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Experience of Stigmatization and Discrimination of Former Psychiatric Inpatients

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Amy Rappaport
Experience of Stigmatization
and Discrimination of Former
Psychiatric Inpatients

Abstract

This is an exploratory study of stigma and discrimination in subjects who have a major mental illness. The study focuses on 11 Caucasian subjects, both men and women, ranging from age 24 to 63, who have diagnoses of major personality disorders and problematic work histories. The researcher conducts in-depth interviews focusing on stigma and discrimination in different areas of life. It is found that all subjects experienced stigma or discrimination in their lives, which often contributed to low self-esteem and feelings of unworthiness. It is also found that the reactions of families, friends, and acquaintances toward each subject changed upon learning of the subject's mental illness. The study presents the subjects' own subjective accounts of the effects of stigma and discrimination in their lives.

EXPERIENCE OF STIGMATIZATION AND DISCRIMINATION
OF FORMER PSYCHIATRIC INPATIENTS

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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1990

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This study could not have been accomplished without the assistance of many people whose contributions are gratefully acknowledged.

I wish to thank all of the consumers who participated in this study for all of their honesty and wisdom, my research advisor, Michael Hayes, for his immeasurable support and sense of humor, Ellen Dibble for her marvelous skills, Jennifer Hawthorne, for her patience and kindness, and Matthew McCue, for his love.

Dedicated to Matt

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CHAPTER I

INTRODUCTION

In our culture as well as other cultures, there are social norms that are prescribed and expected to be followed. If an individual does not act in accordance with these social norms, there are often consequences. In Edgerton's (1971) article, "Anthropology, Psychiatry, and Man's Nature," he states, "Sometimes, of course, the sanctions against deviant behavior are supernatural, consisting of immediate and horrible punishment by gods, spirits, ancestors or the like" (p. 45). In present day culture in the United States, the researcher contends that there are both traditional and modern belief systems that serve to ostracize the stigmatized deviant.

People who have been diagnosed as having a mental illness have often been thought of as people who experience stigma. Goffman (1963) states, "The Greeks . . . originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier" (p. 1). Goffman continues to explain how a stigmatized person becomes "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). Goffman further explains that people in general do not perceive stigmatized individuals as human.

In this study, I plan to explore one population that I believe has a deviant and stigmatized status in this society: people who have been diagnosed as having a mental illness and who are currently living in the community. In this paper, the researcher will use the word "consumer" to refer to the individual with a mental illness. The researcher chose the word consumer because that is the word that most individuals with mental illness have claimed for themselves at this time.

For the reader to draw his or her own conclusions, I recommend listening to the words of the 11 subjects of this exploratory study. My goal is to contribute to the body of knowledge that reveals consumers' descriptions of their own experiences of stigma and discrimination. There has been a growing amount of literature on this subject; yet virtually every author listed in the bibliography has called for further research on the subjective experiences of consumers.

The researcher chose this topic because she is interested in the study of deviance and stigmatized individuals. The researcher is also interested in gaining a deeper understanding of people who have a mental illness. Therefore, she decided to combine these interests for this study.

The researcher will present a review of the literature addressing the topic of stigma and discrimination in the lives of consumers. Following that there will be a presentation of the method chosen by the

researcher to conduct this exploratory study and the findings yielded in the interviews with 11 consumers. Finally, the researcher will present a summary and a conclusion of this study.

CHAPTER II

LITERATURE REVIEW

The central focus of this study is the internalized stigma and discrimination experienced by mental health consumers. The researcher will first present some general ideas utilizing an anthropological, philosophical, and sociological perspective to provide the groundwork for understanding the concept of stigma and discrimination. Following the groundwork, the researcher will present the two areas in the literature that discuss patients' subjective experience of discrimination and stigma: "personal accounts" of consumers' lives and "patient attitude studies."

The term stigma, according to Webster's New Collegiate Dictionary (1977) means,

1 a archaic: a scar left by a hot iron: brand, b: a mark of shame or discredit: stain c: an identifying mark or characteristic. (p. 1142)

The term discrimination defined by Webster's means

3: the act, practice, or an instance of discriminating categorically rather than individually b: prejudiced or prejudicial outlook, action, or treatment. (p. 326)

The word discriminating means,

1: making a distinction: distinguishing. (p. 326)

The researcher looked selectively at anthropological and sociological literature to form the foundation on which to build the

notions of stigma and discrimination. The anthropological concept of taboo is related to the concepts of stigma and discrimination.

"Excessive taboos imposed by a culture upon a population . . . may deprive certain individuals of basic gratifications" (Dubreuil & Wittkower, 1971, pp. 9-10). In the brief search through the discipline of anthropology, this researcher noted that throughout time and in various cultures, different groups have experienced stigma or discrimination.

Other anthropological and philosophical notions that are particularly relevant to this study are the notions of norms and social order. All societies have a social order. Hobbes saw "social order . . . as an accomplishment necessary to the control of men who would otherwise be engaged in the 'war of all against all'" (Edgerton, 1971, p. 31). Once the social order is established it must be maintained. The way in which it is upheld is explained by Mead's notion of "the force of culture over the individual" (Edgerton, 1971, p. 37).

Some sociologists posit that deviance is a natural occurrence in society. Essentially, it is thought that, though there are the forces of social control and order, not everyone will conform to all social norms. If a person deviates from the social norm, the "keepers of conformity" will pressure the deviator to act in accordance with the rules and roles designated by the social order. Kai Erickson explains:

From a sociological standpoint, deviance . . . is not a property inherent in certain forms of behavior; it is a property conferred upon these forms by the audiences which directly or indirectly witness them. Sociologically, then, the critical variable in the study of deviance is the social audience rather than the individual person, since it is the audience which eventually

decides whether or not any given action or actions will become a visible case of deviation. (Erikson, 1967, p. 296)

Out of the sociological notion of social order, the "labeling theory" was born. There have been volumes written by proponents and opponents of the labeling theory. The researcher will give the reader the basic arguments of labeling theory in relation to mental illness offered by both the proponents and opponents.

