The Dissertation Committee for Cynthia Diamond Zolnierek Certifies that this is the approved version of the following dissertation:

The Lived Experience of Nonpsychiatric Hospitalization for Persons with Severe Mental Illness

Committee:

Deborah Volker, Supervisor

Gayle Acton

Mona Shattell

Cherie Simpson

J. Carole Taxis

The Lived Experience of Nonpsychiatric Hospitalization for Persons with Severe Mental Illness

by

Cynthia Diamond Zolnierek, B.S.N., M.S.N.

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Dedication

I dedicate this work to the participants of my study who so graciously and generously shared their stories in order that others may benefit from their experience. I remain deeply touched by our encounters. I hope my work honors their voices.

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Finally, to my family, thank you for your belief in me. And to my best friend and life partner, Gary, thank you for your gentle support and sacrifice in helping me achieve my dream.

The Lived Experience of Nonpsychiatric Hospitalization for Persons with Severe Mental Illness

Cynthia Diamond Zolnierek, Ph.D.
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Supervisor: Deborah Volker

People with severe mental illness experience medical comorbidities to a greater extent than the general population. When hospitalized in general hospital settings, they experience poorer outcomes and are experienced as difficult by nurses. An understanding of the experience of hospitalization from the patient's perspective is important to improving care and outcomes for this population. The purpose of this study was to explore the lived experience of nonpsychiatric hospitalization for persons with severe mental illness.

Heideggarian phenomenology provided the philosophical underpinning and informed the methodology employed. Participants were recruited through mental health providers. Ten individuals with severe mental illness participated in minimally structured interviews and described their experience of hospitalization on a medical-surgical unit. Data, including transcribed interviews and field notes, were analyzed within the hermeneutic tradition as described by Cohen et al. (2000).

The lived experience of nonpsychiatric hospitalization was expressed in four themes*: taking care of me* (subthemes*: being cared for, not being cared for*), *it's my life*, *on my toes* (subthemes: *needing an advocate*, *managing my mental health*), and *being a good patient*. Care providers' comportment, perception of the patient's illness, attentiveness, responsiveness, and personalized caring behaviors characterized the participant experience of *being cared for* or *not being cared for*. *It's my life* reflected participants' desire to be informed and involved so they could contribute to their recovery. Participants felt the need to be *on my toes* in order to look out for and advocate for themselves. The need to be *on my toes* extended to the management of a chronic illness while hospitalized for an unrelated acute condition. The final theme reflected the perceived patient role obligation to be a "good patient." Findings were consistent with the literature regarding experiences of hospitalization from the perspective of persons without mental illness.

Identified themes emphasize the critical importance of the nurse-patient relationship to the patient experience. There are significant implications for how nurses come to know their patients in medical-surgical settings so that they can effectively personalize care. Reflective practices may empower nurses to solicit assistance and support to improve caring practices.

Table of Contents

List of Tables

Chapter 1: Introduction to Study

PURPOSE

People with severe mental illness (SMI) are likely to experience a number of medical comorbidities – such as diabetes, heart disease, and pulmonary disease – at a greater rate than the general population (Leucht, Burkard, Henderson, Maj, & Sartorius, 2007). When these conditions become acute, hospitalization in general medical settings may be necessary. Here, persons with SMI demonstrate a difficult course including increased adverse events, longer lengths of stay, and increased costs of care (Zolnierek, 2009). Little is known about why such patients have poorer hospitalization outcomes than patients without SMI. Patients' perspectives may yield important understandings of the care process that could inform nursing practice.

The purpose of this study was to explore the lived experience of nonpsychiatric hospitalization for persons with SMI. A hermeneutic phenomenological qualitative approach was used to examine the first person perspective of a specific experience. Increasing understanding of the lived experience of persons with SMI when hospitalized for physical conditions in general medical and surgical care settings may enable the development of interventions designed to improve health care outcomes for this population.

BACKGROUND AND SIGNIFICANCE

Severe mental illness includes mental disorders such as schizophrenia, bipolar disorder, and major depression, which are chronic in nature and result in significant impairment in social or occupational functioning (American Psychiatric Association [APA], 2000). SMI affects one in 17 Americans, or approximately 18 million people (Kessler, 2005). While the impairment associated with mental disorders is significant, accounting for 15% of disease burden in the United States (more than the burden of cancer), impairment associated with SMI creates an even greater disease burden (National Institutes of Mental Health [NIMH], 2008).

Persons with SMI experience increased morbidity and mortality (Felkner, Yazel, & Short, 2006) to such an extent that schizophrenia has been labeled "the life shortening disease" (Allebeck, 1989). Further, individuals with a SMI experience chronic medical conditions at a rate two to three times that of the general population (Leucht et al., 2007). Lifestyle, socioeconomic, treatment, and genetic factors appear to play a role in the vulnerability of this population to multiple chronic physical conditions, such as diabetes, heart disease, and pulmonary disease (Lambert, Velakoulis, & Pantelis, 2003; Leucht et al., 2007; Mirza & Phelan, 2002). Poor physical health may predispose persons with SMI to hospitalization in general hospital settings to treat acute exacerbations of chronic illness.

In addition, persons with SMI are likely to receive less adequate health care (i.e. fewer preventative services) in ambulatory settings resulting in increased likelihood of hospital admission for a nonpsychiatric condition (Cashin, Adams, & Handon, 2008; Li, Glance, Cai, & Mukamel, 2008). Persons with schizophrenia may delay seeking care for acute medical conditions such as appendicitis, myocardial infarction, or compartment syndrome due to reduced pain perception (Singh, Giles, & Nasrallah, 2006). Delays in timely treatment of acute conditions can contribute to increased complexity and poorer outcomes during hospitalization (Copeland, Zeber, Pugh, Mortensen, & Restrepo et al., 2008).

When hospitalized in general hospital settings, individuals with SMI have poorer clinical outcomes as well as increased lengths of stay, costs of care, and utilization of resources (Zolnierek, 2009). Yet, little is known about factors that contribute to these poor outcomes. Few inquiries have been done and none have focused on patients' perspectives.

Hospitals routinely gather and report data regarding patient satisfaction (Centers for Medicare and Medicaid Services, 2010). While this data tends to be very general, several studies have been conducted to investigate relationships between patient satisfaction and other factors such as quality and safety measures, organizational and nursing characteristics, and type of hospitalization (Bacon & Mark, 2009; Elliott, Kanouse, Edwards, & Hilborne, 2009; Isaac, Azslavsky, Cleary, & Landon, 2010; Jha, A. K.; Orav, E. J.; Zheng, J.; & Epstein, A. M., 2008). Patient characteristics such as age, gender, and marital status may influence patient perceptions (Findik, Unsar, & Sut, 2010; Oflaz & Vural, 2010). Not surprisingly, perceptions of nursing care are strongly related to overall patient satisfaction ratings (Elliot et al., 2009; Oflaz & Vural, 2010; Otani, Waterman, Faulkner, Boslaugh, & Dunagan, 2010).

Studies exploring patients' experiences of hospitalization beyond satisfaction measures are less prominent in the literature and overwhelmingly emphasize the importance of nurse-patient relationships and nursing care that is individualized, informative, and participative (Blockly, 2003; Bolster & Manias, 2009; Burnett, Rushmer, Ellis, Noble, & Davey, 2009; Eriksson & Svedlund, 2007; Fosbinder, 1994; Irurita, 1999; Kralik, Koch, & Wotton, 1997; Pipe, Kelly, LeBrun, Schmidt, Atherton, et al., 2008; Schmidt, 2003; Williams & Irurita, 2004). The literature is silent regarding specific considerations for persons with SMI hospitalized in general hospital settings.

Several studies have examined nonpsychiatric nurses' experiences of caring for persons with mental illness and the process of care is described as difficult (Atkin, Holmes, & Martin, 2005; Lethoba, Netswera, & Rankhumise, 2006; Reed & Fitzgerald, 2005; Zolnierek & Clingerman, 2012). Nurses associate mental illness with problematic behavior – such as wandering, unpredictability, and wanting to be the center of attention (Lethoba et al., 2006; Priami, Plati, & Mantas, 1998; Reed & Fitzgerald, 2005). Nurses working in nonpsychiatric settings tend to view persons with schizophrenia as dangerous and unpredictable (Björkman, Angelman, & Jönsson, 2008) and have a higher expectation of aggressive and disruptive behavior (Brinn, 2000). Nurses may be fearful of providing care and feel limited in their ability to help the patient (Reed & Fitzgerald, 2005). Many nurses share with the general public stigmatizing attitudes toward persons with mental illness (Ross & Goldner, 2009). Such attitudes affect nurses' ability to manage problematic behavior and provide supportive care (Priami et al., 1998). Although medical and nursing psychiatric consultation-liaison services have been implemented to address the special needs of persons with mental illness hospitalized in general hospital settings, such services fail to demonstrate an impact on patient outcomes (Camus, Viret, Porchet, Ricciardi, Bouzourene et al., 2003; Cullum, Tucker, Todd, & Brayne, 2007).

There is a need to better understand the care process of individuals with SMI hospitalized in general medical surgical hospital settings so that effective strategies can be developed to improve outcomes of care.

STATEMENT OF PROBLEM AND RESEARCH QUESTION

Patients' perspectives of the hospitalization experience hold valuable insight that could inform care delivery, yet these perspectives had not been explored. An understanding of the experiences of persons with SMI when hospitalized in nonpsychiatric settings is critical to address the disparate outcomes this patient population demonstrates. Only with understanding can nurses begin to evaluate and redesign existing care processes to improve patient outcomes.

This study was designed to explore meanings of a particular experience, nonpsychiatric hospitalization, for persons with SMI and thereby construct meaning of that experience. The research question was: What is the lived experience of nonpsychiatric hospitalization for persons with SMI?

SIGNIFICANCE TO NURSING

Nurses who work in general medical-surgical settings will inevitably care for individuals who have a comorbid psychiatric condition as the literature describes a prevalence of psychiatric comorbidity among general hospital inpatients of up to 50 percent (Furlanetto, da Silva, & Bueno, 2003). Because nurses are known to play a powerful role in influencing the health outcomes of hospitalized patients (Kutney-Lee & Aiken, 2008; Montalvo, 2007), nurses have an opportunity to make significant contributions to improve the care of persons with SMI in general hospital environments. To date, there is a paucity of knowledge about the care process for this patient population and how that process may be improved to enhance outcomes. This study introduces the perspective of patients’ experience of hospitalization in a medical surgical setting. This perspective has not yet been reported in the literature and is believed to hold important insight for nursing practice, management, education, and future research.

Nurses are responsible for providing individualized care reflective of patients’ particular values, beliefs, and preferences, and for basing their practice on evidence and research findings (American Nurses Association [ANA], 2010). Research elucidating patients’ experiences will provide new information upon which to plan and provide nursing care: “Because action is based on meanings, common meanings between nurses and patients will provide the most effective base for helpful nurse-patient relationships” (Cohen, Kahen, & Steeves, 2000, p. 4). For example, familiarity with what patients perceive as helpful or difficult during hospitalization may inform the development of approaches that would be experienced as supportive of recovery and that would invite active participation by patients. An understanding of how patients with SMI experience the nurse-patient relationship may assist nurses in establishing positive partnerships with patients that support efficient movement along the hospital treatment trajectory. Finally, new understandings from patients’ perspectives may improve the effectiveness of patient-to-nurse and nurse-to-patient communication thereby improving recognition of potential complications and enabling interventions that prevent adverse events.

The quality of the nursing practice environment within a hospital significantly affects patient outcomes (Aiken, Clarke, Sloane, Lake, & Cheney, 2008). Nurses in administrative practice are responsible for supporting positive nursing practice environments that enable safe practice and quality care (ANA, 2009). Patient feedback is a valuable source of information that hospitals routinely use to identify process and system changes that may improve patient experience. Research findings regarding the experience of patients with SMI hospitalized in medical-surgical settings may inform nurse administrators about opportunities to revise hospital routines or provide different resources to staff (e.g. consultative-liaison psychiatric nursing, other support staff, educational resources) in order to improve outcomes. New understandings may give rise to new models of care for this patient population (e.g. specialty medical-psychiatric units, use of nurses with dual clinical expertise in medical surgical and psychiatric care, collaborative interdisciplinary models, or patient peer support services).

Nurses tend to feel uncomfortable and ill-prepared for providing care to patients with psychiatric comorbidity on general hospital units. An increased awareness of the difficulty patients with SMI experience in general hospital settings may stimulate nursing educational approaches that promote development of the knowledge, attitudes, and skills needed to deliver safe and quality care to persons with SMI regardless of setting. Additionally, an understanding of the special challenges persons with SMI experience in the general hospital may drive implementation of educational approaches that integrate mental and physical health care in various settings (e.g. medical surgical inpatient, psychiatric inpatient, and ambulatory care) and truly promote a holistic approach to nursing care.

Finally, the ultimate value of this study will be in its ability to illuminate the experience of persons with SMI hospitalized in medical-surgical environments and inform further investigations that can guide the development of interventions to positively affect patient outcomes. Findings should provoke new questions for further study and may suggest new care approaches for future development and testing. The care of persons with SMI in medical-surgical environments is a phenomenon of concern to nursing.

CONCEPTUAL ORIENTATION

The conceptual orientation of this study is informed by the philosophical basis of hermeneutic phenomenology as described by Martin Heidegger (1962). Phenomenology is the study of phenomena – what things are really like (van Manen, 1990). Phenomenology is concerned with the direct experience of phenomenon – “to the things themselves!” (Heidegger, 1962, p.58), the ordinary experience of everyday life (Schwandt, 2007), or lived experience.

The Phenomenological Movement represented a significant break with scientific tradition, logical empiricism, which utilizes observation, experiment, and comparison to establish laws predictive of relationships between phenomena (Crotty, 2004). Edmund Husserl (1859-1938), is credited with initiating phenomenology as he departed from a philosophical focus on “things”, and instead focused on consciousness and human beings' experience of their world (Giorgi, 2005): "It is a shift of focus from physical nature, cause-effect analyses, impersonal forces and their manipulation and control to human subjectivity, intentionality, the meaning of actions, and the freedom and responsibility that intrinsically belong to them" (p. 77). Phenomenology is concerned with the meaning of phenomena as they are experienced in ordinary everydayness – a human science that applies methods consistent with qualities of human beings (nonreductionistic) (Giogi, 2005).

As a movement, phenomenology evolved as subsequent philosophers modified Husserl's original work (Lopez & Willis, 2004). While Husserl is known for founding phenomenology and the descriptive research tradition, Heidegger, a student of Husserl, is credited with developing the hermeneutic, or interpretive, research tradition. Heidegger was concerned with the meaning of human experience. As we engage with our world, we make sense of it (Crotty, 2004); we interpret it and create meaning. Hermeneutic phenomenology seeks an understanding of everyday experiences; it attempts to uncover meanings of lived experience. Hermeneutics is "a process and a method for bringing out and making manifest what is normally hidden in human experience and human relations" (Lopez & Willis, 2004, p. 728).

