly interact with the public, to go to school, get a job, be a, just a highly productive citizen.”

This physician, to the researcher’s eye, seemed to indicate that medication was the key to schizophrenia treatment. Medication has come a long way since thorazine of the 1960’s. Medication compliance was an issue. “As we develop new medications that are both extremely effective and may be more effective than previous medicine, and have fewer side effects, what we call the ‘compliance issues’ become less and less.”

This health care professional did not suffer from burnout as he recognized his own needs and would take time off, to get out of town. He hoped “to make a big difference in the lives of (his) patients... to give patients, first of all, hopefulness about the future. That they see themselves as being able to be successful, highly productive, highly functioning individuals, able to use the intelligence that they have without the interference of a debilitating illness. And, to the degree that we can, either by the research that I do, and that others do, develop new medications that are the magic bullet for even one new patient who was unresponsive to previous medications, that, to me, is a success and makes everything worthwhile.”
The doctor's "ability to communicate with people with schizophrenia is very, very, very important." When symptomatology is reduced, "the patient's ability to communicate with the doctor and with their family and with their friends improves very dramatically." He described communication as "the ability for a person to tell other people what they're thinking, what they're feeling, what they desire or hope for...to tell another person 'who I am' and 'who I want to be'; that, to me, is communication."

Psychiatrist 1 concluded the interview by encouraging the researcher, in her thesis, to explore the communication area, "that it's important that individuals outside of our field know more about this illness, and both the devastation if it isn't treated and the promise if it is."

**PSYCHIATRIST 2**

A large man with white hair and a broad smile, 73-year old psychiatrist 2 came to the interview wearing a wild patterned sports shirt, no tie, and suspenders. He was very friendly, jolly, had an extremely positive attitude, and spoke in a deep, gruff voice. During the course of the interview, held in his office at a Medicaid mental health center, he related lots of stories and jokes. He used to be a general practitioner, then became a psychiatrist. He practiced for 42 years, then retired. He currently worked in "a psychiatric practice in a medication clinic that's concerned only with the chronically mentally ill." He has treated thousands of schizophrenics; most of his patients were schizophrenic.

This doctor's definition of "schizophrenic" was "an individual that's got an affliction that involves his mind and certainly makes him dysfunctional in our society." He tried to "control some of the symptomatology by first forming a relationship with the
patient. Then, the next step is ordering medication. But I need the relationship and they need it. And especially schizophrenics, since most people don’t relate to schizophrenics.”

During the 24 minute, 7/23/96 interview, he verbalized that there were stigmas and stereotypes to being schizophrenic since “we have a whole society where very few people understand chronic mental illness... I think the only difference between schizophrenics and the so-called normal is that the dream-time is occurring while they’re awake... And if the general public would realize that, they too, especially in their dream-time, are as schizophrenic as can be.”

Each patient was an individual to psychiatrist 2. When you focused on symptoms, then you’d see a similarity in patients, he said. He trusted and respected his patients 100%, and his training and experience stressed the individuality of the human being.

Psychiatrist 2 divided schizophrenics into four categories: “Number 1, let’s say they’re mildly schizophrenic, and they make their adjustments in their community... And, category 2, they’re just a little more severe. Once in a while, they have to see the psychiatrist. We put them on medication, they have a remission, they don’t take medication (for months, or even years), then they (exacerbate) and we see them again.” In category 3, also, were the schizophrenics that this doctor saw. “Usually, because they are non-compliant, they end up in the hospital. And, category 4 are the ones that are so psychotic that it seems that no matter what you do, it doesn’t stabilize them.” He conveyed that medication “can change them, to some extent. It’s the medication that really does it.” He concurred with psychiatrist 1 that first tranquilizers and more recent
psychotropic medications have emptied out the state hospitals all over the country.

"Then, at least they can find some kind of an adjustment in society... But, very few ever,
ever become independent. In fact, I can’t think of one in 45 years."

Medication compliance was a “big problem... because the patient, number one, a
lot of times, feels that there’s nothing wrong with him. And the other is, ‘I don’t feel
sick, so why should I take medication?’ (After) they exacerbate into a psychotic state
and have to go into the hospital again... after about six of those episodes, my god, you
can’t get them off (medication), because they know that the pills help them...”

Medication usually improved the schizophrenic’s ability to communicate, to relate with
people. But this physician stated that, regarding “schizophrenic communication, most of
our schizophrenics tend to be concretistic. They interpret things literally... the ability to
abstract, they’re, um, they’re dysfunctional in that area... This goes back to
communication, why our patients have a lot of trouble in society.”

When asked, “How do you know you get meaning across to patients?”,
psychiatrist 2 replied: “I don’t know that I ever get meaning across to them... I don’t
think that they truly understand or comprehend... And it depends on what state they’re in,
too.”

Like psychiatrist 1, psychiatrist 2 never suffered from burnout. “The only time I
had burnout was when I quit seeing patients. Really!” He voiced an opinion that, as with
any other disease or illness, we had limited knowledge and understanding of
schizophrenia. He affirmed that schizophrenia has been around “forever.” “I’m one that
is convinced that what, that it’s a biochemical disturbance in their central nervous
system, which is the brain, which is inherited, which is genetic, and, we’re gonna have it
around for a long time. And that dysfunction that occurs seems to be involved in these communication tracks, if you don’t mind: what we hear, what we see, what we smell, what we taste, the whole thing gets into it... There’s a disturbance in how it’s interpreted.” He believed the key to treatment was medication. “The idea that one is going to sit down and counsel for psychotherapeutics, therapeutically, in the old classic sense, to treat these patients isn’t going to work.”

Psychiatrist 2 felt that the role of communication in his treatment of schizophrenics “is quite important. (He) stays very aware of their literal interpretation of things.” In closing the interview, this physician defined communication as “my sharing myself with someone else.” He concluded thus: “I would recommend that any young person go into genetic engineering because that’s where it’s (a cure) gonna be, especially for schizophrenia.”

The doctor was a widower with 4 children and 5 grandchildren; he showed the researcher photos of his family, and gave the researcher literature to read, on medication innovations for the treatment of schizophrenia.

PSYCHIATRIST 3

Now retired, psychiatrist 3 was a 65-year old male, who practiced medicine for over 30 years. Short, bald, bearded, and trim in appearance, he drove up to the interview in a red Toyota, with his name on the license plate. The researcher met the doctor at a mental health center where he was doing evaluations at a committal hearing, for five patients. He invited the researcher to the hearing, following the 16 minute, 7/17/96 interview.
Psychiatrist 3 was friendly, relaxed, calm, and pleasant. He spoke in a melodic voice; he spoke in generalities during the entire interview, and did not give many details. His answers were short and conventional.

He practiced "general psychiatry and also a lot of substance abuse work, and I worked at the prisons, and uh, a whole variety of things." All his degrees are from the University of Illinois, and he estimated he has treated about 2000 schizophrenics. He defined a "schizophrenic" as "a person who's suffering, usually from hallucinations and disordered thoughts and usually is having a lot of problems." He claimed that since "all mental illnesses are very much frowned upon, which goes back thousands of years in our history,... the social implications are very great. There are a lot of prejudice against people who have mental problems."

Psychiatrist 3 entered "the field of medicine to help people get better and to stop suffering... to make the world a little better place than what I'd found." In actual treatment, his role was to first understand the person, then see what factors were causing their illness. Then, he would "try to direct them in the proper direction so that they'd get better, using medications and therapy and understanding." He believed the answer to schizophrenia treatment was not medication alone, but also talking to the people, forming a rapport.

This doctor trusted and respected his patients "as much as I trust and respect anybody." The patients were always persons, to him. He had "always seen the field of medicine as one person helping another person." When asked if he felt his patients looked at him as almost a god, the retired physician responded: "Upon occasion." He
claimed doctors had a lot of education, were above average in intelligence, had a good
deal of collective knowledge, and should be looked up to.

Medication usually improved a patient’s ability to communicate. “It stops the
disordered thinking so that they can understand better what’s going on.” But, there were
a lot of side effects with medication, which made compliance a problem. However, like
psychiatrists 1 and 2, psychiatrist 3 saw medications empty out the hospitals of mental
patients. “I’ve seen miraculous changes. Yes, treatment works.” Although patients did
relapse, he’d “rather see ‘em out (of the hospital) with a productive life and enjoying
some things of life, rather than staying in a hospital their whole life.”

The doctor retired because of burnout, due to long hours. After retiring, he did
some volunteer work a couple days a week, did court evaluations, and loved his new
lifestyle.

He felt, “We understand a lot about all of the mental illnesses...And now, we are
starting to understand the chemical basis of it, and what parts of the brain are affected by
it. And yes, we have a huge impact on the way it’s treated and how people can function
better with their lives.” Schizophrenia has been around “as long as there’s been
people...it’s been written up in the Bible.” Psychiatrists 1 and 2 concurred that
schizophrenia has existed for a long time.

Communication was vital to psychiatrist 3’s treatment of schizophrenics “because
if you don’t understand what the other person's communicating and they don’t
understand what you’re communicating, then you do not have any treatment. So
communication is vital in treating any kind of illness, mental, physical, all illnesses. You
have to have communication.” He gave an ambiguous response to a question about how
he knew he got meaning across to patients. The retired doctor defined communication as “a sharing of information put forth, a two-way street; and, one person has information—they offer it to the other person and then, the other person offers it back—that’s communication.”

