

**HOW PERSONS WITH SCHIZOPHRENIA
EXPERIENCE CONNECTING WITH MENTAL HEALTH PROFESSIONALS**

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Abstract

The purpose of this study was to develop a substantive theory that explains how persons with schizophrenia (PWS) experience connecting with mental health professionals (MHPs). Nine PWS, clients from two community mental health centers, were asked to recount their interactions with MHPs. The interview transcripts were analyzed through the grounded theory methodology of Strauss and Corbin (1998). The interactional problem between PWS and MHPs stems from the stigma associated with schizophrenia. The central concept emerged from the data analysis as **Connecting Through Humanness**. **Connecting Through Humanness** is a three-part process where PWS identify whether MHPs stereotype them as schizophrenics or regard them as unique human beings. The first part, called **Displaying**, encompasses the circumstances under which PWS present themselves to MHPs for treatment. The second part, **Sizing-Up**, is the way in which PWS evaluate whether MHPs communicate understanding, compassion, and normalcy during the interactions. The result of **Sizing-Up** provides the basis for the final part of the process, called **Classifying**. PWS classify MHPs as helpful or not helpful. The MHPs whom PWS classify as helpful, validate their self-perceptions as unique human beings. The resulting theory is that PWS experience connecting with MHPs as interactions that are based upon mutual humanness. Descriptions in the literature of PWS and MHP interactions support the findings of this study. In addition, the conceptualization of the theory's central category, **Connecting Through Humanness**, is supported by nurse researchers in the extant literature. Nurse-patient relationships can be improved by applying the findings of this study to current practice and future research projects.

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Table of Contents

Abstract.....	iii
Acknowledgements.....	v
Table of Contents.....	1
List of Tables.....	6
List of Figures.....	7
Chapter I: Introduction.....	8
Overview.....	8
Schizophrenia.....	8
Grounded Theory.....	9
Purpose of the Study.....	10
Significance.....	10
Literature Review and Theoretical Framework.....	14
Chapter II: Research Method.....	16
Research Design.....	16
Methodology.....	17
Setting.....	17
Participant Recruitment.....	18
Participant Selection.....	19

	2
Data Collection	20
Interview Site	20
Research Tool	20
Mode of Collection	21
Data Analysis	22
Informed Consent	25
Scientific Rigor	27
Researcher's Perspective	29
Chapter III: Findings	31
Participant Characteristics	31
The Problem	32
Analytic Process	33
Displaying	37
Symptoms	37
Threatening	37
Nonthreatening	38
Reasons for the Encounter	38
Emergencies	38
Scheduled	39
Setting of Encounters	39
Inpatient	40
Outpatient	40

	3
Type of MHPs.....	41
Psychiatrists.....	41
Case Managers.....	41
Nurses.....	41
Counselors.....	42
Sizing-Up.....	42
Understanding.....	43
Knowing What to Do.....	43
Knowing What It's Like.....	45
Compassion.....	47
Taking the Time.....	47
Taking Action.....	48
Normalcy.....	50
Safety and Security.....	51
Love and Belonging.....	51
Positive Self-Esteem.....	53
Classifying.....	55
Helpful.....	55
Not Helpful.....	56
Summary.....	56

	4
Theoretical Perspective.....	57
Description of the Model.....	57
Model: Connecting Through Humanness.....	59
Assumptions.....	60
Hypotheses.....	60
Chapter IV: Discussion.....	62
Assumptions About Connecting Through Humanness.....	62
Assumption I.....	62
Assumption II.....	63
Assumption III.....	63
Assumption IV.....	64
Assumption V.....	65
Assumption VI.....	66
Hypotheses of Connecting Through Humanness.....	67
Hypothesis I.....	67
Hypothesis II.....	69
Hypothesis III.....	69
Hypothesis IV.....	70
Hypothesis V.....	74
Hypothesis VI.....	74
Theoretical Comparison.....	75
Type of Theory.....	79

	5
Chapter V: Summary and Conclusions.....	82
Summary of the Study.....	82
Implications for Nursing.....	87
Clinical Practice.....	88
Education.....	91
Theory Development.....	92
Research.....	93
Limitations of the Study.....	95
Chapter Summary.....	97
References.....	98
Appendix A.....	106
Appendix B.....	107
Appendix C.....	110

List of Tables

Table 1: Years First Diagnosed with Schizophrenia.32

List of Figures

Figure 1: Connecting Through Humanness 59

Chapter I: Introduction

Chapter I presents a brief overview of schizophrenia and of grounded theory research. Following the overview is a description of the purpose of the study, followed by the study's significance to nursing and psychological literature. The chapter concludes with an explanation of how the literature review and theoretical framework are used in grounded theory research.

Overview

Schizophrenia

Schizophrenia is a mental illness that "attacks the very core of what makes us human - the capacities for intimacy, communication, and thought" (Selzer, Sullivan, Carskey, & Terkelson, 1989, p. 33). Depending upon the predominant symptoms exhibited, schizophrenia is classified into paranoid, disorganized, catatonic, undifferentiated, and residual types. The symptoms of schizophrenia are often categorized into two groups, those that are "positive" and those that are "negative" (American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 1994).

Positive symptoms are those that "appear to reflect an excess or distortion of normal functions" (DSM-IV, p. 274), and are usually more obvious to others. Positive symptoms are seen most often in the forms of hallucinations, delusions, and disorganized speech or behavior. The most common and characteristic type of hallucination in schizophrenia is the auditory hallucination. Typically experienced as voices that are distinct from the person's thoughts, auditory hallucinations are often degrading or threatening. The most common type

of delusion is persecutory. Affected persons believe they are being watched, followed, tormented, or ridiculed (DSM-IV, 1994).

Negative symptoms reflect losses of normal functioning. These include a flattened affect, poverty of speech (alogia), and an inability to initiate or persist in goal-directed activities (avolition) (DSM-IV, 1994). Persons with positive symptoms are more likely to respond to antipsychotic medication than those persons with negative symptoms.

Schizophrenia typically strikes between the late teens and mid-thirties, a time of life when people are usually embarking on some of the most productive years of their lives. The impact of the disease on their lives is profound. While persons without the disease are developing their careers, those with the disease are barely able to complete their education or maintain employment. While their peers form a network of relationships, persons with schizophrenia socialize little, if at all. Persons with schizophrenia feel alienated from the rest of society (DeNiro, 1995). Fifty to sixty percent of them never marry. These feelings of alienation may explain, in part, their 10% rate of suicide. Although the course of their disease may be variable, the majority of individuals with schizophrenia are unlikely to return to premorbid functioning (DSM-IV, 1994).

Grounded Theory

Grounded theory research grew out of the symbolic interactionist tradition of the Chicago school of sociology (Robrecht, 1995). Symbolic interactionism is based upon the premise that people define reality based upon how they interpret specific symbols in their lives. The ways in which people interpret the symbols are played out through their interactions with others (Streubert & Carpenter, 1995). The grounded theory method,

originated by Glaser and Strauss (1967), is based upon the premise that people who share common experiences also share common meanings and behaviors. Such people may experience a similar problem that they often can not articulate. By conceptualizing a previously unarticulated problem and the ways it is managed through social interactions, grounded theorists are better able to explain and predict behavioral variation within a group (Hutchinson, 1993).

Purpose of the Study

The purpose of the following study was two-fold, (a) to understand the interactional process between persons with schizophrenia (PWS) and mental health professionals (MHPs) from the perspective of PWS, and (b) to form a theoretical structure via the grounded theory methodology of Strauss and Corbin (1998) that explained some aspect(s) of the PWS-MHP interactional processes. Strauss and Corbin assert that "the research question in a qualitative study is a statement that identifies the phenomenon to be studied" (p. 41). The specific research question in the present study was: "How do persons with schizophrenia experience connecting with mental health professionals?"

Significance

Increasing nursing's knowledge about the interactions between health care professionals and PWS is important for several reasons. One reason is the tremendous toll that schizophrenia takes on the nation's resources. An estimated 1.8 million persons in the United States have schizophrenia and occupy 50% of psychiatric hospital beds (Torrey, 1995). The financial cost of schizophrenia has been estimated at 33 billion dollars a year (National Advisory Mental Health Council, 1993). As Torrey (1995) elucidated, "If a fiendish

economist from another planet were trying to devise a disease that would force our society to incur the maximum costs, then he could not do better than schizophrenia" (p.17). The cost of schizophrenia, however, entails more than finances. In their 1993 report, the National Advisory Mental Health Council, concluded that "no dollar figure can begin to account in human terms for the enormous emotional cost and pain borne by Americans with severe mental illness and by their families" (National Advisory Mental Health Council, 1993, p. 1447).

The relationship between nurses and other health care professionals with persons with schizophrenia has treatment implications. One is the failure of the primary mode of treatment, antipsychotic medication, to help a substantial number of sufferers. Standard antipsychotic medications reduce symptoms in only 60% of patients (National Advisory Mental Health Council, 1993). Newer antipsychotic medications such as clozapine and risperidone show promise in reducing negative symptoms, but their side effects and/or cost can be prohibitive.

Another problem with medication treatment is self evident - a substantial number of PWS won't take their medicine. A major feature of schizophrenia is denial, or unawareness of the disorder (Amador et al., 1994), which Mulaik (1992) found to be the primary reason for medication nonadherence. Based on his study, Weiden (1991) advised practitioners to assume medication nonadherence among patients. The rate of medication nonadherence within the first year after hospital discharge was 48%, with a 73% projected rate for the second year. Not all of the PWS in Weiden's study, however, were nonadherent.

The strongest predictor for adherence was a good doctor-patient relationship. This underscores the importance of understanding how such relationships are developed and are maintained.

Alternative or adjunctive treatments to medication are psychosocial therapies, or the "talking therapies." Examples of psychosocial therapies are social skills training, illness-related educational groups, and supportive psychotherapy (McFarland, Wasli, & Gerety, 1992). According to findings of the National Mental Health Council (1993), the rehospitalization rate over a two-year period decreased from 60% to 25-30% when psychosocial treatments were combined with a medication regimen. A major factor in psychosocial treatment's success, however, is the ability to communicate. Many of the symptoms, such as disorganized thinking and perceptual disturbances, impede communication between PWS and with others.

As is generally true of studies concerning schizophrenia, nursing research specific to PWS is more illness-focused. For example, nurse researchers have studied the areas of symptom management (Hamera, Peterson, Young, & Schaumloffel, 1989 ; Puskar et al., 1990; McCandless-Glimcher, 1986; Rosenthal & McGuinness, 1986; & Field, 1985), relapse (Hunter & Storat, 1994; Fetter & Lowery, 1992; & Hicks, 1989), or daily functioning (Kirkpatrick et al., 1995; Lorencz, 1992; Dzurec, 1990; Godschalx, 1987). None of these studies, however, focused on relationships. As one sufferer explained, "Medication or superficial support alone is not a substitute for the feeling that one is understood by another human being" (Anonymous, 1986, p. 70). Thus, Goering and Stylianos (1989) advocate for

more studies of relationships with schizophrenic clients rather than those pertaining to treatment.

The psychology literature is replete with studies (many of them quantitative) of psychotherapist-client relationships, but includes clients with a variety of psychiatric diagnoses (Bachelor, 1991; Coady, 1994; Kivlighan, 1990; Krupnick, et al., 1994). Studies from other disciplines also lack a nursing perspective, and therefore, do not address the context of nurse-client relationships. Nurses interact with their clients, including those with schizophrenia, in many roles in addition to that of psychotherapist.

Studies of nurse-patient relationships may be found in the literature but they are not specific to persons with schizophrenia. These studies also fail to gain the perspective of the clients themselves (Heifner, 1993; Morse, 1991; Ramos, 1992). Three studies that did include the patient's perspectives were those involving psychiatric patients and psychiatric nurses.

Farrell (1991) found that hospital nurses from general medical floors and psychiatric floors adequately perceived patients' needs as a group, but did a poor job on an individual basis. Nolan (1989) uncovered a low level of agreement between psychiatric nurses' and patients' perceptions and expectations of care. In the Nolan study, thirty primary nurse-patient dyads were asked the same set of 11 questions. On average, only seven out of 23 dyads agreed on the responses.

Muller & Poggenpoel (1996) conducted a study with thirteen psychiatric clients, both inpatient and outpatient, to learn more about their perceptions of interactions with psychiatric nurses. The subjects described their experiences from stereotyping, custodialism, rule enforcement, and lack of intimacy, to friendliness, empathy, and caring in their interactions

with psychiatric nurses. Lorencz (1992) emphasized that effective treatment for PWS must address the needs and concerns of the consumers, not just the providers. In view of the previously mentioned disparity between consumer and provider perceptions, attaining the perspective of the consumer is essential.

The interactional difficulties between PWS and health care professionals have a negative impact on their ability to form therapeutic relationships. Nurses consider an inability to form such relationships, the essence of nursing care, as a major contributor to treatment difficulty (Gallop, Lancee, & Shugar, 1993). PWS being viewed as “difficult” may in part explain the results of a survey by Mirabi, Weinman, Magnetti, and Keppler (1985). In their study of 436 mental health professionals (7% psychiatric nurses), 85% moderately or strongly agreed that chronic mentally ill persons were not a preferred population with which to work. If MHPs prefer not to work with persons with schizophrenia, what are the implications for professionals in other specialties?

Literature Review and Theoretical Framework

Grounded theory differs from quantitative methodology in its approach to the literature review and theoretical framework. The aim of grounded theory research is to discover categories of concepts and how they relate, not to identify important variables and test their relationships. Strauss and Corbin (1998) advise a limited search of the literature prior to the research process because too many preconceived ideas may restrict the creative process. On the other hand, knowledge of relevant literature can initially help the researcher decide what, among the vast amount of data, is pertinent to the study.

The concept "connecting" was chosen as relevant to this study because of its frequent association with the nurse-client relationship.

Furthermore, Strauss and Corbin (1998) state that identifying a theoretical framework prior to data collection may bias and constrain the researcher in the process of theory development. In contrast, an in-depth study of the literature upon the completion of data collection and analysis can be used to support or refute one's findings, thereby advancing what is known about a phenomenon.

Chapter II: Research Method

This chapter provides a brief overview of the research methodology that was used in this study. The methodological elements are discussed, including the research setting and participant selection process, data collection, and data analysis. The next topic is a description of the informed consent procedure, followed by an account of the measures taken to achieve scientific rigor. Finally, the researcher's perspective is described.

Research Design

Grounded theory falls within the qualitative research paradigm. Hutchinson (1993) supports the use of grounded theory as a means for nurses to increase their understanding of relationships. Benoleil (1996) maintain that grounded theory research performed by nurses has demonstrated the impact that social and contextual forces have on vulnerable populations. P.B. Lieberman (1989) asserts that the active involvement and interpretation of the qualitative researcher is necessary to understand meaning in persons with schizophrenia.

The grounded theory research methodology used was that of Anselm Strauss (Strauss and Corbin, 1998). Although grounded theory research began as a collaborative effort between Glaser and Strauss (1967), the two disagreed on how to further delineate the methodology described in their book. In her examination of the evolution of grounded theory from the 1967 to the present, Melia (1996) noted the tendency for researchers to cite the original method when they had actually used the Strauss and Corbin method. As a novice researcher, the researcher chose Strauss' method over Glaser's. First, Strauss' method was more familiar because of its frequent use in the nursing literature. Second, although the differences in methods have raised some philosophical issues (Melia, 1996; Robrecht, 1995),

the researcher felt that the Strauss method offered more direction in how to conduct a grounded theory study.