A major proponent of the labeling theory is Thomas J. Scheff. In his book called Being Mentally Ill, he explains:

The theory has two basic components: social role and the societal reaction. Its key assumptions are that most chronic mental illness is at least in part a social role, and that the societal reaction is usually the most important determinant of entry into that role. (p. 28)

From this point of view . . . three hypotheses are stated below which cause the deviant to accept such a stigmatized role.

6. Labeled deviants may be rewarded for playing the stereotyped deviant role. (p. 84)

7. Labeled deviants are punished when they attempt the return to conventional roles. (p. 87)

8. [She or he] may accept the proffered role of the insane as the only alternative. (Scheff, 1966, p. 88)

According to Scheff and other proponents of labeling theory, consumers are locked into a social role and there are strong pressures that force them to remain in these roles.

A major opponent of labeling theory is Walter R. Gove. He states:

From the societal reaction perspective [or the labeling theory] it is very hard to see why persons would voluntarily stigmatize themselves by seeking psychiatric treatment. (p. 42)

Let us turn to involuntary patients. (p. 43)

Officials do not assume illness. (p. 45)

Persons who are reacted to as mentally ill are in fact mentally ill. (p. 48)

In summary, the evidence on genetic propensity toward mental illness, the manifestation of psychiatric symptoms, and the recent experience of critical life events indicates a sharp distinction between those labelled mentally ill and those not so labelled. (Gove, 1975, p. 51)

The opponents of labeling theory believe that genetic, biological, and some environmental factors predispose individuals to mental illness. Often opponents state that labeling theory has some validity, but they believe that the theory is outdated and does not offer a plausible etiology of mental illness nor does it provide an accurate composite picture of the life of the consumer.

The next theoretical construct, called the interactional model, proposed by Lally (1989), Estroff (1989), and others (Dinitz, Mangus, & Pasmanick, 1959; Swanson & Spitzer, 1970), is an important notion to keep in mind while discussing stigma and discrimination. The two halves of the interactional model are essentially the external world and the internal world of an individual. Briefly, the external world refers to the environment or the world outside of the individual. The internal world refers to the self. The self as defined by Webster's New Collegiate Dictionary is "the union of elements (as body, emotions, thoughts, and sensations) that constitute the individuality and identity of a person" (Webster's, 1977, p. 1048). This model observes the interaction between the external and the internal world of an individual. Estroff elaborates on the interactional model in relation to mental illness:

Having schizophrenia includes not only the experience of profound cognitive and emotional upheaval; it also results in a transformation of self as known inwardly, and of person or identity as known outwardly. Schizophrenia . . . is an I am illness [sic]. (p. 189)

Others provide the contrast that permits definition of the self—the object (out there, not me) delineates the subject (in here, I, self). . . . There is a private subject and a public person. . . . These layers must overlap. (Estroff, 1989, p. 190)

Swanson and Spitzer further elaborate the concept of the interactional model in a way that is relevant to the focus of this study. They speak of the internal world as "the 'personal affective' perspective [which] focuses on the shame, embarrassment, and sensitivity [an individual experiences, whereas the external world or] the 'social distance' perspective focuses on the restrictions placed upon interaction for individuals" (p. 44).

The interactional model was also commented on by Dinitz, Mangus, and Pasamanick (1959): "Interacting [sic] persons internalize the cultural and social norms which are valued by the group and thereby define themselves and one another in terms of these norms" (p. 44). For example, if the media portrays people with mental illness as dangerous and irrational, it is probable that a consumer will think of herself or himself as dangerous and irrational.

The crux of the interactional model is the relationship of the external and internal worlds. In this study, the researcher will focus on the experience of stigma which occurs in the internal world and the experience of discrimination which occurs in the external world and the relationship between the two worlds. With these theories and models as

a background, the concepts of stigma and discrimination as they relate to people with mental illness can now be developed more specifically.

The researcher will present how the term stigma has been utilized in the literature. Basically, stigma refers to both the internal world and external world of consumers. Yet, for the purposes of this study, the researcher will use the term stigma when referring to the internal world of the consumer and the term discrimination to refer to external actions of others towards the consumer. The focus of this paper is a discussion of discrimination and stigma and the interaction the two have on consumers' lives.

In reviewing the literature discussing patients' feelings of stigma and environmental discrimination, one is struck by the overall tendency to group and condense the research data which was obtained. "The literature says little about us individually. Most researchers group us, thereby reinforcing the stigma" (Anonymous, 1980, p. 546). More specifically, most studies do not discuss the consumers' subjective experiences of discrimination or stigma in adequate detail or depth; yet the information that is provided does offer the reader some understanding of the subject area.

After a diligent search of the literature, the researcher found two sources in which the topics of stigma and discrimination are discussed in a way that is relevant to this study: consumers' accounts of their experiences and "patient attitude studies." The researcher will first present the themes of stigma or discrimination revealed in

the consumers' accounts and afterwards will report the relevant material to this study from the patient attitude studies.

The only source that this researcher found that provided an ongoing forum for consumers to speak about their life experiences are the personal accounts in Schizophrenia Bulletin. The researcher looked for and read the section called "first person account," starting with the first issue of Schizophrenia Bulletin in 1969 up until the current issue in 1990. (Issue number four of 1970 is not available.) The researcher will present the themes of stigma or discrimination yielded in the personal accounts.

One theme that was prevalent in the personal accounts is the consumers' need for researchers to listen to each consumer talk about his or her subjective experience. "From my perspective, researchers continue to define stigma with statistics" (Anonymous, 1980, p. 546). Most authors have called for additional research on consumers' subjective experiences rather than more statistical analyses.

A major theme that was apparent in the personal accounts is the consumer's individual experience of stigma. "The label 'schizophrenia' . . . implies that I am different in some basic way from other people, when I feel I am not" (Anonymous, 1981, p. 196). "I felt ashamed, helpless, useless, and frightened . . . worthlessness" (Lovejoy, 1982, pp. 606-607). "The stigma of mental illness was the hardest thing to overcome for me. I am embarrassed to admit how prejudiced I was" (Brundage, 1983, p. 584). "Humiliation . . . stigma is a serious

problem for most consumers and keeps them from taking their rightful place in the society" (Anonymous, 1989, p. 638).