In closing the interview, psychiatrist 3 offered these thoughts: “I’m very hopeful about the field of medicine... We know a lot more and we get probably better results than most other doctors get treating heart disease and cholesterol problems. And so, and then there’s a lot of illnesses that doctors are treating that they don’t realize that they’re treating emotional problems. And so, I think we ought to have more preventive medicine for all mental illnesses and approach it in a different way. But, nobody wants to pay for that. So, that’ll be further on down the line.”

As stated earlier, psychiatrist 3 invited the researcher to a committal hearing, at which he was one of two psychiatrists who performed evaluations of the five patients there. Present at the hearing were a district attorney, public defender, clerk, two psychiatrists, three nurses, five patients and their families, representatives from the Alliance for the Mentally Ill, as well as guards. The hearing took 1½ hours. Psychiatrist 3 gave reports on his findings of each patient. Each party at the hearing spoke. Four young men and one young woman were all remanded to hospital for different periods of time. One of the patients signed a voluntary committal form.

MARRIAGE AND FAMILY THERAPIST

The interview of a marriage and family therapist took place in his office on 6/11/96, with a shorter follow-up interview on 7/29/96. The interviews lasted 34 minutes and 14 minutes, respectively. On both occasions, the therapist, a 54 year old male, was
dressed casually, no tie, and was very, very relaxed and friendly. He was a compact, pleasantly healthy-looking man with glasses and an engaging smile. He spoke in a pleasing voice that was very expressive. He was helpful, open and honest, and extremely interested in the researcher’s work. He enjoyed telling stories during the interviews, of related interest to topics discussed.

Preliminary questions involved his education. He was trained as a psychologist, but was licensed as a marriage and family therapist. He held a doctoral degree in counseling and educational psychology from the University of Arizona, 1971. He had 20 years of experience as a professor in counselor education. He also did a stint as clinical assistant professor of psychiatry and behavioral science at a medical school. For the past 3 years, he had maintained a full time, private practice.

The biggest theoretical and philosophical influence on the therapist was Alfred Adler, a contemporary of Freud’s. Adler viewed the human being as basically a social being.

The interviewee defined therapy as “the planned and systematic intervention of one human being into the life of another.” He affirmed that “communication is part of that (therapy) but also a larger thing than that. Therapeutic communication can involve both the spoken word,...contextual cues,...tonal and emphasis cues that one hears, as well as written forms of communication...” What defined communication for this therapist was “the interchange of vocalizations...as well as more specific ideas.”

In his outpatient practice, he had not formally treated many schizophrenics, unlike psychiatrists 1, 2, and 3. However, as an undergraduate student at a state hospital, he saw a good many schizophrenics.
All subjects interviewed, patients as well as health care providers, were asked the question, “When you hear the word “schizophrenic,” what comes to your mind?” This individual took “both an historical view as well as a current view, and hears the word on several levels.” He heard “misconceptions and misdefinitions that were given to it historically, (as well as) grotesque misinterpretations (from) a variety of lay people.” He verbalized, “Literally, schizophrenia means ‘split mind,’ but that, of course, isn’t what it means practically and clinically.” When he “hears the word “schizophrenic,” (he) hear(s) the diagnostic criteria that are used to make that clinical diagnosis.”

“The connotations of being schizophrenic, in terms of the understandings or lack of understandings in the larger community..., is being intractably and perpetually mentally ill,” though this “has been shown to not be true because of more recent treatments being quite effective...”

The therapist saw his role with patients as being involved in two things: diagnosis and treatment process. A correct diagnosis was his “most fundamental obligation.” Regarding the treatment process of therapy, he first had to get the patient to the appropriate psychiatrist to see the patient stabilized on medication and then use a “variety of techniques to move beyond mere stabilization from the medicine into the quality of life issues.”

He saw his patients “entirely as individuals, (being) primarily trained to think individually” and of individual welfare. The patients never blended one into another for this therapist, and he trusted his patients very highly. He often said to his patients that he “respects them too much to feel sorry for them.” Patients did not, he maintained, see him as a god. He exclaimed: “I hope not, I couldn’t stand the pressure.”
The ability to communicate was improved dramatically when patients were on medication. With proper medication, the therapist “can concentrate more on day-to-day living issues.”

“With certain diagnostic groups, there is a perceived difficulty in transforming their lives. But, with schizophrenia, the sense of hopelessness is fading now with the effectiveness of the current crop of medications.” He did not see chronic mental illness that was re-current as an “assault on hope.” This doctor did not ever suffer from burnout. “I think a lot of people who say they are burned out are really just fed up.” He found the process of doing therapy “exhilarating, although oftentimes tiring.” He was able to segment his life, and would take regular vacations, when needed. “The notion of hope” was the key element in treatment, in making a difference.

When asked, “What is the role of communication in your treatment of schizophrenics?”, the therapist replied that he was “trained primarily as a communication-based therapist...Fundamental to a correct diagnosis is communication skill and correct interpretation of the communications that are given to you from the patient...Accuracy of listening is probably the most important element in diagnosis...Communication always occurs except in the presence of death...The communication and quality of the communication are what in effect defines the treatment.”

There was a basic difference in philosophy of the marriage and family therapist, compared to the three psychiatrists. He saw medication as a means to stabilize a patient, so that therapy, the treatment process, could then begin.
SOCIAL WORKER

The researcher's next interview was conducted with "a highly qualified, licensed clinical social worker", (to quote the interviewee). This 38-year old male was "considered the Program Coordinator for the chemical dependency and psychiatric unit" of a major local hospital and medical center, and has been a social worker for 17 years. Dressed for the interview in a red polo shirt, gray slacks, and no socks, he was tall, young, bald, and muscular. With a broad smile and excellent sense of humor, he appeared confident, cocky, and self-assured. He was interviewed at his office in the hospital in which he worked. He had a wife and two kids, got his M.S.W. in 1984, and planned to get his Ph.D. The social worker spoke with a southern accent. He seemed to be very involved with the treatment process he utilized. The 33 minute interview took place on 8/2/96.

When asked what his responsibilities were, he replied facetiously: "Save lives and stomp out infection!" He continued, "Primarily, my responsibility here is to organize, coordinate, and implement a therapeutic treatment program for the patient population that we serve here." He had treated thousands of schizophrenics, and defined a "schizophrenic" as "an individual who is suffering from a grave, severe psychiatric illness." Lay people, he said, think of schizophrenics as being "crazy, out of touch with reality, bizarre, and various stereotypes."

This professional saw his role with patients thus: "to establish a working relationship, and that consists of three major variables, which would be honesty, trust, and mutual respect." Within the clinical setting, the first step was to do a psycho-social
assessment of the schizophrenic patient. “This is a clinical estimate that develop and create a holistic picture of that individual... who they are, where they come from, likes, dislikes, strengths, weaknesses, and history that we include medical,... social family background, economics, vocational history, the whole nine yards. We want a complete picture of the individual.”

He saw medication as the major and initial form of therapy, but deeply believed “therapy also has to be adjunctive for accenting with individual and group therapy ongoing.” He affirmed, “We want an individual to always be able to communicate their very basic needs in life, and once that is communicated, then relationships, I know relationship in the therapeutic treatment process can begin occurring.” The social worker seemed to concur with the marriage and family therapist that medication was a tool to stabilize the patient so that the real treatment process could proceed. “That's one of the major purposes of the medication is to bring some order into the central nervous system to allow the person's thought process to be organized, rather than sporadic and broken down without the medication.” Medication compliance “is a significant problem, and that attributes to the recidivism (the tendency to relapse)... It basically comes down to an individual’s choice... One thing I want to ensure that an individual always have a choice... And remember, my motto is: “The individual is not responsible for their illness, but they are responsible for their cure”... It requires a choice to bring about a change.”

For this health care professional, the patients “are individuals first and foremost and always... and every individual has something unique about them in terms of their personality and characteristic traits... There are significant characteristics that are unique for individuals who suffer from schizophrenic illness.” He started out by trusting and
respecting “any patient or individual... 100%... The individual has a responsibility to maintain that level of trust.”

The social worker stressed that “group therapy sessions is a leading component of my job and more especially in the treatment process itself. We just don’t treat with medication alone. Treatment consist of medication, group and individual psychotherapy, as well as, we have another one; I just call it adjunctive therapy, that would consist of recreational activities, arts and crafts... But yes, group therapy is a major component.” His role is as group facilitator. He “utilize(d) a group therapeutic intervention called “Rational Emotive Behavior Therapy”, by Albert Ellis. It is an off-stand of a cognitive type of therapy... So the ultimate goal of the group therapy and using this therapeutic intervention would be to empower the individual, empower them to put them back in the driver’s seat of being in control of the only thing that they’re in control of, and that would be their own thoughts, their own feelings and emotions, and their behavior.” He proudly affirmed that his “groups are very successful, (although) I have no control over the recidivism in terms of patient being in and out of hospital; that’s a part of the illness.” He looked at recidivism in terms of an “opportunity to provide re-enforcement... A lot of time, all an individual needs is prompting, inspiration, and motivation.” This professional had no doubt he had the ability to transform the lives of the mentally ill, even with the inherent recidivism of the disease. “My ability is unlimited. I am the king of it.” He was certain he made a difference in their lives.