Methodology

The design elements presented first include the setting of the study and the manner in which participants were recruited and selected. After an account of the informed consent procedure, the data collection procedures are described. A general overview of the methodology is used in explaining the procedures for data analysis. The researcher's perspective in conducting the study is explained, followed by the procedural steps taken to ensure scientific rigor.

Setting

The study took place in two publicly funded outpatient mental health centers located in the metropolitan area of a midwestern state. Godschalx (1989) found that choosing persons with schizophrenia based on their outpatient instead of inpatient status was an effective way to screen for their ability to participate in a study. Although there are exceptions, outpatient status assumes freedom from symptoms severe enough to interfere with daily functioning. The centers were in different neighborhoods but similar in their client population and services. Both centers served primarily persons with "severe mental illnesses" (a county-wide category designated for persons with certain diagnoses, including schizophrenia).

In addition to 1:1 case management and psychiatric services, the centers had group programs. The groups were designed for those clients who needed an environment more structured than that of the general community. The first center had two different groups. The

first was on site and emphasized education about mental illnesses and their management (sometimes referred to as psychoeducation). The other group focused on daily living skills and operated out of a house approximately one mile from the center. The program at the second center included psychoeducational and recreational group activities. The following discussion includes the procedures by which participants were recruited from the centers and selected for the study.

Participant Recruitment

The aim of quantitative sampling is to obtain a group of subjects that bear the most resemblance to the entire population under study. The more similar the sample is to the population, the more the results may be generalized to that population. The type of sampling performed in grounded theory, called theoretical sampling (Strauss & Corbin, 1998), differs from that of quantitative research. Instead of similarity, the aim of theoretical sampling is to maximize the opportunities for variation (1998). The more fully developed the categories are in their characteristics and magnitude, the more behavioral variation they are able to explain. Such categories may or may not be representative of the population.

People serve only as the means to discover incidents and events that relate to a phenomenon. Because people are chosen based upon their representations of situations, not other people, the initial sample size of a study can only be estimated. Strauss and Corbin (1998) suggest having approximately ten pieces of data with which to begin coding. In consultation with faculty experienced in conducting grounded theory research, the estimated sample size of this study was ten to fifteen. The final sample size was nine.

Recruitment was contingent upon the amount of access that the researcher was given to clients. Upon the approval of each center's research committee the researcher began the recruitment process. The researcher attended one of the monthly or weekly staff meetings of case managers and group leaders. An overview of the study and explanation of the inclusion criteria were presented to the staff. Each staff member was also given a handout about recruitment and selection procedures (see Appendix A).

Participant Selection

Case managers were asked to select those clients who were aged 18 and older, carried a DSM-IV diagnosis of schizophrenia, and were aware of their diagnosis. The first two inclusion criteria were chosen because schizophrenia typically strikes in young adulthood, and the DSM-IV diagnostic system was the one used by the mental health centers. Finally, participants had to have been told their diagnosis, based upon the procedure recommended by Applebaum and Roth (1982) to ensure informed consent. The informed consent protocol is described in the next section of the report. A copy of the consent form is located in Appendix B.

Having been told the selection plan, only two (one client each) out of more than 35 case managers made referrals. Both of the referrals were able to participate in the study. The remaining case managers from both facilities maintained that none of their clients had expressed interest in participating. The more likely scenario, perhaps, was that the case managers were not interested in participating. Fortunately, three group therapy leaders expressed an interest in helping recruit clients for the researcher.

These three leaders asked their clients who met the inclusion criteria if they were interested in talking to the researcher about the study. Ten additional clients (four from one agency and six from the other) were recruited in this manner. In addition to determining their desire to participate, the clients were screened their for their ability to speak intelligibly and willingness to have the interview recorded either by audiotape or handwritten notes. Clients were informed at this time that they would not be paid for their participation. A total of 12 clients agreed to be interviewed.

Data Collection

Interview site. The interviews took place at the particular center from which the participants were recruited. Each interview site provided adequate space and privacy. Five of the interviews were conducted in an unoccupied conference room and two took place in an unoccupied group therapy room. The five remaining interviews took place in staff offices at the first center's off-site location.

Research tool. In collaboration with faculty committee members, the researcher created a set of six open-ended questions (see Appendix C) as a beginning focus for the interviews (Strauss and Corbin, 1998). The concepts selected as the basis of the questions were considered provisional because they had not been grounded in the data. Despite the invitation in the first question to talk about any type of health care professional, all of the participants focused on mental health professionals (MHPs).

The questions that elicited the most in-depth response from participants were questions two and three. Participants were asked to describe what they liked and didn't like about the MHP's with whom they had interacted. The answers to questions two and three

(described as part of the Findings in Chapter IV) served as a guide for refining emerging concepts in subsequent interviews. Answers to question four, the length of time a participant and MHP had worked together, did not emerge as significant to the developing theory. Questions five and six, where participants were asked to identify characteristics of MHPs that made their interactions easier or more difficult, were confusing to the first two participants. The researcher attempted to reword the questions with the next three interviews, but to no avail. The questions were dropped for the remaining seven interviews, as the analysis revealed that the answers were imbedded in the participants' responses to questions two and three.

Mode of collection. Eleven of the twelve participants agreed to the use of a tape recorder. The lengths of the interviews ranged from 20 minutes to one hour. The participant who declined to be audiotaped was also the only one who initiated termination of the interview. These suggestions of his suspicion towards the researcher were further supported by his wearing sun glasses during the first half of the interview. He was, however, able to take off the sunglasses, and even comment on how much talking helped him to gain a perspective on his illness. In light of his initial suspiciousness, the researcher was surprised that the participant talked as openly, and for as long as he did. Because the interview only lasted twenty minutes, the researcher felt confident that the notes taken throughout the interview were an accurate reflection of what the participant had said.

The remaining participants did not demonstrate discomfort in sharing their experiences with the researcher. The first participant, however, told two jokes to the researcher before he was able to talk about his experiences. This participant thought that he

would not have much to say, but he talked for over 45 minutes and offered to be interviewed again if needed. A total of four participants thanked the interviewer for giving them a chance to talk about their experiences.

Data Analysis

A total of nine interview transcripts were retained for analysis. Two of the tape recorded interviews were unintelligible because of mechanical difficulties (unbeknownst to the researcher during taping). A third interview was not retained because of the participant's propensity for focusing on topics unrelated to the research questions. Because of time constraints, the researcher was unable to re-interview those three participants. The procedures used for data analysis were in accordance with Strauss' version of grounded theory methodology (Strauss and Corbin, 1998). An overview of the procedure is described below. A more detailed account of the analysis of this study's data is presented in Chapter III.

The basis of grounded theory analysis is the development and comparison of concepts. In their joint endeavor, Glaser and Strauss referred to this type of activity as the constant comparison method of data analysis (1967). The purpose of the constant comparison method is to identify, define, and relate concepts through a process called coding (Strauss and Corbin, 1998). Through three different levels of coding, data are fractured, conceptualized, and re-integrated to form theory.

Strauss went on to develop a method of analysis that he termed "theoretical comparison." Theoretical comparisons are used when a researcher comes across incidents that do not relate to preexisting conceptualizations. Instead of looking at characteristics of an

incident so they can be placed in specific categories, the characteristics remain uncategorized and are used as tools to analyze further data.

The initial level of data analysis, open coding, is a process where data are broken down into discrete parts, closely examined, and compared for similarities and differences. Incidents and events that are found to be conceptually similar in nature or related in meaning are grouped under more abstract concepts termed categories (Strauss & Corbin, 1998). The data were coded in the margins of the transcript. Rationale for the coding was contained in written memos, an ongoing record of the research process. "Questions that get best results are who do you like the best, least, asking for advice to give MHPs; ask more about caring, understanding," is an example of such a memo.

Transcript number one was broken down line by line into incidents that represented phenomena of interactions between participants and MHPs. Each phenomenon was underlined and assigned a conceptual label, often the word used by the participants. Concepts such as "defeat" and "don't understand us" were recognized as incidents of what the participants did and did not like about their experiences with MHPs. The two concepts, therefore, became the attributes, or characteristics, of the categories "good" and "bad." As the interviews and transcriptions continued, concepts that emerged from the data were compared with the concepts from prior interviews. Certain concepts emerged as attributes of a more encompassing category. For example, some concepts emerged that were locations, called dimensions (Strauss & Corbin, 1998), or places along a continuum of the attributes. To illustrate, an attribute of the initial participant-MHP encounter was type of symptoms.

Further analysis revealed a dimension of symptoms, i.e., the degree of threat that they represented.

The second level of coding is known as axial coding. One of its goals is to further develop categories by their attributes and dimensions. The second goal is to identify relationships between concepts as they emerge from the data (Strauss & Corbin, 1998). Relationships can be discovered by answering the "who, what, where, when, why," in regards to the phenomenon of concern. Participants, for example, described their interactions in terms of presenting symptoms, the treatment setting, reasons for the interaction, and the type of MHP with whom they interacted. The concepts that relate to the same context become the subcategories of the larger, and more abstract, category. Using the same example, symptoms, treatment setting, etc., became sub-categories of a major component of the interactional process.

The third level of coding, called, selective coding, involves further delineating categories and joining them with relational statements (Strauss & Corbin, 1998). The main theme of the study was revealed in the memo, "treat my illness while valuing my humanity; I may have schizophrenia but I'm still a human being. Participants are feeling regarded as a diagnosis more than human being. Schizophrenic versus person with schizophrenia."

The analysis concluded when the major categories of the theory were saturated. Analysis of the final two transcripts did not yield data that contributed significantly to the already established categories and their relationships (Strauss and Corbin, 1998). By examining each transcript of the research report, two committee members worked with the researcher to concur when saturation had been reached. The decision was also based on the

more practical issues recognized by Strauss and Corbin, "Every analyst has to accept that there are limitations to what can be discovered based on access to data, degree of analytical experience, and amount of personal reserves" (p. 188). A more detailed description of the data analysis is presented in Chapter III.

Informed Consent

The research proposal was reviewed and approved for the protection of human rights by the University of Cincinnati. The review board of each center also reviewed and approved the study. Informed consent is based upon the premise that a person has the mental capacity, or competency, to understand the issues relevant to participating in a research study. Cognitive impairments, including schizophrenia, may affect a person's ability to understand issues such as the nature of the study and the potential risks (Davidhizar & Wehlage, 1984). The researcher used the standards proposed by Applebaum and Roth (1982) in their seminal article on obtaining informed consent with mentally ill persons. The strategies for carrying out the standards were those recommended by Davidhizar and Wehlage (1984) in their research of informed consent specific to persons with schizophrenia.

Applebaum and Roth's (1982) standards are ordered to represent increasing stringency in testing a person's capacity to give informed consent. The first standard, evidence of choice, was confirmed via the participants' expressed desire to take part in the study. Davidhizar and Wehlage (1984) also cautioned against the use of caregivers in obtaining or witnessing consent. Agency staff not involved in the direct care of each participant witnessed the researcher's obtaining consent.

The second standard, factual understanding of the issues, was evidenced by the participant's ability to both paraphrase what was stated on the consent form (see Appendix B) and describe the consequences of deciding whether to participate (Applebaum and Roth, 1982). "Rational manipulation of information" pertains to a person's ability to manipulate information in decision-making. Davidhizar and Wehlage (1984) found that psychotic symptoms, frequently associated with "irrational thinking," did not interfere with the participants' ability to make decisions about participating in their study. Should the researcher, participant, the treating psychiatrist, and/or case manager have witnessed a decline in daily functioning, the participant would have been released from the present study. No such decline was observed or reported for any of the participants.

The strictest, and final, standard is appreciation of the nature of the situation. The two criteria for this standard are, a) that the informants are aware of how their problems or psychiatric conditions are appropriate for the study, and (b) that the proposed procedures are intended to achieve research ends and not necessarily therapeutic ends (Applebaum and Roth, 1982, p. 955). Denial of illness is common in persons with schizophrenia, but Davidhizar and Wehlage (1984) found that denial of illness did not preclude participants' appreciating the objectives and requirements for taking part in the study which, therefore, encompassed the "research vs. therapeutic" outcome criteria. Understanding the ways in which having a psychiatric condition related to the purpose of the study were addressed in the inclusion criteria. Every participant talked about his/her diagnosis throughout the interview.

Provisions for confidentiality were those stated in the consent form (Appendix B). The participants' identities were kept private by removing their names and all personal

identifying information from the audiotapes and written transcriptions. Names were not used to report study findings, nor was information that would enable a reader to link a particular participant with a particular statement. The researcher was also the transcriber and only shared the transcripts with two faculty members on the dissertation committee. Tape recordings and written transcriptions were kept in a locked file that could only be accessed by the researcher. The audiotapes are to be destroyed at the completion of the study. Written transcriptions are to be destroyed within five years of completion of the study.

Scientific Rigor

The standards used to assess the scientific rigor of the present study incorporated those of both nursing and grounded theory. Strauss and Corbin (1998) maintain that evaluative criteria differ according to the area of the study being judged. Their four types of criteria are, (a) those with which to judge fairness and rigor, namely validity, reliability, and credibility of the data; (b) those that are designed to judge the theory itself; (c) those that are used to judge the adequacy of the research process that was used to generate, clarify, or test the theory; and, (d) those that are used to evaluate the degree to which the findings are grounded in the data. Strauss and Corbin cite, among others, the guidelines commonly used in qualitative nursing research as explained by Lincoln and Guba (1985) and Sandelowski (1986) as appropriate methods for evaluating the rigor of grounded theory research.

In her seminal article "The problem of rigor in qualitative research" (1986), Sandelowski points out that each of the many methods of qualitative inquiry has its own rules for judging the aims, evidence, inference, and verification of the research. Although they differ in their use of the terms validity, reliability, and credibility, Sandelowski and Strauss

and Corbin address the evaluative issues discussed by Lincoln and Guba (1981). Lincoln and Guba reframed the quantitative conceptualizations of validity, reliability, and creditability into those that are more appropriate for qualitative research, including the truth value, applicability, consistency, and neutrality of a research project. The overall criteria of Sandelowski were used in addition to those specific to Strauss and Corbin's methodology for grounded theory research.

The first criterion is validity, which in quantitative research is differentiated into internal validity or external validity. Internal validity evaluates the degree to which the findings truly are a reflection of the phenomenon under study rather than the procedures used to test the phenomenon's existence. Strauss and Corbin's (1998) definition of validity is a reflection of a study's internal validity, the "process of comparing concepts and their relationships against data during the research act to determine how well they stand up to such scrutiny" (p. 24). Sandelowski considers internal validity as a measure of the "truth value" of a study. She supports Lincoln and Guba's term "credibility" over internal validity.

Credibility is the degree to which the findings are recognized by persons having experienced similar phenomena. Because of the time limitation the author was unable to return to participants for their feedback. The author did describe her findings to both professionals and nonprofessionals who were experienced in dealing with persons with schizophrenia and with grounded theory research.

Sandelowski prefers the concept "auditability" rather than "reliability" when referring to the consistency of the research findings. Auditability is more a reflection of procedural consistency than experiential consistency. Strauss and Corbin use the term "reproducibility"

in reference to consistency. To both sources, a study is consistent when another researcher can arrive at similar conclusions to the researcher's having followed the same procedures for analysis.

An "audit trail" provides readers with a description of the research methods that were used throughout the study. Sandelowski names memos and drafts as serving the purpose of gauging consistency. Strauss' method is to incorporate the "audit trail" into the research report. In addition to the methods, memos and descriptions within the report can serve as the demonstration of empirical grounding. Two committee members experienced in grounded theory methodology examined all of the author's drafts and a summary of all memos to assure consistency of the findings.