Heidegger was interested in what it means to be (ontology) rather than what or how we know (epistemology). Our essential state is being-in-the-world (Heidegger, 1962): "humans are embedded in their world to such an extent that subjective experiences are inextricably linked with social, cultural, and political contexts" (Lopez & Willis, 2004, p. 729). We are thrown into a world that already exists and our experience cannot be considered outside of that context (Heidegger, 1962). Therefore, hermeneutic phenomenology is interested in uncovering and understanding subjective experience within the context of the individual’s lifeworld.

Hermeneutic phenomenology seeks to “understand an experience as it is understood by those who are having it” (Cohen et al., 2000, p. 3). Phenomenological research “borrows” the experiences of others in order to gain an understanding of a deeper meaning of a particular aspect of experience (van Manen, 1990, p.62). Experiential data is created through interviews, writings, and/or observations (van Manen, 1990). Hermeneutic data analysis occurs through the hermeneutic circle in which the researcher moves continuously between an understanding of the parts and the whole, to eventually identify themes representative of the meaning of the lived experience.

DEFINITIONS

Severe Mental Illness

SMI is defined as Axis I mental disorders described in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (APA, 2000) including schizophrenia and related disorders, bipolar disorders, and major depressive disorder when there is a significant and persistent impairment in social or occupational functioning.

Nonpsychiatric Hospitalization

Nonpsychiatric hospitalization means admission to an inpatient medical or surgical hospital setting for a physical-medical health problem. Examples of medical-surgical settings include general medical or surgical hospital units and specialty units such as gynecology, orthopedic, oncology, telemetry, and others. Hospital units that provide intensive care and those that do not treat acute medical-surgical conditions, such as rehabilitation, psychiatric, or labor/delivery/post-partum units, are not considered a medical-surgical hospital setting. Additionally, for a hospitalization to be considered nonpsychiatric, the primary diagnosis must be a nonpsychiatic diagnosis, for example: hip fracture, pneumonia, congestive heart failure, or cellulitis.

Lived Experience

Lived experience is revealed within the narrative of the individual; it is what the individual says it is and does not require validation from external sources.

ASSUMPTIONS

While acknowledging that there are multiple ways of knowing (Carper, 1978/1999), the following assumptions about espistemology guided this study.

1. Meaning is constructed. There is no single objective "truth" to be discovered. Instead, meaning emerges as individuals consciously interact with and make sense of their world. (Cohen et al., 2000; Crotty, 2004). Knowledge is inductive.

2. Multiple realities exist. Because individuals construct meanings and interpret their world differently, there can be no single reality (Cohen et al., 2000).
3. The hermeneutical circle of understanding provides a methodology for understanding meaning of lived experience.
4. An understanding of the meaning of being can inform nursing practice.
5. People with SMI are open to discussing their experiences of being hospitalized for nonpsychiatric reasons.

LIMITATIONS

This study has several limitations. As a qualitative study, results are not generalizable to a population. The methodology included participation by individuals with SMI who were currently under the care of a mental health provider. Therefore, the results may not reflect the perspective of individuals whose mental illness is untreated, and it is possible that an untreated population may report a different experience than those who are receiving mental health services. Also, because participants were selected and screened by others, it is possible that values and biases of those making the referral will influence who is referred. The methodology did not require representation of all possible SMI diagnoses. Although all three categories of severe mental illness were represented in the sample, most participants experienced mood disorders (depression or bipolar disorder) which are often less disabling and less severe than the schizophrenia related disorders. This limitation may affect results. For example, a sample of participants with schizophrenia may reveal a different perspective than participants with major depression. Despite these limitations, an initial study investigating lived experience is believed to be valuable in providing at least a glimpse of the hospitalization experience from the perspective of persons with SMI. Even a preliminary understanding has value in informing future research designed to improve care outcomes for this population.

SUMMARY

This chapter serves as an introduction to the study and outlines the background and significance to nursing, research question, conceptual orientation, definitions, assumptions, and limitations. The purpose of the study was to explore the lived experience of persons with SMI when hospitalized in nonpsychiatric settings. Hermeneutic phenomenology was briefly described as the philosophical basis informing this study. An understanding of lived experience as proposed in this study has the potential to guide the development of nursing approaches that can improve health outcomes for this patient population.

Chapter 2: Review of the Literature

INTRODUCTION

Mental illness is considered severe or serious when it results in functional impairment and disability. Severe mental illness (SMI) typically includes schizophrenia and related disorders as well as bipolar and major depressive disorder. Multiple factors are believed to contribute to the excess morbidity and mortality persons with SMI experience. Though overall utilization of health care services is low, when hospitalized in general hospital environments, persons with SMI tend to have more complications, longer lengths of stay, and increased costs associated with care. This literature review provides an overview of general medical issues experienced by persons with SMI as well as considerations related to their nonpsychiatric hospitalization.

LITERATURE REVIEW

Medical Mortality

The literature consistently reports an increased morbidity and mortality for persons with SMI. Following a literature review that revealed a life expectancy 10 years shorter for persons with schizophrenia, Allebeck (1989) labeled schizophrenia “a life-shortening disease”. His own investigation confirmed findings of earlier studies: persons with schizophrenia demonstrate twice the mortality of the general population. In an integrated review of 66 studies published between 1934 and 1996, Felkner et al. (1996) found that standardized mortality ratios, for both natural and unnatural causes of death, for persons with SMI were consistently higher than the general population. Likewise, a study examining state death files of adults with SMI who had used state mental health services revealed a reduced life expectancy across all disease and injury conditions (mean 14.1 years for men and 5.7 years for women) (Dembling, Chen, & Vachon, 1999). Most recently, a report *Morbidity and Mortality Among Persons with Serious Mental Illness* cites a life expectancy 25 years shorter for persons with SMI (Parks, Svendson, Singer, & Foti, 2006). While 30% of this excess mortality is due to suicide, "natural causes" – i.e. comorbid medical conditions such as cardiovascular and pulmonary disease – account for 60% (Parks et al., 2006). The worsening trend of premature mortality reported in the literature is of significant concern.

Three studies identified that, while persons with and without SMI shared heart disease as the most frequent cause of death, persons with SMI demonstrated increased mortality. Miller, Paschall, and Svendsen (2006) evaluated leading causes of death, years of potential life lost (YPLL), and standardized mortality ratios for 608 deceased persons with SMI. Preventable conditions, including obesity, hypertension, diabetes, and chronic obstructive pulmonary disease, made up the most prevalent medical comorbidities, and heart disease was the leading cause of death. YPLL and standardized mortality ratios were significantly increased for persons with SMI. Unnatural causes of death contributed to greater YPLL and actual deaths were three times that expected.

Another study (Piatt, Munetz, & Ritter, 2010) sought to broaden the understanding of premature death among persons with SMI by comparing decedents in the same community, persons with SMI receiving community-based services and persons without SMI, to determine whether there were significant differences in YPLL. Although the leading cause of death (cardiac disease) was similar for both groups, persons with SMI died 12 years earlier. YPLL were 2 years greater for persons with SMI and were related to significantly different causes than for persons without SMI. The authors concluded that “accidents, suicide, septicemia, liver disease, and cancer have a greater impact on premature mortality for persons with serious and persistent mental illness” (Piatt et al., 2010, p. 666).

Capasso, Lineberry, Bostwick, Decker, and St. Sauver (2008) documented similar findings. Among the 319 persons treated at the Mayo clinic between 1950 and 1980 and meeting diagnostic criteria for schizophrenia or schizoaffective disorder, 144 were deceased as of February 2005. As in other studies, decedents demonstrated a significantly increased mortality when compared with the general population ($p<0.001$). Coronary artery disease was the most frequent cause of death (29%). The authors highlighted the “lack of association between year of diagnosis and survival…effectively being diagnosed with schizophrenia thirty years later had no impact on improving survival” (Capasso et al., 2008, p. 291). That is, persons with schizophrenia have not benefitted from treatment advances for coronary artery disease. Could mortality rates be tied to the quality of medical care?

Researchers Druss, Bradford, Rosenheck, Radford, and Krumholz (2001) explored this question in a study of the relationship between the quality of medical care and mortality of persons with mental illness following myocardial infarction. Using a large national sample of Medicare recipients, the authors found an increased mortality rate for persons with a mental disorder who experienced myocardial infarction. However, this pattern was normalized when adjusted for quality measures. That is, disparity in mortality rate was related to deficits in medical care – the failure to implement cardiac guideline-based interventions. The authors questioned whether differences in quality of care are primarily a function of patient or provider factors.

Canadian investigators (Kisely, Campbell, & Wang, 2009) reached a similar conclusion for persons with psychosis treated for heart disease and stroke within a universal health care system. A large national database was used to construct a retrospective cohort study of people with and without psychosis admitted with ischemic heart disease (N=49,248) and stroke (N=15,791). Of the sample, 23% had previously received psychiatric services and 3% had a history of psychosis. Persons with a comorbidity of psychosis were significantly more likely to experience one year mortality ($p<0.002$ for heart disease; $p<0.001$ for stroke) and less likely to receive treatment indicative of quality care (e.g. procedures such as cardiac catheterization or cerebrovascular arteriography, and medications such as ACE inhibitors or anticoagulants). The authors concluded that persons with a history of psychosis received inequitable care for vascular conditions.

Regardless of research design and database accessed, study results reported in the literature consistently reveal a shorter life expectancy for persons with SMI. This excess mortality is only partially explained by unnatural causes of death such as suicide and accidents. Instead, preventable health conditions such as cardiovascular and pulmonary disease contribute to shortened life expectancy in persons with SMI. Unfortunately, despite improvements in life expectancy for the general population, the vulnerability of persons with SMI to premature death persists. Recommendations to address these disparities included the development of more effective approaches to improve treatment of the preventable diseases contributing to increased mortality. Implementation of integrated care models in which primary and mental health care are delivered together (such as the provision of mental health care within a patient-centered health care home or the availability of primary care services within the community mental health system) were identified as an approach to improve access and quality of care to persons with SMI (Capasso et al., 2008; Miller et al., 2006).

Medical Comorbidity

An increased burden of medical conditions, in both incidence and complexity, among persons with SMI has been reported. In a comprehensive literature review of comorbidity of schizophrenia with physical illness, researchers identified an increased incidence of the following conditions: tuberculosis, HIV, hepatitis B/C, osteoporosis, poor dental status, impaired lung function, extrapyrimidal side-effects of antipsychotic drugs, motor signs in antipsychotic naïve persons, reduced pain sensitivity, sexual dysfunction, obstetric complications, sexual dysfunction, hyperprolactinemia related side-effects of antipsychotics, cardiovascular problems, obesity, diabetes, metabolic syndrome, polydipsia, and thyroid dysfunction (Leucht et al., 2007). Mirza and Phelan (2002) reported a review of the vulnerability for physical illnesses among persons with SMI and identified an increased occurrence of various physical conditions including cardiovascular disorders, gastrointestinal disorders, neurological disorders, musculoskeletal disorders, endocrine disorders, respiratory diseases, and infectious diseases. Individuals with schizophrenia are known to experience altered pain perception – a quality that places them at risk for delaying medical care for physical health conditions such as myocardial infarction, ruptured appendix, or compartment syndrome (Singh, Giles, & Nasrallah, 2006).

Several studies utilized convenient samples of psychiatric inpatients to describe medical morbidity among persons with mental disorders. In a study of 79 elderly psychiatric inpatients, 75% were found to have a medical comorbidity (Adamis & Ball, 2000). Mood disorders were more frequently associated with hypertension and cardiovascular disease, while schizophrenia was more likely to be associated with endocrine disorders (diabetes). A study of 289 consecutive admissions to a public psychiatric hospital identified 84 patients (29%) with “active and important physical disorders”; medical conditions that had not been previously diagnosed were identified in 10% of patients (Koran, Sheline, Imai, Kelsey, Freedland et al., 2002, p. 1624). The authors noted that undiagnosed medical conditions may exacerbate mental symptoms and point to the importance of identifying and treating medical conditions in the inpatient psychiatric population.

Dickey, Normand, Weiss, Drake, and Azena (2002) accessed the Massachusetts Medicaid database to explore the prevalence of certain medical conditions in persons with and without severe mental illness. They identified all claimants with a psychotic disorder (schizophrenia, bipolar disorder, or other; N = 11,185) and compared them with a random sample of 30% of claimants with no mental illness (N = 15,147). Between group differences were tested for eight medical disorders: diabetes, hypertension, heart disease, asthma, gastrointestinal disorders, infections of skin/subcutaneous tissue, malignant neoplasms, and acute respiratory disorders. After adjusting for age, gender, and race, all eight medical disorders occurred more frequently in the group with psychotic disorders. In addition, those with psychosis were twice as likely to be treated for two or more of the identified medical conditions. The authors posited that persons with psychotic disorders may have difficulty communicating with their physicians, and this difficulty may affect treatment of the medical condition. Integrated care approaches are recommended as a strategy to improve medical treatment for persons with psychotic disorders.

Another study (Jones, Macias, Barreira, Fisher, Hargreaves et al., 2004), explored the prevalence, severity, and co-occurrence of medical disorders within a sample of Medicaid recipients with severe mental illness. Researchers validated the representative nature of their sample (N=147) by comparing sample characteristics to those from the sample obtained by Dickey, et al. (2002) above. Of persons with SMI, 74% were treated for at least one chronic medical condition and 50% were treated for two or more medical conditions. The researchers expressed concern about the underuse of medical services by persons with SMI and emphasized an immediate need to design integrated interventions to ameliorate the combined impact of mental and physical conditions.

Several studies have focused on comorbidities of persons with bipolar disorder. Cassidy, Ahearn, and Carroll (1999) evaluated medical histories of 345 patients admitted to a state facility with a bipolar diagnosis. The frequency of diabetes in the study group was significantly higher than expected and patients with bipolar disorders had a more severe course of illness. In a review of the literature on psychiatric and medical comorbities of bipolar disorder, Krishnan (2005) determined that medical comorbidities occur with greater than expected frequency, although how much of this occurs as a consequence of treatment is unclear. Kilborne (2005) also concluded that "numerous medical conditions may occur disproportionately within bipolar disorder patient populations" (p. 1). Data extracted from a Canadian Community Health Survey, revealed 938 respondents, 2.4 % of total sample, who reported a history of bipolar disorder (McIntyre, Konarski, Soczynska, Wilkins, Panjwani et al., 2006). These individuals were significantly more likely to report at least one chronic medical disorder and were significantly more likely to report three or more cormorbid medical disorders. Greater numbers of comorbid medical disorders were associated with greater dysfunction and increased service utilization. Thompson, Kupfer, Fagiolini, Scott, and Frank (2006) found an incidence of medical comorbidity in 92% of their sample of 174 patients with bipolar disorder. Severity of medical comorbidity was linked with depression and a poorer prognosis. They concluded that medical illness negatively affects the outcome of bipolar disorder.