He also provided “a support group that’s free to patients who’ve gone on outpatient status, called “Rational Recovery... It’s the right arm extension of the therapeutic intervention I use, “Rational Emotive Behavior Therapy.” He repeated: “And remember,
my motto is, 'The individual is not responsible for their illness, but they are responsible for their cure.' In his "therapeutic intervention, beliefs and thoughts are a major component of that individual, and everybody has varied beliefs and thoughts. What brings some uniformity to it is when we define what is rational vs. what is irrational."

He never suffered from burnout. He had both hobbies and activities, was involved with church and youth programs, was a scuba diver, and was in the military reserves.

This social worker defined communication as "the verbal exchange of the English language to communicate a message." It had first to be processed emotionally, psychologically, and clarification had to be gotten. It needed to be received, processed and exchanged. Communication was very important in his treatment of schizophrenics. To this health care professional, an answer of 'I don't know' from a patient was unacceptable. "Something happens in the process of communication when you get that type of response." He utilized the technique of requesting feedback of patients to enable "the individual themselves (to) use their own self-expression, their own self-creativity; therefore, it has meaning for them..." Regarding communication, he explained: "The nonverbal (communication) is always significant to always observe,... when it comes to safety, acknowledging, and understanding...Behavior communication has to be established before any verbal communication comes into play...Nonverbal first, then verbal. Once you establish nonverbal, and trust come into play, then it's just like a rainbow or bridge going across a moat. Nonverbal, trust in the middle of the bridge, and then verbal. And then, if you're on that side of the bridge, you've got to come back across, so there's verbal, trust, and nonverbal."
The interview concluded with the social worker saying, “that the treatment of schizophrenia here in the nineties (is) far better and greater than comparison to the days of old... And I do trust that we’ll find a cure. As the literature states now, there’s not a cure, but there is effective treatment for the illness.”

PSYCHIATRIC HOSPITAL UNIT MANAGER

The psychiatric hospital unit manager whom the researcher interviewed on 7/8/96 had a unique position. Her responsibilities were “to maintain a functioning, safe environment of care for the patient that includes physical aspects, the emotional, the mental aspects of management, infection control, quality of care—so it makes the whole composite of an environment of care.” Her position was markedly different from that of the psychiatrist, marriage and family therapist, and social worker. She had responsibility for the total picture of care of the patient. She saw her role thus: “to be objective, concerned about the patient care, the quality of care. Trying to get families involved. Trying to assist the social workers find appropriate housing and follow-up... Providing unconditional regard while they’re in treatment, trying to get them into some form of aftercare where there are other people to bridge the transition.”

This 59-year old psychiatric unit manager (of the same hospital with which the social worker is associated) was interviewed on her hospital unit (ward). She had a pleasant, peaceful face, a quiet, warm disposition, was soft- and well-spoken, and took charge in an unassuming way. She was very candid and articulate during the 26 minute interview, and was dressed casually in slacks. Her smile made the researcher immediately feel at ease. She worked in this capacity at this hospital and medical center.
for 4 ½ years. This individual had the following educational background: an A.A. in
nursing, a B.S. in social work, and lots of additional continuing education.

Her definition of “schizophrenic” was “a unique individual who’s probably
having some problems due to internal or invisible stimuli... Their classic complaint (is)
disturbance by the voices that disrupt their daily routine and their ability to relax,
increases their fear; there might be some bizarre acting out that makes them more at risk
for harming themselves or others.” Most of the admits she saw were either
schizophrenics or major depressive disorders. Regarding the patient, as an entity, she
believed: “You can’t separate the body and the brain. One or the other is undergoing
some dysfunction; then it affects all: the feelings, the emotions, the physical aspects of
work, for a degree of wellness with the whole person, not just the parts.”

“Medication compliance is necessary to keep them at a level of
individuality... Massive amounts of them decomp (go back to earlier behavior that
presented them to your unit),” by not remaining on their prescribed medication regime.

“The schizophrenics would have the highest rate of recidivism, that means frequent
admissions, because medication compliance is essential, and there are not always people
available to teach and re-enforce medication times and those kinds of things... And you
don’t remove the schizophrenia like you do an appendix, and people have a healing
period and move forward, and that particular ailment does not occur again. That is the
most difficult for us to each and express, that medication compliance is essential.
Otherwise, the symptoms will recur.”

The unit manager genuinely enjoyed interacting with patients. “People present
with special needs... or you listen to some complaints... that you set up within the day that
you're going to have maybe the 3-5 minute little buzz session with each one of them.”
The patients “all have their own uniqueness” for her. “The one commonality that they
have is the disturbance of the voices.” She did not feel she suffered from burnout though
there were some things she would like to have changed (more time to interact with
patients, a feeling of being “powerless to change the matrix of how things are
structured”). Her philosophy was simply: “You give all that you can and spend time
with them and hope that you make a difference with what you provide.” The burden of
the families was tremendous in attempting to care for a schizophrenic family member
over many years. Family burnout was commonplace.

Communication with the schizophrenic was multi-dimensional and not abrupt,
and therefore important. “You’ve got to be very cautious about what you say, because
the receiver may interpret it the wrong way because of their lack of reality orientation, or
say someone is delusional, that they’re confused. So you want to be very basic and soft,
but directing. I don’t think the schizophrenic needs harshness, unless they are at risk for
harming self or others... and, it’s something you got to care about people to do, because
it’s exhausting, it’s repetitive, but it’s necessary and it is productive. It does work. It
does help.”
The nonverbal communication was important to her “because then you wonder what the
next step is going to be. And people don’t tell you what they’re feeling and they can’t
really express what they’re feeling. I think it puts them more at risk. They can’t tell you
why they hurt, but they’re very angry, uptight, or depressed. So, if I’m going to
communicate to them, the first thing I would ask is, probably, ‘tell me how you feel’.
Able to communicate, to me, means that you’ve gotta be able to listen first to what
someone is saying. It may be garbled, and you've gotta look: the body language—is the fist all clenched, are they real flaming red in the face, is their neck engorged and muscles and veins there. Are they soft or teary, or frightened, or really on the verge of acting out with some anger due to their responses to their external, internal, or environmental-type stimuli that they get.”

The psychiatric unit manager closed the interview by stressing that each schizophrenic patient was unique and different. “You don’t have all this knowledge about what could be contributing to this person’s illness, so you want to listen, not be judgmental, set verbal limits of the patient’s safety, encourage them to get involved in therapy as they are able, and work with what you have…and keep going. ‘Cause that’s what it’s all about: people taking care of people.”

NURSE

A licensed practical nurse was interviewed on 7/9/96, for approximately 19 minutes. The nurse was a 58-year old female who had been in nursing for 25 years, off and on. She had been at this hospital for six years; she was interviewed at the nurses’ station. The nurse was dressed all in red, with her hair up. She had a sweet smile and excellent sense of humor. She was dedicated, direct, very honest and sincere, and tolerated no nonsense. She was serious about her work, and was easily able to visualize a total patient picture of those she treated.

Her major responsibility was: “I do meds. I do all medications on day shift.” She dispensed medications to the patients, monitored the effects of the various mediations on the patients, and charted all the information for the doctors and other nurses. She strongly felt that a lot of patients were not on the right medication. She also
believed you first had to observe a new patient, but “I believe that before I can even talk to a patient, you must medically calm the patient. Once the patient has had a couple of doses of medication and the patient will feel calmer, then you can sit down and talk with the patients and find out why the patient is the way he is, or she is.” Trust had to be mutually felt and exchanged. Depending upon what dose of medication a patient was on and what level was in their blood will affect their ability to communicate. Medication compliance was a problem, in most cases, because of the side effects of many medications. Also, a major issue was the fact that many patients needed much supervision in taking their meds. “Without that supervision, you’re going to have the ‘swinging door effect’ (of repeated hospitalizations).”

She voiced the following: “There’s a lot of people out there who’s taking [sic] medication for different reasons… that patient just has a chemical imbalance. The same as we have a chemical imbalance for diabetes and blood pressure. You know, no one stereotyped them because you take insulin. So, I think the world and people themselves have to understand what the meaning is as far as ‘mentally ill’. It’s a chemical imbalance.”

She affirmed that “mentally ill patients need someone they can trust… trust and understand them. A lot of people do not understand mentally ill patients. They sort of just sweep ‘em up under the carpet.” She noted that “95% of our illness is mental. Because you can make yourself ill by thinking it. And I think we have to also deal with the physical problems and also the mental in order to get that person well.”

The nurse defined “schizophrenics” as very, very smart people, with very, very high IQs, who were up and down (“some of them seem to bounce”) until their medication
is adjusted. She asserted that a lot of them were not able to cope with their illness. "The patient has to want to get better... A lot of 'em are playing the system and using their illness as an excuse... Each one of 'em are individual... Their personalities and what they understand about the disease. They deal with their illness different. Some of 'em want to get better and some of 'em use it as an excuse. They want someone to take care of them."

The concept of "self" was important for this health care provider. "because you can't deal with anyone else until you start dealing with self... become selfish with self. You need to be honest. You need to talk about what is bothering you." She did not suffer from burnout because she, too, dealt with self, and relaxed while exercising at the gym after work.