Researcher's Perspective

Strauss and Corbin (1998) propose that a brief explanation of the researcher's own perspective may assist readers in deciding how much the study was influenced by personal reactions. The researcher's perspective was based primarily upon 20 years of clinical experience with PWS. As a psychiatric nurse, the researcher observed differences in attitude among mental health colleagues toward working with PWS. The researcher's perspective of interacting with PWS was very positive. Some colleagues shared the researcher's comfort and satisfaction of helping PWS cope with the many challenges posed by their illness. The majority of colleagues, however, voiced a collective "how could anybody like working with schizophrenics."

An ongoing record of the researcher's reflections about the research process was used as a means to prevent personal perceptions from overshadowing those of the participants

(Strauss and Corbin, 1998). The ongoing record also helped to maintain an awareness of feelings about the role as researcher versus that of clinician. The following is an example of an entry reflecting such a role conflict: "I have to watch myself from getting lulled into the comfort of asking participant about the disease." Finally, the researcher shared her reflections with committee members and colleagues.

Chapter III: Findings

The first two topics presented as part of the findings are participant characteristics and the interactional problem with which they struggled. The next topic is an illustration of the conceptualization process that was used to formulate a hypothesis from the raw data. The chapter concludes with a list of assumptions, hypotheses, and a diagrammatic model of the central concept, *Connecting Through Humanness*.

Participant Characteristics

The nine participants whose transcripts were retained for analysis ranged in age from 28 to 54 with a mean age of 38. Five participants were male and four were female. Five were African American and four were Caucasian. None of the participants had ever been married. Demographic variables did not emerge as pertinent to this study, possibly a reflection of the select population served by community mental health centers.

Clients are typically of a low income level because of their inability to maintain gainful employment and lack of financial support from . They therefore, share a similar economic status. Because they rely on public transportation, clients usually reside in the vicinity of the center. transportation with severe mental illnesses and low income, and little to no services, i.e., have to utilize community mental health centers are there because of their low income, decreased level of functioning, and diagnosis. There are conflicting reports in the literature of the effect, if any, of demographic variables on the lives of PWS. The number of years each participant recounted since first having been treated for schizophrenia ranged from 11 to 30 years.

Table 1

Years Since First Treated for Schizophrenia

	Participants								
	1	2	3	4	5	6	7	8	9
Years	30	20	17	30	25	16	11	18	16

The Problem

Participants had been struggling with the ramifications of their illness for an average of 20 years. The struggle was illustrated by one's participant's declaration, "I hate this schizophrenia, working with it, me trying to cure myself, and the doctors trying to cure me." Although they perceived themselves as "normal," participants were acutely aware that "society" viewed them with stigma. Otherwise, to participate as "normal" members of society, all nine relied on some type of assistance from mental health professionals (MHPs). Unfortunately, certain MHPs shared society's stigma of schizophrenia. Thus, while trying to maintain "normalcy," the participants were forced to "confess" that which stigmatized them. This resulted with difficulty establishing an interpersonal connection with MHPs. The problem emerged as participants explained how they perceived themselves having been typecast as "schizophrenics" rather than regarded as unique human beings.

As "schizophrenics," participants felt they had lost their individual identities. As one participant said, "they (MHPs) think everybody with schizophrenia is the same." As a result, MHPs were skeptical of participants' own accounts of events. In the words of one individual,

“everything I said wasn’t worth anything.” Another participant recalled how her complaints of worsening symptoms were dismissed. When asked how she felt MHPs could better help those with disease, her advice was not to “doubt them.” Participants appreciated not having been typecast as dangerous. This was exemplified by one participant who said, “She (the case manager) never judged me. And she treated me like, though I was schizophrenia I wasn’t gonna hurt her or something.”

Even apparently benign perceptions were damaging to the participants when magnified by the MHPs’ attitude of “they’re all the same.” Being stripped of their individuality stripped many participants effective treatment, self-esteem, and/or getting their basic needs met.

Analytic Process

In order to better understand the interactional problem and its management, the following topic is a more detailed illustration of the data analysis mentioned in Chapter II. Portions of data are taken through the three levels of coding that comprise grounded theory analysis.

Open coding commenced when phenomena were identified, based upon the research purpose, to discover how persons with schizophrenia experienced connecting through mental health professionals. The first question used to initiate data collection was “what kinds of experiences have you had with health care professionals?” The answer to this question guided further data collection, and axial and selective coding. The following excerpts have been taken from the text of the first interview.

1. Well, there was one that sent me a...see, I used to have tardive dyskinesia....Anyway there was this lady working for HUBE...she was the top person there...they get clients different janitorial jobs and monogram things....She's been a real good help, and she's staff here at (community mental health center).
2. Well, when I was in the (long-term, public hospital), them nurses are like, well, have you ever seen movies of old asylums and stuff? That's how they were ...they were mean and they did not care how my feelings and other peoples feelings were.
3. Well, my doctor (at community mental health center) gave me that medicine...I started to quit one time and he said, "I still believe you should keep taking it," I had to quit the stuff... I told him (case manager)...he said, "we're not gonna make you take anything you don't want."

The concepts abstracted from the above data were, a person who helped people get jobs, nurses, doctors, case managers, hospital, community mental health centers, and the professionals' behaviors. The concepts were categorized into three categories: health care professionals, treatment settings, and characteristic behaviors of professionals. One property of health care professionals and treatment settings was type of services provided.

Continued open coding of additional data for types of treatment settings resulted in long-term public hospital, short term public, long term public, community mental health centers, doctors offices, emergency rooms, and a prison infirmary. Those types were grouped into two categories, inpatient and outpatient. The properties of inpatient settings included

public, private, short-term, and long term. Outpatient settings were either community mental health centers or doctors' private offices.

Axial coding occurred as categories one (inpatient) and two (outpatient), continued to develop, prompting an examination of how they related to one another. When compared against further data, categories one and two had to do with mental health. Again, through ongoing comparisons, theoretical coding took the form of the hypotheses, PWS encounter MHPs when they go to mental health treatment centers.

Axial coding continued with the discovery or clarification of the relationship between type of setting and type of MHPs. Psychiatrists were found in both types of settings. Nurses were mentioned in both but most often in inpatient settings. Counselors were in both settings as were psychotherapists. The vocational counselors were found exclusively in outpatient settings. Aides were located in hospitals and case managers were found only in mental health centers.

The relationship was further defined by selective coding in the attempt to explain why the participants went to these settings to see these professionals. Coding for reasons uncovered the concepts, hearing voices that potentiate wanting to kill self or others, voices that decrease self-esteem, and feeling that others are purposely taking action against oneself. The concepts were categorized as symptoms of mental illness, auditory hallucinations and paranoia. The auditory hallucinations could threaten violence or not, but the paranoia did not pose a threat to self or others.

The next question asked of the data was "what relationships are there between mental health settings and symptoms?" Answering through axial and selective coding, those

symptoms considered a threat to safety were treated in inpatient settings and those considered nonthreatening were treated in outpatient settings. Outpatient treatment is on a scheduled basis and inpatient is initiated primarily on an emergency basis.

The relationships among the types of mental health professionals, settings, and symptoms were explored through selective coding. The resulting relational statement was that PWS go to MHPs in mental health settings for treatment of their symptoms, auditory hallucinations and paranoia. Where they go for treatment depends upon whether the symptoms are threatening, i.e., having the potential to cause violence; or nonthreatening, i.e., disturbing but not to the point of violence.

The interactions among categories and properties emerged as the concept Displaying. PWS present themselves to MHPs for treatment of their symptoms. Depending on the potential threat of the symptoms, the person receives emergency treatment on an inpatient basis or by scheduled appointments at the outpatient settings. They will encounter different types of MHPs, influenced by whether the setting is inpatient or outpatient. Inpatient settings include psychiatrists, nurses, nurses aides, and counselors. Encounters in outpatient settings are most likely to involve psychiatrists and case managers, but to a lesser degree there are nurses and counselors.

The process “Connecting Through Humanness,” emerged from the data as the central category. This three-stage process happened every time participants encountered MHPs as a treatment strategy for their illness. The three stages, or categories, were “Displaying,” “Sizing-Up,” and “Classifying.” Descriptions of the categories are followed by the

assumptions and hypotheses related to the central category, and finally, a conceptual model of Connecting Through Humanness.

Displaying

Participants displayed themselves to MHPs with each encounter. Displaying was chosen as the name of the category because participants described having shown, or exhibited themselves and their needs to MHPs. Several factors were involved in displaying during these interactions. Factors included the types of symptoms participants exhibited, reasons for the interaction, the settings in which interactions took place, and type of MHPs encountered. The interacting components of displaying will be described in the following section.

Symptoms

The most frequently mentioned symptoms were auditory hallucinations (six participants) and paranoid ideation (four participants). Three participants had both. Depending upon the potential threat to themselves or others, the participants' symptoms were classified as threatening and nonthreatening. The researcher imposed these categories based upon those used to categorize symptoms in clinical settings.

Threatening. Threatening symptoms, specifically auditory hallucinations, were described by five of the participants. One female depicted the torture caused by auditory hallucinations, "all these voices going on in my head, every day, 24 hours a day, nonstop, almost made me want to commit suicide." Two participants attempted suicide based on the orders of their auditory hallucinations. Another participant feared the consequences of not following "orders," "I hear the voices real bad. And they talk about my family, they gonna hurt my family if I don't listen to this voice. And they're going to kill my baby." A female

participant explained the motive behind the assault on her mother, “I just feel like I can see me hurt somebody when I hear voices.”

Nonthreatening. Two participants discussed auditory hallucinations that did not suggest violent behavior. A female participant stated that her sister’s taunting voice “really hurt me.” Another participant took a more analytical approach to his hallucinations, “how can you differentiate if a person is hearing voices or if it’s just a regular thinking process?” The paranoid ideation admitted by four participants revealed fear, but did not insinuate the threat of violence. One of the participants asked the researcher for her definition of the term paranoia as a prelude to his verbalization of the concept. Having experienced paranoia for most of his life he explained, “you know if you think you’re gonna die because of a feeling that’s not good.” Another participant felt his paranoia was caused by a mental health system that had a conspiracy to “defeat” or “break the spirit” of persons treated for mental illness. His primary example of “defeating” was the system’s alleged practice of over-sedating patients with medication. He reasoned that sedated patients were less likely to recognize practitioner malpractice than alert patients. The following section will delineate the reasons for which participants had presented themselves for treatment.

Reasons for Encounter

Emergencies. Eight of the nine participants described encounters that were treated by MHPs, psychiatrists and nursing staff, as emergency situations. For three participants, males, their first experience with the mental health care system was having been hospitalized as teenagers for suicide attempts. The fourth male “got very sick” and was hospitalized after he stopped taking his antipsychotic medication. A female participant was sent to the emergency

room and hospitalized for having heard voices that “made me keep saying that I was thinking about killing everybody.” Another participant was put in seclusion and restraints on her hospital unit when the nursing staff felt she was in danger of harming herself. An imprisoned participant was sent to the infirmary or to “C Ward, for mental health patients” when hallucinations made her bang her head against the walls. Finally, a female participant was picked up by the police and taken to a psychiatric hospital when she was “out in the street, nowhere to go,” pregnant and hearing voices.

Scheduled. The majority of encounters took place as part of the participants’ outpatient psychiatric care. All met with their psychiatrists at least every three months for the management of psychotropic medications. Medications were also managed via scheduled appointments with case managers. When the participants displayed worsening symptoms, some case managers intervened directly with the psychiatrists for the participant. Participants also met with case managers for needs involving housing, employment, and medical care. All but two of the participants attended scheduled group and/or individual therapy sessions. The next characteristic involved in displaying is the setting.

Setting of Encounters

Most of the encounters between participants and health care professionals took place either in hospitals or outpatient clinics. The exceptions were a participant who, while an outpatient, saw one of his psychiatrists in his private offices, and a participant who received psychiatric treatment in a state prison. All participants recounted having been treated on inpatient psychiatric units when they had first become ill. Throughout the years, their

encounters with MHPs also took place in prisons, private offices, and outpatient community mental health centers.

Inpatient. The types of inpatient facilities included one public short-term, two public long-term, and two private short-term hospitals. All participants had been in a state facility at some time, but only one had been in hospitals that were private. That particular participant had been in two different private hospitals. Length of stay, having ranged from a few weeks to several years, did not come across as a major factor in the participants' perceptions of the facilities. The atmosphere of public and private hospitals, however, made an impact. One participant described the public facilities he had been in as "like the asylums in the movies." Staff members of long-term public hospitals were portrayed as uncaring, "just putting in time." In contrast, a participant regarded the concern of the staff at a private hospital as "treating me like a king." The short-term public hospital received mixed reviews, depending on the participant.

Outpatient. The outpatient facilities, except the private physician offices, were community mental health centers. Participants were usually involved with more than one type of service. Besides seeing a psychiatrist and case manager all but one of the participants, a male, attended group therapies and/or job training. The dissenting participant saw no reason to associate with other clients, "I'm not tryin to be a snob or anything like that, but most of the people around here are very strongly medicated, and I have nothing in common with them." The final factor of displaying included the various types of MHPs involved in the encounters.

Types of MHPs

Participants referred to five types of MHPs as they described their experiences. The types of MHPs varied with inpatient versus outpatient encounters. The types include psychiatrists, case managers, nurses, nurse assistants, and counselors.

Psychiatrists. Participants mentioned their interactions with psychiatrists more than with any other type of MHPs. All of the participants were taking at least one type of antipsychotic medication, and therefore needed psychiatrists for issues such as the initial prescribing, managing side effects, and deciding when to change medicines.

Case managers. Participants mentioned case managers as the second most encountered type of MHPs, consistent with the case manager's role as the coordinator of living in the community. Case managers, overall, were responsible for ensuring clients receive the necessary services to remain out of the hospital. They performed services for the participants such as finding a place to live, transporting them to appointments, and ensuring participants received the correct medications. As opposed to other nursing specialties, i.e., home health, case managers in the mental health field are rarely registered nurses. A supervisor of one of the case management teams in the present study had a masters degree in psychiatric/mental health nursing.

Nurses. Nurses (there was no mention of RN versus LPN) were associated almost exclusively with inpatient treatment, most likely a reflection of the small number of nurses employed by outpatient facilities. Nursing assistants were mentioned only as members of the public long-term facility's staff. Nurses played a more significant role in hospital rather than outpatient experiences for the participants. Participants were not asked to discriminate

between registered nurses and licensed practical nurses. Although having talked specifically about nursing attendants, participants did not differentiate their job status from that of nurses. Nursing staff dispensed medications and performed milieu activities such as medication groups or socialization activities. They also handled crises on the unit, such as one patient trying to hurt another. Although nurses were most often encountered on inpatient units, they did run therapy groups and administer depot injection medications when in outpatient facilities.

Counselors. Finally, counselors were described within the contexts of both inpatient and outpatient settings. As with case managers, counselors are rarely nurses. More often, they hold degrees in social work or psychology. Both “therapist” and “counselor” were terms used to describe MHPs whose purpose was to talk about feelings with the participants. One participant named the counselor she saw while incarcerated as the MHPs who had helped her the most. This counselor had talked with the participant whenever the participant felt upset. The other worked out of a community mental health center, and was only mentioned by the participant in reference to another MHPs. Two participants talked about their interactions with vocational counselors. One participant mentioned a very positive experience with a vocational counselor. Another did not like the work at a mental health center that had been arranged by a vocational counselor. Upon or concurrently displaying themselves to MHPs, participants engaged in the subprocess Sizing-Up, discussed in the next section.

Sizing-Up

Sizing-Up entailed the participants’ having perceived and given meaning to certain verbal and nonverbal cues from MHPs. Depending upon the presence or absence of the cues,

MHPs were evaluated, as helpful or not helpful. The types of cues and their attributes will now be discussed.