The consumers stated the following accounts of discrimination that they experienced. "The discrimination is subtle and quiet. . . . How many thousands of people who need help do not seek it out of fear of what others will think" (Anonymous, 1981, pp. 736-737). "There are those who see mental illness as a demonic possession" (Minor, 1981, p. 316). "A condition, which I call 'justifiable paranoia,' developed from experiences of rejection (covert and overt) persecution. . . . I wanted and expected to be embraced for my suffering, not rejected because of it" (Houghton, 1982, p. 550).

Another theme that was revealed in the personal accounts is the difficult reality of daily living, for example, in relationships with others, employment, housing, etc. Here is what consumers had to say: "But you're still isolated and by yourself. Most of all, you aren't living in a place you chose for yourself. It was simply arranged for you. When you have no job, are on welfare, have no references, no money" (Peterson, 1982, pp. 610-611). "To get this job, I concealed my medical history. The great majority of the staff there seemed to think that as I had a menial job, I must be a menial person" (Woodman, 1987, pp. 329-330). "Families continue to treat mental illness as a silent, shameful disease" (Anonymous, 1980, p. 546).

The final theme of the patient accounts the researcher will present is a hopeful one, discussing therapy, medication, and general thoughts. "I feel that I have been on the leading edge of the medical

breakthroughs in the treatment of schizophrenia" (Fortner, 1988, p. 706). "The human connection I have developed with the therapist has helped me" (Anonymous, 1989, p. 345). "If given a chance, we can do lots of things in the community. . . . We can be helpful to each other" (Peterson, 1982, p. 616).

Turning to the "patient attitude studies," the reader can note the varying ways in which the term stigma is used throughout the studies. Generally, the authors use the words stigma and discrimination interchangeably. For clarity, this researcher will use the term stigma and discrimination in the manner explained in the beginning of this literature review, unless otherwise stated.

The researcher will present the 11 patient attitude studies that are relevant to this study. (There are 12 studies, but the Rosenblatt and Mayer 1974 study is unavailable.) The researcher will present what kinds of stigma or discrimination are reported and what factors, if any, played a role in exacerbating or mitigating stigma or discrimination.

Before this researcher considers 11 of the 12 patient attitude studies, she will first present Weinstein's interpretation of the 12 studies in light of one of his propositions that "ex-patients tend to express unfavorable attitudes toward the stigma of mental hospitalization" (1983, p. 73).

Weinstein's study was important to this researcher in that he collected information about studies done concerning stigma or discrimination and the mentally ill. Though this researcher has

reviewed the same 11 patient attitude studies with a different purpose in mind, Weinstein's interpretation does shed light on the concept of stigma in relation to the labeling theory. In his study, Weinstein claims that labeling theory proponents have neglected to pay adequate attention to consumers' attitudes and feelings. Therefore, he decided to write a review of labeling theory and its relation to the attitudes of consumers.

Weinstein deemed a study to be "unfavorable" if more than half of the subjects expressed negative attitudes "toward stigma or the effects of mental hospitalization" (p. 79), and conversely the study was "favorable" if half or more of the subjects expressed positive attitudes toward stigma or the effects of mental hospitalization.

According to Weinstein (1983),

Proposition 4 revealed [that] attitudes tended to be unfavorable in five studies (Allen and Barton, 1976; Miller and Dawson, 1965; Nuehring, 1979; Small et al., 1965; Spiegel and Younger, 1972); ambivalent in one (Wood et al., 1962) and favorable in six (Chastko et al., 1971; Cumming and Cumming, 1965; Gove and Fain, 1973; Kotin and Schur, 1969; Rosenblatt and Mayer, 1974; Swanson and Spitzer, 1970). (p. 75)

He claims that "labeling theory appears to underestimate the positiveness of former patients in the community" (p. 79).

Essentially, Weinstein's argument is that if labeling theory were true all of the time, all patients would feel unfavorably towards the stigma and the effects of being hospitalized. This researcher interprets these findings to mean that some consumers feel positive, others feel negative, and yet others feel both ways concerning the stigma and the effects of their hospitalization.

The first of the 12 studies is Allen and Barton's (1976) study of 184 people. Age, diagnosis, sex, marital status, and employment were not statistically significant in relation to all responses given by the subjects. The terms stigma or discrimination were not used directly; yet the measure of attitudes towards disposition possibly allude to stigma or discrimination that was experienced after consumers left the hospital. All 15 patients who commented on their hospital discharge outcomes felt negatively about them. One example of a response given is that "people who leave are only able to exist, not live" (p. 635).

Miller and Dawson's (1965) study of 1,082 people reveals that males tend to experience more feelings of stigma. Subjects of this study reported various forms of stigma and discrimination. Throughout the study, the researchers generally refer to stigma as being considered undesirable or disgraced by others. Of the subjects in this study, 16% reported that their mental illness was in some way threatening, 33% had difficulty with employment, virtually 100% experienced unwanted financial dependence, 35% reported self-esteem problems, and 16% experienced relational difficulties. It appears that the remaining percentage of patients did not experience the unfavorable aspects of stigma or discrimination.

Nuehring's (1979) study of 414 people reveals that the following variables increased the amount of stigma or discrimination experienced: living in urban areas, not living with others, feelings of depression, and being non-white. Nuehring utilizes the word stigma to describe

shame, embarrassment, rejection, being a burden to family and friends, and being shunned.

Small, Small, and Hayden's (1965) study of 68 people essentially reports that the attitudes and expectations of staff members have an influence on patients' prognoses. The study reveals that positive expectations and attitudes yield a better prognosis. Therefore, this researcher infers that if the staff have positive attitudes and expectations of their patients, the patients will feel less stigmatized and discriminated against in general. There are no other factors clearly stated that had an effect on prognoses.