She saw her role with patients as a nurse who also did a lot of counseling. "In order to be in any type of mental health situation, you have to be able to communicate with the patient... on their level. You have to explain what the medication is doing, and why they are feeling this way... And then, once you explain this to the patient (the mechanics of their medication), the patient understands what to look for once they leave you."

"Communication is important in all cases in medicine. (It's important to) talk to a person and find out what that person is thinking, how that person is feeling, what the effects of the medication is doing to that person... Not even talking (just) about the medication, but just to find out what other problems that patient is having." She strongly voiced that "you have to have the whole family involved in the treatment as a treatment team... The support network is very, very important." Here, the nurse concurred with
many of the patients who were interviewed. "Because, without that, the patient will not
get better." For this nurse, the four important factors in the health of her patients were:
"their (the family's) support, the communication, along with the medication and the
counseling."

She frequently utilized nonverbal communication: "I use a lot of eye contact with
patients. I use a lot of direction, a lot of re-direction." The nurses were taught to observe
patients. Her definition of communication was "eye contact. If you cannot look me in
the eye, then you're not communicating, and also, you're not telling me the truth. So, eye
contact, touching, hugging, holding, crying—all this is communication."

In concluding the interview, the nurse commented how proud she was of the researcher's
efforts.

**NURSE'S AIDE**

On 7/22/96, the researcher interviewed a psychiatric nurse's aide, who is a Certified
Nursing Assistant (CNA), also known as a mental health tech. This quiet, soft-spoken
53-year old female was hesitant, not extremely verbal, and simple in her use of language.
She was a high school graduate with very little formal training; all her experience was on
the job. She had worked as a psychiatric aide for five years. The researcher interviewed
her at the hospital where she worked, day shift. This is the same hospital and medical
center at which the social worker, psychiatric unit manager, and nurse are employed.
Although not intellectual, she seemed to have great compassion for patients. She was
dressed completely in black, casually in slacks and a shirt. She presented a very neat
appearance.
The mental health tech voiced the fact that she knew nothing of schizophrenia or schizophrenics when she started her job. She defined a “schizophrenic” as “someone that, whose behavior is a little different... and they have a hard time.” Many of the patients on her unit were schizophrenic, several of whom were on experimental drug studies. She said that, with a schizophrenic, “it depends on their medication.” She stated, “I give them (schizophrenics) respect because of the fact is that once they take they medication and they become more aware of their surroundings or the things that they’re doing, they become a different person.”

She did not trust her patients when they first came into the hospital. “You have to see what that person’s like, kind of evaluate that person to see if that person can be trusted. And as time goes on and if they get their medication, they do become trustworthy because they’re more like themselves. So, it do take some time to perform or trust because you don’t know the thinking or the process that they’re going through.”

Her responsibilities “are to monitor patients q 15 minutes (every 15 minutes), to see what attitude they’re having, if they’re frustrated. I do nurses notes. We chart on the patient as far as their, um, if their affects is flat or they’re brighter today. The moods—if they’re sleeping more, or alert.”

The researcher observed the aide at work on her unit, before and after the interview. She was markedly different on the job: confident, capable, authoritative, with a strong voice, knowing just how to handle each situation. During the 26 minute interview, however, the researcher became aware that her knowledge of the field was limited to “gut” responses to situations that presented themselves to her, with patients.
She affirmed, “Each patient has their own individuality. Each person have their own personality, and I treat each one according to their personality and the behavior of that person, cause each person is different. Sometimes they start to have someone else’s personality. And it doesn’t last because they become themselves again, but it do happen.”

She was responsible for patients eight to nine hours a day. She tried to show affection toward patients to make them feel more at ease. “Whatever it takes to make a person feel more comfortable in my surroundings...to feel comfortable and feel like you’re being cared for.” The aide considered herself a teacher to the patients “because I try to carry myself in a way that they can see that life can be this way or that way.”

The CNA suffered from burnout because “you see the same repeaters are doing the same things, so I will question myself to say if I’m doing anything to change this person’s behavior. Because, I don’t know, I feel that maybe I’m not doing, or the program’s not doing their job...” She dealt with burnout by taking days off, or long weekends, and anticipated vacations. “If a person continues to come back and repeat the same behavior, that person is not really working on the problem that he say, or she say, that they are having. Um, because, if you want to change, you try to get something from the program so that you don’t come back.” She claimed that many patients were repeatedly hospitalized because of medication compliance issues. Medication “slows them down. It slows their process, their thinking process.” But she voiced that it was a positive thing “because once you do get on the right type of medication, it does change your life.” The aide had no responsibility for medications during her shift.
Dependent relationships of patient to aide were not a problem for her. "If someone shows that person some kindness or gentleness, that they do become a little attached to you... I don’t take it as being clinging, I, I, I see it as a safety net for that person. But, as time go on,... they are not, say, ‘clinging’ to you as much."

She saw her role thus: "My role is to tell them to get up, to think positively in the morning, get dressed, um, put your make-up on, think of something positive for today as a goal..."

Communication was very important in her care of schizophrenics "because that person is not aware of what they’re saying or doing, sometimes. So, it takes a lot of patience, understanding, and really caring about that person. And, by understanding it, you do become, um, more compassionate with that person.” She knew she got meaning across to patients by looking at the person, “by a look, or just a nod, or just the reaction of that person, or the behavior of that person... The more you’re around that person, you could just about kind of tell what that person’s thinking. You know, sometimes you don’t have to say it in words. People do communicate without words.”

The mental health tech “accepts body language.” She claimed: “sometimes that speaks louder than words. Body language has a lot to do with how you are feeling, how you’re doing things. So you learn the different body language, or the signs or hand gestures, or the way you walk, and you don’t have to say a word sometimes to understand... so you will give that person space ‘til they are ready to communicate with you verbally.” Communication, to this psychiatric nurse’s aide, did not need to be verbally spoken.
She concluded the interview by stating: "It (communication) can be a gesture, or a body language, or just a nod. And you can go from there. And wait until that person is ready to have a conversation with you..."

The CNA had a great deal of responsibility for the patients' welfare, during her shift. Formal education and training for this position were minimal. The researcher observed that judgment, concern, and patience were crucial.
COMPARISON OF HEALTH CARE PROVIDER INTERVIEWS

In order to delineate a comparison of the health care provider interviews, the researcher considered three sets of elements: education and training, position and job responsibilities, and personality and philosophy. These parameters were markedly distinct for the individual health care providers.

Psychiatrists completed the highest education and training, followed by the marriage and family therapist, shadowed by the social worker, and then psychiatric unit manager, then nurse, then aide. Utilizing the “Dictionary of Occupational Titles,” a U.S. Department of Labor publication (1991), the researcher ascertained the nature of the position and responsibilities of each provider.

PSYCHIATRISTS

The psychiatrist “diagnoses and treats patients...organizes data concerning family and medical history...examines patients...orders diagnostic tests and evaluates data...determines nature and extent of mental disorder...formulates a treatment program; and treats or directs treatment of patient, utilizing variety of psychotherapeutic methods and medications,” (“Dictionary of Occupational Titles,” 1991). The three psychiatrists interviewed were all male, each was attired uniquely, and ranged in age from 45 to 73. Two are practicing, one is retired, one was retired. All three were sharp, professional in demeanor, confident as they spoke, and thoughtful of what they said. Two were serious in affect, one was jocular.

The three defined schizophrenia as a malfunction of the brain that is treatable but presently not curable. They voiced the opinion that we had much more knowledge of schizophrenia now than we did in the past and that the disease has been around thousands...
of years. The doctors had each treated thousands of schizophrenic patients. They
stressed that they saw their patients as individual and unique. All respected their patients
and trusted patients, but psychiatrist 1 said that his trust was tempered with the
knowledge that the nature of the illness might interfere with a person’s insight and
understanding.

The three thought that a doctor’s ability to communicate with people with
schizophrenia was very important. Definitions of communication varied, but contained
similar elements; for example, that communication is the sharing of information, the
sharing of yourself with someone else, and the ability to tell others what you’re thinking
and feeling. The psychiatrists seemed to be in the field of schizophrenia treatment for
altruistic reasons. Psychiatrist 3 entered “the field of medicine to help people get better
and to stop suffering... to make the world a little better place than what I’d found.”
Psychiatrist 1 affirmed that if he could develop a new medicine for even one
unresponsive patient, “that, to me, is a success, and makes everything worthwhile.”
Psychiatrist 2 said, “I need the relationship (with the patients), and they need it.”

The psychiatrists each saw schizophrenia on two levels, treated and untreated.
All spoke of hallucinations and delusions as integral aspects of schizophrenia.
Psychiatrists 2 and 3 discussed the stigmas and stereotyping of mental illness.

The physicians gave very different definitions of their role with patients.
Psychiatrist 1 saw his role as team leader, and three times during the interview stated that
he saw himself as “an instrument of God, to help my patients as best as I possibly can.”
Psychiatrist 1 also saw his role thus: to evaluate or diagnose, discuss with patients the
alternatives and, with patients’ consent, to implement a treatment plan.” Psychiatrist 2’s
role was to form a relationship with a patient, then order medication. Psychiatrist 2 stated that he didn’t know that he ever got meaning across to schizophrenic patients. “I don’t think they truly understand or comprehend.” Psychiatrist 3’s role was “to understand the person, see what factors were causing their illness, then direct them, utilizing medications, therapy, and understanding. Psychiatrist 3 thought doctors should be looked up to, that they often had superior intelligence.