The cues discussed by all nine participants were divided into three categories, those categories being "Understanding", "Compassion," and "Normalcy." Although the third category, Normalcy, was more difficult for participants to articulate, the first two were readily expressed. Using one participant's words, "the two most important things to be a nurse or a doctor are compassion and understanding."

Understanding

Participants felt "understood" depending upon, in part, how skillfully their MHPs treated their symptoms and medication side effects. The other part was whether participants felt their MHPs appreciated how those symptoms and treatment affected their lives.

Participants not only wanted MHPs to understand how to treat their disease, but how the disease and treatment affected their lives.

Knowing what to do. The most frequently mentioned measure of "know-how" was medication management. All participants talked about at least one physician in terms of medication successes and failures. Successes and failures referred to how well symptoms of the illness and side effects of the medication were handled. One participant assessed his psychiatrist's intelligence due to his ability to alter medications if they need to be altered, and prescribe different types of treatment. The participant perceived that the psychiatrist also saved his life by having administered electrical shock treatments for a suicidal depression. The participant has remained a patient of this psychiatrist since first becoming sick 18 years ago. Another said she liked her doctor because he had prescribed the correct medications to

decrease her auditory hallucinations. One female participant spoke highly of a physician who had cared for her during a recent hospitalization. She said, "He worked hard, he changed the meds around, but he gave me something that really helped." The day treatment center staff were helpful to one participant because, "at least they're trying to understand what my problem is." The staff were reportedly helping her remember to take her medications so her symptoms would not worsen.

Three participants spoke not of medication, but of helpful attitudes of MHPs. One participant had been in the hospital and cited an example of a nurse he liked. The participant used marijuana, and had been told numerous times to stop. This nurse instead suggested that he "get high on life." He said her positive attitude made a difference in his thinking, and helped him to stop using marijuana. The second participant, when asked what advice she would give to MHPs working with persons with schizophrenia said, "I'd tell them (MHPs) to teach them (PWS) or say to them that things is possible, and they'll be alright." A third participant suggested that his outpatient staff make themselves available to patients between therapy appointments for educational videos and discussions, "something to get their (consumers') mind to exercise, and if they keep trying they could wake up a lot of people out there."

MHPs were not seen as understanding when their treatments did not help reduce either symptoms or side effects. One participant's physician had increased the dose of the prescribed antipsychotic without increasing the medication needed for preventing side effects. As a result, the participant suffered extreme discomfort. He decided that "I don't trust doctors, they're playing a guessing game." One expressed his doubt of physicians' skill in

prescribing medication. A similar opinion was expressed by another participant who said, “Sometimes the doctors don’t know whether it’s good for you or not.” A female participant said she had requested an increase in her medication because her nightmares had worsened. The physician denied the increase because he believed that the nightmares were not an indication of her needing more medication. She had to wait until her next appointment, described by the participant as two weeks of a “living hell,” to have requested another increase. At her next appointment, her newly assigned doctor increased the dosage of the medication, which lessened the nightmares. When her auditory hallucinations worsened in prison, the same participant’s physician “was telling me that the medicine he gave me should help right now. It should help and he wouldn’t put me on any more.” She concluded, “they just throw meds on you. And throw you out. A lot of them do that.”

Knowing what it’s like. The two gauges of “knowing what it’s like” were how MHPs reacted to the effects of the illness and the treatment on the participants. As one participant described her current case manager: “He understands my problems, what I am, what I have.” Another explained why she liked her current psychiatrist, “he understands that he’s trying to get me well so I can learn how to cook again.” Eight of the nine participants described experiences where they had felt that their MHPs did not understand the severity of the symptoms, and therefore expected too much of them. One participant was admonished by her doctor and case manager for not keeping up with assigned chores at her foster home. What she could not tell them, because her thoughts were so disorganized, was that she had not been taking her antipsychotic medicine for the past few weeks. The participant’s “foster mother” had used her disability check to pay bills and had no money left over for medication.

The participant was too sick to do chores but too sick to explain why. Her present doctor, on the other hand, “just tells me to do what comes natural.”

Another participant told of a previous case manager who “maybe was thinking of me as being more independent than I could take on.” She had him working at a janitorial job and expected him to keep track of his doctor’s appointments. He described himself as needing a “simple” life: “that’s all I can handle.” A female participant had asked her psychiatrist for more medication to help decrease auditory hallucinations. According to the participant, the psychiatrist “just didn’t think I needed more medication. He thought I can deal with it. But you can’t deal with that kind of stuff.”

One participant gave an example of a case manager who misperceived the participant’s symptoms. She described the case manager: “She didn’t understand me. I couldn’t tell her my feelings or she’d think I was crazy. And she’d call the police. Every time I talked to her she called the police.” The participant decided the case manager didn’t understand because “she just thought she knew too much about me.” In contrast, another participant described how her counselor showed understanding by having been able to help even when the client was too sick to ask: “Sometimes I get all mixed up. And I could tell her that the schizophrenia was torturing me. Cause I didn’t know how to help myself.”

The participants also evaluated the way in which MHPs had reacted to the side effects of antipsychotic medication. As explained by one participant, “it’s kind of hard to relate to problems clients have because doctors have never experienced it and they don’t understand the severity of some of the things they do.” His example involved having taken medication as prescribed by his doctor after being released from the hospital. The side effects were so bad

he could not continue his job of mowing lawns. Although he complained to the doctor and nurses who had treated him, the dosage was kept the same. He eventually stopped taking the medication on his own.

Another participant also had an experience where his prescribed medication had him “in a stupor, but he (the physician) couldn’t see that.” Although he was directed to continue taking the drug, the participant stopped, and consequently, became “very sick.” A third participant stopped taking a medication on his own after trying to explain to his doctor that it made him feel like he was going to die. His doctor “didn’t understand the way I was really feeling, sometimes they think I’m just a little uncomfortable or something.” MHPs were sized up not only by their understanding of schizophrenia, but also by their attempts to have addressed the participants’ suffering. This addressing of suffering, termed compassion, is the next attribute of sizing up.

Compassion

“Compassionate” MHPs not only empathized with participants’ suffering, but attempted to diminish it in some way. Demonstrating compassion with participants involved “Taking the time” and “Taking action.”

Taking the time. Participants felt that compassionate MHPs took the time to listen to them rather than ignore their concerns or resort only to medication to help them. When asked how MHPs could better help persons with schizophrenia one participant advised, “not to turn their back on them (persons with schizophrenia) when they come up asking for help.” The same participant told of one psychiatrist whom she had especially liked, “I talked to him...and I cried and cried. He would talk to me, and pat me on the back, and say it was going to be

alright.” Another participant felt comforted by the nursing staff of one hospital who initiated contact with patients by having “checked up” on them. She also liked the nurses because she could “go and tell them every time I had a problem. They’d sit there and talk to me.”

When asked to describe MHPs who were not compassionate, a male participant spoke of a psychiatrist who rarely spoke or looked up from the notes she had been writing during their sessions together. He was unsure as to whether she had listened to him. When asked to give an example of compassionate behavior, the same participant said, “finding out what the person is depressed about instead of prescribing a pill.” Although he acknowledged the importance of medication, another participant felt that “doctors are always ready to medicate.” A third participant told of a psychiatrist who “was just throwin meds on me and throwin me out the door when I really needed help.” A female participant felt disliked by her case manager because: “She would get on me, saying she didn’t want to hear me sing, she doesn’t want to hear what I got to say about stuff and all I ever did.”

Taking action. Another act of compassion was attempting to correct, or at least better cope with participants’ concerns. The same psychiatrist portrayed above as having listened to the crying participant also took action. He attempted to help by changing her medications and making referrals for other needed services. Four participants appreciated their case managers’ advocating to the psychiatrists for a change in medication. One stated that his case manager told him, “we’re not going to make you take anything you don’t want.” Another participant described her counselor, who had talked to the psychiatrist “when I couldn’t explain myself. And I love her for that.” Another said her doctor changed her medication because “he knew that I wasn’t feeling too good, he wanted to help.”

Dealing with the side effects of medications was another example of taking action. One participant's medication caused him to have little energy, to shake, and to drool at night. It was not until he went to a different doctor that he was helped. The new doctor told the participant "I've watched you shake for six months in this office and I'm tired of seeing it." He then changed the participant to a medication that was effective but without the side effects. A vocational counselor was of great comfort to a different participant who had trouble feeding himself because his hands shook so much from his medication. She had taken him out to lunch and assisted him with eating.

Five participants described incidents when their discomfort from medication had been ignored by MHPs. One participant told of a situation in the hospital when a nursing assistant ignored the "muscle paralysis" that was caused by the medication he had just taken. The antipsychotic he took can cause severe muscle spasms, called an acute dystonic reaction. The spasms can be quickly relieved by an injection of another medication, benztropine (Kaplan & Sadock, 1993). Unfortunately, the assistant waited for over an hour before calling for help. This same participant developed a migraine headache, along with flu symptoms, while hospitalized for schizophrenia. After having started a new drug, lithium, the headache turned into "the worst headache of my life." For the next 3 ½ weeks, despite his request for something stronger, he was given "mild aspirin" for his pain.

Another participant told of the staff of a homeless shelter who, when she was vomiting and asking for help, told her to go down the street to a phone booth and call an ambulance. Another participant suffered with constipation caused by his prescribed medication. He talked at length about his futile attempts to obtain relief from the MHPs. One

participant told how she felt about her doctor's unwillingness to take action to decrease her auditory hallucinations, "he just put me on some meds, and he wouldn't change them or nothing." One participant believed psychiatrists and nurses used medication "as a club." According to the participant, "you don't tow the line, you get your medication doubled and you feel miserable until you do what they say or what they want you to say." The final attribute of sizing up is Normalcy.

Normalcy

The essence of Normalcy was captured by a participant who had been asked to clarify what she meant by having described her psychiatrist as a "nice gentleman:" "Someone who is kind to you, who tries to treat you like a person and not a monster or something like that." Another participant's description of one hospital's staff provided a negative example of normalcy, "they were mean and they did not care how my feelings and other peoples' feelings were. The people in there, I think they got worse because they didn't have people that were nice, smiling. They just wanted to do their job and sometimes didn't understand the human needs of others. An that's not right."

MHPs who were considered helpful attended to the full range of human needs, not just those that concerned symptom remedies. The participants' needs were those regarding safety and security, love and belonging, and the need for positive self-esteem.

Safety and security. One participant depiction represented the different ways in which the participants' safety needs were handled. She described incidents that involved self- or other- directed harm. When taken to the emergency room for threatening to kill people, the participant felt reassured when a doctor told her, "we're gonna put you upstairs and you're

gonna do okay.” As a result, “I felt much better and I felt safe.” In contrast, she described having been afraid of the “quiet room” (seclusion room) on the unit. The nursing staff reportedly would put her in seclusion if they thought she was a danger to herself. The participant accepted the rationale but feared the intervention, “I had a rough time going in there.”

The environment was also a potential threat to safety and security. While in a public, long-term hospital, one participant was afraid of the other patients and repeatedly turned to the nursing staff for help. The staff, who spent most of their time in the nurses’ station, downplayed her fear. They directed her to go back to her room because there was “nothing to worry about.” Another participant feared for his safety when living in certain neighborhoods. He claimed that his case manager got him apartments in crime-ridden areas heavily populated by African Americans. An African American himself, he felt that the case manager (also African American) cared only about his being in a culturally similar neighborhood, not his safety. When this case manager left for another job, the new case manager helped him move to a safer neighborhood.

Love and belonging. Attempting to get love and belonging needs met were addressed by five of the participants. Only two participants, one female and one male, mentioned having had family members for support. For the most part, the rest had relied on mental health care workers to feel part of a family or close-knit group. When asked about having had friends, one participant said, “I have a family of friends that I work with, health care providers.” Another participant described two situations, previously mentioned, with MHPs in which he had felt treated with compassion and understanding. When asked to describe nonprofessional

people who had treated him the same way, he said there was “nobody.” One participant’s auditory hallucinations taunted her by having said, “you’ll never marry, you’ll never be happy.” What she wanted more than anything in life was to “be happy, be married, and help my husband clean the house and somethin like that.” Another participant considered his vocational counselor to be his “friend,” for among other things, sending him a card on all the holidays and his birthday. One of the participants appreciated getting “hugs and smiles when I needed them” from her day treatment staff. Although one participant had ongoing relationships with his children and girlfriend, he still referred to the people at his mental health center as “one big family.”

Three participants spoke of having desired an intimate relationship with their health care providers. All of them, however, accepted the boundaries imposed by the patient-MHPs relationship. One participant said that she thought her psychiatrist was “cute” and made her happy, but “I know he can’t be my boyfriend or nothing like that.” The other two expressed appreciation for the boundaries. One said he could enjoy his daily therapy groups because though he found the group leaders attractive, “I didn’t have to act like my old rifferaff self.” In other words, he didn’t have to make advances towards the leaders because he “knew it wouldn’t do any good.” Consequently, he was able to concentrate on the content of the group. Another participant was also appreciative of the limits set on his behavior with female staff. He compared experiences with hospital nurses, saying his attraction toward women got him “into trouble” at one hospital. He went on to explain, “I kind of transferred my improper learning to other hospitals, but once I knew what the score was it was okay.”

Positive self-esteem. The importance of self-esteem resounded in every participant interview. All but one participant referred to some situation in which they had suffered low self-esteem at the hands of MHPs. The one exception was the participant who had been with the same psychiatrist for 18 years. One of the ways MHPs impacted self-esteem was whether they had treated the participants with respect. The importance of respect was brought up by all nine participants. The simplest of gestures, such as having called someone by name, affected self-esteem. One of the criteria a participant had used to describe his case manager as having been a “gentleman” was “polite.” Another participant depicted the respectful behavior of his psychiatrist, “He listened to what I had to say. When I’d say something stupid he’d tell me why it was stupid rather than just say I was wrong and let it go at that.” This doctor did not assume that just because the participant had schizophrenia, he couldn’t or wasn’t worthy of benefitting from correct information. Respectful behavior was also a trust issue. One participant said she trusted her doctor because “of the way he talks to me, he has a polite way of talking.”

Two participants told of disrespectful behavior on the part of MHPs. Both participants were male and both settings were inpatient hospitals. The one male participant had raced miniature cars as a hobby, and placed in the top 20 of the US National Championship one year. The next year he was hospitalized for a suicide attempt. He proudly wore a tee shirt from the championship while in the hospital. Instead of having recognized him for his accomplishment, the nurses reportedly derided him, “You’re never going to be anything unless you take your medicine.” The participant lamented, “I was so proud of what I

did, it was the first time I'd ever been to the nationals." He had wanted to say to them, "Well, have you ever finished 18th in the nation in anything?"

The other way in which MHPs enhanced the participants' self esteem was by having sent a message of equality. One of the participants explained, "a lot of it doesn't have to do with being sane or insane, it's that all them people are different. And people's got to learn what we are, what we have done, and what we're supposed to do." Another participant described her case manager, "She always treated me as being just like her, without no problems." Simple acts such as going out to lunch, talking about topics other than schizophrenia, and asking about the participants' family and social life communicated MHPs' attitude of equality. Five of the six participants talked about how much they had enjoyed going out to lunch with their case managers. Three mentioned their having appreciated "normal" conversations, described by one of the participants: "We'd just have a conversation, it wasn't nothing about no schizophrenia at the time." One participant liked the fact that his psychiatrist had talked with him about sports and current events. He noted how this doctor had asked about his family and job in addition to symptoms and medication. The psychiatrist also shared a little about his day with the participant.