Spiegel and Younger's (1972) study of 725 male patients reveals several kinds of stigma or discrimination: 34% had readjustment difficulties in the community; 14% had relational difficulties; 15% had employment-related problems; 2% had difficulty obtaining clothing; and 12% had financial problems. No other significant demographic data are presented.

Wood's study (1962) of 36 male subjects reveals a positive correlation between post-hospital adjustment and being married. He also shows that if a subject was married, it was more unlikely that he or she would be rehospitalized. Of the 36 subjects, 44% stated that they felt that their life circumstances had improved since hospital discharge, and 38% of the patients needed to be rehospitalized.

Chastko, Glick, Gould, and Hargreaves' study (1971) of 70 subjects reveals that poor post-hospital adjustment is directly related to the

unhelpful treatment by the staff. Age and diagnosis do not have an effect on the post-hospital experience in this study.

Cumming and Cumming (1965) conduct two studies in the paper. Cumming and Cumming utilize two definitions of stigma in this study, "The first an outright expression of shame or inferiority because of the hospitalization, and the second an expectation of discrimination or inferior treatment from others" (p. 138). Of the 22 patients studied, 41% felt stigmatized. The first study shows that age, sex, work status, education, or household composition do not affect level of stigma or discrimination. Of the 87 women in the second study, 40% have a low stigma score and 47% have a high stigma score. In the second study, single women have the highest stigma scores, women with the diagnosis of neurosis have high stigma scores, and separated and divorced women are usually stigmatized. Education and occupation are unrelated to stigma scores. It is also reported that the longer the amount of time one was living in the community, the lower the stigma score.

Gove and Fain's (1973) study of 429 subjects show that stigma is generally transitory. They define stigma as addressing the areas of employment, relationships, and financial status. They find that employment status is generally unchanged after hospitalization; 26.5% of the men and 15.7% of the women report improved financial situations, and 12.8% of the men and 8.1% of the women report it was worse after hospitalization; 68% report excellent marital relationships after hospitalization; 85.9% report excellent relationships with their

children after hospitalization; and 56.8% report excellent relationships with others after hospitalization. No clear demographic data are reported.

Kotin and Schur's (1969) study of 49 subjects shows that 53% say that their hospital experience was positive and not harmful, and 35% say that being hospitalized was harmful or not helpful. There is no clear, significant relation of demographic data to the results of the study.

Swanson and Spitzer's (1970) study of 670 patients reveals that females, younger, and more educated patients experience fewer stigmatizing experiences. Stigma in this study refers to the fact that people in general distance or remove themselves from consumers, and show negative attitudes towards consumers. The study shows that when consumers are hospitalized "that individuals are most conscious of their spoiled identity, [experiencing] the greatest amount of stigmatization" (p. 49).

Other studies reveal the negative effects that stigma can cause, such as employment discrimination (Farina & Felner, 1973); people believing that people with mental illness are dangerous (Link, Cullen, Frank, & Wozniak, 1987); occupational, marital, social, and life-long discrimination (Scheff, 1966); feelings of shame and social barriers (Anonymous, 1980); negative societal images (Clausen, 1981; Crumpton, Weinstein, Acker, & Annis, 1967; Crumpton & Groot, 1966; Quadagno & Antonio, 1975).

In addition to the studies mentioned in this literature review, Linn's (1968) study and Quadagno and Antonio's (1975) study point out the active role patients can take in challenging the discrimination they might encounter. Quadagno and Antonio suggest that patients can actively resist labeling, rather than being passive recipients.

In conclusion, an important step in the process of developing empathy and effective treatment methods for people with mental illness has been taken by means of patient attitude studies and personal accounts of consumers lives. Initially, patients' attitudes and feelings were not seen as a significant part of the research on the topic of deviance and stigma. This study will serve to further the understanding of patients' experiences of discrimination or stigma.

CHAPTER III

METHODOLOGY

The goal of this study is to talk directly with people who have had a history of mental illness to ask them about their experience of discrimination or stigma. The purpose of the project is to make a contribution to the growing body of literature which reveals consumers' attitudes and feelings about their experiences of stigma or discrimination.

The general research design is that of an exploratory study. The research was conducted by asking questions to subjects about their subjective and objective experiences. The interviewer chose this method due to the fact that it allowed the respondents a high degree of freedom in the range of their potential responses.

Subjects

The 11 subjects in this exploratory study have all had a history of major mental illness. All 11 subjects have had multiple hospitalizations and carry the diagnosis of depression, schizophrenia, or bi-polar disorder. All subjects are not employed and have had a problematic work history. All subjects are Caucasian and range between the ages of 24 to 63 years of age.

All of the subjects that attended Site A and Site B met the aforementioned criteria. At Site A, a psychosocial rehabilitation club, the researcher left a sign-up sheet in a central location. The researcher interviewed every subject who signed up. At Site B, a weekly support group, the researcher asked members verbally if they would like to participate in the study. The first 4 members who volunteered were selected to be subjects in this study.

Data Collection

At Site A, the researcher met with all group members who were present for approximately an hour. The researcher explained the purpose and the nature of the study, reviewed the Human Subjects Review Sheet (see Appendix A) and the consent form (see Appendix B). The researcher explained that this study was being conducted as part of the degree requirements for a master's in Social Work. The researcher responded to any questions that were asked by group members. A group member volunteered to design a sign up sheet which was placed at Site A.

At Site B, the researcher met with the group members once a month from October 1989 to February 1990. (Researcher had prior informal contact with group members at Site A. Therefore, she decided to spend time at Site B in order to develop a rapport with group members there.) The researcher followed the same procedure for introducing the study to group members of Site B as in Site A.

The interviewer met with each subject alone in a separate room in Site A or Site B for 60 minutes or less. Initially, the interviewer

asked the subject to read the consent form, and to sign if he or she then agreed to be interviewed. If the subject had any questions at any point, the interviewer would answer them. The researcher reminded the subjects during the interview that they could refuse to answer any question. Furthermore, the researcher asked each subject at the end of the interview if there was anything that he or she would like to add.