Studies considering comorbidities of persons with schizophrenia are no less discouraging. Carney, Jones, and Woolson (2006) examined insurance claims data to identify medical comorbidity in persons with schizophrenia. Results confirmed findings of earlier studies: persons with schizophrenia experienced increased medical comorbidities. Additionally, they were more likely "to have a greater number of conditions spanning several disease categories” (p. 1136). Chaftez, White, Collins-Bride, and Nickens (2005) reviewed data from primary care episodes among 271 individuals with schizophrenia or related disorders. Persons with schizophrenia were twice as likely to have a diagnosis of diabetes or lung disease. Interestingly, lifestyle and environmental factors did not appear related to medical conditions. In a study evaluating the interrelationship of psychiatric symptoms, medical comorbidity, and psychosocial functioning, researchers found no significant associations between the number of medical conditions and severity of psychiatric symptoms (Chwastiak, Rosenheck, McEvoy, Keefe, Swartz et al., 2006). They ascribed this finding to a “floor affect”: “Among patients with severe disability resulting from psychiatric illness, physical illness cannot make social functioning much worse” (p. 1107). However, depression and neurocognitive impairment were associated with an increased medical burden and impaired functioning in this patient population. Weber, Cowan, Millikan, and Niebuhr (2009) examined short term hospital discharges for patients with a primary diagnosis of schizophrenia (N=26,279) and found increased comorbid medical conditions of hypothyroidism, obesity, epilepsy, type 2 diabetes, essential hypertension, and chronic obstructive pulmonary disease among others.

The research literature is consistent and compelling – persons with SMI experience increased incidence of a number of chronic medical conditions. In addition, medical comorbidities for this population tend to be more complex – increased in severity and covering several categories of disease (Carney et al., 2006; Jones et al., 2004).

Miraz and Phelan (2002) proposed three categories of factors leading to poor physical health among those with SMI:

1. Lifestyle: poor diet, smoking, substance misuse, lack of exercise, sexual practices, long term use of antipsychotic medication;
2. Social consequences of mental illness: poverty, unemployment, poor housing, stigma, low self-esteem;
3. Difficulties accessing health care: poor communication skills, doctors' focus on mental health, erratic compliance with health screening and treatment. (p. 535)

Psychotropic medications, particularly the new generation antipsychotics, have been related to several significant medical comorbidities, specifically metabolic syndrome, diabetes, obesity, and cardiovascular disease (Lambert et al., 2003; Nasrallah & Korn, 2004; Rettenbacher, 2005). However, some of these conditions appear to be increased in medication naïve patients (those who have not taken such medications) as well, indicating a possible genetic link between SMI and certain medical illnesses (Chaftez et al., 2005; Fernandez-Egea, Bernardo, Donner, Conget, Parellada et al., 2009). Potential drug interactions pose an additional threat to physical health (Kiraly, Gunning, & Leiser, 2008; Mirza & Phelan, 2002). Regardless of the cause, individuals with SMI experience chronic physical disease to a disproportionate extent.

Utilization of Services

The increased prevalence of medical illness among persons with SMI would seem to position them as high utilizers of medical services. However, a number of barriers impede their access to care (Berren, Santiago, Zent, & Carbone, 1999). Patient related factors include avoidance and poor treatment compliance, difficulty in communicating needs, and masked symptoms (e.g. high pain tolerance). Healthcare system factors include reluctance of nonpsychiatric practitioners to treat persons with SMI, focus on psychiatric problems, and poor follow up (Lambert et al., 2003).

Such barriers may affect access to care as well as utilization of services. A review of data from the 1994 National Health Interview Survey, which interviewed 45,705 households in 198 regions of the United States (included 77,183 respondents to both the core survey and access to care supplements) revealed that, while people who reported mental disorders were no less likely to be insured or have a primary care provider, they were twice as likely to delay seeking needed medical care (Druss & Rosenheck, 1999). Berren et al. (1999) examined Medicaid claims data and found that physical health care claims for individuals with SMI were 18% less than for those without SMI. And, although both groups received care for similar conditions, persons with SMI tended not to seek treatment until an urgent (more costly) setting was required, such as an emergency department.

A study evaluating adequacy of medical treatment of older adults with schizophrenia revealed evidence suggesting insufficient care rather than poor access to services explained the less adequate treatment provided to persons with SMI (Vahia, Diwan, Bankole, Kehn, Nurhussein et al., 2008). Persons with schizophrenia received lower rates of treatment for three (hypertension, heart disease, and gastrointestinal ulcers) of four medical conditions evaluated despite equivalent rates of physician visits. An association of positive symptoms of schizophrenia (e.g. hallucinations and delusions) with low treatment led the authors to postulate that provider discomfort with positive symptoms may result in inadequate histories and physical examinations and misinterpretations of physical symptoms. The authors suggested that a focus on treatment adequacy rather than just frequency of visits is needed.

Researchers investigating somatic hospitalizations for long-stay psychiatric patients with psychosis found that 86.5% (N=253) were hospitalized at least once for physical illness following their admission to the psychiatric hospital (Räsänen, Meyer-Rochow, Moring, & Hakko, 2007). They challenged the notion that somatic illness is under recognized and untreated during long term psychiatric hospitalization.

There is little in the literature regarding incidence of hospitalization of persons with SMI for medical conditions. However, a number of researchers have begun to explore nonpsychiatric inpatient encounters for persons with mental disorders. Saba, Levit, and Elixhauser (2008) reported findings from the Healthcare Cost and Utilization Project regarding mental health stays in community hospitals. Mental illness was identified as a secondary diagnosis for 17.9% of all hospital stays. Because the study combined data from hospital stays due to primary and secondary psychiatric diagnoses, further data related to nonpsychiatric hospitalization is not reported. Following an analysis of “somatic” admissions of persons with schizophrenia, Munk-Jørgensen, Mors, Mortensen, and Ewald (2000) hypothesized:

> Schizophrenic patients are not aware of symptoms from physical diseases, and nor might their psychiatrists be; or may the symptoms be misinterpreted as psychotic symptoms or somatic hallucinations? Consequently, diseases remain undiagnosed

> and thus untreated for a long time and identified only when they appear in acute and potentially lethal forms which lead to admission. (p. 98)

Hansen, Fink, Frydenberg, and Oxhøj (2002) assessed 294 internal medicine inpatients for presence of psychiatric disorders, severity of medical illness, self-rated disability and health, and health service use. Patients with one or more mental disorders were more than three times as likely to be high users of nonpsychiatric inpatient services. They also utilized more resources even after adjusting for medical severity.

Hospitalization rates for Ambulatory Care Sensitive (ACS) conditions represent a measure of the availability and quality of primary care services. At least two studies have demonstrated increased hospitalization rates for ACS conditions for persons with SMI. Li, Glance, Cai, and Mukamel (2008) studied New York hospital admissions and identified concurrent diagnoses of mental disorders among 25% (N=38,514) of the total sample (N=155,312). Those with mental illness were more likely to have an emergent admission. While mental illness was significantly related to an increased likelihood of ACS admission, SMI was associated with a 2-4 increased odds of ACS admission. In addition, ACS admissions with mental disorders experienced increased length of stay and greater costs of care.

Cashin, Adams, and Handon (2008) analyzed data of 70,462 California Medi-Cal beneficiaries with SMI to identify the independent effect of SMI on the likelihood of nonpsychiatric hospitalization. Persons with SMI had a 23% increase in the odds of non-psychiatric hospital admission and a 63.9% increase in the odds of an ACS diabetes hospital admission. The authors emphasized the disparities in care for persons with SMI and suggested development of innovative approaches to care that overcome barriers to access and quality.

Utilization data offers a picture of a patient population likely to receive less quantity and lower quality of outpatient, ambulatory care and may have higher and more urgent hospitalization rates. Persons with SMI are less likely to receive effective treatment in the community for chronic medical conditions that would prevent exacerbations leading to hospitalization. When admitted, their medical conditions are likely to be more complex and severe. Recommendations for improving outpatient care delivery, e.g. integrated care models, to improve cost, quality, and outcomes of care, are discussed in the literature; however, to date, such models have been minimally implemented largely due to the bifurcated payment systems for physical and mental health care services. Health policy reforms are needed to support the adoption of integrated models (Bartels, 2004).

Outcomes of Hospitalization: Length of Stay

Hospital length of stay (LOS) is commonly used as a measure of efficiency and resource use during the period of hospitalization (Kroch, Duan, Silow-Carroll, & Meyer, 2007). LOS for an individual patient may be affected by many factors including severity of illness, complications, and discharge placement. It is a significant indicator as it is directly related to costs of care.

LOS has been the most frequently studied outcome of nonpsychiatric hospitalizations of persons with mental disorders, however studies including persons with

SMI are less common (Zolnierek, 2009). Several prospective studies have associated an increased LOS with psychiatric comorbidity. Fulop, Strain, Fahs, Schmeidler, and Synder (1998) conducted a prospective study of 467 geriatric individuals admitted to a medical surgical hospital ward. All subjects were interviewed and evaluated to identify the presence of a psychiatric comorbidity: cognitive impairment, depressive disorder, or anxiety disorder. Over 50% of the sample had a cognitive disorder that was associated with a 30% prolonged LOS. Other psychiatric comorbidities did not significantly influence LOS. Furlanetto, da Silva, and Bueno (2003) considered the impact of psychiatric comorbidity on LOS in a prospective study of 317 admissions to an adult medical ward. Psychiatric comorbidity was identified in 49.2% of the sample, and 20.2% demonstrated cognitive impairment, although SMI was not identified. Only cognitive impairment was related to LOS. The authors posited rationale for this finding: “Delirious patients do not understand, do not cooperate, do not explain their needs, do not sleep, and are frequently agitated withdrawing their IV lines and other devices which postpones their treatment.” (p.17) This description of patient behaviors is characteristic of behaviors medical surgical nurses experience as “difficult” and ascribe to persons with SMI (Lorber, 1975; Morrison, Ramsey, & Synder, 2000).

Another prospective study (Wancata, Benda, Windhaber, & Nowotny, 2001) considered non-psychiatric hospitalization of 821 patients of which 32.2% met criteria for a psychiatric diagnosis; 2.1% met criteria for major depression and 1.2% for psychoses and bipolar disorders. Although presence of a psychiatric disorder was a predictor of longer LOS, the relationship between SMI and LOS was not significant. Koopmans, Donker, and Rutten (2005) reviewed prospective studies reported in the literature which considered medical inpatients with comorbid mental disorders. They suggested that the relationship between psychiatric comorbidity and LOS is not “sharp” due to the number of additional factors that affect LOS; however the exclusion of persons with schizophrenia and psychosis from the study likely influenced the significance of the relationship.

Although retrospective studies rely on diagnostic coding to identify persons with a mental illness, they are usually studies with high levels of power due to large samples. Medicaid claims for hospitalization of patients with AIDS (N=24,975 hospitalizations), revealed significantly greater LOS for patients with SMI comorbidities (Hoover, Sambamoorthi, Walkup, & Crystal, 2004). In analysis of the data the authors suggested that the increased LOS was related to treatment of the SMI rather than any interaction of the psychiatric comorbidity with AIDS conditions. Bourgeois, Kremen, Servis, Wegelin, and Hales (2005) examined hospital discharge billing data for medical surgical patients from July 1998 through June 2001 (N=48,601). Psychiatric disorders were identified in 35% of patients and, with the exception of substance use and anxiety disorders, were correlated with an increased LOS. Utilizing a large (N=1,617,710) random sample drawn from a national database of hospital medical discharges, Bressi, Marcus, and Solomon (2006) analyzed the impact of psychiatric comorbidity on LOS. They found that psychiatric illness, particularly schizophrenia, had a significant impact on increasing LOS. Sayers, Hanrahan, Kutney, Clarke, and Reis et al. (2007) studied the effects of psychiatric comorbidity on health care utilization and costs of Medicare beneficiaries with heart failure (N=21,429) . Psychiatric comorbidity was prevalent in 15.3% of the sample and was associated with increased hospitalizations, longer mean LOS, and higher costs of hospitalization.

The prevalence of psychiatric comorbidity among persons hospitalized for general medical or surgical conditions differed significantly (from 15% to 50%) between studies reviewed. This variance may be attributable to study design (prospective vs. retrospective) and method of identifying the psychiatric comorbidity (Abrams, Vaughan-Sarrazin, & Rosenthal, 2008). Despite these discrepancies, there is considerable agreement in the literature that persons with psychiatric comorbidities experience longer LOS and costs of care when hospitalized for general medical surgical conditions.

LOS offers a limited perspective of outcomes of nonpsychiatric inpatient care. Effective management of medical and psychiatric conditions during hospitalization can affect longer term costs by potentially reducing readmissions (Andreoli, Citero, & Mari, 2003). Booth, Blow, and Cook (2001) provided evidence that supports this proposition in their longitudinal study of men with comorbid psychiatric and substance abuse disorders who were discharged from medical and surgical hospital settings: "…substantial impairments in functioning associated with psychiatric disorders during medical hospitalization are not short-term and do not subside, but continue over the space of 1 year despite statistical control for two measures of severity of the medical illness" (p. 63).

Outcomes of Hospitalization: Quality Measures

Consistent with national interest in healthcare safety and quality over the past decade, researchers have begun to move beyond LOS and costs of care for persons with SMI to focus on quality and safety measures. Daumit, Pronovost, Anthony, Guallar, Steinwachs et al. (2006) utilized Patient Safety Indicators (PSIs) defined by the Agency for Healthcare Research and Quality to identify adverse events occurring during the medical surgical hospitalization of persons with schizophrenia (N=1746) as compared to persons without schizophrenia (N=732,158). Patients with schizophrenia were more likely to: be admitted though the emergency department (75%), have an ICU stay, experience inpatient mortality, have a longer LOS, and have higher median charges. Except for primary pulmonary diagnoses, which were more common for patients with schizophrenia and for patients experiencing PSIs, primary medical diagnoses were similar for both groups. The odds of the occurrence of PSIs during hospitalization for persons with schizophrenia were at least twice that for persons without schizophrenia for infections due to medical care, postoperative respiratory failure, postoperative deep venous thrombosis, and postoperative sepsis. Not surprisingly, patients with schizophrenia had longer LOS (medial adjusted increase of 10 days) and increased costs of care (median hospital charges increased by $20,000). The authors suggested:

> The quality of care given to patients while hospitalized, and not principally the severity of medical conditions, was a true contributor to the increase in the odds of PSIs between those with and without schizophrenia….it is in the prevention or timely detection of medical complications where patients with schizophrenia may be at higher risk than those without schizophrenia, not in the treatment of complications once diagnosed. (p. 271)

Finally, the authors concluded by suggesting that further research is needed to better understand the contributions of patient, health care professional, and hospital factors to outcomes for this patient population.

Khaykin, Ford, Pronovost, Dixon, and Daumit (2010) accessed nonpsychiatric hospitalization discharge data for 37,092,651 patients without schizophrenia and 269,387 patients with a diagnosis of schizophrenia to evaluate the occurrence of adverse events. Patients with schizophrenia were more likely to have a medical (vs. surgical) and a non-elective (vs. elective) admission; to have congestive heart failure, chronic obstructive pulmonary disease, liver disease, diabetes, HIV/AIDS, and substance abuse; and to experience inpatient mortality, increased hospital charges, and longer length of stay. The PSIs were similar for both groups, however, patients with SMI had increased odds ratios of experiencing pressure ulcer, infection due to medical care, postoperative respiratory failure, sepsis, and pulmonary embolism/deep vein thrombosis. The authors postulate that perioperative medication management may contribute to postoperative cognitive changes (e.g. delirium, oversedation) which could lead to respiratory complications. Further, confusion and behavioral issues may lead to sedation and restraints that limit mobility and contribute to complications such as pressure ulcers, thromboembolism, and respiratory problems. The authors concluded by suggesting that persons with schizophrenia are vulnerable to medical injury during hospitalization and emphasized the importance of further research to better understand factors related to outcomes.