Two psychiatrists were very specific in their answers, and gave examples. Psychiatrist 3 was general and vague, throughout. Only psychiatrist 3 suffered from burnout.

Regarding treatment with medication, the three concurred on three issues: that medications had emptied out psychiatric hospitals, that medications usually improved a patient’s ability to communicate, and that medication compliance was a major problem. All thought medication made dramatic differences in the lives of their patients. Psychiatrists 1 and 2 seemed to indicate that medication was a key element in treatment. Psychiatrist 3 felt treatment equally involved medication, therapy, and understanding. Psychiatrist 1 thought appropriate medication restored a schizophrenic patient’s ability to communicate to that of an individual without schizophrenia. He also said that compliance issues would become less and less as more effective medications with fewer side effects were developed. Psychiatrist 2 affirmed that once a patient has had about six psychotic episodes, you can’t get them off medication, “because they know the pills help them.” Each believed medication had come a long way since the 1960’s.

Psychiatrist 2 was very unique. He alone could not think of one schizophrenic patient, in all his 45 years of practice, who ever became independent. He also thought we
would have schizophrenia around for a long time. He felt we had limited knowledge and understanding of the disease. However, psychiatrist 1 said we had learned a great deal in the past 100 years, and looked forward to better treatments and ultimately, to a cure. Psychiatrist 3 stated, "we know a lot more and probably get better results than most other doctors get treating heart disease and cholesterol problems."

Psychiatrist 2 summed up his interview thus: "We have a whole society where very few people understand chronic mental illness...the only difference between schizophrenics and the so-called normal is that the dream-time is occurring while they're awake. And if the general public would realize that, they too, especially in their dream-time, are as schizophrenic as can be.

MARRIAGE AND FAMILY THERAPIST

According to the "Dictionary of Occupational Titles," a marriage and family therapist "provides individual, marital, and family counseling services...to assist clients to identify personal and interactive problems, and to achieve effective...development and adjustment." The therapist collects information about clients, analyzes the information, checks advisability of referral to a specialist or institution...counsels clients utilizing psychotherapy and hypnosis, and evaluates results of counseling methods.

Training and education for this male marriage and family therapist were different than for the psychiatrists, but still extensive. The interviewee was more friendly and candid than the three psychiatrists, and his philosophy differed greatly from theirs. He saw medication as only a major initial means to stabilize a patient so that therapy, the treatment process, could commence. He saw the great importance, in therapy, of "quality of life issues," and discussed theory a lot. He viewed his role with patients as being
involved in both diagnosis and treatment process. He felt that communication and quality of communication were what defined the treatment.

Unlike the three psychiatrists, he did not treat many schizophrenics in his practice, and he defined communication in a different way than they did. He spoke more about communication in his practice, and concurred with the other doctors that the ability to communicate was improved dramatically with medication. His definition of schizophrenia also differed greatly from that of the psychiatrists.

Like psychiatrist 2, he enjoyed telling stories during the interview. Like all three psychiatrists, he saw his patients entirely as individuals; he trusted and respected his patients highly. Like psychiatrists 1 and 2, he did not suffer from burnout. He spoke of taking patient concerns seriously, and was very involved with his work. The three parameters: education and training, position and responsibilities, personality and philosophy, all appeared different for this marriage and family therapist, compared to the psychiatrists.

**LICENSED CLINICAL SOCIAL WORKER**

Providing psychiatric social work assistance to mentally or emotionally disturbed patients and to their families, and collaborating with psychiatric and allied team in diagnosis and treatment plan, the psychiatric social worker investigates case situations and presents information to psychiatrist and clinical psychologist and other members of the health team (“Dictionary of Occupational Titles,” 1991). Additionally, the social worker whom the researcher interviewed was involved in the group therapy process as an integral part of his job. Obviously, the job scope contrasted greatly with the other interviewees. The licensed clinical social worker’s education was less extensive,
requiring an M.S.W. His personality was over-confident and cocky, although he was thoughtful and self-assured about his responses. His appearance differed from the others, too. Like psychiatrist 2 and the therapist, he was very friendly. He spoke on a different level than the psychiatrists, but was just as dedicated as the other professionals. He did, however, stress his other interests in life.

The social worker, in contrast to the others, worked primarily within the hospital setting, and was very involved, as was the therapist, with the treatment process. He agreed with the therapist that medication was only a tool so treatment therapy could begin. He spoke of individual will and choice. He asserted, “the individual is not responsible for their illness, but they are responsible for their cure...It requires a choice to bring about a change.” As did the marriage and family therapist, he discussed his philosophy a lot during the interview. Too, the social worker saw treatment as consisting of medication, psychotherapy, and adjunctive therapy.

This individual has treated thousands of schizophrenics, but gave only a non-specific definition of schizophrenia. He saw his role with patients in a very different way than the others. He concurred that patients are individuals and unique, and he trusted his patients 100% initially; but, “the individual has a responsibility to maintain that level of trust.”

Group therapy was the leading component of his job, and of the treatment process itself, as the social worker viewed it. His role was as group facilitator. He never suffered from burnout.

He agreed that medication improved the ability to communicate. He argued at length that medication compliance was a significant problem, as was recidivism. Unlike
the others, he stressed different forms of communication, and emphasized the nonverbal. He thought he had an infinite ability to transform the lives of the mentally ill, and voluntarily offered a free support group to outpatients.

The social worker noted there were stereotypes to being schizophrenic. He concurred with all previously interviewed, that treatment of schizophrenia was far better in the 90's. Like psychiatrist 1, he trusted we will find a cure, but said there was effective treatment now. His personality and philosophy were markedly different from that of the three psychiatrists, and similar in only some aspects to that of the therapist.

**PSYCHIATRIC HOSPITAL UNIT MANAGER**

Of the subjects interviewed, the psychiatric unit manager was the most relaxed, peaceful, unassuming, and yet self-assured. Like most of the others, she was candid and warm. She was very articulate and, more than anyone, stressed the total well-being of the patient. Her responsibilities differed from the other interviewees in that they involved total patient care. She worked solely within the hospital setting, like the social worker, although he also maintained a private practice. Her position appeared similar to that of a nurse supervisor. According to the "Dictionary of Occupational Titles," a nurse supervisor directs, plans, and organizes activities in the nursing services to ensure patient needs are met in accordance with instructions of physicians and hospital administrative procedures. The nurse supervisor coordinates on nursing problems and interpretation of hospital policies to ensure all patient needs are met.

The manager held a nursing degree and a B.S. in social work, where the social worker had a masters degree. However, her practical experience and training were somewhat extensive.
The psych manager's definition of schizophrenia included hallucinations, but unlike any of the others, encompassed a picture of the total patient. She saw her role differently than the other subjects. She treated mostly schizophrenics and major depressives, and has treated many, many schizophrenics over the years. She focused on wellness of the whole person. Like the social worker, she stated that recidivism was a major problem, and concurred with all interviewed that medication compliance was the cause of this problem. She strongly believed that medication and medication compliance were essential.

Like the others, the patients were all unique for her. Also, she maintained several times during the course of the interview that she genuinely enjoyed interacting with patients; she seemed very dedicated. More than anyone, she stressed the issue of the "disturbance of the voices," in schizophrenic patients.

The manager never suffered from burnout, but empathized that family burnout was commonplace. She found communication with the schizophrenic very sensitive, and her definition of communication involved more of the body and the mind and how they work. Like the social worker, nonverbal communication was very important for her.

In stressing the uniqueness and difference in each schizophrenic patient, she voiced a much more simple philosophy than the researcher heard previously: "You give all you can... and hope that you make a difference... That's what it's all about—people taking care of people." The psychiatric unit manager's personality, philosophy, job scope, and training were far removed from all the doctors interviewed, as well as from that of the social worker.
LICENSED PRACTICAL NURSE

The nurse whom the researcher interviewed passed a state board examination and was licensed. According to the "Dictionary of Occupational Titles," (1991), she provided prescribed medical treatment and personal care services to patients on the psychiatric unit of a hospital, and was primarily involved with dispensing and monitoring of medications, as well as charting on the patients. Her formal education was much less extensive than those previously interviewed, but she had a lot of on-the-job experience in nursing. Her responsibilities concentrated on one facet of treatment (medications), although she was involved with general patient care, too. Like the unit manager, she was very dedicated. More than the others, she was extremely serious about her function and the nature of her work. She was outspoken, like the social worker, and was a no-nonsense type of individual.

Her definition of schizophrenia was a non-medical one. She believed "95% of our illness is mental," and one must deal with the physical and the mental to get the person well. The unit manager voiced the same sentiment. The nurse stated that mental illness was just a chemical imbalance, and was appalled at the stereotyping.

This nurse thought patients needed someone they could trust, who would understand them. She, like the therapist, social worker, and manager, discussed her philosophy: "Trust had to be mutually felt and exchanged." She also stressed the importance of the concepts of "self" and honesty, and saw her role with patients as a nurse who also did counseling.

Medication was necessary for a schizophrenic to communicate. She felt a lot of patients were on the wrong medication. Medication compliance was a problem because
of inherent side effects and the fact that medication supervision was often necessary, also stated by the unit manager. The nurse was the only health care provider to voice the following: “Before I can ever talk to a patient, you must medically calm the patient.”