The use of humor also was an important way in which MHPs minimized the differences between themselves and the participants. Five of the participants identified "sense of humor" as a characteristic of their favorite MHPs. One said his case manager's sense of humor allowed him to be himself, to "act like a kid." He appreciated the opportunity to be playful but still be respected by a MHP. Another enjoyed informal conversations with her case manager where they "just joked and had a good time." Two participants mentioned their

psychiatrists as having shared humor with them. Another sought the researcher's reaction to two of his jokes before disclosing personal issues.

Classifying

Depending upon the results of Sizing-Up the participants classified MHPs into those who were helpful and those who were not helpful. The two categories are described below.

Helpful

MHPs in this category were perceived as such because of their emphasis on the person with schizophrenia over the schizophrenic. Although the features of the illness were not ignored by the MHPs, they considered them to be only one part of the participant's life. MHPs helped participants by having conveyed a sense of understanding, compassion, and normalcy.

MHPs who were understanding knew what to do in order to accurately diagnose and treat symptoms of the disease. The treatment most often used for symptoms was medication. MHPs were familiar with the side effect profiles of each medication and how to adjust the medications accordingly. MHPs also demonstrated an appreciation for how their prescribed treatments impacted other areas of a participant's life.

Another characteristic of treating the participants as human beings was compassion. Compassionate MHPs recognized the suffering that so often accompanies a disease such as schizophrenia. Besides recognizing suffering, MHPs also sought to determine its source. Compassionate MHPs then went one step further and took action to alleviate the suffering by some means.

Finally, participants felt helped by MHPs who were interested in the needs common to all human beings. Such MHPs attempted to meet participants' needs for safety and security. They recognized that fear could stem from residing in a crime-ridden neighborhood as much as from hallucinations that threatened to kill family members. Participants also felt helped by MHPs who facilitated the participants' needs for love and belonging. An important way that MHPs met the need for positive self-esteem was having treated participants in a respectful manner. Helpful MHPs minimized their differences as professionals from the participants'. MHPs promoted self-esteem when they engaged in informal activities with participants such as going out to lunch, joking with one another.

Not Helpful

The participants did not feel helped by MHPs who diagnosed and treated them according to the canons of the diagnosis, effective or not. Such MHPs did not demonstrate understanding, compassion, and normalcy. The ways in which their prescribed treatments impacted other areas of the participants' lives were not taken into consideration. Any kind of suffering, illness related or not, was either ignored or minimized. Participants did not feel helped by MHPs who only showed concern with the symptoms and modes of treatment. The participants' needs for love and belonging could not be met by MHPs who interacted with them in an impersonal manner.

Summary

As the participants were Displaying themselves to MHPs, they were also evaluating the MHPs in a process termed Sizing-Up. The behavioral cues of the MHPs were judged according to whether they demonstrated three characteristics, understanding, compassion,

and normalcy. Based upon the results of the evaluation, the participants engaged in Classifying the MHPs as helpful or not helpful. The main criterion for both categories was whether participants felt regarded as individual human beings or typecast as schizophrenics. Helpful MHPs were those with whom the participants felt regarded as fellow human beings. Within this context, the participants felt connected with MHPs through their mutual humanness. Participants did not feel helped by MHPs who recognized their illness over their humanness. In this case, the participant-client connection did not occur.

Theoretical Perspective

Strauss has defined theory as "a set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena" (Strauss and Corbin, 1998, p. 15). The theory, or integrated framework, generated from the data analysis, may be presented in the form of hypothetical statements. As an emerging theory, Connecting Through Humanness is presented via its list of assumptions, the theoretical model (see Figure 1), and list of hypotheses.

Description of the Model

This emerging middle range theory, entitled "Connecting Through Humanness" arose from having used Strauss and Corbin's (1998) methodology. The focus is PWS interacting with MHPs in the course of the treatment of their mental illness. The encounter begins as PWS "display" themselves to MHPs for treatment. The context of the interaction is the severity of symptoms, which in turn determines whether the reason for the encounter is on an

emergency basis or a scheduled appointment, in an inpatient or outpatient setting. The reason for the visit also influences the types of MHPs encountered.

As PWS "display" themselves, they "size-up" MHPs for the conveyance of three criteria: understanding, compassion, and normalcy. MHPs who demonstrate the three criteria are "classified" as helpful. In opposition, the MHPs who do not demonstrate the three criteria are "classified" as not helpful.

"Helpful" MHPs are those with whom PWS experience "connecting." PWS perceive themselves as connecting with such MHPs on the basis of mutual humanness. PWS do not experience a connection with MHPs who are "not helpful." Throughout these interactions, PWS perceive themselves as regarded as an illness, or as "schizophrenics."

The Connecting Through Humanness process takes place with every interaction between PWS and MHPs. PWS are constantly monitoring the interactions for whether they experience themselves treated as human beings or illnesses (schizophrenics). The process takes place whether the client-MHP relationship has taken place over a span of 30 minutes or 18 years. PWS' experience of "connecting" feeds back into the next interaction with MHPs, forming a continuous loop. PWS continue to perceive themselves as human beings whether or not they experience a connection with MHPs.

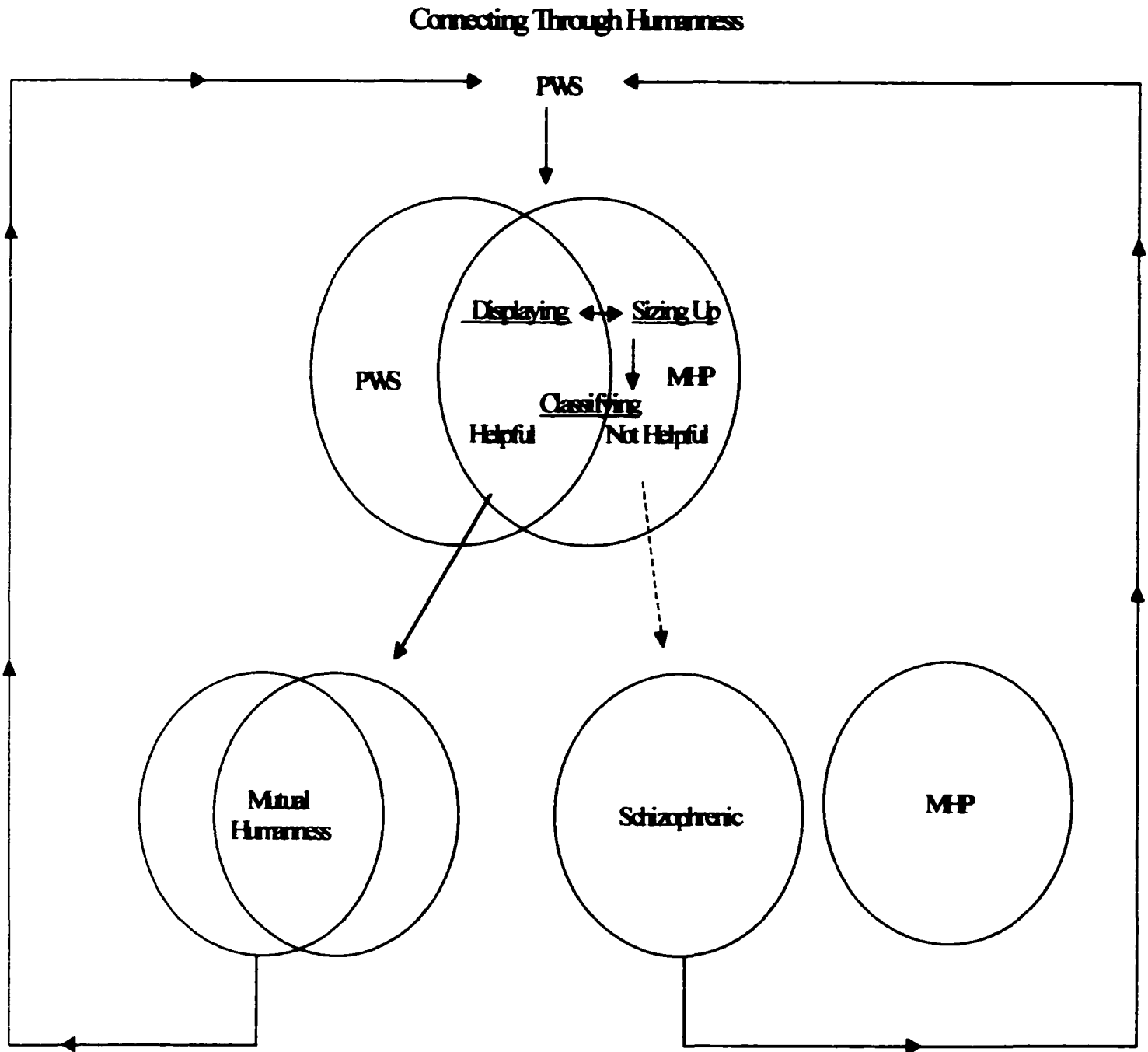


Figure 1. Connecting Through Humanness

Assumptions

1. PWS are capable of describing their reality.
2. PWS identify with their humanness more than with their mental illness.
3. All human beings have the same basic needs for, safety and security, love and belonging, and positive self-esteem.
4. The interpersonal relationship is an important means of meeting basic needs.
5. Because nurse-patient relationships develop through communication, some PWS have difficulty forming such relationships.
6. Connectedness is an important factor in establishing a relationship.

Hypotheses

1. PWS experience stigma through their interactions with some mental health professionals.
2. When PWS interact with MHPs, they Display themselves within the contexts of symptomatology, reason for interaction, place, and type of MHP.
3. The perceived threat of PWS' symptoms serves as a catalyst for whether the interaction takes place on an emergency or scheduled basis, whether the setting is inpatient or outpatient, and with what type of MHPs they interact.
4. As PWS are Displaying themselves to MHPs, they Size-Up MHPs' behavioral cues as to whether they convey understanding, compassion and a sense of normalcy to them.
 - a) Understanding is demonstrated by identifying the correct treatment for disease symptoms and medication side effects, as well as identifying the impact of the disease and treatment on a person's life.

- b) **Compassion is demonstrated by wanting to help and taking action to help.**
 - c) **Normalcy is attending to three basic human needs, safety and security, love and belonging, and positive self-esteem.**
5. **PWS classify MHPs who demonstrate understanding, compassion, and normalcy as helpful.**
 6. **PWS perceive helpful MHPs as those who regard them as fellow, individual human beings and connect with them based upon mutual humanness.**

Chapter IV: Discussion

The first part of the chapter is a discussion of the degree of support the data and the literature provided for the assumptions and hypotheses of *Connecting Through Humanness*. The final section is a description of the findings and the nursing literature in relation to the development of the emerging theory.

Assumptions About Connecting Through Humanness

Assumption I

PWS are capable of describing their reality. All but one of the research participants in the present study were able to give detailed accounts of their experiences. One participant could not stay focused on describing his interactions with MHPs. His case manager later told the researcher that the participant had probably been distracted by the researcher's educational status. The participant held a master's degree in urban planning and, prior to his first schizophrenic episode, was employed as a city planner in Los Angeles, California.

Brix (1989) described his experience of providing therapy to a group of hospitalized, overtly psychotic (i.e., patients presenting with obvious hallucinations, bizarre behaviors) patients. The patients in Brix's study formed a cohesive, nurturing group that tolerated the behavioral symptoms of its members. The fact that PWS took part in group therapy suggests their ability to not only accurately describe their reality, but engage in others' reality as well. Pollack (1989) and Coursey (1989) voiced similar opinions about psychotherapy with PWS. Both said that the psychotherapy should be grounded in the experiences of the clients.

Godschalx (1989) said that the results of her study refuted an assumption of the medical model, that PWS cannot validly describe their life experiences. In order to better

understand the life experiences of PWS, she conducted interviews with those who were in outpatient treatment. Her entire sample of 30 PWS gave a vivid portrayal of what it was like to live with such a devastating illness.

Assumption II

PWS identify more with their humanness than with their mental illness. The participants in the present study discussed their illness only within the context of daily life. Their participation in groups at the mental health centers, for example, centered around life-skills such as job or social skills training.

Dzurec's (1990) study on the self perceptions of 15 PWS suggested their identification with humanness over illness. She collected one set of data from semi-structured interviews with the respondents. The second set was a comparison of the progress evaluation scores (PES) between each respondent and caregiver. The respondents based their degree of mental health on day to day circumstances, such as employment or housekeeping tasks.

Godschalx (1989) again took aim at what she believed was an unfounded assumption of the medical model, i.e., that PWS have no life beyond their symptoms. Her study revealed that symptoms are experienced as isolated, discrete episodes that encompass only one aspect of life. Her participants usually identified their humanness with the less symptomatic times in life. She described her participants as diverse in every area of life except for their diagnosis of schizophrenia.

Assumption III

All human beings have the same basic needs for safety and security, love and belonging, and positive self-esteem. The participants in the present study wanted to interact

based upon mutual humanness. This supports the assumption that they need what is basic to humanity. All spoke of wanting to feel safe, accepted, and considered as valued citizens in the community.

Coursey (1989) and Godschalx (1989) identified similar beliefs about what type of assistance PWS need from MHPs. Coursey reasoned that the issues addressed in psychotherapy with PWS are the same as for others, e.g., trauma, relationships, childhood, or autonomy. Godschalx stated that experiences of security, meaning, and managing emotions were the "dilemmas of being human," dilemmas also faced by PWS.

Walton (1996) and Travelbee (1971) focused on suffering and pain as conditions that confront everyone. Walton defined spiritual nursing as that which deals with the universal experiences of illness, suffering, and death. Travelbee believed that the goal of the nursing discipline was to help people cope with pain and suffering. Particularly because Travelbee based her theory upon on her experience as a psychiatric clinician and educator, one can assume that she had some appreciation for the pain and suffering born by PWS.

Assumption IV

The interpersonal relationship is an important means of meeting basic needs. Whether the needs of the participants in the present study were met was based upon their perceptions of the interactional experiences between themselves and MHPs. The participants wanted MHPs to spend time with them, regardless of whether the interaction concerned medication dosage or the results of last night's basketball game.

McFarland, Wasli, and Gerety (1992) viewed the interactional technique of active listening, which requires spending time with the client, as integral to helping develop and

maintain their self-esteem. Stuart and Sundeen (1995) defined the therapeutic nurse-patient relationship as one that is based upon underlying humanity and mutual respect. Joyce Travelbee (1971) based her entire nursing theory on the nurse-client interaction. Travelbee defined nursing as an interactional process between a person in need of help (the client) and a person who is able to provide that help (the nurse). In their grounded theory study of hospitalized clients, Williams and Iurita (1998) discovered that both nurses' and clients' perceptions of the quality of health care were gauged by the nurse-client relationship.

Assumption V

Because nurse-client relationships develop through communication, some PWS have difficulty forming such relationships. Communication can either facilitate or impede the development of a therapeutic relationship. According to Stuart and Sundeen (1995), the key to facilitating the therapeutic relationship with a client is the nurse's ability to "perceive and communicate, accurately and sensitively, the feelings of the patient and the meanings of those feelings" (p. 34).

Godschalx (1989) found that developing and maintaining intimate relationships with others was both a goal and ongoing source of frustration for PWS. In addition to Godschalx, studies by Farrell (1991), Nolan (1989), and Muller and Poggenpoel (1996), support Assumption V. As illustrated by the present study's participants, the majority of health care providers do not hold the "key" to communicating with PWS in a way that is perceived as helpful.

Unfortunately, three features typical of schizophrenia can make it difficult for PWS and others to communicate effectively: a) alexithymia, the difficulty naming and describing

emotions; b) apathy, the apparent lack of emotions, interests, or concerns; and, c) anhedonia, the decreased ability to experience pleasure (Stuart & Sundeen, 1995). As a result, PWS are often considered as devoid of emotion. Fred Frese, (1993), the Director of Psychology at Western Reserve Psychiatric Hospital and a PWS, contests this perception. Frese asserts that "insults, hostile criticism and other forms of psychological assault wound us deeply. Other people need to know this" (p. 42).

