

She Took the Time to Make Sure She Understood": Mental Health Patients' Experiences of Being Understood

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Abstract:

The foundation of psychiatric/mental health nursing is the relationship between nurse and patient. Caring for persons with mental illness within the context of this relationship requires knowledge of the individual. To gain this knowledge, understanding the patient's perceptions and concerns is essential. Research suggests that this understanding does not always occur. The study reported here examined what it means to individuals with mental illness to be understood. In-depth phenomenological interviews revealed three predominant themes: "I was important," "it really made us connect," and "they got on my level." Nurses can use these findings to improve the care of those with mental illness.

Article:

The foundation of psychiatric/mental health nursing is the relationship between nurse and patient. Caring for persons with mental illness within the context of this relationship requires knowledge of the individual. To gain this knowledge, understanding a patient's perceptions and concerns is essential. For decades, clinicians have been urged to listen intently and to paraphrase accurately as bases for establishing the patient's major problems and for establishing a plan of care (Peplau, 1952/1991; Rogers, 1980). Textbooks are replete with therapeutic communication techniques. Yet, there is scant empirical evidence regarding their effectiveness, especially from the patient's point of view. Notes Baldwin (2004), "the significance of everything we try to do is dependent upon the meaning others give to it" (p. 28).

There is abundant documentation that social stigma makes it difficult for people with mental illness to seek care, in part for fear of being misunderstood or shamed (Corrigan, 2005). Indeed, research has shown that many people with mental illness do not feel understood and do not connect with or trust their mental health care providers (Breeze & Repper, 1998; Shattell, 2002; Thomas, Shattell, & Martin, 2002). How should the nurse enter the patient's world? A psychiatric nurse and a patient come together as strangers (Peplau, 1952/1991). The nurse sees a "man from the outside" (Merleau-Ponty, 2004, p. 79). How does one achieve those "rare and precious moments at which human beings come to recognize, to find, one another?" (Merleau-Ponty, 2004, p. 90). What can we glean from the extant literature?

LITERATURE REVIEW

Research on nurse–patient interactions has increased our knowledge on how nurses communicate (Baer & Lowery, 1987; Jackson & Stevenson, 2000), how patients perceive nurse–patient relationships, and how patients perceive nurse–patient interactions (Altschul, 1971; Breeze & Repper, 1998; Drew, 1986; Fosbinder, 1994; McCabe, 2004). Altschul found that nurse–patient relationships formed after very few nurse–patient interactions, even when interactions were of relatively short duration. Patients believed that these relationships were more important than other aspects of care. Other studies have shown that patients wanted nurses to be genuine, unhurried, available, willing to talk to them (Altschul, 1971; Shattell 2002), and respectful to them as individuals (Breeze & Repper, 1998; Plaas, 2002).

Several studies of patients' perspectives of nurse–patient relationships, in both psychiatric and nonpsychiatric settings, found that patients wanted nurses to know them. For example, Williams and Irurita (2004) studied 40 hospitalized nonpsychiatric patients regarding their perspectives of therapeutic and nontherapeutic interpersonal interactions and found that patients felt more secure with nurses who had greater knowledge of the disease process and who had knowledge of them as individual persons. Adam, Tilley, and Pollack (2003) interviewed 13 persons with serious mental illness about their perspective of the value of community mental health nurses and who found the relationship as the most valuable aspect of their care. Relating to another human being who listens, cares, and does not judge was highly beneficial to those who could not find this nonjudgmental experience elsewhere (family, friends, and significant others) (Adam et al., 2003).

Understanding was a central concept in findings from studies of hospitalized mentally ill patients' perspectives of good psychiatric care (Johansson & Eklund, 2003) and being helped (Koivisto, Janhonen, & Väisänen, 2004), and of therapy patients' experiences of positive events in therapy (Bradley, 1993). Johansson and Eklund (2003) interviewed outpatient and inpatient individuals with mental illness in Sweden about their satisfaction with psychiatric care. In both samples, the quality of the relationship and the experience of "being understood by the therapist formed the most central aspects of the quality of care" (p. 342). A phenomenological study of nine mentally ill persons admitted to a psychiatric unit for psychosis in Finland revealed that the most helpful aspect of nursing care was protecting patients from vulnerability. This protection included feelings of safety, understanding, respect, and trust (Koivisto et al., 2004). Bradley (1993) studied positive events in therapy from patients' and therapists' perspectives and found "being understood" as the most salient aspect of therapy. Cleary, Edwards, and Meehan (1999) interviewed 10 nurses about factors that influence the nurse–patient relationship and found that that the nurse's ability to understand patients had a significant influence on nurse–patient interactions in the acute psychiatric/mental health setting. In summary, research and theoretical literature supports the experience of understanding as an essential aspect of care and caring (Benner & Wrubel, 1989; Peplau, 1952/1991; Rogers, C., 1980; Rogers, S., 1996; Swanson, 1991, 1993, 1999; Watson, 1985, 2005), but no studies describing how persons with mental illness actually experience the phenomenon of being understood were located. The study described here examined mentally ill patients' experiences of what it is like to be understood.