The interviewer utilized a tape recorder for 10 subjects, as well as simultaneously recording notes. One subject requested not to be recorded; therefore, there is only the written documentation of her answers. The interview schedule consisted of 33 questions (see Appendix C). The questions were designed to obtain demographic data and information concerning the subjects life experience in a variety of areas. Two examples of the 33 open-ended questions that were asked are as follows:

1. "Do you feel that you have ever been discriminated against in any way due to your mental illness?"
2. "Under what circumstances would you decide to tell or not to tell someone about your mental illness?"

The subject selection was a sample of convenience.

Additionally, the interviewer needed to explain questions 22, 28, and 29 to the majority of subjects. The reason for so doing was that people did not understand the question adequately.

Data Analysis

Having selected 11 subjects, the researcher created a matrix of responses organized by subjects and questions. The researcher looked

for similar and dissimilar themes that were apparent in the data. The data were then divided into major findings and additional findings. Furthermore, the researcher noted differences between the two age group modes. The researcher labored to utilize the actual words of the subjects and to make the process and content of her own inference drawing clear to the reader for the latter's scrutiny.

CHAPTER IV

FINDINGS

Each subject in this study has had a significant mental illness for a prolonged period of time. The subjects were asked about their experiences of discrimination and stigma. In this study, discrimination refers to the external actions of others towards the subject; stigma refers to the internal reactions of the subject to the actions of others. The main findings that emerged in this study are that each subject has experienced discrimination or stigma in his or her life; that the reactions of others towards the subjects have changed upon learning of their mental illness; and that the discrimination or stigma that the subjects have experienced has caused feelings of unworthiness, self-blame, and low self-esteem. These findings will be further elaborated after a description of the 11 subjects in this exploratory study.

Subjects

The subjects interviewed for this study are currently attending two separate programs for people with a history of mental illness. The age range is 24 to 63 years of age; clustering into two modes, one in the 20s to 30s and the other 50s to 60s. Each subject is Caucasian. There are 5 females and 6 males. Each subject is not employed, has a

history of multiple hospitalizations, and has one or more of the major personality disorders.

Jennifer is a 24-year-old white female who has been involved in her program for a year. She is not presently employed. She does not have any children. She lives alone in a suburban area. She has been psychiatrically hospitalized five or six times. She is involved with a program Monday through Friday. She visits her parents and brother every day, goes to church on Sundays. Sometimes she goes out with friends. Her goals are to "learn how to play guitar, be able to be happy, and not to be lonesome."

Irene is a 29-year-old white female who has been involved in her program for a year. She is not presently employed. She has two children. She lives alone in a one-bedroom apartment in a suburban area. She has been hospitalized two times. She says that she is "gradually establishing herself." Her goals for the future include "getting her children back and striving to be healthy and realistic."

Emily is a 26-year-old white female who has been involved in her program for about a year. She is not presently employed. She does not have any children. She lives alone in an apartment in a suburban area. She has been hospitalized five times. She is a volunteer at a day care center, works at a training site, and goes to therapy. Her goals are "to try to be more independent and to be out of the mental health system."

Matt is a 63-year-old white male who has been involved in his program for nineteen years. He is not presently employed. He has one

child. He lives alone in a rooming house in a suburban area. He has been hospitalized three or four times. He said, "My goals are to try to get more money. For the future, I don't know."

Bruce is a 55-year-old white male who has been attending his program for approximately 25 years. He is not presently employed. He does not have any children. He lives "comfortably" with his wife in their home. He has been hospitalized many times, but was not able to state the exact number of hospitalizations. He volunteers his time to many human service organizations. He said, "My goals are to travel with my wife and enjoy the good things of life."

Dean is a 55-year-old white male who has been attending his program for 10 years. He is not presently employed. He does not have any children. He lives alone in a room in a rooming house in a suburban area. He has been hospitalized on and off for about 7 years. He is currently volunteering in a human service organization. He said, "My goals are to read Summa Theologica by St. Thomas Aquinas, and to reread my old chemistry and calculus books."

Michael is a 30-year-old white male who has been attending his program for 3 weeks. He is not presently employed, but said, "I would love to be." He has one daughter, and lives with his wife in a "beautiful" apartment in a suburban area. He has been hospitalized three times. He presently attends his program daily. He said, "My goals are to learn how to work with the medication, to get off of SSI, and to learn what I can do as a worker."

Alan is a 40-year-old white male who has been attending his program since it began (approximately 20 years). He is not presently employed. He does not have any children. He lives with his mother in her home in a suburban area. He has been hospitalized many times. He presently helps his mother around the house, and swims regularly. He did not state any future goals at this time.

Patty is a 33-year-old white woman who has been attending her program for a month and a half. She is not presently employed. She does not have any children. She lives alone in an apartment in the suburbs. She has been hospitalized two times. She presently attends her program regularly. She has not thought about her goals for the future.

Evan is a 31-year-old white male who has been attending his program for 2 to 3 weeks. He is not presently employed. He does not have any children. He lives in a shelter, and is currently waiting for subsidized housing. He has been hospitalized several times. He is currently attending his program and is slowly adjusting. His goals include finding "adequate housing and being employed."

Linda is a 42-year-old white female who has been involved in her program for 2 years. She lives in a supervised apartment with a roommate in an urban area. She is not currently employed. She does not have any children. She has been hospitalized off and on for the past 20 years. She currently attends her program regularly. Her goal is to "get a job."

Major Findings

Discrimination or Stigma

The first major finding is that each subject in this study has experienced stigma or discrimination in at least one area of her or his life. Some of the areas of discrimination and stigmatization that were reported by these subjects are the following: experiencing job discrimination, being ridiculed or harassed by people, being labeled, being feared, and being blamed for mental illness.

The researcher asked the subjects whether they had ever been discriminated against in any way due to their mental illness. The responses the subjects gave revealed their shared experience of stigma or discrimination. Interestingly, many subjects stated that they did not experience stigma or discrimination and then later gave an example in their lives of an experience of stigma or discrimination. Furthermore, the researcher used the word discrimination but did not use the word stigma in the interview schedule. Yet, it is interesting to note that many subjects used the word stigma in response to the researcher's questions.