Contrasting results were reported in a study involving the veteran population. Abrams et al. (2010) studied the hospitalization of nonsurgical intensive care patients with mental illness in Veterans Health Administration hospitals. Out of 66,672 discharges, comorbid psychiatric conditions were identified in 18,698 (28%) and included depression, anxiety, psychosis, bipolar disorder, and post-traumatic stress disorder. The odds of inpatient mortality for patients with a psychiatric condition were only slightly higher (odds ratio 1.07) than those without psychiatric comorbidity, and 30 day mortality was similar for both groups. The uniqueness of the veterans' healthcare system and specific focus on nonsurgical intensive care may account for the incongruent findings.

Several studies focused on outcomes of surgical patients with SMI. Cooke, Magas, Virgo, Feinberg, and Adityanjee et al. (2007) utilized Veteran's Health Administration hospital data to identify 5527 patients who underwent appendectomy; 55 of these patients were also diagnosed with schizophrenia. During hospitalization, these patients exhibited the following behaviors: confusion (38%), hallucinations (16%), delusions (24%), and suspiciousness (33%) among other psychiatric symptoms. For patients with schizophrenia: 27% had comorbid medical conditions, 80% had advanced appendicitis (gangrenous or perforated), 56% experienced complications, and 40% received psychiatric consultation. Morbidity (56%) and mortality (4%) for this group exceeded that experienced by patients without schizophrenia (16% and 1.8% respectfully). The authors related the disparate outcomes to cognitive disturbances, perceptual abnormalities (including reduced pain perception), and behavioral difficulties. They suggested that schizophrenia may be an independent risk factor for adverse outcomes in surgical procedures.

Copeland, Zeber, Pugh, Mortensen, and Restrepo et al. (2008) examined outcomes of surgical patients with SMI in a systematic review of the literature. They evaluated ten studies: two case studies, four cohort studies, and four randomized clinical trials. Except for two studies which considered patients with major depression, all studies involved patients with schizophrenia. The authors concluded:

> The available evidence suggests that patients with schizophrenia undergoing elective and emergency operations may have more advanced surgical disease at presentation (e.g. perforated appendix), higher postoperative complication rates (e.g. cardiovascular events, venous thromboembolism, or respiratory failure), deteriorating psychiatric status if psychotropic medications are discontinued preoperatively, and increased postoperative mortality. (p.37)

Few studies have looked at the course of hospitalization in attempt to identify factors contributing to longer lengths of stay and higher costs of care for nonpsychiatric hospitalization of persons with SMI. Jutley and Mason (2001) presented the case study of a woman with bipolar disorder hospitalized with vague physical symptoms. The authors described clinical difficulties, such as her “playing down” her condition and general uncooperativeness with diagnostic testing, which resulted in diagnostic and treatment delays.

Researchers investigating nonpsychiatric hospitalization outcomes for patients with SMI identified significant differences and attributed these to difficulty in the course of hospitalization. Several suggest that this difficulty may arise from patient behaviors and communication challenges. Nurses are the primary coordinator of care in the hospital setting and have a key role in managing such “difficulty”.

Role of Nursing

Nurses are important providers of care in hospital settings and play a critical role in patient outcomes, particularly PSIs which have been directly related to nursing care (Montalvo, 2007). Kutney-Lee and Aiken (2008) examined the aspect of nurse staffing and education on the outcomes of surgical patients with SMI. The sample included 228,433 surgical patients; 10,666 had a diagnosis of SMI, 80% had major depressive disorder. Patients with SMI were significantly more likely to be admitted through the emergency department, have medical comorbidities, experience more postoperative complications, and have longer lengths of stay. Nurse staffing (number of patients cared for by a nurse) and education (nursing degree of baccalaureate or above) had a protective effect on outcomes for patients with SMI beyond that demonstrated for surgical patients without SMI. The authors postulated that "patients with serious mental illness are vulnerable to poor outcomes because of their impaired cognition and because their poor communication skills require nurses to spend more time understanding them" (p. 1469). Their results indicated that nursing care is an important contributor to positive outcomes for surgical patients with SMI.

Nurse perceptions

Nurse perceptions of patients with mental illness in the general hospital setting have been investigated in several studies. Nonpsychiatric nurses tend to view patients with psychiatric comorbidity negatively: difficult and problematic (Priami, Plati, & Mantas, 1998; Zolnierek & Clingerman, 2012); disruptive (Atkin et al., 2005); more complex (de Jonge, Zomerdijk, Huyse, Fink, Herzog et al., 2001); and unpredictable (Lethoba et al., 2006). This perception is consistent with negative stereotypes of persons with mental illness and has been shown to affect nurses' responsiveness to medical symptoms (McDonald, Frakes, Apostolidis, Armstrong, Goldblatt et al., 2003). Generally, nurses feel they lack the knowledge, skills, and support needed to effectively care for persons with mental illness in general hospital settings (Atkin et al., 2005; Bailey, 1998; Clark, Parker, & Gould, 2005; Lethoba et al, 2006; Mavundla, 2000; Sharrock, 2006). Nurses lack confidence and experience fear, but education and support from others may increase their comfort in providing care (Brinn, 2000; Reed & Fitzgerald, 2005).

Nurses are not immune from the negative stereotyping surrounding mentally ill persons. Ross and Goldner (2009) synthesized several themes from a literature review regarding stigma, negative attitudes, and discrimination towards mental illness within the nursing profession. The first theme considered "nurses as the stigmatizers" and the negative attitudes of nurses in general medical surgical settings toward patients with psychiatric comorbidities. Nurses feared patients with mental illness because they lacked confidence in their ability to competently manage behavioral symptoms. Blame and hostility was related to beliefs that patients were responsible for their mental illness. A second subtheme, fragmentation of care and devaluation of psychiatry, was reflected in an attitude that psychiatric aspects of care were "not their job" (p. 561) and that mental health needs were not a priority. Lack of skills and education to meet the needs of patients with psychiatric comorbidity comprised the third subtheme. Finally, a lack of resources and infrastructure to support the care of patients with psychiatric comorbidities led to nurses feeling “on their own” (p. 562) to ensure safe care.

In a study involving medical-surgical nurses, psychiatric nurses, and lay people, Rogers and Kashima (1998) validated that a “reasonably consistent and negative stereotype of the mentally ill exist” (p. 202). However, they suggested that education and exposure to mentally ill persons can assist individuals to inhibit this negative stereotype and respond more positively. Bailey (1998) found similar negative stigmatizing in an investigation of nurse and physician attitudes toward patients with a psychiatric illness who had attempted suicide and were hospitalized in an intensive care unit. She concluded that “assumptions and prejudices…are related to a deficit in knowledge and prevailing social stigma” (p. 8).

Psychiatric comorbidity impacts nurse perceptions of care needs. Patients on general internal medicine wards with high scores on a depression and anxiety screen were perceived by general nurses as having more complex needs than patients with lower scores, even though there were no actual differences in limited functional status and nursing interventions (de Jonge et al., 2001). That is, nurses perceived and experienced an increased complexity of care for patients with mental illness, even though such care could not be objectively substantiated from documented interventions in the medical record. The authors conclude that nurses may need additional help in caring for patients with mental illness.

McDonald et al. (2003) utilized a post-test only experimental design to explore how the presence of a psychiatric diagnosis would affect nurses’ plan of care for medical problems. Sixty medical surgical nurses were randomly assigned to one of three groups. Each group considered a vignette about a patient admitted to rule out myocardial infarction. The two experimental groups received additional information about the patient's medication regimen. The nonpsychotic psychiatric condition group was informed that the patient regularly took alprazolam (anxiolytic); the psychotic psychiatric condition group was told the patient regularly took haloperidol (antipsychotic), benztropine (anticholinergic), lorazepam (anxiolytic), trazadone and fluoxetine (antidepressants), and lithium (mood stabilizer). The control group received no further information. The authors found that:

> The mention of medications used in the treatment of schizophrenia caused registered medical surgical nurses to plan to respond differently to the hypothetical patient….Nurses in the psychotic patient condition were less likely to believe the patient was experiencing a MI and were less likely to respond to sudden symptoms of a possible evolving MI. Nurses with a baccalaureate education or higher were more likely to predict that the person was experiencing an MI. (p. 229)

The authors concluded that nurses may stereotype patients with psychiatric diagnoses and plan to respond differently toward these patients.

In a qualitative descriptive study examining nurse perceptions and experiences in providing care for persons with mental illness, half of general hospital nurses interviewed (five of ten) expressed dislike for caring for persons with mental illness (Reed & Fitzgerald, 2005). The authors suggested that such attitudes directly influence a nurse's ability to provide care. Interestingly, when Sharrock (2006) interviewed four general nurses about their experience of providing care to persons with mental illness in a medical surgical setting, all reported positive attitudes toward people with mental illness;

yet, they lacked confidence in their competence in providing quality care. This was a grounded theory study in which the author reports saturation at four interviews. Since the findings represent a stark contrast to other studies, the sample may have been unique to the particular context of the nurses and transferability may be limited.

The difficult patient

Because persons with SMI may exhibit unusual behavior and challenge the comfort of nursing staff, they are at risk to be labeled difficult in the general hospital setting. Macdonald (2003, p. 305) referred to the concept of the difficult patient as “common parlance” among nurses; mutual understanding is assumed, yet shared meaning is unexplored. The concept “difficult patient” is most commonly discussed in the literature in terms of patient characteristics: the difficult patient is described as one whose behavior obstructs nursing care (Manos & Braun, 2006), or care routines (Atkin et al, 2005), and challenges the nurse’s sense of competence (Gallop & Wynn, 1987; May & Kelly, 1992). Macdonald (2003) offers this definition:

> The difficult patient is a person who does not assume the patient role expected by the health care professional, who may have beliefs and values or other personal characteristics that differ from those of the caregiver, and who causes the caregiver to experience self doubt. (p. 307)

In describing the difficult patient, the literature most frequently locates the difficulty, or problem, within the patient. Noonan (1998) distinguished this approach as a one-person model focused on certain characteristics believed to make a patient inherently difficult. Difficult patient behaviors include those considered uncooperative, overemotional, complaining (Lorber, 1975; Podrasky & Sexton, 1988), demanding, egotistic (Strandberg, & Jansson, 2003), deviant, rule breaking (Johnson & Webb, 1995), manipulative, angry, noncompliant (Morrison et al., 2000; Pill, Rees, Stott, & Rollnick, 1999), and sexually provocative (Nield-Anderson, Minarik, Dilworth, Jones, Nash et al., 1999). Notably, these descriptors are highly subjective, contain a moral tone, and rely on the nurse's interpretation and judgment. The process of labeling patients is inconsistent, changing over time and conditions, as well as enduring, communicated from shift to shift, unit to unit, or for long periods, e.g. when a patient is readmitted (Johnson & Webb, 1995; Juliana, Orechowsky, Smith-Regajo, Sikora, Smith et al., 1997). Difficult patients may not be consistently labeled as such by different nurses with varying interpretations of the behavior. "Patients' behaviour and attitudes do not reside objectively in the patients but rather reside in definitions attributed to the patients by staff" (Kelly & May, 1982, p. 152). Other, more objective, attributes of the difficult patient include high utilization of services (Haas, Leiser, Magill, & Sanyer, 2005; Tandeter, 2006; Shaw, 2004), unemployment, lack of education (Koekkoek, van Meijel, & Hutschemaekers, 2006), type of illness/disease, and social background (Kelly & May, 1982).

The context of the behavior may influence perceptions of difficulty. Some have suggested that difficult behaviors represent coping responses to the stress of illness and hospitalization and infer that this perspective may assist nurses in dealing with the difficult behaviors (Juliana et al., 1997; Nield-Anderson et al., 1999). Strandberg and Jansson (2003) found that nurses' interpretation of dependency on care as "easy" or "trying" was largely determined by the degree to which the patient was social, considerate, easy to know, and responsible. In a study of the reactions of physicians and nurses to the behavior of surgical patients, Lorber (1975) observed that patients with extraordinary medical conditions who evidenced troublesome behavior were “forgiven” as understandable in light of their medical status, while problem patients whose behavior was considered unnecessary were censured. Again, moral judgment of the patient’s situation influences nurse’s determination of difficulty.

Koekkoek et al. (2006) reviewed 94 articles published over the past 25 years to explore definitions and treatment strategies for difficult psychiatric patients, concluding that “difficult” was a judgment ascribed to a patient who was “hard to be with” (p. 800). They grouped observed behaviors into four dimensions: withdrawn and hard to reach, demanding and claiming, attention seeking and manipulating, and aggressive and dangerous. In attempt to provide a frame of reference for defining interventions for difficult patients; the authors described three subgroups of difficult psychiatric patients who emerged from their literature review: care avoiders, psychotic patients who do not recognize their illness or need for treatment; care seekers, individuals with chronic illness whose relationship with caregivers is inconsistent; and, claimers, persons who only need short term mental health resources. The authors argued that treatment strategies exist for care avoiders and claimers, but for ambivalent care seekers who pursue care, but display uncertain behaviors that could be interpreted as both difficult and sick, lack the support of effective treatment strategies.

Difficult patients include those who are perceived as responsible for their illness (May & Kelly, 1982; Olsen, 1997) as well as those with certain conditions such as pain, substance abuse, mental illness (Manos & Braun, 2006; Morrison et al, 2000). When the difficulty is identified within the patient, nurses are advised to employ intervention strategies to either cope with or impact the difficult behavior (Juliana et al., 1997; Manos & Braun, 2006; Morrison et al., 2000; Nield-Anderson, et al., 1999). This one-person model is simplistic and fails to consider the significance of context beyond the individual's circumstance and illness.

While these descriptions situate the difficulty with the patient, several authors have investigated attributes of the nurse (Halberg & Norberg, 1995; Koekkoek et al., 2006; Normann, Asplund, & Norberg, 1999; Pill, et al., 1999), the nurse-patient relationship (Breeze & Repper, 1997; Kelly & May,1982; Laskowski, 2001; Noonan,1998; Russell, Daly, Hughes, & Hoog, 2003), and the environmental context (Lilja, Ordell, Dahl, & Hellzen, 2004; Macdonald, 2007; Podrasky & Sexton, 1988) to the experience of difficulty.

Attributes of the nurse

Characteristics of the nurse have also been associated with the determination of patient difficulty. Podrasky and Sexton (1988) conducted an exploratory survey study regarding patients described as difficult and how nurses respond to them. Nurse factors of mood, hours worked, busyness of the unit, years of nursing experience, and past experience with difficult patients impacted the nurses' levels of frustration and anger with patients considered difficult. Halberg and Norberg (1995) utilized assessment scales (strain in nursing care, emotional reactions, and inventories for assessing burnout and strain) to investigate nurse perceptions of and reactions to the actions of patients with dementia. They concluded that the achievement of a cooperative relationship between the nurse and the patient was related to ease of care and the experience of less strain. In addition, full time and day shift nurses had more positive views of patients; the authors suggested that more time with patients had a positive influence on the nurse-patient relationship.