METHOD

Setting and Sample

A purposeful sampling design was used to obtain participants with varying demographic characteristics who self-identified as having a mental illness and as having experienced being understood by a health care professional. Potential participants were recruited through an advertisement in a weekly university newspaper. Participants were included if they said they had been understood and were willing to talk about their experience. The 20 participants were English-speaking individuals aged 21–65 years ($M = 39.6$ years): 15 (75%) Euro Americans, 4 (20%) African Americans, and 1 (5%) Native American. Eight were male (40%), and 12 were female (60%). One had less than a high school education (5%), three were high school graduates (15%), six reported some college (35%), six were college graduates (30%), three had a master's degree, (15%) and one held a doctoral degree (5%). The number of previous psychiatric hospitalizations ranged from 0 to 33 (mode = 0; $Mdn = 0.5$); most of the sample ($n = 11$; 55%) had no prior psychiatric hospitalizations. Participants reported past and present psychiatric diagnoses, including depression ($n = 10$), anxiety ($n = 3$), generalized anxiety disorder ($n = 1$), bipolar disorder ($n = 9$), postpartum depression ($n = 1$), panic attacks ($n = 1$), posttraumatic stress disorder ($n = 1$), attention deficit hyperactivity disorder ($n = 1$), antisocial personality disorder ($n = 1$), and schizophrenia ($n = 1$). Seven participants reported more than one psychiatric diagnosis (mode = 2). Six participants (four women and two men) were homeless at the time of the interview.

The study was approved by the university's institutional review board, and written informed consent was obtained from all participants. Individuals were compensated with US\$20 for participation in the study. Names and references to places were changed to protect the identity of the participants.

Data Collection

This existential phenomenological study was conducted within the tradition of Husserl (1913/1931) and Merleau-Ponty (1962), as interpreted by Thomas and Pollio (2002). To illuminate human experience, the researcher must seek a "rigorous description of human life as it is lived and reflected upon in all of its first-person concreteness, urgency, and ambiguity. For existential phenomenology, the world is to be lived and described, not explained" (Pollio, Henley, & Thompson, 1997, p. 5).

Phenomenological interview was used to explore and to obtain a rich description of the lived experience of being understood. Participants were asked to describe an experience when they felt truly understood by a health care professional. Consistent with the procedure outlined by Thomas and Pollio (2002), the opening question was crafted as broadly as possible, rather than limiting participants to descriptions of their interactions with nurses. Follow-up probes such as "tell me more about that" were used to clarify descriptions. Interviews were audiotaped and transcribed verbatim. Most interviews took place in the researchers' offices. One interview was conducted in a participant's home. Interview length varied from 45 minutes to 2.5 hours ($M = 60$ minutes). The longest interviews were with participants who were homeless.

Data Analysis

An existential phenomenological approach informed by Pollio et al. (1997) and Thomas and Pollio (2002) was used to develop an initial description of the experience of being understood. Existential phenomenology attempts to "explicate the essence, structure, or form of both human

experience and human behavior as revealed through essentially descriptive techniques" (Valle & Halling, 1989, p. 6).

Data were analyzed using the systematic data analysis method described by Thomas and Pollio (2002). The researchers analyzed each transcript for meaning units. Transcripts also were read from the part (meaning units) to the whole (entire transcript). Meaning units were eventually aggregated into themes (recurring patterns that constitute important aspects of the participants' descriptions of their experiences). The major outcome of these readings was development of a thematic description for each transcript. An initial overall structure of the experience was then developed and presented to a research group to enhance rigor, and interpretations from the group were considered in addition to the re-reading of all transcripts to finalize the thematic structure. This finalized thematic structure was then presented to three participants for validation. These participants were chosen based on availability. They reviewed the thematic structure and confirmed that it was representative of their experience of being understood. From the analysis, the experience of being understood was consistent across the sample; there were no differences by sex, diagnosis, education, or interview length.