The relationship of discrimination and stigma can be viewed as two sides of the same coin. For the purposes of this study the researcher will present segments of the responses given by each of the subjects describing her or his experience of discrimination or stigma. The subjects spoke of their internalized feelings that were associated with the deviant status of being an individual with a mental illness.

Jennifer said, "Yes, at the hospital, people look at you like you are a sick person. . . . Outside the hospital [there is] no discrimination."

Irene stated,

Some people are only friendly to you in the office situation, and on the street they will avoid you, they don't want anything to do with you on the street. . . . I am part of a large community of people with mental illness who are all being stigmatized.

Emily answered,

Not by staff, but by people in the community. . . . People look down on me . . . call me a lunatic. [There was an incident] and all of the mental health clients are being told that they have to reveal their names and that is a violation of my rights.

Matt said,

Yes, I went to get a job [and the] guy was interested in me. I told him the truth about my hospitalization, and [he said], Sorry, no job. . . . I am still waiting for a letter [from him]. . . . I lied about [taking medication to someone]. I used to tell him I was just taking a cold tablet.

Bruce said,

People make sarcastic remarks in church and clubs.

Dean commented,

Just because you are paranoid does not mean that they are not picking on you.

Michael stated,

I was going to college, [I] made the Dean's list, I was working at a lab, until they found out that I had schizophrenia, so my job ended. . . . The stigma really killed me, it is not fair.

Alan said,

No, [but later added] people make fun of me sometimes.

Patty said,

No, [but then later added] people don't realize that even though somebody is mentally ill that they are still people.

Evan said,

I have to swallow my pride a lot. . . . Stigma is very difficult for a person on the outside to see.

Linda said,

I think a lot of community people are afraid of people from the hospital. They treat us with disrespect, [which] lowers my self-esteem. . . . Too bad people can't open up their hearts. It isn't our faults. . . . I think people look down on you. . . . [I also believe] the budget cuts are another form of stigma.

Reactions of Family, Friends, and Acquaintances

The second major finding is that the reactions of family members, friends, or acquaintances changed towards the subjects upon learning of their mental illness. The majority of people said that their families' reactions were both positive and negative. In general, subjects' friends who were not involved in the mental health system were not supportive. Subjects were also discriminated against by acquaintances or community members.

The following statements are excerpts from subjects' responses to questions asking if people's reactions towards them had changed upon learning that the subject had a mental illness. The researcher noted that many subjects felt that people in general did not have a full understanding of what it is like to live with a mental illness. The researcher hypothesizes that the difficulty that people have with understanding and empathizing with people who have a mental illness is a major contribution to the painful and traumatic changes that occur in the subjects' social networks.

Jennifer said,

Yes, my family's reactions have changed, they treat me like I am really different. . . . I am pretty restricted from all past friendships. . . . It hurts, changes in friendships. . . . If my parents would let me stay at the house, I would not feel so abandoned. . . . My mother and father do support me a lot . . . but I am driving them to early graves.

Irene said,

Some people's reactions have changed. Some had a hard time dealing with my illness. It is hard on your family. . . . It had a traumatic effect on my children. . . . I don't know how to describe it to you. You just have to think what if that was [sic] me in a mental block, how would my family react to it?

Emily answered,

Most of my friends are in the mental health system. My family understands my mental illness more [now].

Matt remarked,

My family has always been behind me . . . but my so-called bar-room friends used to beat me up. [Now, I have] learned about my disability from others, we help each other out. . . . Some of my friends are insupportable [sic] because they don't understand the illness.

Bruce said,

People can accept heart disease, they can accept blindness, but they cannot accept paranoid schizophrenia. . . . Some people are ignorant, no matter how intelligent they may be.

Dean stated,

[I] use a mechanism to sort of block out what you [sic] don't want to see.

Michael said,

My family gets closer to me. . . . My friends don't know.

Alan said,

I love my brother, but my brother gets cruel sometimes [concerning my schizophrenia].

Patty said,

No, not that I know of.

Evan remarked,

I have yet to tell my friends in college that I do have a mental illness.

Linda said that in her family she is seen as

the weak, sick one. . . . My younger sister does not know how to treat me. . . . They were ashamed of me, they felt responsible. . . . Now, we are more like friends. . . . I feel very socially restricted. I feel like have have to stay in my own class or I will have hell to pay.

Internalized Feelings of Stigma

The third major finding is that many subjects reported that they have low self-esteem that is in part due to discrimination or stigma. The subjects reported often that they would not tell people about their mental illness unless they felt safe enough to discuss their history. The subjects spoke of their feelings of shame, pain, and rage in response to questions asking them about their right to self-determination, readjustment after hospitalization, and how discrimination has affected their sense of themselves.

The researcher hypothesizes that the discrimination that the subjects have been forced to endure has led to internalized feelings of unworthiness, self-blame, and self-hatred. If one listens to the words of the subjects in the study, one can hear the stories of stigma. The following are segments taken from the subjects' responses to questions concerning their experiences.

Jennifer said,

At times I am ashamed of it. If I wanted the person to think good of me, I would not tell them. . . . I decide to tell or not to tell people because of internal feelings and external reactions.

Irene stated,

If they don't like it or can't deal with it, it is their problem. I am not going to clam up, it doesn't help me.

Emily commented,

I would not tell if I did not know the person very well. . . . Sometimes people say that they understand about my problem, but they really don't.

Matt explained,

Initially I did not know that I had schizophrenia, I was thinking God was punishing me. . . . People do not understand.

Bruce exclaimed,

Don't tell people [about your mental illness] if you are getting your passport to go to Europe. . . . I used to cry a lot. I thought I was an outcast of society because I had to be locked up in a cage.

Dean said,

I would never tell anybody about my mental illness unless they were a close friend. . . . When I was ape, my sense of myself was way down. I am doing better now.

Michael commented,

I would tell people if people needed to hear, I am getting a little freer with the stigma of the label.

Alan remarked,

If I am in a good mood, I explain to them that I have an illness, [but] I don't let it bother me because they have their own problems.