Also interested in nurse attitudes toward patients with dementia, Normann et al. (1999) piloted a questionnaire based on a clinical situation designed to measure the approach used by the nurse: the reality orientation approach that emphasizes reorienting the patient to here-and-now reality in attempt to reduce confusion versus the personhood focused approach that considers disordered behavior and communication as meaningful. Nurses with post-basic or psychiatric nursing education and those who worked in team (vs. primary) nursing systems were more likely to choose a personhood focused approach. The authors attributed this to the opportunity for reflective practice which is provided in post-basic nursing programs, in psychiatric nursing, and in team nursing models.

A study examining the failure of nurses to sustain designated patient interventions, despite initial enthusiasm among the nurses, found that those with a reflective attitude were more likely to support negotiated decision making and patient autonomy with difficult (noncompliant) patients with diabetes (Pill et al., 1999). Nurses' perceptions of their role impacted perceptions of patient difficulty. Koekkoek et al. (2006) identified personality traits of the therapist (mental health provider) that may increase the likelihood of difficult relationships with patients: strong desire to cure, intense need to care, difficulty accepting defeat, and a confrontational or blaming attitude. Since the nurse is determining the difficulty of the patient, it is not surprising that personal attributes of the nurse influence this judgment.

Nurse-patient relationship attributes

Another locus for development of difficulty is the relationship between nurse and patient rather than either individual in isolation. Noonan (1998) refers to this perspective as a two-person model which acknowledges a dynamic interplay between the health care professional and the patient. Expectations and affective needs of the health care professional are imposed on the relationship with the patient. When feelings of frustration and inadequacy are experienced, the patient may be labeled difficult (Noonan, 1998). Laskowski (2001) utilized a grounded theory approach to examine difficult behavior within the context of the nurse- patient relationship. She found that, although nurses identified specific behaviors that created difficulty, patients were recognized as difficult when their relationship with the nurse became problematic. Thus, intrinsic patient behaviors alone do not determine difficulty, rather it is within the context of the relationship that difficulty is experienced.

Following a comprehensive literature review and critique, Kelly and May (1982) proposed that patients were defined as good or bad as a consequence of nurse-patient interactions. Further, the problem patient is defined as one who fails to validate the nurse's authority and therapeutic competence, that is, the professional role of the nurse. Breeze and Repper (1997) confirmed this assertion in their qualitative ethnographic study consisting of patient and nurse interviews. The nurse's sense of competence and control in relationship with the patient influenced the degree of difficulty experienced. Likewise, noncompliance – a difficult behavior ascribed to patients who do not follow advice – can "be seen as a label used by professionals to maintain power and control over patients" (Russell, et al., 2003, p. 284). When the nurse's professional role is challenged, the patient may be labeled difficult. An alternate view of noncompliance places patient behaviors within the context of their lives and considers how that social context affects the patients' ability to follow recommended treatment (Russell et al., 2003). This perspective eliminates blame and enhances the effectiveness of advice because it fits the patients' circumstances.

Patients' perceptions of their relationships with nurses yield interesting perspectives. In a phenomenological study of patients' (without mental illness) experience of seeking nursing care in a medical-surgical hospital setting, Shattell (2005) concluded that the therapeutic relationship and problem solving as described by Peplau was not evident and may not exist in the contemporary hospital environment. Allen (2007) would agree. In an analysis of 54 field research studies regarding nurses' work, she concludes that nurses' actual practice reflects the role of health care mediators within health systems, and that expectations for emotionally intimate relationships with patients are exaggerated, setting nurses up for dissatisfaction and low morale. Yet, "knowing the patient" has been identified as an important factor in the establishment of effective nurse-patient partnerships. Macdonald (2007) found knowing the patient to be a prerequisite to a harmonious nurse-patient encounter. In a study regarding dependency on care, dependent patients who were easy to know were experienced positively by nurses (Strandberg & Jansson, 2003). Fagermoen (1997) cited others in emphasizing the significant value nurses place on knowing the patient. If the contemporary hospital environment does not support therapeutic familiarity between nurse and patient (as Allen, 2007 and Shattell, 2005 suggest) the environment itself may contribute to difficulty. While international studies have examined nurses' experiences of patients with mental illness in the general hospital setting, no studies to date have considered the relationship between the nurse and patient with mental illness in the context of the general hospital environment.

Environmental context

Patients, nurses, and their interactions or relationships are embedded within the environmental context of the hospital inpatient unit. This context offers potential for difficulty. Podrasky and Sexton (1988) suggested that the emotional tone of the unit influences nurse-patient interaction. Breeze and Repper (1998) conducted nursing focus groups to determine characteristics of difficult patients and unexpectedly discovered the importance of available resources, e.g. staff time, in determining perceptions of difficulty. This finding is consistent with nursing staff's ability to "know the patient" – knowing takes time. Macdonald (2007) found that origins of difficulty in the nurse-patient encounter relate directly to available time of the nurse. Environmental factors affecting the nurse's time included availability of supplies and equipment, families, who is working, and care space changes (lengths of stay, patient complexity). Juliana et al. (1997, p. 2) similarly found that difficult patients "consumed more nursing time than reasonable for their condition” considering the context of health care reform in the 1990’s – reduced length of stay for hospitalized patients, rapid patient turnover, and “short staffing”. Lilja et al. (2004) conducted a quantitative survey utilizing the semantic differential technique validating typologies of good, evil, crazy and invisible patients, elucidated in a previous qualitative study. The good patient was unproblematic in that they did not interfere with nursing efforts to preserve order and structure within the inpatient unit.

In a survey of emergency department nurses and staff, researchers found that perceptions of a fair and equitable work environment were associated with stronger empathy toward persons with mental illness (Wright, Linde, Rau, Gayman, & Viggiano, 2003). Additionally, work group cooperation and facilitation predicted greater clinical involvement with persons with mental illness. In contrast, role ambiguity – a sense that the emergency department was not an appropriate place for providing psychiatric care – was related to lower levels of understanding and clinical interaction with persons with mental illness. The authors concluded that creating an organizational climate that is empathetic towards the needs of persons with mental illness may improve the quality of care provided.

PATIENT PERSPECTIVES

While most hospitals regularly survey their patients, and may inquire about perceptions of nursing care, these surveys tend to focus on patient satisfaction and do not explore the nurse-patient relationship in any depth. Although several studies have explored the psychiatric hospitalization experience of patients, the literature is devoid of studies exploring the experience of persons with mental illness hospitalized in a medical-surgical setting. Shattell (2005) utilized an existential phenomenological approach to study nursing care seeking behaviors among hospitalized medical-surgical patients (without mental illness). A prominent theme emerged: “make them your friend”. Additional themes included: “be an easy patient” and “try to get them to listen” (p. 212). Patients were aware of the labeling process and actively avoided being labeled “bad” or “difficult” by developing relationships with nurses. These relationships were instigated with social cues to “bait” nurses into interpersonal relationships with the intention of ensuring the quantity and quality of care received. Perhaps patients with mental illness are less able to recognize and utilize social cues to do “their part” in developing relationships with nurses.

Shattell, McAllister, Hogan, and Thomas (2006) conducted a phenomenological inquiry to explore how persons with mental illness experience the phenomenon of being understood by a health professional. The sample included 20 individuals of various ethnicities and levels of education with diagnoses including SMI. Identified themes were summarized as “moments of interpersonal connection with listeners who made them feel important and connected on their level” (p. 240). Of interest, medical-surgical nurses were among those most commonly identified as individuals with whom they shared an experience of being understood. Exploration of the characteristics of that context – when persons with mental illness felt understood by medical surgical nurses – may instruct the development of therapeutic environments within medical surgical settings.

Clarke, Dusome, and Hughes (2007) explored the perspective of patients with mental illness who presented for care in the emergency department. Focus group participants described feeling “shamed and guilty” (p. 128) and “not a priority” although they desired recognition of their needs as legitimate. Diagnostic overshadowing occurred as patients felt labeled as “psychiatric” regardless of their presenting problem. Patients wanted a holistic approach that considered their mental and physical health issues in entirety.

PERCEPTIONS OF QUALITY OF LIFE

Quality of life (QOL) is a subjective assessment of well being defined by the World Health Organization (1998) as an “individual’s perceptions of their position in the life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 17). Persons with SMI tend to have more negative perceptions of their QOL. A study considering the QOL of persons with long term illness (e.g. cancer, multiple sclerosis, diabetes) found that schizophrenia had a significantly negative influence on physical health, psychological well-being, social relationships, environment, and overall QOL (Kilian, Matschinger, & Angermeyer, 2001). Further, persons with schizophrenia had statistically significant lower QOL measures than all other groups in the social and psychological domains. Fenn, Bauer, Alshuler, Evans, Williford, et al. (2005) found a worsening health related QOL among patients with bipolar disorder. Likewise, Jacobsen, de Groot, and Samson (1997) found that, of patients with diabetes, those with psychiatric comorbidity rated their QOL significantly lower, and the effect of the presence of mental illness was pervasive.

Patients with SMI experience a lower QOL – how does is this manifest during nonpsychiatric hospitalization? At least one study (Lykouras, Vassiliadou, Adrachta, Voulgari, Kalfakis, et al., 2006) found that neurological patients with psychiatric comorbidity tended to demonstrate more illness behavior than those without such comorbidity. Such illness behavior contributes to the complexity of care experienced by nurses (Hansen, Fink, Frydenberg, de Jonge, & Huyse, 2001) and perhaps the experience of difficulty. Baumeister, Balke, and Härter (2005) evaluated 45 studies that considered the relationship between comorbidities and QOL in persons with physical illness. While somatic comorbidity was negatively associated with physical aspects of QOL, psychiatric comorbidity had a significant effect on both somatic and psychosocial aspects of QOL.

INTERVENTIONS

Interventions implemented in attempt to improve care and support the care process for patients in general hospital units with psychiatric comorbidities have primarily consisted of consultant-liaison psychiatry and nursing services. While such services are perceived positively by nursing staff, they fail to demonstrate an improvement in LOS or clinical outcomes when controlling for confounders (Andreoli et al., 2003; Camus et al., 2003; de Jonge, Latour, & Huyse, 2003; Baldwin, Pratt, Goring, Marriott, & Roberts, 2004; Sharrock, Grigg, Happell, Keeble-Devlin, & Jennings, 2006; Cullum et al., 2007). However, two studies suggested that the timing of psychiatric consultation may improve outcomes such as LOS (Kishi, Meller, Kathol, Swigart, 2004; Johnston & Cowman, 2008). Yakimo (2006) argued that documentation of outcomes related to psychiatric consultation-liaison nursing is needed for evidence based practice to develop. To date, there is a paucity of research in this area.

A unique approach – the implementation of a specialized acute psychiatric and acute medical unit – has reported some success (Kishi & Kathol, 1999); however, this model is not easily replicated and may not be practical for most hospitals. The literature does not yet identify effective approaches for improving care outcomes for patients with SMI hospitalized in general hospital settings.

While mental illness can adversely affect outcomes of care for somatic illness, the reverse also appears to hold true. Thompson et al. (2006) found that medical illness could influence the outcome of SMI (bipolar disorder) and posited that appropriate treatment of the medical disorder could enhance the psychological well being and course of the SMI. Thus, there exists a compelling need to identify strategies to improve care for persons with SMI receiving nonpsychiatric inpatient care. Successful approaches will be based on a better understanding of factors contributing to adverse outcomes.

GAPS IN THE LITERATURE

Excess morbidity and mortality for persons with SMI is well documented in the literature. Likewise, increased LOS for this patient population is consistently recorded. Research is just beginning to specify what adverse events and negative clinical outcomes this patient population may be more likely to incur. Evidence of provider and organizational behaviors, such as implementation of clinical guidelines and nurse staffing levels, which may affect outcomes is just beginning to develop. Although consultation-liaison psychiatric services are implemented in general hospital environments, evidence about effectiveness beyond general satisfaction is missing. To date, studies have failed to explore the patient's experience of hospitalization. A first person perspective of the experience of nonpsychiatric hospitalization for persons with SMI is conspicuously absent from the literature and needs exploration.

SUMMARY

Disparities in morbidity and mortality for persons with SMI are related to a number of factors including poorer quality of care. Persons with SMI experience a number of chronic medical conditions at a rate greater than the general population due to lifestyle, socioeconomic, treatment, and genetic factors. Medical treatment for this patient population is characterized by access challenges, insufficient care (lower rates of treatment and lower quality of care), and delivery in more acute settings, such as hospitals. When hospitalized in nonpsychiatric settings, persons with SMI have a difficult hospital course: they are more likely to experience adverse events, longer lengths of stay, and increased costs of care. Several researchers have suggested that communication and relationship difficulties may contribute to their poor outcomes in general hospital settings, yet none offer evidence to substantiate this supposition. General hospital nurses do experience patients with SMI as difficult and unique features of the nurse-patient encounter may influence outcomes, but this relationship has not been explored. SMI has a significant negative impact on QOL perceptions, but the effect of SMI on the experience of nonpsychiatric hospitalization is unknown. While studies of patients’ experiences of hospitalization emphasize the importance of the nurse-patient relationship, the literature is devoid of studies investigating such relationships when patients have SMI comorbidities. Perhaps what is most lacking in the literature is a patient perspective: what is the experience of the person with SMI who is hospitalized in a nonpsychiatric setting? This understanding from a patient perspective is important and can inform the development of effective interventions to improve inpatient care and health outcomes.

Chapter 3: Methodology

INTRODUCTION

The purpose of this study was to explore the lived experience of persons with severe mental illness (SMI) when hospitalized for physical health conditions in medical-surgical environments. This chapter describes Heideggerian phenomenology as the philosophy informing the study as well as the research methodology for conducting the research. A research design – including participant selection, data collection procedures, and data analysis methods – consistent with hermeneutic phenomenological inquiry is presented.

PHILOSOPHICAL PERSPECTIVE

Phenomenology is literally the study of phenomena – “things” as they are observed or perceived (Schwandt, 2007). Phenomenology emerged when approaches used to study the natural sciences, controlled experiments and quantitative measurements, were thought inappropriate for studying the human sciences (van Manen, 1990). The Phenomenological Movement encompasses three stages of development:

1. The Preparatory Phase: associated with Franz Brentano (1838-1917) and Carl Stumpf (1848-1936) who established the value of inner perceptions and the notion of intentionality;
2. The German Phase: associated with Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) known for descriptive and interpretive phenomenology (respectively);

3. The French Phase: associated with Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980), and Maurice Merleau-Ponty (1908-1961) who are associated with existentialism (Cohen, 1987).

Although the Preparatory Phase laid the groundwork for phenomenology, Edmund Husserl is identified as the father of phenomenology. Veering from prevailing scientific tradition, he argued that conscious experience was the source of knowing (Koch, 1995). Knowing comes from “the things themselves” (inductively) rather than deductively from theories (Cohen, 1987). Husserl introduced the notion of intentionality – that consciousness is directed at something (Koch, 1995). Intentionality reflects the relationship between persons and their conscious awareness (Kutney, 2006); our inseparability from the world (van Manen, 1990). We are always conscious of something, always engaging with the world (Crotty, 2004). Therefore, meaning occurs in the context of being in the world. Phenomenological inquiry seeks to describe phenomenon as it presents itself to consciousness (van Manen, 1990).