She noted that a lot of schizophrenics use their illness as an excuse and play the system, but she never suffered from burnout.

The nurse fervently believed that communication was so vital in medicine, and that effective treatment consisted of family support, communication, medication, and counseling. She stressed the value of the support network in treatment.

She stated that nurses were taught to observe patients and, like the social worker and unit manager, utilized much nonverbal communication. Her definition of communication directly involved the nonverbal elements.

Like the psychiatric manager also, the nurse emphasized the total picture of the patient. She said, it’s important to “talk to a person to find out what that person is thinking, how that person is feeling, what the effects of the medication is doing to that person...what other problems that patient is having.” These facets were not stressed by any of the psychiatrists. The mutual exchange of trust she spoke of was also voiced by the social worker. The nurse’s philosophy was most like that of the psychiatric unit manager, who was also a nurse.

**PSYCHIATRIC NURSE’S AIDE**

The psychiatric aide, or Certified Nursing Assistant, had a high school diploma and only some very limited formal training, but had great responsibility for patient welfare. She worked solely within the hospital setting, like the others, excluding the psychiatrists and marriage and family therapist. The scope of her job, per the “Dictionary
of Occupational Titles," (1991) was to assist patients, working under direction of nursing and medical staff. This included assisting with the physical needs of the patient (cleaning and feeding), encouraging, escorting, and observing patients, as well as noting and recording their behavior on their charts. For approximately nine hours a day, she was responsible for patients; and, more than any of the other subjects interviewed, worked directly with patients and saw to their general safety and well-being. All this accomplished with minimal formal training. The psychiatric aide confirmed that she had never seen a schizophrenic before taking on her job.

Her personality during the interview, timid, quiet, nonverbal, was distinctly separate from her on-the-job demeanor, which was outspoken, brash, assertive, and supportive of patients. All her experience was on-the-job. She saw many schizophrenics on her unit; her definition of schizophrenia was non-descriptive.

The aide did respect patients and saw each as an individual, but said that a lot depended on their medication. She did not trust patients when they were first admitted to the unit. Trust took time and medication, about which she concurred with the nurse. The aide tried to show affection to patients and to make them more comfortable. She did suffer from burnout. For unclear reasons, the aide considered herself a teacher to the patients. She concurred with all that medication compliance was a problem. The aide and social worker were the only two health care providers who had no responsibility for medication of patients.

Dependent relationships (patient to aide) did not present a problem to her, and she saw her role in simple terms of basic, everyday functioning of patients. The psychiatric
aide, more than any of the other subjects, was responsible for the basic needs of the patients, as well as their safety from harm by self or others.

She thought communication was very important, and that patience, understanding, and caring were vital. She saw a need to be compassionate. The aide stressed nonverbal communication and spoke of “body language.” Like the social worker, manager, and nurse, her definition of communication involved nonverbal elements.
CHAPTER 7

COMPARISON OF THE RESEARCHER'S FINDINGS TO THE LITERATURE

The review of the literature treated scholarly articles as well as ethnographies. Two ethnographic dissertations were studied. The researcher concurred with Nomura (1987) that the three groups of people—patients, staff, and doctors—lived in quite different cognitive worlds of their own. Perception, judgment, philosophy, level of functioning, awareness, quality of life, were all unique for the individual health care providers as well as the patients, as observed by the investigator.

The researcher did utilize Nomura's and Robins' (1994) methodology of audio recording interviews, and Nomura's interactional approach of looking at people's face-to-face behavior while interviewing them. However, the investigator did not find, as Robins did, that achieving some level of rapport with the staff was difficult. Robins also argued the absence of the concept of "respect" in the hospital. This endeavor found quite the opposite. The doctors and staff respected and trusted patients, and were very dedicated to helping patients.

Regarding Chaika's (1974) article, "A Linguist Looks at 'Schizophrenic' Language," Chaika took the stance that the schizophrenic's difficulty in thinking and his difficulty in speaking are not necessarily the same phenomenon. The researcher discerned that the schizophrenic patients spoke in like manner to how they seemed to be
thinking; that is, with difficulty verbalizing thoughts. The intermittent aphasia (loss of the power to use or understand words) that she spoke of was not noted during the interviews. Chaika also commented on the richness of the associations employed by some schizophrenics. The investigator found no such richness. To the contrary, a paucity of ideas, simple speech and vocabulary, and a lack of the ability to utilize abstractions, was witnessed.

The researcher did concur with Lanin-Kettering & Harrow (1985) that outward speech was a good clue to what a person was thinking. Some delusional beliefs and ideas were detected by the researcher, in patients. One patient thought people might think schizophrenia was “catchy”; another thought her divorce was the cause of her illness.

Rieber & Vetter’s (1994) scholarly study of the different philosophies and opinions of twentieth century researchers on schizophrenic thought and language recognized that the term “schizophrenia” referred to a group of disorders with similar features. This researcher’s interviews abounded with similar features in the content of the conversation of patients as well as health care providers. Patient definitions given of the term “crazy” were similar, as was the nature of patient speech and lack of expressiveness. The five most frequent behavioral manifestations of schizophrenia, as listed by Rieber & Vetter, were not observed by the investigator. Bizarre behavior also was not noted. Lorenz (1968) cautioned against assuming there was such a thing as schizophrenic language. The researcher found similarities in patient language that may have differed from use of same by non-schizophrenics, but she could not conclude there was such a thing as schizophrenic language in those whom she interviewed.
Another philosophy explored in this article was Ferreira's (1960) notion that "the schizophrenic manipulates or disguises his or her language in order to conceal thoughts known to be dangerous and forbidden." From the interviews, the researcher received this impression of most of the patients. Very little came out in actual conversation; but, from the fears that were verbalized, it appeared disturbed thoughts were present.

Rieber & Vetter concluded their review with a statement that also summed up the researcher's findings: "The schizophrenic's apparent flatness of affect, inappropriate expression of affect, combined with withdrawal or loss of interest in the social and physical environment, are probably the most widely cited characteristics of the disorder."

Articles from the literature that treated the nonverbal characteristics of schizophrenic communication were reviewed. In Gaebel & Wolwer's (1992) study, Andreasen (1982) spoke of reduced facial expression as one sign of affective flattening in schizophrenia. This was observed in four of the patients interviewed. Manschreck, Ames, Maher, & Schneyer (1987) stated that one noticeable aspect of disturbed speech in schizophrenics was repetitiousness. The investigator witnessed this frequently during many of the patient interviews. Kraeplin, as early as 1919, characterized communication disorder as "marked confusion and incoherent speech." The researcher did not detect this peculiarity.

Rogers (1952) claimed that good communication is essential for mental health, and that mental illness is a breakdown of a person's intrapersonal communication. The researcher observed this phenomenon in her patient and staff interviews. The health care provider interviews were full, rich, detailed, filled with examples of creativity and health. The patient interviews were, however, more limited, with many of the patients so
involved with self and illness and getting through the days, that their communication signaled this. There was, though, a simplicity of ideas expressed, a stark honesty and candor, fear, and above all, courage. Rogers (1961) felt that real communication occurs when we listen with understanding. The researcher truly felt that real communication flowed during each of her interviews with patients and health care providers.
CHAPTER 8

SUMMARY AND CONCLUSION

SUMMARY

The scope of the thesis has covered a broad spectrum of material: the Introduction was a general description of schizophrenia and the theories generated to explain its development. Laing and Rogers were discussed. The Purpose section indicated that the thesis would assess the communication process within schizophrenia from the perspectives of individuals who were affected by it, both personally and professionally. The researcher was included, herein. Definitions of communication were elicited.

In the Review of the Literature, two ethnographies relating to the thesis topic were examined. Three articles on schizophrenic language and thought were reviewed. Four articles from the literature that treated the nonverbal characteristics of schizophrenic communication were also studied.

The researcher explained, in the Methodology section, that the thesis was autoethnographical as well as comprising ethnographic interviews and comparisons, with health care providers and schizophrenic patients. One chapter concerned the researcher’s own struggles with schizophrenia, which was compared to other autoethnographies.
The criteria for selection of interview subjects was explained and the limitations of the research, considered. All interview questions were listed, and a validation for choice of questions was presented. Much of the thesis concerned patient and health care provider interviews, and comparisons. The researcher compared her data to the current literature. These, then, are the concluding thoughts:

CONCLUSION

Schizophrenia is a debilitating, presently incurable, genetic disease with diverse, but similar features that affects all aspects of life, but particularly alters communication, with self and others. The researcher has endeavored to consider just how communication occurs and is affected in schizophrenics, both verbally and nonverbally. The speech of schizophrenic patients has been depicted as a sign of the disease since Kraepelin first described schizophrenia in 1896. A characteristic disorder of the disease is a reduction in the capacity to express and communicate emotion.

The researcher concluded that an inherent distinction could be observed in the schizophrenic patients, compared to the health care professionals. The patients, on the whole, were extremely preoccupied with self, and with the quandary and uncertainty and fear that schizophrenia presented to them. Each day was a struggle. The level of functioning of the health care providers, in contrast, was higher. They were, in general, more relaxed, able to extend beyond themselves, contribute more to society. Patients and providers lived in different cognitive worlds. The researcher was impressed with the honesty and candor of all the interviewees, and particularly with the raw courage and
perseverance of the schizophrenic patients, and their hopes for a better, more peaceful life.