Frese (1993) acknowledged that the interactional behaviors characteristic of PWS, i.e., avoidance of eye contact for a delay in responses, are perceived by others as communication deficits. He explained, however, that such deficits are ways for the PWS to compensate for the perceptual difficulties caused by their illness. Frese advised persons without the disease, whom he termed "normals," to learn the reasons for the deficits and coping behaviors of PWS. He went on to say that, in order for communication to improve, PWS need to learn about the behaviors that are likely to be perceived as deficits.

Assumption VI

Connectedness is an important factor in establishing a relationship. The findings of the present study demonstrate that not only is connectedness an important feature in establishing a relationship, it is integral to helping PWS. The deciding factor for a helpful interaction was whether PWS perceived themselves regarded as human beings or as a diagnosis.

Authors in the extant literature also considered connectedness as an important component in forming helping relationships with clients. Walton (1996) conceptualized connectedness as primary to forming a spiritual relationship. Her definition of a spiritual relationship is one that encompasses a connection to self or soul, to others, to a higher

power, or to nature. Henson (1997) and Schubert and Lionberger (1995) integrated connectedness with the concept mutuality. Both associated connectedness with an open, or knowing "exchange." Morse, Bottorff, Anderson, O'Brien, and Solberg (1992) conceptualized the ideal response to suffering as the engaged response. The engaged response involves a "connected" style of communication. Finally, from their study of nurse-client relationships, Hagerty, Lynch-Sauer, Patusky, and Bouwsema (1993) proposed that connectedness was a necessary component of relating to others.

Hypotheses of Connecting Through Humanness

Hypothesis I

PWS experience stigma through their interactions with some MHPs. The problems of stigma that were experienced by this study's participants were widely acknowledged in both research and in personal accounts by PWS. The word stigma literally means "mark of shame" (Stuart & Sundeen, 1995). The shame associated with having schizophrenia cost the participants dearly.

The participants were typecast as "schizophrenics." This label resulted in their loss of individuality. Whatever perceptions a MHP held about PWS were conveyed regardless of the individual. As published author and PWS Esso Leete (1989) explains, "Your label is a reality that never leaves you. It gradually shapes an identity that is hard to shed" (p.200).

The most painful consequence of the label to the participants was the loss of self-worth. Leete (1989) again describes the impact of stigma. "There is nothing more devastating, discrediting, and disabling to an individual recovering from a mental illness than stigma. To be a patient or even ex-client is to be discounted" (1989, p.199).

Fred Frese (1993) expressed a similar sentiment, stating "I cannot tell you how difficult it is for a person to accept the fact that he or she is schizophrenic. Since the time we were very young we have all been conditioned to accept that if something is crazy or insane, its worth to us is automatically dismissed. We live in a world that is held together by rational connections. That which is logical or reasonable is acceptable. That which is not reasonable is not acceptable" (pp. 39-40).

In contrast to the above findings, Dzurec (1990) did not find a painful recognition of stigma in the majority of her participants. When asked whether they were awareness of other's negative attitudes towards their mental health, nine of the 15 respondents were "uncertain." Only three said that they perceived others' regard for them as different because of the schizophrenia. However, this discrepancy may have been due, in part, to a sheltered living environment. The respondents in Dzurec's study had been discharged directly from a state psychiatric facility to a supervised living situation. Because of the more sheltered environment, they were less likely to encounter the same degree of stigma as PWS living independently in the community.

A loss of individuality also cost the participants individualized, and therefore effective, treatment. Their opinions about the treatments effectiveness were not sought. One of the participants in the present study voiced that "some doctors think they know everything." Leete (1989) stated that PWS' progress is gauged by professionals with concepts like "consent," "cooperate," and "comply" instead of choose. "This insinuates that we are incapable of taking an active role in our own recovery" (1989, p. 200). Indeed, pleas for relief from the participants' symptoms and medication side effects were ignored.

This loss of control over treatment experienced by PWS is not unique to them. Anyone who receives care under the medical model loses some amount of control over their treatment. The predominant model in health care, including psychiatric care is the medical model. The focus of the relationship in this model is the diagnosis and subsequent treatment for the symptoms of a particular illness. The physician identifies the illness, designates the treatment plan, and prescribes therapy. The client is then expected to comply with treatment and get well (Stuart and Sundeen, 1995). Individual variations are not necessarily deemed important.

Hypotheses II and III

When PWS interact with MHPs, they display themselves within the contexts of symptomatology, reason for interaction, place, and type of MHP; the perceived threat of PWS' symptoms serves as a catalyst for whether the interaction takes place on an emergency or scheduled basis, whether the setting is inpatient or outpatient, and with what type of MHPs they interact. The literature did not support Hypothesis II and III as being distinct from the other hypotheses. The participants of the above-mentioned studies, as well as Frese (1993) and Leete (1989) did not begin their descriptions of their interactions with MHPs with the display of themselves. The catalyst of the symptoms for the remaining components of Displaying was not apparent in the literature.

One reason for the discrepancy could be an artifact of grounded theory methodology. A grounded theorist is guided by the emerging concepts and their relationships. As the importance of the events leading to a participant's encounter with an MHP emerged, the more focused the questions became in that area. Particularly since most of the above studies were

conducted from the nurse's, not the client's point of view, Displaying may have not been relevant to their experiences. Perhaps the reason for the discrepancy is the researcher's conceptualization of Displaying as a distinct process rather than the context for the process. The severity of symptoms, setting, etc., provide the social context in which Connecting with Humanness develops.

Hypothesis IV

As PWS are displaying themselves to MHPs, they size-up MHPs' behavioral cues as to whether they convey "understanding," "compassion," and a sense of "normalcy" to them.

"Understanding" is demonstrated by identifying the correct treatment for the disease symptoms and side effects, as well as identifying the impact of the disease and treatment on a person's life. "Understanding" as it relates to symptoms and treatment is especially important for people who must depend on the correct management of their illness in order to function well in the community. This study's participants gave numerous examples of the impact their illness and its treatment had on their ability to remain in the community. The side effects of medication rendered one person unable to maintain his job of mowing lawns. Another was caught in a catch-22 situation with her psychiatrist. Her money for medications was used by her foster mother to pay household bills. Due to a lack of medication, the symptoms worsened, which resulted in the participant's decreased ability to do daily chores. Because her psychiatrist did not understand her situation, he scolded her for not doing her share of the housework.

"Compassion" is demonstrated by wanting to help and taking action to help. Listening and spending time together were the behaviors of MHPs that PWS perceived to convey

wanting to help. One of the most poignant examples of taking action was the vocational counselor who helped feed the participant whose hands shook as a side effect of his medication.

"Compassion" was also a major concept in Travelbee's theory, and was achieved by spending time with clients and listening to them. One of the referents of Henson's (1997) concept of mutuality was the existence of conversations between nurses and clients that reflected give and take, and comfort. One of the properties of Schubert and Lionberger's (1995) conceptualization of mutuality was compassion. Williams and Iurita (1995) discovered a positive association between comfort measures and quality in the respondents' assessments of their nursing care. Morse (1992) identified that the determinant of whether nurses' achieved an the engaged response correlated with their ability to identify with a client's suffering.

"Normalcy" is attending to three basic human needs, safety and security, love and belonging, and positive self-esteem. The behavioral cues for the concept "normalcy" related to basic human needs. The work of Godschalx (1989) strongly supported the findings of the present study.

Godschalx (1989) believed that the type of health care necessary to improve the quality of life for PWS was driven by their needs for "security", "meaning," "managing emotional pain," and "being like everybody else." Her conceptualization of "safety and security" encompassed the researcher's conceptualization love and belonging needs. As described by Godschalx (1989), "security" is categorized into four types: a) physical security, which relates to the degree of vulnerability; b) psychological security, related to the stability

of symptoms; c) economic security, i.e., safety from homelessness and hunger; and, d) interpersonal security, described as knowing someone in the world cares about you versus experiencing loneliness.

A major challenge to PWS' fulfilling their needs for love and belonging is their lack of resources. Only three of the present study's participants gave accounts of support provided by their families. One participant blamed his brother for exploiting his fear of homelessness in order to control him. The remaining eight indicated that their disease had cost them their ties with family members. Only one out of nine participants described having a friendship with someone outside of the mental health system. As opposed to friends, fellow consumers were looked upon with disdain and distrust.

The participants' love and belonging needs were met, almost exclusively, by MHPs. A major problem with this situation is the role conflict created by what MHPs are taught regarding relationships with their clients. MHPs are discouraged from being "friends" with the clients. Such a relationship increases the risk of "boundary issues" interfering with their ability to produce therapeutic outcomes. In order to help a client, MHPs must not cross the arbitrary line that has been drawn between the "professional" and "social" relationship.

As an example, one definition of the therapeutic nurse-client relationship is "a specific, time-limited interaction of a nurse with a client who has a problem" (McFarland, Gerety, & Wasli, 1992, p. 19). Stuart and Sundeen's (1995) criterion for a potential boundary violation is "whenever the nurse is doing or thinking of doing something special, different, or unusual for a patient" (p. 58). Any nurse-client interaction, for example that takes place "over lunch" or "in the car," is a potential boundary violation. In order to remain within the

boundary, any interaction that takes place outside of the health care facility must be for an explicit, therapeutic reason. Another warning was issued to nurses who "routinely hugged" their clients.

In light of the finding from the present study, the value of the traditional therapeutic relationship between nurses and mental health clients is questionable. Travelbee (1971) refuted the attitude of emotional distance. She believed that nurses must become involved with their clients in order to fulfill their purpose, i.e., to assist their clients who are suffering.

Godschalx's (1989) concept "being like everybody else," primarily addresses the participants' needs in this study for positive self-esteem. She discovered two ways in which her respondents satisfied the need to be a valued member of society. One way was to engage in activities that involved caring for others, e.g., as an adult child or volunteer. Another activity important to the perception of meaning was work.

Frese (1993) supports the importance of work, attributing it to increasing self-confidence, and therefore, self-image. He contends that being a member of the work force decreases stigma and contributes to the acceptance of PWS by the community. Godschalx (1989) found that hobbies were also considered as a type of work. She criticized MHPs' trivialization of PWS' hobbies. A perfect example was the participant in the present study whose nurses, instead of recognizing his achievements in model car racing, told him that he would "be nothing" unless he took his medication.

Leete (1989) argues that positive self-esteem must begin with PWS themselves. "We can overcome the stigma and prejudice we have experienced and reclaim our personal validity, our dignity as individuals, and our autonomy" (p.200). While her point is well-taken,

the findings of the present study indicate that PWS' efforts at improving their self-esteem must be supported by community members.

Hypotheses V and VI

PWS perceive MHPs who demonstrate understanding, compassion, and normalcy as helpful; PWS perceive helpful MHPs as those who regard them as fellow, individual human beings and connect with them based upon mutual humanness. The literature supports Hypotheses V and VI as a blend of the four previous hypotheses. Travelbee's (1971) definition of nursing embodies the idea of humanness. Nurses can not engage in a helpful relationship with their clients unless they interact with them as unique individuals.

Henson (1997) named "humanness" as a behavioral indicator of a helpful relationship between nurses and clients. A relationship of mutuality is demonstrated by interactions that "reflect give and take, exchange of ideas, respect for all possibilities, creativity, comfort , humor, and humanness" (p 80).

Williams and Iurita (1998) also conceptualized the helpful relationship as one where the client is treated with mutual humanness. According to their findings, the behavioral indicators of high quality care were individualized care, taking action to ensure comfort, using touch, and serving as client advocates. One of their respondents articulated the essence of the helpful relationship. As a result of "treating a person like a person, not just a patient or object" (p. 42), the respondent considered himself to have received high quality nursing care.

Godschalx (1989) summarized the central role of mutual humanness in establishing helpful interactions between PWS and MHPs. "The mind and thought processes are closely

identified with a sense of self... Feeling like everyone else is an important goal for people with schizophrenia because the mind is closely associated with humanity" (p. 52).

Theoretical Comparison

An examination of nursing and nonnursing theories reveal limited guidance and no testing of their applications to PWS. Other authors' use of the concept connectedness support only part of the interactional process between nurses and clients.

According to Travelbee (1971), the goal of nursing is an interaction between the nurse and client that proceeds through five phases: the original encounter, emerging identities, empathy, sympathy, and rapport. The nurse and client progress from viewing each other only within the boundaries of their roles, to perceiving and communicating their experiences, thoughts, and feelings. Travelbee's work however, failed to include the perceptions of the clients as a measure of goal achievement.

Two other grand nursing theorists describe the phasic development of the nurse-client relationship. Peplau's theory of interpersonal relations in nursing (1991) includes a progression of four overlapping phases: the orientation phase, the identification phase, the exploitation phase, and the resolution phase. With each phase, the nurse serves as a maturing force towards the client's increased independence from others. By the time the resolution phase concludes, the client has resolved formerly unmet interpersonal needs. Throughout the four phases the nurse assumes different roles, those of stranger, resource person, teacher, leader, surrogate, and counselor.

The phase of "displaying" in the present study includes several of the ideas put forth by Peplau (1991). The orientation phase of her theory occurs when a nurse and a client come

together regarding a health problem. Likewise, PWS and MHPs encounter each other regarding some aspect of treatment for the schizophrenia. She also identifies a setting and reason for treatment. The typical treatment settings in Peplau's theory are hospitals, physician's office, and clinics. As does the researcher of the present study, Peplau makes the distinction between encounters occurring on an emergency versus a scheduled basis.

The reason for a client-nurse encounter in Peplau's theory are described as "felt needs" (1991). The orientation phase is initiated through the client's "felt need" that a problem exists and that professional assistance would be necessary. As shown in the present theory, however, MHPs are most often the ones who determine when PWS need assistance. According to Peplau, in order for interpersonal growth to occur, the nurse must understand the client's felt need.

During the orientation phase (1991), the client attempts to clarify the "felt needs." his or her first perception of the health problem. The needs include those for care, comfort, shared goals, sustaining relationships, and feelings of acceptance. Peplau implies, however, that these needs are normally met by a client's family. Through the various roles the nurse plays, particularly surrogate (for significant other) the patient re-enacts and examines feelings that were generated in prior relationships. The result is an increased understanding of what those needs are and how to meet them in a more mature manner. The nurse serves only to meet the client's needs until the family can take over again.

Three of Peplau's conditions for the successful completion of the orientation phase illustrates the theory's limited use with PWS. The first factor is time. According to Peplau, progression through the orientation phase cannot occur at once. takes time. Even if PWS

remain with the same health care facility, their time with a particular MHP only consist of one visit. PWS rarely get beyond the orientation phase because of the constant turnover of staff. The second factor is for staff to demonstrate interest in helping clients through the orientation phase. The participants in the present study gave numerous examples of the disinterest demonstrated by MHPs. Finally, the families of PWS do not, as suggested by the Peplau theory, routinely meet their interpersonal needs. MHPs do not just temporarily meet their clients needs until the family takes over again. PWS frequently consider MHPs as their families, and therefore, could be threatened by working towards independence.

The focus of the interpersonal relationship in Peplau's theory raises another concern. From the perspective of interpersonal theory, personality development is based upon the insight of one's own inner needs, and how those needs affect relationships with others. Anxiety results when those needs go unmet, but with the nurse's help, can then be used as a tool to facilitate insight. Torrey (1995) strongly opposes any type of psychotherapy with PWS that uses anxiety as an intervention strategy. Using insight-oriented psychotherapy with PWS, he says, is akin to "directing a flood into a town already ravaged by a tornado" (1995, p. 168).