FINDINGS

Findings from a phenomenological study include both the context (background) and the figural (predominant) themes of the experience. For persons with mental illness, the ground for the experience of being understood is misunderstanding. Persons with mental illness did not describe the experience of being understood without also describing painful experiences of being misunderstood. Aspects of misunderstanding included vulnerability, self-doubt, discrimination, loneliness, and isolation. Against the ground of misunderstanding, the experience of being understood was expressed in three figural themes, titled by using the participants' own words: "I was important," "it really made us connect," and "they got on my level."

"I Was Important"

Feeling important was a major consequence of being understood. Being understood made patients feel like human beings rather than being treated like a number or being treated like in a factory. Participants wanted to be treated like human beings, not as sick, mentally ill persons; like persons, not a set of diagnoses. One participant said, "Most psychiatrists and case managers treat you as a number. You [are] just a person that they have to pass on through the system. But when you find somebody ... you showed your concern for me as a person, and that is what is important."

Participants felt important when the nurse thought about them in between interactions; it was meaningful to participants to hear that they were thought of. Examples of this included a description of a counselor who explored the Internet for information for the participant, and a psychiatrist who did some research on medications on the participant's behalf outside the session. Another activity during interactions or therapy sessions that made participants feel important was note taking. One participant said this of her counselor who took notes during sessions, "she wants to review it, she wants to remember me, my story, all these deep, troubling, horrible things." This participant approvingly referred to her "fat file," which seemed to serve as a transitional object between therapy sessions.

The sense of importance was brought about by behaviors shown by others (psychiatric/mental health nurse, psychiatrist, counselor, friend, or family member), such as care, compassion, patience, empathy, tenderheartedness, acceptance, honesty, openness, objectivity, respect, and love. The other's interest, willingness, or desire to understand was more critical than the actual understanding of the experience.

The experience of being understood was very much a physical, somatic experience. Participants described a gut feeling such as "you just know in your body." Understanding, although often difficult to articulate, was easily described in visceral terms (i.e., "you just feel it"). Participants also described an actual physical connection that made them feel important to the other person who was trying to understand, as discussed in the "It Really Made Us Connect" section.

"It Really Made Us Connect"

The sense of being understood was always preceded by the establishment of a connection with others. Participants often described a physical connection that was initiated both by the person trying to be understood and the person trying to understand. Research participants felt connected if the other person hugged them or used other forms of touch, such as a simple hand on the shoulder. They believed that if they touched the person who was trying to counsel them, they would be more able to truly connect and get others to understand:

"Once you touch the person, there's a little commitment. You have a connection because they touch you."

Listening or having a good ear was considered crucial to connecting and to achieving understanding. One participant said it succinctly:

"Understanding is listening." Another participant said, "A person can listen without caring but can't care without listening." In order for a person to be understood, the other person has to be a good listener and has to "listen without thinking about what you are going to say." Concentration, full eye contact, and attention all contributed to the feeling that the other person was listening and trying to understand.

Although listening is important to understanding, listening alone was clearly not enough. Participants were keenly attuned to nonverbal behaviors of the listener that might indicate shock or revulsion, and expressed relief when their verbalizations were met with calm acceptance. For example, one participant reported, "When I would tell particularly harsh or extreme things, she wouldn't show surprise or that she was appalled ... just kind of understanding and showing, just with her expression, that I was not so strange or different or bad." Participants appreciated active responses of the other person, such as giving suggestions, constructive advice, feedback, hope, and encouragement. One participant said, "He puts himself right there and he asks the questions that need to be asked, and he wants to get your input ... 'How does this make you feel?' And 'how do you feel when such and such?' You can tell he is a hands-on doctor and he really wants to help you and it shows."

Sympathy and consoling were considered inadequate and inappropriate by many participants. For example, one said, "I don't respond well to sympathy. If somebody is going to sit there and

say, 'Oh, you poor thing.' I don't like that. She did not do that ... it seemed like she wanted to take care of the problem, rather than just console me, or rather than just try to make me feel better." Active listening involved wanting to know what the participant was speaking about (e.g., "making sure she had things clear. Like she would repeat back and say, 'Do I have that right?'").