Patty said,

If I feel comfortable with someone, I feel they should know.

Evan explained,

[I would decide to tell someone or not to tell someone about my mental illness based] on how friendly I want to get with them.

Linda said,

[She would tell someone about her illness] depending on how well I knew them and how understanding they were. . . . We are treated like third class citizens.

Messages

The fourth major finding is the messages that the subjects wished to give to staff and society at large. Overall, the message given to staff is that the subjects would like the staff to relate to them in an empathic and patient manner. From society at large, people asked for understanding, knowledge of mental illness, respect, empathy, support, and prayer. The following remarks are segments from the subjects' comments to questions asking them to give messages to staff people and society at large.

Jennifer said,

I would like staff to be more sensitive to my not readiness; [in general, have] patience for these people and sometimes giving of your time.

Irene said,

Staff should put themselves in our shoes. [In general] we probably could be doing more if we were not so stigmatized. . . . Being understanding and treating you like you are a person can help tremendously.

Emily said,

Staff should let me have more control. [In general] people with mental health problems are just like everybody else, only [sic] difference is we have to live in a program or an institution. . . . We can work, we can tell people how we feel, just like I did with the mayor three weeks ago.

Matt said,

Schizophrenia is not a very nice monogram to have sewn on your coat, mostly mental people stick with their own, hawks don't go with doves, they kill them and make food out of them.

Bruce stated,

Pray for them, have patience, wisdom, understanding, and knowledge of the sickness.

Dean said,

People with mental illness do not fit these weird stereotypes.

Michael said he hopes that

staff people have respect for what I [sic] have accomplished [and] that each [person] has a quality that can be given to each individual when they need it. [In general] look at a person's work history, ambition, and what they have to offer.

Alan said,

Show love towards people with schizophrenia. . . . Schizophrenia has no age limit, does not [choose] between rich or poor, good or bad. You can still get schizophrenia. . . . I thank God for schizophrenia sometimes. I really think that God has a reason, and I look at life a lot differently [sic].

Patty said,

Respect them for who they are, be supportive, and let them be who they are without criticising them.

Evan said,

[There is the] pain of relying on the medication forever and the internal stigma.

Additional Findings

The additional findings were that 10 out of 11 subjects stated that they had never experienced housing discrimination. One subject said that she had experienced housing discrimination. Eight (8) out of the 11 subjects received housing assistance, and all 8 subjects found

it to be very helpful. Seven (7) out of 9 subjects said that readjustment after hospitalization was difficult. Two (2) subjects said that they did not find it difficult to readjust after hospitalization. Two (2) subjects did not answer the question on readjustment after hospitalization. Five (5) subjects reported that they see predominantly negative images portrayed of people with mental illness in the media; 2 subjects said that they saw both positive and negative images in the media; 3 subjects said that they did not know; 1 subject said "It is becoming more positive because of the work that the AMI [Alliance for the Mentally Ill] is trying to do." Finally, 7 out of 11 subjects described mental illness as a biochemical disorder, 1 subject did not know, and 3 subjects defined it as a label for an illness or a problem.

Two additional findings require further elaboration. On the subject of job discrimination, 7 subjects said that they had experienced at least one instance of job discrimination. The subjects defined job discrimination as receiving low pay, being fired or not hired based solely on their history of mental illness. When the researcher asked the other 4 subjects if they had ever experienced job discrimination, 3 subjects said that they had not; yet later they told the researcher of an instance in which they had been discriminated against. One (1) person said she never experienced job discrimination. Eight (8) out of 11 subjects had been involved with a job assistance program and found it to be helpful. The remaining 3 subjects had not been involved in any kind of job assistance program.

It was interesting to this researcher to note that there were not major differences between the two age group modes. The only differences noted were that the 50- to 60-year-olds all told the researcher an adage: "that it was vital that if one has a mental illness, one must be involved in therapy, take medication, and educate oneself about the illness." Overall, the older subjects were more appreciative of present-day psychotropic medication and the increased knowledge of mental illness. Furthermore, the older subjects seemed less aware of negative or positive images of people with mental illness in the media.

It was overwhelmingly clear to this researcher that all subjects, regardless of age, had experienced discrimination or stigma in their lives due to their mental illness. In particular, all subjects' comments were remarkably similar in responding to questions about discrimination, peoples' changing reactions towards them, internalized feelings of stigma, readjusting after hospitalization, and the messages given to staff and society at large. The researcher hypothesizes, based on the striking similarity of responses given by each subject, that the experience of stigma or discrimination is ageless and timeless.

It appeared to this researcher that there were three findings that were not directly asked for but that were revealed in the interviews. The majority of the consumers felt that the low wages they earned and budget cuts in human services are unfair and stigmatizing. Also, when this researcher asked the subjects if they were employed, most answered

the question in a sad tone of voice, with a dejected expression on their faces. Overall, the researcher found the subjects to be remarkably honest in their portrayal of the often painful effects of discrimination or stigma.

CHAPTER V
DISCUSSION

The major findings that emerged are that each of the 11 subjects in this study have experienced stigma or discrimination in their lives; that the reactions of others towards the subjects have changed upon learning of their mental illness; that the discrimination or stigma that the subjects have experienced has caused feelings of unworthiness, self-blame, and low self-esteem; and that they wished to tell people in general to take the time to gain knowledge, respect, support, empathy, and pray for them.

The additional findings that emerged were as follows: Most subjects had primarily positive experiences finding adequate housing; the majority of subjects had difficulty readjusting after hospitalization; subjects saw both positive and negative images in the media of consumers; most subjects defined mental illness as a biochemical disorder; almost all subjects have experienced job discrimination; and most subjects felt that the low wages they earn and budget cuts in human services are a form of discrimination. Finally, this researcher noted that the only major difference in the two age group modes is that the older consumers were more appreciative of modern day advances in medication and overall knowledge of mental illness.

The researcher presents the literature that is relevant to this study, which encompasses the notions of stigma and discrimination. The subjective experiences of consumers, which are often written anonymously, are presented. Furthermore, most authors have stated that there is a limited amount of research on the subjective experience of such consumers.