Husserl’s ties to the scientific method (logical positivism) are evident in his emphasis on essences which exist outside of conscious experience, but can be discovered through description (Mackey, 2005). That is, there are phenomena to be experienced and described that have not yet been subjectively experienced. Husserl’s descriptive phenomenological method seeks to discover and describe essential structures of an experience that represent the true nature of the phenomenon (Koch, 1995; Lopez & Willis, 2004); such description would “return things to themselves” (Koch, 1995, p. 828).

Husserl asserted that researchers seek answers to questions and must “bracket out” subjectivity, that is eliminate all assumptions and preconceptions about the phenomenon in order to provide an objective, valid description of the data (Koch, 1995). The goal of bracketing is to achieve transcendental objectivity, to neutralize researcher bias and preconceptions, so that the researcher can objectively identify and describe universal essences of the lived experience (Lopez & Willis, 2004). Husserl’s philosophy is referred to as descriptive phenomenology.

Martin Heidegger (1889-1976) studied with Husserl and proceeded to develop an alternate philosophy of phenomenology known as interpretive or hermeneutic phenomenology. Like Husserl, Heidegger was interested in meaning in context, but he criticized Husserl’s focus on description rather than understanding. He believed that human beings are self-interpreting and that understanding is a way of being in the world (Koch, 1995). Hermeneutic philosophy therefore focuses on the “experience of understanding” (Koch, 1995, p. 832).

Heidegger believed the appropriate focus of inquiry was the meaning of being (ontology) rather than the nature of knowledge (epistemology) (Mackey, 2005). Heidegger argued that meaning exists only through our experience or encounter with the world; there are no essences to be discovered. He rejected Husserl’s notion of bracketing, instead arguing that one is inseparable from the world: “Pre-understanding is a structure of our ‘being-in-the-world’. It is not something we can eliminate, or bracket, it is already with us in the world” (Koch, 1995). Heidegger went so far as to *value* the personal knowledge, the *forestructure*, the investigator brings to the research (Lopez & Willis, 2004). Heidegger also believed that description without interpretation was impossible and described phenomenology as an interpretive process (Mackey, 2005); thus the term *hermeneutic* phenomenology came into being.

Heidegger described his philosophy in *Being and Time* (1962) where he addressed the meaning of "Being" – "the most universal and the emptiest of concepts" (p. 2). He moved the focus of philosophy from epistemology – how we know – to ontology – what it means to be. "Phenomenology is to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (p. 58). Phenomenology describes how phenomena are to be considered directly – "to the things themselves!" (p. 58). Hermeneutic phenomenological researchers remain close to experience itself (Smythe, Ironside, Swenson, & Spence, 2008). Heidegger further contended that ontology is only possible in phenomenology.

Heidegger described the essence of being by introducing "Dasein": the "entity which each of us is himself and which includes inquiring as one of the possibilities of its being" (p. 27). Dasein is distinguished by understanding itself as being; it has awareness of existence; it is conscious. Dasein's essential state is "being-in-the-world", and therefore cannot be considered separately from the world. *Thrownness* belongs to Dasein's state of being (Heidegger, 1962); human beings are thrown into a world that is already there and find themselves situated in cultural, historical, and social contexts (Koch, 1995; LeVasseur, 2003). Understanding cannot occur outside of context.

Being must always be considered in context – time and space. Heidegger argued that being can get "covered up" and become hidden – uncovering and understanding being becomes the object of concern for phenomenology. To understand Dasein, a method of access and interpretation must be selected "that this entity can show itself in itself and from itself …in its average everydayness (Heidegger, 1962, p. 37-38). Discourse becomes the method of access and the basis for interpretation in hermeneutic phenomenology (Chang, 2008).

Heidegger's philosophy of phenomenology provides the foundation for the hermeneutic research tradition. The focus of hermeneutic inquiry is lived experience and the meaning of being in the world. Hermeneutic methodology provides a systematic method for researching lived experience (Kutney, 2006).

HERMENEUTIC PHENOMENOLOGY RESEARCH METHOD

The philosophy of hermeneutic phenomenology informs the hermeneutic phenomenology research method for understanding meaning constructed through an individual's conscious engagement with the world. Therefore, "phenomenological questions are meaning questions" (van Manen, 1990, p. 22). They explore the nature of lived experience of a certain phenomenon.

Data Collection and Analysis

People interpret their experiences as they are lived in attempt to make sense of them; ascribed meanings are embedded in narratives or stories (Chang, 2008). Discourse enables access to lived experience. The face-to-face shared conversation allows the story to unfold, rather than direct its iteration. The method of the interview allows an "openness to what 'is' – to the play of conversation" (Smythe et al., 2008, p. 1392) in keeping with Heidegger’s understanding of Dasein. Therefore, a minimally structured interview – an open-ended research question with potential probes – in which the participant is encouraged to talk about a specific experience, is used to obtain data. Rich or thick descriptions of everyday being are desired as they can reveal essential structures of Dasein (Mackey, 2005). The transaction between the participant and interviewer becomes the unit of analysis (Koch, 1995). The participant is viewed as the expert (Stubblefield & Murray, 2002); their description is valued as their reality and understanding (Mackey, 2005). The researcher is called to listen with their whole being and with openness to understanding.

Meanings are uncovered through an analysis of descriptions. There is an emphasis on understanding, and this occurs through interpretation. “Phenomenological Interpretation must make it possible for Dasein itself to disclose things primordially; it must, as it were, let Dasein interpret itself” (Heidegger, 1962, p. 179). Interpretation uncovers what is already there, reveals what is already understood, and achieves meaning (Mackey, 2005). Interpretation “works out” the ontology (Heidegger, 1962).

Interpretation is grounded in *forestructure* – what we understand in advance (Heidegger, 1962): prior awareness, anticipation of meaning, previous experience. This notion is consistent with Heidegger’s assertion that we are always already in the world and cannot divorce ourselves from it – e.g. bracket out subjective influences.

Heidegger (1962) describes a circle of understanding in which we work out meaning: the hermeneutic circle. Because we are thrown into cultural, historical, and social contexts, and are always already in the world, nothing is encountered separate from our pre-understanding (Koch, 1995). We understand based on our background, our "historicality", and co-constitute our world (Koch, 1995). The interpreter must enter the hermeneutic circle in a manner that will facilitate interpretation. The interpreter must make *forestructure* explicit so that the phenomenon can reveal itself; the hermeneutic circle is "an expression of the interpreter's forestructures" (Geanellos, 1998, p. 241). The interpretive process is circular and never fully complete, "every interpretation relies on every other interpretation" (Schwandt, 2007). As new understandings are uncovered, the whole is re-considered in new ways (Mackey, 2004). Thus, the process is circular.

Interpretation is an engaged interactive process in which one moves back and forth between partial understandings and the whole (Mackey, 2005). One comes to understand parts of the data in order to understand the whole, and greater understanding of the whole enables fuller understanding of the parts, driving the analysis deeper and round and round (Cohen et al., 2000). Understanding develops through this circular process and within one's *forestructure*.

Data analysis begins with an immersion in the data to obtain an "orienting gestalt" (Cohen et al., 2000, p. 76), a general sense of what is there. Through the hermeneutic circle, data reduction occurs. The researcher makes decisions about what is or is not relevant and reorganizes the data (Cohen et al., 2000). Patterns of meaning are clustered into categories and themes are identified. Themes are then described and analyzed from an ontological perspective (Chang & Horrocks, 2008) – the meaning of a lived experience.

Sampling Procedures

Sampling concerns associated with empirical research, such as random selection, independence, and size to achieve adequate power, are not relevant to phenomenology. The phenomenon of interest guides the selection of a homogenous sample who share a particular experience (Crist, 2003). The research question may reflect an interest in an experiencing place (e.g. a general hospital unit), experiencing events over time (e.g. the process of receiving integrated health care), or ways of talking about experience (e.g. shared traditions of interpreting events such as birth) (Cohen, et al., 2000).

Morse (2000) outlines several factors for determining appropriate sample size for a qualitative study: study scope, nature of topic, quality of data, study design, and use of shadowed data. A broad scope, indistinct topic, lack of thick description, or limited contact with participants may result in the need for a larger sample in order to obtain adequate data.

Appropriateness to Nursing Research

Phenomenology has been proposed as an appropriate approach to psychiatric nursing research (Chang & Horrocks, 2008; Kutney, 2006; Stubblefield & Murray, 2002). As a human science, nursing is concerned with persons' meanings and experiences (Meleis, 2007). Narratives provide unique perspectives of experience and understanding that can inform nursing care:

> Because nursing is an art and a science that concerns itself with human responses to actual and potential health problems, specialized knowledge for the practice of nursing must reflect the live, contextual realities and concerns of the clients for whom nurses provide care. (Lopez & Willis, 2004, p.726)

At least 35 investigators – including nurses (15 studies), occupational therapists, psychologists, social workers, and others – have utilized a phenomenologic research method to explore the lived experience of persons with SMI. Experiences investigated have included: life in the community (e.g. recovery, relationship), illness (e.g. depression and treatment, finding meaning in illness), and inpatient care (e.g. involuntary hospitalization, ward rules). Research findings indicate that persons with SMI have very basic desires: normalcy, social relationships, meaningful activities, and opportunities for involvement and participation in treatment (Zolnierek, 2011).

Understandings about the experiences of persons with SMI, can inform nurses and other providers about the design of interventions and services that may greatly improve the quality of life for persons with SMI. A particularly impressive example is described by Davidson, Stayner, Lambert, Smith, and Sledge (1997). After an intervention failed to achieve a reduction in psychiatric hospital recidivism among adults with SMI, researchers conducted a phenomenological study to explore the readmission process from the perspective of adults with SMI. New understandings enabled the design of an intervention that effectively reduced recidivism by 70% and hospital days by 90%. The patient's perspective is a powerful source of information.

Pilot Study

The researcher conducted a pilot study (Spring 2010) to test the methodology used in this study. IRB approval was obtained for the pilot study. A provider of psychiatric services signed a letter of support and referred a woman to the researcher. The participant and researcher discussed the nature of the research over the telephone and arranged to meet in a community library. At the onset of the meeting, the researcher explained the purpose of the research and anticipated risks and benefits and the participant signed an informed consent document. The researcher utilized the interview guide for the interview which lasted approximately 75 minutes. The participant described her experience of hospitalization from the time she was injured (fell and broke her hip) until she was stabilized and returned home. The participant was open to discussing her experience and, at the conclusion of the interview, thanked the researcher for the opportunity to share her story, “This has been so pleasant for me.” (Participant 1, personal communication, June 7, 2010).

RESEARCH DESIGN

Research design describes the plans and procedures for investigating a topic. The research problem is a key factor in determining the best approach for conducting the inquiry. Problems concerning the relationships among factors are suited to quantitative inquiry. When little research has been done on a topic and variables are not identified, qualitative inquiry is appropriate (Creswell, 2009).

The topic of this study wass the lived experience of nonpsychiatric hospitalization for persons with SMI. To date, research on nonpsychiatric hospitalization of persons with SMI consisted of quantitative studies and reveals hospitalization outcome measures that differ from persons without SMI. Although some explanations for this finding have been offered (e.g. communication difficulties of persons with SMI), such propositions have not been validated. This study employed a phenomenologic, qualitative inquiry to explore the hospitalization experience from the patient’s perspective and uncover meanings of that experience. New understandings are expected to provide insight into the care experience and suggest factors that may contribute to poorer hospitalization outcomes for persons with SMI.

Data Collection

Population and Sample

Consistent with phenomenological methodology, this study utilized a purposive sample of individuals who experienced the identified phenomenon. The population of interest was adult persons with SMI who had been hospitalized on a medical or surgical unit within the past 12 months for a nonpsychiatric condition. Other phenomenological studies investigating experiences of persons with SMI utilized sample sizes of two to 44 participants (N=35, mean = 12.06, median = 9.5, mode = 10) (Zolnierek, 2011). A convenient purposive sample of up to 20 participants was originally proposed. Ten participants actually participated in the study. The sample size of ten is believed to have provided adequate data to answer the research question as saturation was achieved. Participants met the following criteria:

- Adult, 19 years of age or older so that hospitalization experience will have occurred while participant was at least age 18
- English speaking

- Currently stable (not experiencing an acute exacerbation of the psychiatric disorder, able to adequately focus attention and process information necessary to respond to interview questions, as evaluated by the referring psychiatric professional)
- Currently under the care of a medical and/or psychiatric provider for their psychiatric disorder
- Hospitalized on a medical-surgical unit within the past year for at least 36 hours
    - "Medical surgical unit" includes: hospital inpatient general medical, general surgical, blended medical-surgical, and specialty, such as gynecological, orthopedic, oncology, telemetry, and others
    - "Medical surgical unit" excludes intensive care; other hospital units that do not treat acute medical-surgical problems, such as rehabilitation, psychiatric, and labor/delivery/postpartum; and outpatient stays, such as emergency department and procedural areas
- Primary diagnosis for incidence of hospitalization is a nonpsychiatric diagnosis (e.g. infection, chronic obstructive pulmonary disease, fracture, diabetes, etc.)
- Comorbid psychiatric diagnosis of schizophrenia (include schizophrenic spectrum disorders), bipolar disorder, or major depression (these diagnoses are considered to be SMI when they have disabling affects on social or occupational functioning)
- Not dually diagnosed with substance related disorders
- Voluntary consent to participate in audio recorded interview
- Access to telephone or email

As displayed in Table 1, the actual sample included eight women and two men who were hospitalized for both medical (e.g. pneumonia) and surgical (e.g. hip fracture) conditions. Hospitalizations were both planned (e.g. total knee arthroscopy) and unplanned (e.g. diabetic ketoacidosis). Mental illnesses experienced by the participants included mood and schizophrenia related disorders.

Participant Recruitment

Participants were recruited through outpatient providers (psychiatrists, advanced practice registered nurses, clinical social workers, etc.) who regularly provide services to persons with SMI. Both public (community mental health) and private (independent) providers in central Texas were identified and invited to participate in recruitment of participants. Interested providers signed a support letter (Appendix A) indicating their understanding of participation expectations (agreement to screen individuals for appropriateness, awareness of confidentiality of the interviews, and notification of immediate referral should the participant indicate dangerousness) and their willingness to refer potential participants. Signed support letters were presented to the University of Texas at Austin Institutional Review Board (IRB) for approval prior to the referral of potential participants from a particular provider.

A flyer (Appendix B) with basic information about the focus of the study and the researcher's contact information was supplied to IRB approved providers. The support letter indicated that providers would identify the study opportunity and hand out the flyer to patients who meet the above criteria. Providers were instructed not to refer any individual who they believe may face greater than minimal risk by participating (e.g. delusional system that may be aggravated by the recording of the interview), who is experiencing an acute exacerbation of their mental illness, or who may not be able to provide informed consent for participation. This screening process was designed to reduce risks to the participant while ensuring that persons with SMI have an opportunity to have their voice heard. Providers were clear to potential participants that their decision to contact the researcher was voluntary and would not have any influence on the individual’s care. The researcher utilized a prepaid cell phone and special email account by which participants were able to contact the researcher; the cell phone was deactivated upon completion of the research.