King's (1981) general system's theory of nurse-client interactions encompasses the dynamic interaction of the personal, interpersonal, and social systems. This theory focuses on transactions that are related to goal attainment, satisfaction, effective care and enhanced growth and development. The personal system encompassing each individual interacts with one another to form interpersonal systems. The personal and interpersonal systems function as subsystems within the context of the environment, the social system. In order to function

effectively with a client, the nurse must recognize the interrelationships among the three systems.

The interpersonal system as described by King (1981) is a goal-directed process, represented by a sequence of verbal and nonverbal behaviors, that takes place between two or more personal systems. Based upon one's own perceptions, feelings, and experiences, a person perceives, judges, acts, and reacts to the behavior of others. Perceptions, judgements, actions, and reactions are not directly observable and are, therefore, inferred. Interactions, however, can be observed. When two personal systems interact to achieve a mutual goal, transaction occurs. The experience of the transaction is fed back to each personal system, and the entire process repeats itself.

The description of Connecting Through Humanness as a process is similar to King's theory. PWS base their inferences of understanding, compassion, and normalcy on specific behaviors of the MHPs. Because the present study only included the PWS' perceptions, it is not known how their behavioral symptoms impacted the perceptions of the MHPs. The primary goal of PWS was to interact with MHPs as mutual human beings. Such an interaction produced an experience of connecting with the MHPs. Using the language of King's model (1981), transaction occurred with MHPs who conveyed an attitude of "normal people" versus schizophrenics. As with King's conceptualization, the process of Connecting with Humanness repeated itself with each interaction between PWS and MHPs.

Meleis (1999) identifies an important aspect of the theory that affects its relevance to PWS. Both the assumptions and propositions of King's theory are based upon "rational thinking." King (1991) stresses the importance of nurses and clients basing their interactions

on accurate perceptions of each other. What was considered "accurate," most likely, was defined by the nurse. Thus, King's theory provides limited guidance in understanding the interactional process between PWS and MHPs.

Rather than phases, some authors presented a typology of the nurse-client relationship (Morse, 1991; Morse et al., 1992; & Hagerty, 1993). Schubert and Lionberger's (1995) model of mutual connectedness is the dynamic process between four types of relationships. Walton's (1996) model of the spiritual relationship illustrates the linkages between knowing oneself and knowing other. As true of the other's, Walton's model did not target the relationship between psychiatric nurses and PWS. In summary, existing theories provide little help in understanding the interactions of PWS and MHPs.

The final topic of the chapter is an explanation of the type of theory that Connecting with Humanness represents. Liehr and Smith (1999) assert that there is no one precise and clear definition of middle range theory in the nursing literature. The criteria selected by the researcher to define the theory's type were those of Meleis (1999) and of Strauss and Corbin (1998).

Type of Theory

Theory serves as an important way of examining the concepts that comprise the nursing paradigm. The central concepts of concern to the nursing discipline, according to Meleis (1999), include nursing client, transitions, interaction, nursing process, environment, nursing therapeutics, and health.

Scope is a criterion often used to describe nursing theories. Theories can be located on a continuum ranging from a broad to narrow scope, which in turn affects the way it is

used in research and practice. To determine the scope, Meleis (1999) suggests looking at the number of problems in nursing that are addressed by the theory. Conceptual models, also referred to as grand theories, are highly abstract. They are designed to cover all of the domain's concepts within each particular theory or model. On the other end of continuum, single-domain theories are composed of concepts that are derived more from direct observation than interpretation. Such theories describe a single aspect of a concept based more upon facts and principles than on relationships.

The development of middle range theories, attributed to sociologist R.K. Merton, was the attempt to bridge the gap between grand and single-domain (Meleis, 1999). Middle range theories are conceptualized at a higher level of abstraction than single domain theories, and thus, cover a wider range of phenomena. Their scope does encompass the entire domain of a discipline, but covers a more limited number of variables than grand theories.

Based upon Meleis's criteria, the emerging middle-range theory from this study lies mid-range between grand theories and single-domain theories. Unlike grand theories, *Connecting Through Humanness* only addresses one concept within the domain of nursing, the nurse-client interaction. Furthermore, although the present theory does focus on one domain, it is not a single-domain theory. The concepts in *Connecting Through Humanness* were only initially derived from direct observations. In addition, this emergent middle-range theory was developed through relating concepts derived from the raw data.

Strauss and Corbin (1998) identified the properties of abstraction and scope as central to characterizing grounded theory. The property of abstraction refers to what degree a concept is derived from interpreted as opposed to observed empirical findings. Scope refers

to the degree to which the theory can be generalized to different situations. The higher the level of conceptual abstraction, the more problems a theory can address. The two types of theory, formal and substantive, are classified in relation to their scope (Strauss and Corbin, 1998). Formal theory has a wider scope than that of substantive theory. Substantive theory is the type that evolves from investigating one particular aspect of a problem as it affects a specific population. The theory should be able to explain or predict events for users, and therefore offer guides to action. A substantive theory deals with one aspect of a problem with a specific population. Because the focus of *Connecting Through Humanness* is one aspect, stigma, with a specific population, PWS, it is a substantive theory.

In summary, *Connecting Through Humanness* is a substantive theory that falls midway between addressing the broadest and most narrow range of phenomena. Within the domain of nursing, the central concern is the nurse-client interaction. As opposed to the scholarly definitions described above, one of Merton's principles of middle-range theory brings it to life. "When individuals tell stories to one who really listens, a change takes place" (Liehr & Smith, 1999, p. 82).

Chapter V: Summary and Conclusions

This chapter begins with a brief summary of the study, followed by the implications of the findings for nursing practice, education, and research. The chapter ends with an account of the study's limitations

Summary of the Study

The purpose of the study was to discover how PWS experienced an interpersonal connection in their interactions with MHPs. The study was conducted according to the grounded theory methodology of Strauss and Corbin (1998). The specific research question was: "How do PWS experience connecting with MHPs?" The significance of the study was demonstrated by the costs exacted by the disease on societal resources, and most important, on the tragic ramifications for the human beings who have the disease. The lack of research in the area was also cited as a justification for undertaking the study.

A group of twelve clients with schizophrenia was recruited from two outpatient mental health centers. In order to participate the clients had to have been 18 years of age or older, have a DSM-IV diagnosis of schizophrenia, and to have been informed of their diagnosis. Because of the potential vulnerability imposed by their disease, clients could not be approached unless they had first been cleared for participation by their respective psychiatrists and case managers. Participants were also screened for their ability to be understood and willingness to be interviewed. In order to decrease their risk for emotional distress, participants had to agree to the researcher's contacting the treating psychiatrist and case manager with concerns about continued participation.

The participants were interviewed in private areas within the mental health centers. Eleven of the twelve participants allowed their interviews to be audiotaped by the author. One participant chose to have the interview recorded by the author's written notes. Three of the eleven audiotaped interviews were not clear enough for transcription. The researcher compiled demographic data on only those nine whose interviews were included in the analysis. The participant group included nine persons ranging from 28 to 54 years old. Three of the five male participants were Caucasian and two were African American. Three of out of four female participants were African American, the fourth having been Caucasian. Participants had been dealing with their illness, on average, for 20 years. The amount of time that had elapsed since diagnosis ranged from 11 to 30 years.

Interviews were transcribed by the researcher and analyzed according to the Strauss and Corbin (1998) methodology. The researcher used the analysis of the concept Displaying to demonstrate the analysis procedure. The theory emerged from the data as the researcher proceeded through three increasingly abstract levels of coding: open, axial, and selective coding. As definitive categories were linked by relational statements, the researcher was able to designate a central category that explained the main theme of the study. The central category, *Connecting Through Humanness*, explained the process by which participants managed their encounters with MHPs. The central strategy for maintaining scientific rigor was that of the audit trail. Two members of the researcher's committee, both with expertise in grounded theory, examined the transcriptions, memos (written notes) and interpretations of the analytical procedures throughout the research process.

The interactional problem described by participants was their perception of being regarded by some MHPs as an illness rather than a human being. They perceived themselves to have been stereotyped as "schizophrenics," and therefore considered by some MHPs as dangerous or unable to participate in treatment decisions. As a result of the stigma, participants sometimes received ineffective and disrespectful treatment on the part of their professional caregivers.

The participants went through a process of deciding whether their experiences with mental health professionals were positive. The process began with participants "displaying" themselves to MHPs. Participants interacted with MHPs in order to receive treatment for their schizophrenia. Whether an individual's symptoms were considered as threatening or nonthreatening determined the reason for the interaction, the setting of the interaction, and the type of MHP encountered.

Five participants described having had auditory hallucinations that threatened their own or someone else's safety. Two participants, for example, attempted to kill themselves in order to obey the "commands" of the voices. Participants also described symptoms that did not provoke violent ideation, but were no less distressing. One participant, for example, heard the voice of her sister relentlessly criticizing and taunting her. Another believed that he was going to die from the medication that had been prescribed for him. Four participants discussed their beliefs of MHPs "plotting" against them, but never mentioned or alluded to plans for violent retaliations.

Participants received treatment, driven by the potential threat of their symptoms, on what the researcher conceptualized as an "emergency" or "scheduled" basis. Emergency-type

situations, i.e., those involving threatening symptoms, were most often handled through inpatient settings. The inpatient settings included three public long-term facilities (one psychiatric hospital and two prisons), and one public and two private acute care hospitals. Although only five of the participants had described threatening symptoms, a total of eight reported encounters in inpatient facilities. All nine participants recounted some type of outpatient care in community mental health centers. Two of the nine had private psychiatrists but attended programming at the centers.

The types of MHPs varied with inpatient versus outpatient encounters. All of the participants were taking at least one type of antipsychotic medication that, therefore, necessitated some degree of physician involvement. Perhaps because of the central role medication plays in their treatment, in both inpatient and outpatient settings, participants talked about psychiatrists more than about any other type of professional. The case manager's role is to coordinate all aspects of care so that PWS stay out of the hospital. Consistent with their important role in treatment, case managers were discussed second most frequently by the participants.

Nurses (there was no mention of RN versus LPN) were associated almost exclusively with inpatient treatment, most likely a reflection of the small number of nurses employed by outpatient facilities. Nursing assistants were mentioned only as members of the public long-term facility's staff even though they typically provide the majority of client contact in acute-care hospitals. Finally, counselors were described within the context of both inpatient and outpatient settings. One provided therapy to a participant during the participant's incarceration and the other worked out of a community mental health center. Two

participants talked about their interactions with vocational counselors.

As the participants displayed themselves to MHPs they also engaged in a process entitled "Sizing-Up." They sized-up certain MHPs' behavioral cues as to whether they conveyed understanding, compassion, or normalcy. All participants gave at least one positive and/or negative example from at least one the three categories.

Understanding took two forms, "knowing what to do" and "knowing what it's like." In order to have been categorized as "knowing what to do," MHPs needed to have correctly diagnosed and treated the symptoms of the illness as well as the side effects caused by some of the treatments. MHPs demonstrated "knowing what it's like" by inquiring and learning about the impact of symptoms and treatments on all areas of life.

Compassionate MHPs spent time with and listened to the participants in order to determine how they could alleviate any type of suffering. Once they learned of a problem they took action towards its resolution. A counselor, for example, advocated a medication change to a participant's psychiatrist when the participant was too sick to advocate for herself. In an opposite scenario, a nursing assistant allowed a participant to suffer without treatment for an hour with severe muscle spasms caused by his medication.

The third category of the sizing-up process, called Normalcy, constituted whether participants felt that MHPs treated them in the same fashion as "everybody else." Characteristics of normalcy addressed three basic human needs, the need for safety and security, love and belonging, and positive self-esteem. To MHPs who conveyed normalcy, the fear caused by living in a crime-ridden neighborhood was as important of an issue as the fear generated by paranoia.

The participants' needs for love and belonging were primarily met by staff members of the mental health centers. Very few of the participants mentioned close contact with family members or friends. The need that was most affected by the stigma of schizophrenia was the need for positive self-esteem. MHPs who increased the participants' self esteem treated them with respect and interacted with them more as equals than as superiors.

The culmination of sizing-up was the process of "Classifying." PWS classified MHPs as helpful or not helpful. Participants perceived themselves regarded as human beings during helpful interactions with MHPs. In contrast, participants felt treated as "schizophrenics" during interactions that were considered not helpful.

In conclusion, as a result of the entire process of Connecting Through Humanness, participants perceived connecting as an interaction with a MHP in which they experienced mutual humanness. The findings of the present study, supported by findings in the extant literature, illustrated the importance of humanness over illness when interacting with PWS. Connecting Through Humanness was explicated as a theory by a list of assumptions, a theoretical model and list of hypotheses.

Implications for Nursing

This section of the chapter is an explanation of the importance of the findings to the discipline of nursing. In addition to nursing, the implications for the medical field are addressed. A theory that allows for a better understanding of the interactions between PWS and their professional caregivers has implications for clinical practice, education, theory development, and research. Williams and Iurita (1998) warn that unless more nurse researchers focus on nurse-clients interactions, the less significant the nurse-client relationship

will be regarded in health care. Benoleil (1996) also stresses the need for researchers to revisit the traditional 1:1 nurse-client interaction as it relates to modern health care. "In the real world of health care delivery, caregiving is offered by multiple nurses, not one; and the larger environment of the work setting influences how nurses practice as individuals, how they work as colleagues, and what happens to patients and families " (p. 418).

Clinical Practice

As health care providers, practicing nurses must be adept at interacting effectively with clients regardless of the type of health problems. Decreasing lengths of stay require nurses to interpersonally reach their clients as soon as possible. Basing their interactions upon the idea of shared humanity can serve as the guiding principle for facilitating those interactions.

One application of the present findings could be to promote awareness among nurses as to how they are perceived by persons with schizophrenia. What many practitioners, including nurses, learn about interacting with PWS is from their co-workers. In this manner, unless other educational opportunities exist to refute the stigma, the negative attitude towards PWS is perpetuated.

The types of educational programs offered in many facilities, however, are inadequate. A considerable amount of training on psychiatric units is devoted to the management of "psychiatric emergencies." Psychiatric emergencies are situations in which a client is considered an immediate threat to himself or others on the unit. In many cases, the client has schizophrenia. Acknowledging the necessity of such training, perhaps there would be fewer "emergencies" to manage if the staff could interact with clients in a more supportive

manner. Staff inservices dedicated to increasing the interpersonal knowledge and skill level of nurses would cover the specific behaviors, e.g., use of humor, that are most supportive of PWS: understanding, compassion, and normalcy.

Another area of learning was identified by Frese (1993). He advised persons without the disease, whom he termed "normals," to learn the reasons for the deficits and coping behaviors of PWS. One of the participants in this study called for persons without schizophrenia to better understand PWS. He went on to say that, in order for communication to improve, PWS need to learn about the behaviors that are likely to be perceived as deficits. Psychoeducational groups would be an excellent forum for PWS and MHPs to discuss the communication gap between them.

The premise of mutual humanness also has implications for client assessments. Most client assessments, even in mental health, are disease-focused. A typical assessment tool includes a section on demographic data, the presenting problem, current and past medical treatment, and a review of systems. The assessment concludes with a few token questions that are meant to address the client's "psychosocial status." Although the "presenting problem" is supposed to be from the client's perspective, it is often the nurse's opinion of why the client is being seen. Physicians are taught to base their treatment upon the DSM-IV diagnosis. The client's perception of the "presenting problem," as with nurses, is frequently ignored.

An assessment that incorporates the principles of Connecting Through Humanness would be based upon basic human needs, regardless of the client's diagnosis. Nursing care that is focused on human needs would facilitate positive nurse-client interactions, and in turn,

client improvement. Such a demonstration would support the integral role of the nurse-client interaction in quality health care.