The strength of this study is its in-depth presentation of consumers' feelings and thoughts about discrimination and stigma. This researcher is in agreement with all of the authors presented in this study who call for further research in the area of exploration of consumers' subjective experiences. This study is a contribution to the growing body of literature addressing this subject area.

A limit of this study is the fact that its subjects cannot be demonstrated to be a representative sample of consumers. An area of future research that would be most beneficial would be a continuation of providing a forum for a larger number of consumers. This researcher believes that it is vital for clinicians, and indeed all of society, to listen to what consumers have to say about their lives. In so doing, they will allow for more empathy and understanding between consumers and their community. In this way, perhaps one day the attitudes and forces that stigmatize people with mental illness will be removed from our society.

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Appendix A

Human Subjects Review Sheet

Exploratory Study of People With a History of Mental Illness:
Subjective and Objective Experience of Stigma.

Amy Rappaport

Purpose of the study is to conduct an exploratory study ascertaining patients' subjective and objective experiences of stigma. Interviewer will meet with eleven people for one hour sessions and ask the same questions to each person. There will be two study samples. One group will consist of members of a psychosocial rehabilitation club and the other group will be members of a weekly support group for people with a history of schizophrenia. The goal of the project is to make a contribution to the growing body of literature which reveals patients' attitudes and feelings about their experiences of stigma.

Characteristics of the people: The eleven people in the study will be members of either a weekly support group for people with a history of schizophrenia or a psychosocial rehabilitation club. All participants will be older than age eighteen. All participants will have had a history of mental illness. Sample size will be eleven people.

Nature of the participation in research: Each participant will first be asked to sign a consent form. If they consent, each person will then participate in a one-hour interview responding to thirty-three questions (see attached interview schedule).

Risks and benefits: The researcher believes a possible risk is that subjects may find it difficult or painful to answer some of the questions. A benefit that will hopefully come out of this research is the contribution that will be made to the literature on consumer attitudes and feelings. The more data that exist, the more beneficial treatment services can be for the consumers. Also, consumers' voices about their experiences will be added to the literature, thereby increasing understanding and empathy.

Type of consent: The researcher will present a synopsis of this study to the potential participants at each program site. After the presentation, the researcher will then field any questions. The researcher will ask each participant to read and sign a consent form if they agree to participate in the study (see attached interview schedule). The researcher will give subjects a copy of the consent form as well as retain a copy.

Precautions: The researcher will not reveal participants' names, nor will the researcher reveal the location of the research. The researcher will respect each subject's right to confidentiality. The researcher will be prepared to make appropriate referrals if any participants experience any degree of pain or difficulty due to the study.

Interviewer _____

Advisor _____

Date _____

Appendix B

Consent Form

I am conducting a study of people who have had a history of mental illness. The purpose of the study is to explore people's subjective and objective experience of stigma. (Stigma means a mark of shame or discredit.) I will do this by interviewing people for one hour or less.

You are being asked to participate in this study. If you agree to participate in this study, you will be asked to meet with an interviewer for one hour or less and answer thirty-three questions. These questions try to ascertain your feelings about whether or not you have been discriminated against ever based solely on your history of mental illness.

There will be no financial benefits to you, and no other benefits anticipated, other than perhaps feeling that you have contributed to the further understanding of people with a history of mental illness.

Your decision whether or not to participate will not affect present or future relations with the agency you are currently affiliated with.

Confidentiality will be protected by coding the information and filing it under lock and key and will be disclosed only with your permission. Every effort will be made to ensure your anonymity. If you give your permission by signing this document, the data will be used anonymously in scientific presentations and publications.

If you have any questions, please feel free to ask them. Your cooperation is entirely voluntary. You may refuse to answer any question. You may also change your mind and withdraw from the study at any time. If you decide to withdraw, all data describing you will immediately be destroyed.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.

If you have any questions or wish to withdraw your consent, please contact:
Amy Rappaport
Smith College
School for Social Work
Northampton, MA 01063

Name _____

Date _____

Interviewer _____

Appendix C

Interview Guide

1. How old are you?
2. What race are you?
3. How long have you been coming to this club?
4. Are you presently employed?
5. Do you have any children?
6. What are your living circumstances?
7. Do you live alone or with others?
8. Do you live in an urban or rural area?
9. Have you ever been hospitalized?
10. If so, when and for how long?
11. Why did you go to the hospital?
12. Briefly describe your present situation and your goals for the future.
13. Do you feel that you have ever been discriminated against in any way due to your mental illness?
14. Do you feel that you have been treated in a beneficial way by staff and others involved in your life?
15. Have people's reactions towards you changed since they have learned of your mental illness? Friends, family, and/or acquaintances?
16. Have you ever experienced any kind of job discrimination?
17. Have you ever been involved in a program to help you find employment? How would you evaluate it?
18. Have you ever received any kind of housing assistance? Was it helpful?
19. Have you ever experienced any kind of housing discrimination?

20. Under what circumstances would you decide to tell or not to tell someone about your mental illness?
21. Do you feel supported and/or discriminated against because of your mental illness? If so, how?
22. Do you feel that there are negative images or positive images portrayed of people with a mental illness in the media? In society at large?
23. How do you feel that the discrimination that you have heard about or experienced (if any) has affected your sense of yourself?
24. How would you define the term "mental illness"?
25. Do you feel that your right to self-determination has been decreased or increased?
26. In general, have you had any difficulties readjusting after your hospitalization? If so, in what ways? If not, what has been helpful?
27. Do you feel that people in the community at large wish to form connections with you or distance themselves from you?
28. Has there ever been an occurrence where someone did not give you a responsibility that you were capable of handling because of your mental illness?
29. Do you feel socially restricted or socially unrestricted in any way? If so, how?
30. Do people treat you differently? If so, how so?
31. What things would you like to tell staff people in order to enable them to be more helpful to you?
32. What messages would you like to give people in general about people with mental illness?
33. Is there anything you would like to add?