A total of 15 individuals were referred to the study. In most cases, the provider spoke with the potential participant about the research study and obtained permission to share the individual’s contact information with the researcher, who then phoned the participant to explain the purpose of the study and the requirements of the participant (meet for 60-90 minutes to talk about his/her experience, consent to audio recording of the interview). Initial verbal consent was obtained and arrangements were made to meet for the interview. Only twice was the researcher contacted directly by the potential participant. Five of the 15 referrals did not result in an interview: three individuals were unable to follow through with scheduled meetings, one individual did not have phone access and did not respond to email requesting scheduling an appointment, and one individual lost phone access and did not respond to postal mail contact.

Procedures for Data Collection

Once a potential participant indicated interest in the study, the researcher and the participant mutually agreed upon a time and location for the interview. Attempts were made to select a public but discrete location that afforded auditory privacy (for example a park, community room at a church or library). Most participants had a limited ability to travel, so participant convenience often determined the meeting location. Frequently the location was a food establishment, such as a coffee house or restaurant, and on three occasions the researcher purchased a nonalcoholic beverage (tea, coffee) for the participant as approved by the Investigational Review Board.

In order to elicit information about the participant's lived experience of hospitalization for a nonpsychiatric medical condition, the researcher utilized a minimally structured interview guide to provide initial direction to the interview (Appendix C). The interview guide was pilot-tested in a study (N=1) in spring 2010 and was found to be effective in guiding the interview process. Minor revisions were made to the interview guide (specifically demographic information regarding previous psychiatric hospitalization) following conclusion of the pilot study. The participant's story was used to guide questions and probes were used as necessary to ensure a rich and thick description of the experience. Interviews were audio recorded and transcribed verbatim. None of the participants had concerns or questions about the audio recording.

A data collection form (Appendix D) was used to gather basic demographic information – age, sex, ethnicity, history of pervious psychiatric and nonpsychiatric hospitalizations, psychiatric diagnosis, medical diagnosis, dates of nonpsychiatric hospitalization, marital status, employment status, living situation, and educational background – at the onset of the interview. This data is displayed in Table 1. Field notes were documented before, during, and after the interview to record environmental observations, nonverbal and paraverbal behaviors, impressions, and other perceptions.

Trustworthiness and Accuracy

Lincoln and Guba (1985) argue that the criteria (internal and external validity, reliability, and objectivity) established for evaluation of conventional (quantitative) inquiry is not appropriately applied to naturalistic (qualitative) inquiry as the two approaches are based in different paradigms. However, trustworthiness – a level of confidence in research findings – is relevant to all studies whether conventional or naturalistic inquiries. Trustworthiness is demonstrated via alternate criteria that provide a better fit with assumptions underlying naturalistic studies (Lincoln & Guba, 1985). Strategies for trustworthiness and accuracy consistent with the hermeneutic phenomenological research approach were utilized in this study.

Prior to initiating data collection, the researcher engaged in a reflexive exercise to identify her *forestructure* and assist her in developing a greater level of self-awareness regarding preconceptions of the research topic. The researcher has previous experience as a clinical nurse specialist providing direct care to persons with SMI and consultative-liaison services in a general hospital. In addition, the researcher has had administrative responsibility for inpatient medical-surgical hospital services in which persons with SMI received care for physical health conditions. These experiences have influenced the researcher's interest in the proposed study. They shape the *forestructure* the researcher brings to the research context and create the lens through which the interpretation of participant experiences occurred. An awareness of preconceptions assisted the researcher to consider and minimize the influence of personal bias. Reflexive journaling was one strategy used to address the researcher's forestructure.

The researcher initiated and maintained a reflexive journal throughout the research process. Reflexivity involves critical examination of previous experience and its influence on further action (Smith, 1999). Kahn (2000) suggests reflexive journaling consider two relationships: that of the researcher with the participant and the researcher with the data. Field notes documented before and after each interview can reflect the researcher's experience with the participant. Journal entries reflecting interaction with the data and describing decisions made throughout analysis within the hermeneutic circle create an audit trail that contributes to dependability and confirmability of the data.

To support credibility of findings, the researcher used minimally structured, face-to-face interviews to support the development of a relationship (albeit short-term) and mutual respect and participation. The researcher established procedures to ensure that transcripts of audio recordings accurately represented the interviews. Seven of ten interviews were transcribed by the researcher; three interviews were transcribed by an outside transcription service who guaranteed confidentiality of data. Once transcribed, each transcript was read while listening to the audio recording and reviewing field notes to verify accuracy of the transcription and additional notes were made regarding overall impressions of the meaning of the experience for that individual. Before the final data analysis, the researcher again listened to each recorded interview while reviewing the transcript for final data cleaning and to refresh her understanding of the data. Observations documented in field notes provided additional data that guided analysis and interpretation. The researcher consulted with the dissertation committee chairperson for guidance and periodic debriefing throughout processes of data collection and analysis.

Data Analysis

Analysis of data followed the hermeneutic phenomenological tradition as described by Cohen et al. (2000). The hermeneutic circle guided analysis – that is, parts of the data are considered in order to understand the whole, and greater understanding of the whole enhances understanding of the parts. As the analysis continues back and forth between the parts and the whole, analysis is driven deeper into a fuller understanding of the meaning of the experience.

Cohen et al. (2000) describe four basic steps in analysis of interview data. Data analysis begins as data are collected during interviews and the researcher is “actively listening and thinking about the meaning of what is being said” (p. 76). During the interview, the researcher reflected initial understandings back to the participant for validation of meaning. The researcher documented initial impressions and constructions of meanings in field notes immediately after each interview and later as additional thought and reflection on the data yielded new insights.

The next step of analysis involves an immersion in the data to establish an “orienting gestalt” (Cohen et al., 2000). The researcher listened to recordings, read the transcripts, and reviewed field notes several times to make an initial interpretation and identify essential characteristics of each interview. Reflexive journaling was an ongoing process throughout analysis and provided an audit trail of the researcher's *forestructure,* thought processes, and decision making.

Next, line by line coding prepared the text for thematic analysis; initial themes were identified and phrases were paired with themes. Each line of the text was examined and units of meaning (phrases) were identified. The researcher looked for patterns in the data; possible themes were identified and revised and related to passages thought to reflect that theme. This process occurred within data from each interview as well as across data from all interviews. The researcher engaged the hermeneutic circle, moving back and forth between parts (phrases, passages, themes) and the whole (gestalt of the meanings of the participants' experiences), during data analysis. A reflective process of writing and rewriting was used to facilitate insight and an understanding of the whole. Themes were further refined and subthemes identified to explicate key elements of the theme. Finally, exemplars – participant quotation(s) that captured the essential meaning of the theme – were extracted from the data (Cohen et al., 2000).

Protection of Participants

Prior to participant recruitment and data collection, approval for the study was secured from the University of Texas at Austin Institutional Review Board (IRB). The researcher had previously obtained approval for a pilot study which guided the design of the proposal for this investigation. This IRB approval was modified to include additional participants (N≤20) and additional providers who agreed to refer potential participants.

Procedures for obtaining informed consent

The initial contact with potential participants included a basic description of the purpose of the study and participation requirements. The individual was asked if they would be interested in participating without attempting to lead the individual to provide a desired response (e.g. “Are you interested in participating in this study?” rather than “Certainly you would want to participate in this study, wouldn’t you?”). Individuals who agreed to participate in the study provided initial verbal consent at that time.

When meeting with participants and before initiating the interview, the researcher again reviewed the nature of the study and participation requirements. Formal written consent was obtained immediately prior to the interview. The researcher provided participants with a consent document (Appendix D), reviewed the document with the participant, explained the research study, offered to answer any questions, and requested the participant provide written consent by signing the document.

Privacy and confidentiality of participants

Several measures were taken to protect the participant’s privacy and confidentiality. First, the meetings were scheduled at a convenient time and a public location that provided for auditory privacy. Next, the researcher informed the participant that s/he may chose what information is shared or not shared with the researcher. The researcher explained to the participant that the information shared in the interview was confidential except that, if the participant discloses an immediate risk of harm to self or others, the researcher would contact the participant's psychiatric provider and disclose the identified risk. The nature of the researcher-participant relationship was explained to participants; that is, the relationship was limited to the interview process and any questions participants had about that process. The researcher would not able to offer any services or assistance and would not be available to participants as a contact in the future. Instead, participants were advised to contact their psychiatric provider and/or the emergency contact numbers listed on the consent document if in need of mental health services. Participants were advised of their right to stop the interview and/or withdraw from the study at any time; no participants exercised this right.

Confidentiality of research data

The data consist of audio recorded interviews, related transcripts, and field notes. Data was labeled with the date of the interview and a number, e.g. "Interview 1." All data is stored in the researcher's personal home office in a locked file cabinet and/or password protected computer. Personal identifying information, i.e. signed consent form, is kept separate from all other files, hard copy or electronic, and bears no label so that it cannot be directly linked to data or to a particular participant. The researcher avoided stating the participant's name during the interview. Any mention of the participant's name in the transcript was changed to "Participant." Interview data was shared with the dissertation committee chairperson. Interpretive results were utilized in this writing and may be utilized in future writing by the researcher. The audio recording is being kept until completion of the study.

SUMMARY

This chapter described the philosophy of hermeneutic phenomenology and its relevance as a research methodology for exploring lived experience. The application of this philosophy and methodology to a study exploring the lived experience of nonpsychiatric hospitalization for persons with SMI was then considered. A discussion of research methodology, including participant selection, data collection procedures, and data analysis methods was discussed. The research study is presented as an opportunity to better understand an experience so that nurses can design responses that improve patient care and outcomes.

Table 1

Characteristics of Participants

Sex	Age	Ethnicity	Highest Education	Reason for hospitalization	Psychiatric Diagnosis	Employ-ment Status	Living situation
F	70	EA	HS	Hip fracture	Bipolar I	D	I
F	71	EA	GD	Multi-organ failure (s/p OD)	MDD	PT	I
F	70	EA	HS	Fall/laceration	MDD	R	I
F	62	EA	GD	TKA	MDD	R	I
F	76	EA	HS	TKA	MDD, anxiety	R	I
F	55	EA	C	Diabetes, hyperglycemia	MDD	PT	I
F	50	EA	C	Bilateral pneumonia	Bipolar II, SAD	SE, FT	I
F	59	EA	C	Pneumonia	Bipolar	D	I
M	49	AA	11th grade	Seizures	SA, Bipolar	D	H
M	45	EA	GED	Sepsis	SA	D	R

Sex:	F=female, M=Male
Ethnicity:	EA = Euro-American, AA=African American
Education:	HS=high school diploma, GED=high school equivalency certificate, C=some college, GD=graduate degree
S/p OD:	status post overdose (suicide attempt)
TKA:	Total knee arthroplasty
Psychiatric diagnosis:	MDD=major depressive disorder, SAD=seasonal affective disorder, SA=schizoaffective disorder
Employment status:	FT=full-time; PT=part-time, SE=self-employed, D=disabled, R=retired
Living situation:	I=independent, R=residential facility, H=homeless

Chapter 4: Presentation, Analysis, and Interpretation of Data

INTRODUCTION

The purpose of this study was to explicate the lived experience of nonpsychiatric hospitalization for persons with severe mental illness. Heideggerian phenomenology provided the philosophical underpinning and guided the research methodology employed. Ten individuals with severe mental illness shared their experience of hospitalization on a medical-surgical unit in a minimally structured interview. Data analysis through the hermeneutic circle revealed four themes describing the lived experience: *taking care of me, it's my life, on my toes,* and *being a good patient.* Each of these themes is elucidated in the discussion below.

TAKING CARE OF ME

The first theme uncovered in data analysis was *taking care of me.* This theme involved the extent to which providers in the hospital (e.g. physicians, nurses, allied health personnel, etc.) connected with the participants in a meaningful way and met their needs. A sense of understanding and acceptance was or was not conveyed in providers' comportment, perception of the illness, attentiveness, responsiveness, and personalized caring behaviors – descriptors of the subthemes b*eing cared for* and *not being cared for.* These five descriptors are exemplified below to define the identified subthemes.

Comportment

Being cared for was experienced through the comportment of care providers, as one participant describes:

> They way she talked to me and she patted me and that kind of thing… I mean her facial expression was that of a very caring person. It was her tone of voice. It was her warm contact…those were the things. We didn't sit and talk for a long time, it was instant.

The full presence of the provider – verbal, paraverbal, and nonverbal behavior nuances – communicated a sense of *being cared for* or *not being cared for*. Participants related a sense of connectedness with *being cared for*. Calming, comforting, supportive, and compassionate were words used to describe behaviors that communicated caring. Conversely, providers' behaviors communicated a lack of caring just as effectively: "She just clearly did not want to be there. It was just obvious… her mannerisms, the way she held herself, the way she talked to me… I didn't think she wanted to be my nurse."

Comportment associated with *not being cared for* was described as "abrupt," "rude," "mean," or "calloused." One participant recounted: "The way they talked to me was very, very rude and mean. They didn't have any compassion." Another, "There was a couple of calloused nurses… they didn't have any social skills." *Not being cared for* was interpreted from the provider's attitude: "She was not compassionate at all. She was just very clear cut, 'we're going to do this, this, and this' (chopping gestures with hands). No, I didn't see any compassion in her." Another participant stated:

> She wasn't *mean* to me, but for instance, I had to take this banana flavored stuff to do one of the scans. And, I have a severe aversion to bananas and I said is there any *other* (emphasis) flavor that you have. She said no, and I said, well, I don't know if I can do this. And she said, so are you refusing the test? Is that what

> you're doing, you're refusing the test? And I said, no, I'm not refusing the test. But, I'm just… I hate bananas. It was gross to me, and so it's just the way she talked to me. The others were caring. I mean, you can tell the difference between caring and not caring. Just the way she talked to me. She was sharp.,, I didn't want to ask for anything from her. Not at all. And I didn't. I just laid there.

Another participant related how the behaviors of others within the context of the hospital, but not necessarily directed at him, affected his experience of *not being cared for:*

> I was in a lot of pain and I remember being very angry because, all the doctors was out there and they was laughing and carrying on. And, I was like, I need to do something. I'm in a lot of pain here and you all are out there just, you know laughing and stuff and in my mind I thought they was laughing at me, but I'm sure they wasn't.

The experience of *not being cared for* reflected a lack of connection and involvement – a separateness – between the provider and participant.

Perception of the illness

Participants were conscious that knowledge of their psychiatric comorbidity might influence how their physical illness was perceived (and therefore cared for) by providers: "I didn't say anything about my depression this time because anytime I've ever been in a hospital, I always tell them that I have major depression and I think that colors my care in a bad way because they tend to think that 'she's just depressed'."

Participants didn't want their psychiatric diagnosis to interfere with care and treatment for a physical problem: "Please don't overlook my physical problems just because I have been diagnosed with a mental illness." Another participant expressed concerns about being taken seriously once her mental disorder was known:

> Don't just look at the depression. They know I have depression with the meds I am on. Don't just look at the depression, there may be something else there

> besides depression. Because it seems that once they figure that out, once they realize that I had depression, it's like it's an assumed diagnosis.