The impact of health care policies on nursing practice necessitates activity that influences the formation of these policies. Nurses have several avenues of educating and informing professionals and community members of the discrimination against PWS. An imperative group with which to begin is themselves. State and local chapters of the American Nurses Association (ANA) or Sigma Theta Tau provide numerous opportunities for nurses to educate their peers about the need to see the humanness in PWS. Mental health nurses are as much in need of education as those in other specialities.

In order to educate the larger community, nurses must position themselves in public policy groups. As members, or better yet, leaders, of groups such as city council or community mental health boards, nurses could inform policy makers of the impact of stigma related to or surrounding PWS.

As members of national associations such as the American Nurses Association, nurses can take advantage of lobbyists to push for legislation that is pro-PWS. The power of a national association such as the National Alliance for the Mentally Ill (NAMI) is another way to improve the quality of life for PWS. Through the efforts of its constituents, NAMI has campaigned for an end to stigma. A major result of their work is in legislation involving insurance parity. In large part due to NAMI support, more and more states are requiring businesses to offer their employees health insurance that provides the same amount of coverage, regardless of whether the illness is mental. NAMI was in the forefront of a campaign against a major network television program. After only two episodes, ABC

Television took its new program, "Wonderland," off the air. The program's storyline was about life on a psychiatric hospital unit. Consumers and their families protested about the program's perpetuation of the stigma of mental illness (NAMI Northern Kentucky, 2000).

Education

Nursing educators are no less responsible than health care administrators for fostering a negative attitude toward PWS. Fostering an increased understanding and caring attitudes among students must begin with the instructor. Students need to be mentored by clinical instructors who are experienced in, and more importantly, enjoy working with PWS. Clinical instructors who are prejudiced against PWS serve only to reinforce whatever stigma the students possessed upon entering their mental health rotation. The following example was an account told to the researcher by a former nursing student.

On the first day of a medical-surgical rotation, the instructor asked the clinical group what area(s) of practice appealed to them. When the student answered "mental health," the instructor held out her two crossed fingers, as if warding off a vampire. Connecting Through Humanness offers nurse educators a framework with which to examine the interactions between nurses and PWS. Through the use of self-awareness exercises, such as role plays and attitude inventories, the students and instructors could develop insight into their communication of understanding, compassion, and normalcy.

Another example of reinforcing a negative attitude towards working with PWS is the advice frequently given to graduating students. Students, regardless of their interests, are advised to get their first job on a medical-surgical unit. At least a year of such experience will prevent them from "losing their skills." The term "skills" is understood to mean tasks, such as

starting IVs or dressing wounds. The ability to interact with a client in a way that promotes healing apparently does not count as a "skill." As the situation pertains to medicine, the abysmal "bedside manner" of many physicians attests to their minimizing the importance of interactional skills.

A powerful strategy used by one researcher to promote understanding and compassion among nursing students was a television news program. One of the segments featured a woman with schizophrenia. The students audibly gasped as they witnessed how schizophrenia had transformed a beautiful, bright-eyed teenager into a 35 year-old, disheveled woman who could barely produce an intelligible sentence. Fostering interactional skills to deal with such clients will improve the nursing student's attitude and the care provided to PWS.

Nurse educators also need to teach students the societal context of PWS. Teaching strategies could include assigning students to follow the media's accounts of PWS, or to watch one of Hollywood's many negative renditions of PWS. Public policy ramifications could come to life if the instructor attended a city council or community mental health board meeting with the students. The meeting could be processed the next time the class met. Again, all of these learning experiences would bring the humanness of PWS to the forefront.

Theory Development

Several authors emphasize the importance of theory regarding the nurse-client relationship. Morse (1991) noted that although there are some studies on the establishment and development of the nurse-client relationship, the literature lacks an explanatory model for how different types of nurse-client relationships develop. Hutchinson (1993) views grounded

theory as an effective means of understanding relationships because the theory is built from actual interactions. She warns us, however, that as more professional nurses are replaced by paraprofessionals and their roles continue to be restricted, the opportunities for studying nurse-client interactions will diminish.

Based upon their analysis of the past 10 years of published middle-range nursing theories, Liehr and Smith (1999) recommend ways to advance the nursing perspective through future theory development. One of their suggestions of particular relevance to the present study is to combine nursing middle range theories with those of other disciplines. The model of mental health care practice is multidisciplinary. The research conducted for *Connecting Through Humanness* included multidisciplinary caregivers. A collaborate examination of the social processes that take place between PWS and each of the disciplines could shed light on the distinctions between interactions with nurses versus those with other disciplines.

The hypotheses of *Connecting Through Humanness* could be a starting point with which to develop grounded theories that focus on the MHPs. Do nurses, for example, "size up" their clients, and if so by what criteria? How do professionals rate themselves according to the person with the disease's criteria for understanding, compassion, and humanness? Interviewing and observing nurse-PWS dyads would broaden our understanding of the dynamics involved in connecting.

Research

The theory's major theme, that persons with an illness want to be treated by professionals as fellow human beings, can be studied from a variety of perspectives. The

greater the variations in this substantive area and population, the greater the number of concerns to nursing can be addressed.

One area of study could be the impact of improved PWS-MHP relationships on treatment outcomes. Nurse researchers could examine how mutual humanness relates to outcomes such as medication adherence, the number of hospitalizations, and the ability of PWS to socialize with persons outside of the mental health system.

According to Benoleil (1996), the findings obtained "from carefully done grounded theory research by nurses, have provided images of the powerful influence of social and contextual forces on the life experiences of vulnerable people in crisis and change. How to assist nurses in practice to define their work in these context-dependent terms is a challenge for the future" (p. 418).

Future research using *Connecting with Humanness* could illuminate social processes that are part of nursing interventions. One example could be a comparison of intervention strategies used by inpatient versus outpatient nurses. Research needs to be done in order to increase understanding of the factors affecting where nurses are employed. If nurses want to become more a part of outpatient care, they need to understand who or what is standing in their way.

Strauss and Corbin (1998) suggest testing hypotheses across different substantive areas. The author could apply her theory to persons with different illnesses, particularly mental illnesses. Is the process of connecting, for example, the same for persons diagnosed with mood disorders or personality disorders as for PWS?

The hypotheses could also be applied to persons with cognitive impairments unrelated to mental illness. Persons with Alzheimer's Disease, for instance, may also feel considered as an illness entity by health professionals. Much like persons with schizophrenia, persons with Alzheimer's Disease are viewed by many as incapable of describing their realities.

Another area for research includes subgroups of PWS. A researcher may want to compare the interactions between male PWS and female PWS. Although gender differences have been explored from an epidemiological perspective, there is a need for studies pertaining to how men and women experience schizophrenia.

A final situation where the findings could contribute to nursing theory involves the components of Connecting Through Humanness.. Additional theoretical sampling among PWS, for instance, would further illustrate what is meant by "understanding," "compassion," and "normalcy." Another example is the concept "classifying." Perhaps there are additional outcomes other than "helpful" and "not helpful."

Limitations of the Study

The major source of limitations was a combination of factors involving the researcher and research environment. The researcher's lack of experience with any type of research, much less grounded theory, were difficult to overcome. Almost 20 years of clinical experience as a psychiatric nurse clinician and educator made it impossible for bias not to be an issue. The main area this was thought to affect was labeling phenomena. As an example, the classification of symptoms into threatening and nonthreatening was based upon the standard commonly used in the mental health field. The potential threat of symptoms to the PWS or to others is a major determinant of treating the PWS in the "least restrictive

environment." This standard is played out when deciding between treatment issues, e.g., seclusion room versus unit, inpatient versus outpatient, and voluntary versus involuntary hospitalization.

Whatever bias caused by the researcher's clinical experience, however, was balanced by how comfortable the participants felt about interviewing. Rapport was established with participants within minutes after initiating the interview. The fact that the participants agreed to even talk suggested their perception that it was safe to share their experiences, i.e., the researcher was a safe person with whom to talk.

Another limitation was the result of environmental issues posed by the study sites and of the type of employees. Access to clients was in the hands of the case managers. As a former employee of a community mental health center, the researcher was aware of the huge caseloads that case managers carried of persons with mental illnesses. It was easy for the researcher, then, to understand how recruiting clients for someone they had no history with was low on the case managers' priority lists. The keys to eventual access to participants turned out to be former colleagues. One of the group leaders had been in graduate school with the researcher. She was very interested in the study and facilitated the access process. The interest of another group leader resulted in getting almost half of the participants. The source of her motivation is unknown to this day. When the researcher called to thank her for all of her help, she was told that this particular staff member was no longer at the center.

The inexperience of the researcher and limited access to clients had a negative impact on the amount of theoretical sampling that was performed. Because the researcher had to go through a number of persons to get to the participants, sampling was based more on access

than on opportunities for variation. There were likely missed opportunities for theoretical sampling that the researcher overlooked because of the lack of experience.

Finally, Strauss and Corbin (1998) recommend coding each interview before conducting another one in order to focus the questions on what emerged from the previous analysis. Because of the participants' schedules, they tended to be available on the same days at the same times. The researcher was then left with several interviews at once that needed to be transcribed and analyzed. Through the process of transcription, however, the researcher was able to generate relevant questions of the data from transcript to transcript.

In summary, limitations to the study were a combination of restrictions within the researcher and within the environment. In future studies, more time spent with case managers at the centers, a greater amount of time to spend with clients, and the ability to code and transcribe interview by interview will allow for a denser theory that more comprehensibly captures the "connecting with humanness."

Chapter Summary

Chapter V included a summarization of the entire study, including the problem, question, significance, methodology, data gathering and analysis, theoretical model, and findings. The remaining topics were the implications of interacting with PWS as mutual human beings for nursing practice, education, theory development, and research. Implications were also related to other MHPs. The final subject was a description of the study's limitations.

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Appendix A

RECRUITING CLIENTS FOR PARTICIPATING IN THE STUDY

1. **Get the names of clients (nonhospitalized) from your caseload who have a DSM-IV diagnosis of schizophrenia (it doesn't matter what subtype or if they have additional diagnoses).**
2. **Ask clients if they would like to be in a study about what it's like for them to work with health care professionals.**
3. **Explain to interested clients that:**
 - a. **they would be interviewed by a psychiatric registered nurse who is working on getting her PhD degree.**
 - b. **the interview(s) would take place at ...(name of facility).**
 - c. **there would be AT MOST 3 interviews, and each interview would last NO LONGER than 1 hour.**
 - d. **they WOULD NOT be paid for their time.**
 - e. **the interviews would be confidential - only the client and researcher (nurse) would be present, and would be the only ones to know what was said by whom.**
4. **Give the names of clients agreeing to participate, along with information on how to best reach them, to the researcher.**
5. **The researcher will meet the client(s) to do final screening, sign the consent form, and if the client desires, have the interview.**
6. **The researcher, Sue Brammer, is available by digital pager on weekdays (552-7469) and by home phone (861-1152) any other time.**

Appendix B
 UNIVERSITY OF CINCINNATI
 COLLEGE OF NURSING AND HEALTH
 CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Study: Connecting with Health Care Professionals for Persons with Schizophrenia

Principal Investigator Name: Susan V. Brammer

Telephone Number: 552-7469

I. Introduction

"Before agreeing to participate in this study, it is important that the following explanation of the proposed procedures be read and understood. It describes the purpose and procedures of the study and any foreseeable risks or potential benefits. It also describes the right to withdraw from the study at any time."

II. Purpose of the Study

The purpose of this study is to learn more about the kinds of relationships people with schizophrenia have with health care professionals, such as doctors, nurses, or case managers. "I _____ agree to participate in this research study in which the researcher will ask me to tell about my experiences with health care professionals." I will be one of about 10-15 people to take part in this study.

III. Duration

My participation in this study will involve at most three sessions. Each session will not last longer than 60 minutes, unless I want to talk longer. Sessions will take place over a period of approximately six months.

IV. Procedures

I have been told that during the study I can expect several things to happen. First, the researcher will ask me questions about my experiences with health care professionals. An example of such a question is: "What helps you feel close to the people who you go to for health care?" I will be asked to talk about my thoughts and feelings until I think I have no more to say. If I begin to talk about things that don't have anything to do with my experiences with health care workers, the researcher will stop the interview and ask me to get back to the questions she is asking me. The discussion will be tape recorded and later written down, or transcribed, on a computer. The researcher and I will talk in a private area at my mental health center. We will talk no longer than 60 minutes, unless I want to take longer to answer the researcher's questions. I also understand that the researcher may ask me to further explain my answers during this talk or one in the future. At most we'll talk three times. During these talks I may be asked to give my opinion of what the researcher has written about them.

V. Possible Risks and Advantages

I understand that one of the risks of being in this study is that I may get upset when talking about my experiences. However, if this happens I can drop out of the study. I also have the right to talk about feeling upset with a health care specialist. I

understand that if the researcher thinks I am upset enough to be unsafe, she will tell my case manager and/or psychiatrist that I am too upset to be in the study, and request that I be seen. I understand that a good thing about my participation is that it may help health care professionals learn how to better work with people with schizophrenia. I may also contact the researcher, Susan V. Brammer, at 552-7469 with concerns regarding our discussion(s).

VI. Confidentiality

I understand that the tape-recorded interview is considered information for the study. My identity will be kept private by removing my name and all personal identifying information from the tapes and written transcriptions. My name won't be used in reporting study findings, but part of what the researcher and I talk about may be used to support study findings. The researcher will not tell anybody at my mental health center or any health care professional I talk about what I have said. The person(s) who writes down the content of the taped interview will have to sign a form for the researcher agreeing not to tell anybody but the researcher about what is on the tapes. Tape recordings and written transcriptions will be kept in a locked file. Only the researcher will have access to this file. Tape recordings will be destroyed at the completion of the study. Written transcriptions will be destroyed within five years of completion of the study.

VII. Compensation in Case of Injury

"The University of Cincinnati follows a policy of making all decisions concerning compensation and medical treatment for injuries occurring during or caused by participation in biomedical or behavioral research on an individual basis. If I believe I have been injured as a result of research, I will contact Susan V. Brammer at 552-7469 or Dr. David Kushner at 556-0493."

VIII. Right to Refuse or Withdraw

"I understand that my participation is voluntary and I may refuse to participate, or stop my participation AT ANY TIME, without penalty or loss of benefits to which I am otherwise entitled. I also understand that the investigator has the right to withdraw me from the study AT ANY TIME."

IX. Consequences of a Subject's Decision or Withdraw

Should I wish to withdraw from this study, I have been assured that I will not be punished in any way.

X. Offer to Answer Questions

If I have any questions about this study, I may call Susan V. Brammer at 552-7469, or Dr. Elaine Miller at 558-5298.

XI. Signatures

I, the undersigned, have understood the above explanation and have given my consent to voluntarily participate in "Connecting with Health Care Professionals for Persons with Schizophrenia."

Signature of the Study Participant

Date

Signature of the Investigator

Date

Signature of the Witness

Date

Appendix C

Interview Questions

1. I'm going to ask you some questions about the different professionals you go to when you're sick or you see to prevent you from getting sick. By professionals, I mean people like nurses, doctors, dentists, social workers, case managers. Are there types of professionals you see or have seen in the past that I haven't mentioned? If so, who?
2. Who, of those professionals, do you like the best? What about them do you like?
3. Who, of those professionals you see, do you like the least? What about them don't you like?
4. Of those professionals you have seen, who have you seen the longest? Tell me a little about her/him.
5. What about a person, any person, makes it easy for you to talk to him or her?
Will you give me an example?
6. What about a person makes it hard for you to talk to her or him?
Will you give me an example?