The investigator also concluded that the support network was vital to the patients, and aided in well-being and recovery. The health care professionals were cognizant of the fact that they were the integral support team for the patients. The patients affirmed this, and also stated that family and friends were crucial to their mental health. The professionals were very dedicated; on this, the patients concurred. Each patient saw him or herself as an individual to each provider.

It is interesting to note that the nature of communication and interaction between patient and health care provider was distinct, depending on the position of the health care provider as well as on the personality and situation of the individual patient. To put it simply, patients communicated differently with their psychiatrist than they did with a nurse's aide. And the interaction in a group therapy session was often more intense than daily encounters with a staff member. Patients also communicated very differently with each other than they did with health care providers. Schizophrenia is a lens through which one sees the world.

There was a basic distinction in philosophy between the psychiatrists and the counselors (marriage and family therapist, social worker). The psychiatrists saw medication therapy as perhaps a cure. The counselors saw medication as a stabilizing mechanism so that therapy, the treatment process, could proceed. Counseling, then, became the "cure". Thus, the therapist and social worker practice psychology; the psychiatrists practice biology.
Is schizophrenia a disease of communication? Perhaps it is more apt to say that schizophrenia is a barrier to full and effective communication. The marriage and family therapist interviewed for this thesis said: “Communication always occurs, except in the presence of death.” However, communication is challenged in schizophrenia. One of the motives for the writing of this thesis was that since schizophrenia has an affect on everyone in society, there is a great need to know more about its inherent problems in communication. The researcher believes she also has shared her personal communication experiences with schizophrenia.

The literature has many exhaustive scholarly studies in the field, but there is much still not known. Medications are far better today, and target specific areas of the brain—with fewer side effects. Many of the health care professionals and patients concurred that medication is an answer to treating schizophrenia. One of the psychiatrists interviewed, said: “We have more knowledge of schizophrenia today than we did 100 years ago... It may be that we make far more progress in the next ten years than we’ve made in the past 100 years.”

Schizophrenia is an arduous journey through places unknown, traversing the heights as well as the depths, with destination uncertain. The researcher will conclude her thesis with a quote from the autoethnography of Janice Jordan (1995): “Thank you very much for listening to me. It is my hope that I have been one more voice in the darkness—a darkness with a candle glimmering faintly, yet undying.

LIMITATIONS OF RESEARCH

Reliability and replicability of data were not sought in this thesis. The researcher was using a purposive sample. Specific subjects were chosen with the hope they would
yield data relevant to the study. Subjects were chosen to identify specific issues they knew about. Choice of subjects was limited to availability. Because of this sampling technique, the researcher is aware that this was a bias sample. However, the investigator was seeking in-depth and uniquely qualitative information and not necessarily the reliability of the data.
BIBLIOGRAPHY


Ross, Diana. Out of darkness. An HBO made-for-TV movie.


APPENDIX A

INTERVIEW QUESTIONS AND PROBES

SCHIZOPHRENIC PATIENTS

1. How long have you had schizophrenia?
2. How old are you?
3. When you hear the word schizophrenic, what comes to your mind?
4. What are some of the connotations of being schizophrenic?
5. Do you tell people you are schizophrenic?
6. What does “crazy” mean to you?
7. To what extent do you feel your doctor, nurses, and social worker care about you?
8. Are you a person to your doctor, or just another patient?
9. To what extent are you dependent upon your doctor; what are you dependent on him (her) for?
10. To what extent do you have a feeling of helplessness or futility? How do you deal with this?
11. How does medication affect your sense of self, of who you are, of what you are?
12. Do you have any side effects from your medication? How do you deal with these?
13. Do you hear voices?
14. What do you do with your time?
15. How important is communication to you, in your treatment?
16. What is your definition of communication, not a dictionary definition, but your own definition?
17. Is there any question I didn’t ask that I should have asked, or that you feel you would like to answer?

PATIENT PROBES

PATIENT 1

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1. How would people react if they knew you were schizophrenic: Would there be a question of trust and respect?
2. How do people respond to you when they know you’re schizophrenic?
3. What are some of the stereotypes of being schizophrenic?
4. How does your doctor give you emotional support?
5. Is lack of understanding about the disease, by people, a problem for you?
6. So, you think there’s a stigma to being schizophrenic?
7. Are the voices the worst thing there is?
8. Do you hesitate to communicate with family about schizophrenia?
9. How important is honesty of communication to you?

PATIENT 2

1. How do people respond to you as a schizophrenic?
2. Do you tell people you’re schizophrenic? Who would you tell and who would you not tell?
3. Are there stereotypes of being schizophrenic? What are some of the stereotypes you have encountered?
4. Are there stigmas from society, to schizophrenics?
5. Can you give me an example of how your doctor gives you emotional support?
6. Do you ever feel you can’t do anything about yourself, or that you’re not worth it?
7. If it isn’t medicine, what makes you feel more full as a person, more complete?
8. How important is honesty of communication to you?

PATIENT 3

1. How do people who know you have schizophrenia respond to you?
2. Do you tell people you have schizophrenia?
3. Do you think there are stereotypes of schizophrenics?
4. What else do you depend on you doctor for, aside from medication?
5. How does it work out, having both a brother and a mother who are also schizophrenic?

PATIENT 4

1. How have people responded to you as a schizophrenic?
2. What are some of the stereotypes of being schizophrenic?
3. How does your doctor care about you?
4. What else are you dependent on your doctor for, aside from medication?
5. How does your doctor give you emotional support?
6. I understand you have another schizophrenic member in your family?

PATIENT 5

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1. How do people respond to you as a schizophrenic?
2. Do you tell people you're schizophrenic?
3. Are you dependent upon your medication?
4. How does your doctor give you emotional support?
5. Are the voices the worst thing?
6. Is lack of understanding about the disease a problem for you?
7. I understand you have a mother and a brother who are also schizophrenic. How does that work out? How do you support each other emotionally with this illness?
8. Are there problems in the home with three people having the same illness?
9. How have you been able to help each other, where doctors and others couldn't help you?
10. Do you feel you're in sync with each other?
11. Has the illness brought you closer?
12. Do you hesitate to communicate with others?
13. Is honesty of communication important to you?

PATIENT 6

1. What do people think when they hear you're schizophrenic?
2. Do you tell people you're schizophrenic?
3. Are the voices the worst thing?
4. So, the voices have been a problem, but the divorce was most upsetting?
5. Is medication important?
6. Is lack of understanding about the disease a problem for you?
7. I understand you have two sons who are also schizophrenic. How do you support each other emotionally?
8. How do you help each other in ways that doctors or other people cannot help you?
9. Are you in sync with each other?
10. Are the voices destructive, or are they pleasant? What do the voices do?
11. Do you think the schizophrenia would go away (if you could resolve your divorce)?
12. Do you hesitate to communicate with people?

INTERVIEW QUESTIONS

PSYCHIATRISTS

1. What type of practice do (did) you have?
2. How long have (had) you been practicing?
3. What is your educational background?
4. How old are you?
5. Have you treated many schizophrenics?
6. When you hear the word “schizophrenic,” what comes to your mind?
7. As a doctor, how do you see your role with patients? What function or part do you play in the actual treatment, of patients?
8. To what extent do you really trust and respect your patients?
9. Are the patients persons to you, or merely patients?
10. Do the patients ever blend, one into another, for you?
11. Do you feel your patients look at you as almost a god?
12. When patients are on medication, how does this affect their ability to communicate?
13. To what extent do you have the ability to transform the mentally ill? Is there a perceived impossibility of changing their lives?
14. Do you ever suffer from burnout?
15. Given the nature of the illness and what we know of it today, to what extent can you hope to make a difference in the lives of your patients?
16. How long do you think schizophrenia has been around?
17. What is the role of communication in your treatment of schizophrenics?
18. How would you define schizophrenia, not a dictionary definition, but your own definition?
19. Is there any question I didn’t ask that I should have asked, or that you feel you would like to answer?

PSYCHIATRIST PROBES

PSYCHIATRIST 1

1. What are some of the connotations of being schizophrenic?
2. What is the nature of the doctor/patient relationship, and to what extent are the patients individuals to you?
3. Given the “revolving door” policy of repeated hospitalizations and recurrent illness, how does this affect it (your ability to change patients’ lives)?
4. Are you able to segment your life, to divide it up so work is one thing and play, another?
5. Do you feel we have very limited knowledge of schizophrenia?

PSYCHIATRIST 2

1. I understand you’re retired?
2. What are some of the connotations of being schizophrenic?
3. What do you think is the value of different treatments, medications versus psychological, with schizophrenics?
4. Do patients see you as something more than a doctor?
5. What are some of the results or ramifications of treatment with medications?
6. Is medication compliance a problem?
7. If treatment works, then what about the “revolving door” policy of repeated hospitalizations and recurrent illness?
8. Was the nature of your burnout what you saw, or the hours, or?
9. But, you’re still working? Are you enjoying your retirement?
10. Don’t you feel we have limited knowledge and understanding of schizophrenia?
11. How do you know you get meaning across to patients?