Giving time was an important part of connection. Grasping concepts can consume considerable time over the course of a relationship. One participant recalled that she had no concept of a safe place when her therapist first suggested that she create such a place for herself: "It was like hearing a math theorem and not knowing what it means." The therapist was patient and allowed the client to proceed at her own pace. Other participants talked about health care providers taking their time, those who took out the time to sit down and talk, and had the time to sit and listen. One participant described his community mental health psychiatrist fondly:

"Dr. X took time out with me. He was doing this free of charge, but he took time out and listened to me."

Those listeners (professionals or peers) who have had the same or similar experiences were better able to connect and understand than those who were perceived as different. Common life experiences, similar backgrounds, and mutual adversities made participants feel connected and therefore understood. One participant said, "People that are in the same position I'm in ... I left my husband ... he was very abusive ... right now I'm staying at the [homeless] shelter and all the women are in the same predicament. All the anxieties and everything else that go with it ... it's hard for somebody else, like you, or even someone in my family, because they can't fathom the idea." Another participant talked about her experiences of being understood by other patients on an inpatient psychiatric and detoxification/rehabilitation unit: "They really understand where you're coming from. If you learn it from a book, it's just not the same as really actually living it."

Participants connected to health care providers and others who self-disclosed their own negative life events. In describing a positive relationship with his nurse, one participant said, "As I got to know her, she done had adversity in her life. Her husband died and everything like that there, and we became close ... she was a person I could talk to and she would try to understand me." One participant told a story of his need for pain medication for back pain. He said his doctor, whom he described as like a sister, denied his request. The participant then talked to a nurse who "was going through some medical thing and her husband had something like the same thing I had. And she told me, she said, 'I know what you're going through ... I'm gonna get you this [medication]'. "

When the other person focused on differences (being mentally ill vs. not being mentally ill), stigmatization and misunderstanding were often the result. One participant described the vulnerability felt once the other person knew of the mental illness diagnosis: "With each disclosure, you open yourself up to vulnerability." Everything, the participant added, was subsequently viewed within this pejorative framework:

The physician transposed everything I said and did ... into the framework of everything had to be accountable by the mental health diagnosis ... nurses ... they have a real lack of understanding, I

think, of a lot of mental health problems ... this is my biggest point of difficulty in negotiating health care, as a person with a mental illness, is that ... everything about you starts being attributed either to the mental illness diagnosis that you have, although it's stabilized, or the medication that you're on for the mental illness. And ... then other things just get ignored. You're not seen as a whole person."

"They Got on My Level"

The figural theme "they got on my level" had both geographical and metaphorical meanings. Geographical descriptors included the following: get on their level, up to your level, down to your level, not talking down to, and down to earth, and denoted working from the same physical plane. Participants felt it was important for health care providers to be on the same physical level and, most often, they did so by sitting down and maintaining eye contact.

Being on the same level also was symbolic of the health care professional or counselor's ability to patiently work at the level where the participant was at that point in time. One participant spoke of this in terms of equality: "You're like their neighbor or you're like their friend. Don't talk to them like you're their counselor. Talk to them like a human being. Treat me like you would treat your colleague. I don't want to feel like your patient. I want to feel like a colleague of yours. You know, because everyone likes equality." Through these relationships, health care providers provided safe, comfortable, and relaxing environments. Casual conversation provided a way for participants to equalize the perceived power differential. Social conversations helped participants positively impact the developing relationship.

In addition to casual or social conversation, skillful communication was required by mental health professionals to get on the level of participants psychologically. For example, one transcript showed that the counselor accurately understood that her patient was like a child in some ways and took on a parental role, patiently teaching her about normal emotions and behaviors, giving her an emotion fact sheet, and holding her hand while she took steps to create the necessary boundary between herself and her critical, intrusive mother, creating her own safe place. Working at a pace that is commensurate with the capacity of the individual is an essential aspect of the theme "they got on my level."