PSYCHIATRIST 3

1. Do you feel there are stigmas and stereotypes to being schizophrenic?
2. Are the patients of unique character for you?
3. Is medication compliance a problem?
4. So medication has been a big boom to emptying out (the psychiatric hospitals)?
5. How do you know you get meaning across to patients?
6. How do you know patients understand and comprehend what you’re saying?
7. What do you think causes schizophrenia?

INTERVIEW QUESTIONS

MARRIAGE AND FAMILY THERAPIST

1. Are you a psychologist?
2. What educational degrees do you have?
3. How many years have you been practicing?
4. How old are you?
5. When you hear the word “schizophrenic,” what comes to your mind?
6. What do you think are the connotations of being schizophrenic?
7. Have you treated many schizophrenics?
8. As a doctor, how do you see your role with patients?
9. What is the nature of your doctor/patient relationship, and to what extent are the patients individuals to you?
10. Do the patients ever blend, one into another, for you?
11. To what extent do you really trust and respect patients?
12. Do you feel your patients look at you as almost a god?
13. When patients are on medication, how does this affect their ability to communicate?
14. To what extent do you have the ability to transform the mentally ill? Is there a perceived impossibility of changing their lives?
15. Do you ever suffer from burnout?
16. Given the nature of the illness and what I known of it today, to what extent can you hope to make a difference in the lives of your patients?
17. What is the role of communication in your treatment of schizophrenics?
18. How would you define communication?
19. Is there any question I didn’t ask that I should have asked, or that you feel you would like to answer?

THERAPIST PROBE

1. What part do you play in the patient’s discovery to a better way of life?

INTERVIEW QUESTIONS

LICENSED CLINICAL SOCIAL WORKER

1. What is your position at the hospital?
2. How long have you worked as a social worker?
3. What are your responsibilities in this position?
4. What is your educational background?
5. How old are you?
6. Have you treated many schizophrenics?
7. When you hear the word “schizophrenic,” what comes to your mind?
8. What are some of the connotations of being schizophrenic?
9. How do you see your role with patients?
10. Regarding your relationship to patients, to what extent are they individuals to you?
11. Do the patients ever blend, one into another, for you?
12. To what extent do you really trust and respect patients?
13. In the group therapy sessions that you lead, what is your role and what do you hope to accomplish?
14. To what extent do you have the ability to change the lives of the mentally ill, given the “revolving door” policy of repeated hospitalizations and recurrent illness itself?
15. Do you ever suffer from burnout?
16. When patients are on medication, how does this affect their ability to communicate?
17. Is medication compliance a problem, and why?
18. How important is communication in your treatment of schizophrenics?
19. How would you define communication?
20. How do you know you get meaning across to patients?
21. Is what patients don’t say important to you?
22. Is there any question that I didn’t ask that I should have asked, or that you feel you would like to answer?

23.

SOCIAL WORKER PROBES

1. How do you work with patients?
2. I understand you lead group therapy sessions. Is this a big part of your job?
3. How successful are the groups?
4. What do you mean by “re-enforcement”?
5. So you feel medication is a lifeline and a vital link?
6. Is that (medication) the most important form of therapy?
7. Can you tell me a little about this group (“Rational Recovery,” a free support group) that you have?
8. Do you feel the ultimate answer to schizophrenia will be medication?

INTERVIEW QUESTIONS

PSYCHIATRIC HOSPITAL UNIT MANAGER

1. What is the title of your position?
2. What are your responsibilities?
3. How long have you had this position?
4. What is your educational background?
5. How old are you?
6. When you hear the word “schizophrenic,” what comes to your mind?
7. How do you see your role as Unit Manager?
8. Does the fact that so many patients are repeatedly hospitalized affect your job attitude?
9. What is the nature of your relationship, your role, with patients?
10. Do the patients ever blend, one into another, for you?
11. Do you ever suffer from burnout?
12. Given the nature of the illness and what is known of it today, to what extent can you hope to make a difference in the lives of your patients?
13. How important is communication in your treatment of schizophrenics?
14. How do you know you get meaning across to patients?
15. Is what patients don’t say important to you—the nonverbal communication?
16. How would you define communication?
17. Is there anything I didn’t ask that I should have asked, or that you feel you would like to answer?

UNIT MANAGER PROBES

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1. Are most of the patients whom you see schizophrenic?
2. What is “decomp”?

INTERVIEW QUESTIONS

LICENSED PRACTICAL NURSE

1. What is your position?
2. How long have you worked at this position at this hospital?
3. What are your responsibilities here?
4. How old are you?
5. When you hear the word “schizophrenic,” what comes to your mind?
6. What are some of the connotations of being schizophrenic?
7. Regarding your relationship to patients, to what extent are they individuals to you?
8. Do the patients ever blend, one into another, for you?
9. To what extent do you really trust and respect patients?
10. When patients are on medication, how does this affect their ability to communicate?
11. Is medication compliance a problem?
12. Are you a parent, servant, counselor, teacher, custodian, or something else to patients? What is your role, and why do you see it this way?
13. Given the nature of the illness and what is known of it today, to what extent can you hope to make a difference in the lives of your patients?
14. Does the fact that so many patients are repeatedly hospitalized affect your job attitude?
15. Do you ever suffer from burnout?
16. Mentally ill patients seem to form protective and dependent relationships with nurses. Are dependent relationships a problem?
17. How important is communication in your treatment of schizophrenics?
18. How do you know you get meaning across to patients?
19. Is what patients don’t say important to you?
20. How do you respond to nonverbal communication, gestures, body language?
21. What is your own definition of communication?
22. Is there any question that I didn’t ask that I should have asked, or that you feel you would like to answer?

NURSE PROBES

1. Can you separate work from home?
2. How do you encourage independence?
3. How important is the support network?
INTERVIEW QUESTIONS

PSYCHIATRIC NURSE’S AIDE

1. What is your position?
2. How long have you worked as a psychiatric aide?
3. What are your responsibilities?
4. What is your educational background?
5. How old are you?
6. When you hear the word “schizophrenic,” what comes to your mind?
7. Do you treat many schizophrenics here at the hospital?
8. What are some of the connotations of being schizophrenic? When people hear “schizophrenic,” what do they think?
9. Regarding your relationship to patients, to what extent are they individuals to you?
10. Do the patients ever tend to blend, one into another, for you?
11. To what extent do you really trust and respect patients?
12. Are you a parent, servant, counselor, teacher, custodian, or something else to patients? What is your role and why do you see it this way?
13. Does the fact that so many patients are repeatedly hospitalized affect your job attitude?
14. Do you ever suffer from burnout?
15. When patients are on medication, how does this affect their ability to communicate?
16. Mentally ill patients tend to form protective and dependent relationships with aides. Are dependent relationships a problem for you, and do patients tend to cling and want to be with you?
17. How do you know you get meaning across to patients? Is what a patient doesn’t say important to you?
18. What is your definition of communication?
19. Is there any question that I didn’t ask that I should have asked, or that you feel you would like to answer?

AIDE PROBES

1. What is your role in encouraging independence in patients?
2. How do you respond to nonverbal communication, like gestures and body language?
DATE: May 23, 1996

TO: Pauline Bukantz Paz = COS
M/S: 5007

FROM: Dr. Frederick W. Preston
Chairman, Social Behavioral Committee of the
Institutional Review Board

RE: Status of Human Subject Protocol entitled:
"An Autoethnography, and Ethnography of the Cognitive
and Social World of Schizophrenics as Perceivved by
Health Care Professionals and Experienced by
Schizophrenics Themselves"

OSP #103s0296-146

This memorandum is official notification that the protocol for
the project referenced above has been approved by the Social/
Behavioral Committee of the Institutional Review Board. This
approval is approved for a period of one year from the date of
this notification, and work on the project may proceed.

Should the use of human subjects described in this protocol
continue beyond a year from the date of this notification, it
will be necessary to request an extension.

If you have any questions or require any assistance, please give
us a call at 895-1357.

cc: Dr. Anthony Ferri (COS-5007)
OSP File

Office of Sponsored Programs
4505 Maryland Parkway • Box 451037 • Las Vegas, Nevada 89154-1037
(702) 895-1357 • FAX (702) 895-4242

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INFORMED CONSENT

I am Pauline Paz, a graduate student in the Greenspun School of Communication at UNLV. I would appreciate your participation in my thesis study which is on the nature of communication for schizophrenics. Essentially, this study will seek to understand the difficulties and nature of communication for the schizophrenic.

The method will be a one-on-one personal interview, lasting one hour or less, and including about 16 questions. Also, each interview will be audio tape recorded. This recording is strictly for gathering statements only. After the statements are typed, the recordings will be erased. The questions will be about communication and nothing in the interview will be directed toward you as a person or your unique personality.

If you agree to participate and find that you would want to withdraw at some point in time during the interview, you may do so. Your participation in this study would be completely voluntary.

Your interview will be confidential. All statements you make will be used to summarize major themes across subjects. In other words, your individual identity will be kept completely private.

If you have any questions, please feel free to contact myself, at (702) 228-4032; or Dr. Anthony Ferri, of the Communications Department at UNLV, at (702) 895-1371; or Ms. Marsha Green, the Sponsored Programs Coordinator for Research Involving Human Subjects, at UNLV, at (702) 895-1357.

Date:_____________________

I, ________________________, agree to participate in this study of schizophrenia and communication, in accordance with the conditions outlined above.

Signature:__________________