DISCUSSION

This study explored the experience of being understood by health care professionals from the perspective of individuals diagnosed with mental illness. Three themes dominated participants' descriptions of what it means to be understood:

"I was important," "it really made us connect," and "they got on my level." The experience of being understood made individuals feel important in a world that often disregarded them. Our findings are consistent with Johansson and Eklund (2003) who found that understanding someone with mental illness meant being treated as a person. Persons with mental illness wanted someone to listen to them, a finding consistent with that of Koivisto et al. (2004). Similar to findings from Roth, Crane-Ross, Hannon, Cusick, and Doklovic (1999), listening, however, was not enough. The person trying to understand had to be active in the interaction, either by making suggestions or by offering feedback. Specific communication techniques were rarely mentioned, but of those described, reflection and restating were the most common. Several patients brought

into question long-held taboos (e.g., touching psychiatric patients and disclosing personal experiences to them).

Contrary to the taboo about touch, psychiatric patients in this study expressed appreciation for being touched. Salzman-Erikson and Eriksson (2005) also reported that psychiatric patients in their study viewed touch positively: "Touching creates feelings between bodies" (p. 843). Although acknowledging that touching can be a boundary violation in some instances, the researchers concluded, "Our interpretation of the informants' stories is that ... concrete, corporeal, contact... creates... positive feelings of solidarity and affinity" (p. 851).

Some study participants valued having therapists who had dealt with the same types of problems that they had and who disclosed their own personal struggles and suffering. Erskine (2005) points out that "While a therapist cannot possibly know first hand everything her clients have gone through, she has had (in reality or in fantasy) similar experiences. When she senses the need for mutuality in a client, it can be useful to talk about herself, her thoughts or feelings or experiences that parallel the client's experience in some way" (p. 16). Therapist self-disclosure is especially important with traumatized patients, notes Novac (2005): "Trauma patients want to know what the therapist's personal experience with trauma has been. Such credentialing is important ... before they can open up and trust ... This can be done safely without creating boundary problems and will lead to strengthening of the therapeutic alliance" (pp. 1–2).

To summarize the interrelated themes of this study, moments of interpersonal connection with listeners who made them feel important and connected on their level helped study participants to transcend their isolation: to "experience myself as something more than I am given to be by myself" (Macann, 1993, p. 192). Being understood was a powerful visceral experience that stood out as unique against the contextual ground of misunderstanding, stigmatization, and vulnerability, which are ordinarily experienced by these persons with mental illness. Participants found it easier to articulate experiences of misunderstanding: Understanding was something that participants could feel but had difficulty expressing in words. There were few reports of understanding by psychiatric nurses. Those professionals most commonly mentioned were psychiatrists, psychologists, counselors, mental health technicians, and medical–surgical nurses.

IMPLICATIONS

Understanding patients is an essential ingredient for helping them. Without an accurate appreciation of patients' experience of the problem, it is difficult to meet their health care needs. Often stereotyped, labeled, and categorized, psychiatric patients express a particular value to the experience of being understood. Nurses should therefore take time to examine whether their actions and attitudes are conducive to understanding patients. Curiosity and a desire to understand seem to be a requisite to understanding.

In this study, evidence of being understood was often derived from the health care professional's behavior during verbal encounters and in making treatment decisions. Only a few patients mentioned specific actions that validated that they were understood, such as eye contact and time. Because contemporary nurses have time constraints and multiple demands on their time, we recommend being clear with patients about the time allotment for interaction, as opposed to avoiding patients because of insufficient time. Being clear with patients may help avoid

unrealistic expectations. Consistent with McCabe (2004) and Shattell (2005), periodically checking in or being there communicates interest to patients. At the very least, nurses should make eye contact and be fully present with patients even during brief interactions.

Psychiatric/mental health nurses and other health care providers can draw from the findings of this study to develop a deeper understanding of and to create more meaningful therapeutic relationships with persons with mental illness. Nurse educators who teach psychiatric/mental health nursing can incorporate study findings into teaching about communication and therapeutic nurse–patient relationships.

The findings from our study illuminate the experience of being understood but also bring forth questions for further research. For example, can a nurse's skill at understanding patients be assessed? If this skill can be assessed, what is the best way to do so? What are the antecedents and consequences to being understood? What interventions could we develop and test to enhance understanding and connection with persons with mental illness?

CONCLUSION

The experience of being understood increased participants' self-understanding. That is, feeling understood by another human being helped participants understand themselves better. Therapeutic relationship was described by one person as "facilitating me helping myself." As expressed by another participant, the therapist provided a metaphorical "platform" on which to stand, so that she could move from being "entrenched, in a dark room by myself," to speaking publicly (at least in the safe space of the therapy office) about the hidden world of her childhood.

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