Several participants related prior experiences of seeking care in emergency departments (ED) in which they were *not cared for* because of providers' awareness of their mental illness and preconceptions about their physical condition:

> I went in there (ED). He (physician) told me there was nothing wrong with me, I was an asshole, I was nothing but a junkie. He said, 'I'm doing blood work on you, that's all we're ever gonna do on you. If your blood work's okay, I'm getting your ass out of here… the whole time I'm there, the whole three hours I'm there, I'm running back and for the to the bathroom with explosive diarrhea and I know what C-dif smells like and I told him I had C-dif. I mean he even came in and said my blood work was fine. And so, we went to (another hospital) and they admitted me and I was there for two weeks with a really bad UTI and C-dif.

Another participant related:

> I had gall bladder surgery and they thought that was depression. They thought… because I was having chest pains. They did an EKG and it was fine. Oh, I was so sick. I was so sick, and they didn't do anything. They wouldn't do an ultrasound. They just *didn't do anything* (emphasis). They just let me suffer… I was in *a lot* (emphasis) of pain… The doctor who treated me was my primary care physician at that time. He was an internist and he knew my history of depression. And he just let it… let me suffer.

So, when providers' responded in a manner that acknowledged legitimacy of the participants' illnesses and need for care and treatment, participants perceived *being cared for*: "I felt like somebody really cared for my health and are not judging me… it made me feel really good. It made me feel like they were genuinely concerned about my health and I liked it." Another commented, "I was genuinely sick and they treated me that way." And, another: "They paid a lot of attention to me because I was so sick." Other experiences that communicated legitimacy and *being cared for* included being admitted promptly and having pain managed: “They admitted me right away. They got me in right away.” “They didn’t let me stay in pain.”

Attentiveness

Perceived attentiveness of care providers was related to the experience *of being cared for*. Two participants had a “sitter” (unlicensed assistive personnel assigned to only one patient) assigned to them and described the experience as comforting. “I had been alone for so long and I had felt so lonely that it was comforting to have somebody with me… I felt like I got more attention because somebody was there all the time.” Yet, being physically present seemed to be a necessary but insufficient component of caring: “there was a couple (sitters) that I got a little bit close to that helped me, but some of them were just, obviously just there to have a job, and you could tell, or I could tell, and so it was kind of a different experience.”

Care providers were viewed as attentive when “they checked on me,” “they spent time with me,” and “they responded to me.” Physician daily rounds and staff routines – medication administration, respiratory treatments, glucometer checks – that caused providers to be in the patients’ room were perceived as attentive behaviors consistent with the experience of *being cared for*.

> They would just come and check on me when everything was okay. I hadn’t asked for medicine. It wasn’t time for my regular medicine. I got breathing treatments four times a day and it was always on the dot, you know the time they were supposed to be there. They would come in, just come in, and I was in (isolation) – everybody who came in there had to put on a gown, scrub, everything. So, they would come in in full regalia and they would just say how you doing? Sometimes they would just stay with me and talk to me… And sometimes it was about my health, sometimes it was about, you know, was I able

> to enjoy the food, how did I feel about the food they're giving me, the chest xrays or the breathing treatments. And sometimes just to shoot the breeze, just to see if I was okay… They came in and checked on me a lot.

Conversely, participants related experiences of being avoided or abandoned which were experienced as *not being cared for*. One participant described respiratory therapists who came to her room regularly to provide "breathing treatments." While "some were really engaging in what they were doing, stayed right there with me," the participant described a particular respiratory therapist:

> Every time, she would start me on my breathing treatment and then she would say, 'do you want me to get you anything?' because I couldn't go out and I couldn't go in the common area. That's strange. Everyone stayed right here with me, and she always leaves the room as soon as she gets started even if I'd say, 'no I don't want anything'… and I just got the feeling that she didn't want to be in those rooms, and she's just looking for any excuse to get out of there.

Another participant explained, "It was a couple of days before I got a shower and I was very weak doing that and they put me in the shower on a seat and they left. And they came back, but I probably needed someone to stay with me that first time." Being with the patient participant was experienced as *being cared for*.

Responsiveness

Participants seemed pleasantly surprised when providers were responsive to requests and such responsiveness was experienced as *being cared for*. "When they'd say they'd get back with me on something, they got back with me on something! It made me feel like I wasn't just a person in the bed there, and well, ok, we'll come and get you when we can." Similarly, "I'd say, 'the machine's beeping, can you come in here and turn it off?', and they would come in!" (incredulously).

Yet, lack of responsiveness was also described. A lack of follow through contributed to a feeling of *not being cared for*: “They were just real rude with me and they didn’t do what they said they was gonna do. And they really let me down.” One participant spoke of her need to wear protective undergarments because nursing staff were not responsive to her need to get up to the bathroom during the night: “I had to wear diapers and I could wet in them. It made me feel like a little baby, you know, *god*! So uncomfortable!” Another participant activated her call bell when she had complications with her intravenous (IV) line: “Something was going on with it (IV) – all of a sudden, severe unrelenting pain. And I cried, I cried. And I asked them to come check on it. And they didn’t, and they didn’t, and they didn’t…”

Personalized caring behaviors

Several participants found *being cared for* in behaviors that were personalized: “They didn’t treat me like a number. They treated me like a person,” “They cared for me *in a sense that I needed somebody*,” “They were taking care of me *in a manner that I really needed* and they were there for me and helped me.” Personalization of care was also reflected in physical behaviors that were sensitive to individual needs, “He was so attentive. He was just so sweet. He just handled me so carefully and everything. He spoiled me.” A participant with a chronic back problem related “they were real careful with me” because of their sensitivity to her physical issues.

Behaviors that made participants feel special were experienced as *being cared for*. One participant described a nurse who came in on her scheduled day off to say good-bye:

"They were so thoughtful, like there was one young nurse, and she had to walk to work, and on her day off I was gonna leave, and so she walked to the hospital to just come in there and tell me bye. Good-bye and that she wished me well and everything." Another spoke of a nurse who baked cookies at home and brought her one. One participant celebrated his birthday in the hospital:

> The nurses took care of me. They were my best friend. I had a birthday in there. They brought me cake, sang to me, happy birthday. They brought me chocolate cake with icing and they brought me a balloon. They used to comb my hair like a little Barbie doll, the nurses did.

Alternately, *not being cared for* lacked a sense of being appreciated as an individual. Instead, *not being cared for* was experienced as being separate, "the other:" "They (providers) acted like they were my enemy or something." Participants related a sense of not being helped: "I was supposed to be getting some help and I ain't got no help yet."

Taking care of me depicts study participants' experiences of *being cared for* and *not being cared for*. *Being cared for* was characterized by providers' comportment, perception of the illness, attentiveness, responsiveness, and personalized caring behaviors. All participants experienced both *being care for* and *not being cared for*.

IT'S MY LIFE

Study participants were invested in their care and treatment; they wanted to get well. Hospitalization represented an interruption in their life trajectory, their "normal state," and was only one component of the illness experience. The episode of illness disrupted stability of mental health, required additional care (subsequent psychiatric hospitalization, rehabilitation, home care) for full recovery, and affected physical functioning on a long term basis. The theme *it's my life* was expressed as a desire to be involved in care – to recover, to resume their lives.

> I've taken care of myself, so I know what it takes to be physically strong… There was a lot of fear and it was based on helplessness – am I going to be able to get better, how much better can I get, am I going to be able to take care of myself… and so the fear is that may be… this may be as good as it gets.

Participants wanted to be listened to and informed so they could actively participate in getting well. To several participants, being listened to was a novel experience – "They asked *me* (emphasis) questions," "They asked if there was something they could do to help me more, which is refreshing," and "When I was telling them things, they listened to me. They took everything into account. For some reason they believed me when I told them things about my own body that I knew." Participants appreciated being able to take part in their care. Participants had knowledge about themselves, believed they could make valuable contributions to their care, and desired the opportunity to do so.

Yet, being listened to was not a consistent experience, as several participants related: "I felt like I was not listened to… it was somewhat disturbing," "There are things I know about this (physical illness) and nobody is listening to any of it," "It felt strange not to have that control and not to have people listening to me." Not being listened to or taken seriously was distressing and affected the process of care: "When they started inserting it (nasogastric tube) it was horribly painful and I kept telling them that I couldn’t tolerate it. And they didn’t listen to me because they kept shoving it in. Finally, I started screaming. I couldn’t take it…”

Being informed was also important: “I appreciate the doctors telling me what he’s gonna do so I can know. It’s important to know.” Being informed enabled participants to focus energies on getting well: “It gives you more time to lay back and get well if you’re not worried about what the doctors or nurses are doing to you.” Being informed empowered the individual to be involved in care: “I was just so sick and I was so glad to find out what was wrong with me so *we* could make it better.” Participants desired being part of the team: “I just wanna get better. I just wanna find a solution and *we* can take care of this – we can all take care of this *together*.” Communication that included the participant supported involvement in care:

> They always gave reports to the nurse who was coming on, the nurse who was going off, right there in front of me, and they’d never done that before. It’s like it’s a big secret and we don’t want her knowing anything, because they’ve done that to me a lot… I liked it. I knew more about what was going on… It made me feel like I was part of the team and I really like that. And it made me feel like, you know, that I knew what was going on. Now what they said outside the door when it was closed, I don’t know, but the things they talked about in front of me were pertinent to what I was going through at that specific time. It made me feel like they genuinely cared and they wanted me to be part of the team.

One participant described her attempts to develop relationships with providers in order to obtain information and be involved in her care: “I asked them about everything, not to the extent that I was annoying, but to the point where, they were like, well, she’s interested in this, like I opened the door for them to say, let me tell you this…”

Yet, requests for information and involvement in care were met with paternalistic attitudes on the part of some providers:

> And I did ask both of those doctors to just let me know what they're doing, when they changed my medicine. It went in one ear and out the other. 'You don't need to know. You're just a patient. We know better than you what your body can and can't take.'

Similarly, another participant related: "I was telling them that I don't understand and one of the lady doctors told me that it's not my place to understand, that just to let them make the decisions and take care of me." Still another, "I questioned the Ativan they were giving me… and she said, 'I'm your nurse. You shouldn't ask questions like that.'"

Not being informed was distressing. One participant had been in septic shock and in a medically induced coma early in his stay. He described waking up and his attempts to become oriented:

> I thought I had been shot because I seen a hole on my left arm that was as big as a gunshot wound. And I had another one right here on my leg…so I thought I had been shot. Nobody told me what was wrong with me…and I was trying to figure out, who would wanna kill me?

Another participant experienced an episode of deoxygenation to which hospital staff responded to in an urgent manner. She recalled, "Afterwards, nobody told me what had happened, what was going on, and… *what's the story here*?" (emphatic)

It's my life expressed participants' perspective of their illness within their life trajectory. Participants sought engagement with providers; they wanted to be listened to and informed so they could be fully involved in their treatment and recovery. Participants desired partnerships with their providers. An invitation to be involved may have been experienced as a sign of respect, of being valued as a competent person capable of participating in their care. Not knowing, not being informed, was disturbing to participants.

ON MY TOES

On my toes reflects the participants' experienced need for advocacy – the need to advocate for oneself and to have an advocate – as well efforts to manage their mental health. Participants felt they needed to be alert and aware of what was happening to them during the hospitalization so they could "look out" for themselves. Yet they were not always able to be vigilant due to their vulnerability as a patient and they depended on others – family or friends – to advocate for them. Confusion, as evidenced by inability to recall certain periods of time during the hospitalization, was identified as a common experience that illustrated such vulnerability. Episodes of confusion were related to the psychiatric illness (e.g. hallucinations and delusions), pain medication, low oxygen saturation, elevated temperature, blood glucose level, seizures, and medically induced coma.

Needing an advocate was the first subtheme under *on my toes* which expressed the need to be able to speak up for oneself or to have someone able to speak up for them. The second theme, *managing my mental health*, related specifically to participants' efforts to maintain their mental health, e.g medication regimen, while in the hospital. Participants had been involved in active treatment of their mental illness and strove to maintain their mental health while hospitalized.

Needing an advocate

Needing an advocate signified the vulnerability participants felt while hospitalized.

> I really think it is dangerous for somebody to go in the hospital without somebody else to advocate for them. I really do. Because, you have to remember, I was so sick, I couldn't… I wasn't really functioning to where I could look out for myself. I just did what they told me to do… my friends being there was a great comfort.

There was a general awareness that hospitals may not be a safe place: "You know you hear bad stories about hospitals." Another participant discussed an error that occurred during her hospital stay when two physicians involved in her care had ordered conflicting treatment. When she questioned her treatment, the error was uncovered: "I just felt like they (physicians) didn't communicate a lot. It gets a little bit scary sometimes, but you just have to be on your toes when you're in the hospital… I just know that a lot of weird stuff can happen when people don't communicate."

Previous encounters with hospitals informed the belief that advocacy was needed: "I've learned from being in the hospital before that you've got to speak up. You've got to be proactive in your care. I watched my mom be in the hospital before and unless I stepped in, they wouldn't have taken care of business with regard to my mom." Another participant related a near death experience in a previous hospital encounter when she went into anaphylactic shock following administration of an antibiotic:

> I can't tell you how many times I've been in the emergency room and they're bringing me morphine, and it said very clearly, morphine. I'm allergic to morphine. That is why they are not putting anything in my veins till I know what it is. You can make so many mistakes like that. Doctors have tried to give me antibiotics that I'm allergic to, you know, when I went into anaphylactic shock, I died. I heard the doctor say we're losing her, we're losing her, and all of a sudden I was up in the ceiling looking down watching the defibrillator. And the first time they did that, I went back in my body. So when you have something like that happen, you don't really wanna go there again… and sometimes it pisses the nurse off, sometimes it pisses the doctor off, but I don't care. I do not wanna die because of a medicine… I will advocate for myself. I advocate for myself and I don't care if they like it or not.

An unspecified “incident” that occurred during a previous hospitalization alerted one participant of the need to be more alert: “it was just an incident… so that’s when I started really remembering things. It made me come to and take note of what was going on around me.” When she was readmitted to the same hospital, she was prepared to advocate for herself:

> I knew some of them (nursing staff) and they, some of them, knew me. One nurse came in and said, she was an RN and she said, ‘don’t try to remember anybody from your last stay.’ And I thought that was unusual. I said if you think I’m going to forget the other one that was, it was a male nurse, I will never forget it. So don’t give me that. I’m not going to forget it – ever. I know his name, I know what he looks like. And you may have thought I was crazy, but I wasn’t. I remember very vividly. So I guess she was trying… that’s what she was saying, don’t try to remember. And, it wouldn’t matter. If he would have walked in, I would have known it and he would have been out real fast… I would have pitched a fit.

The need to advocate or to have an advocate was related to the desire to be involved in care, yet advocacy extended beyond involvement and included speaking up, raising concerns, and looking out for oneself. One participant reported concerns through the chain of command:

> I had a PICC line and all the other nurses would clean – clean off with alcohol- and give it (pain medication) to me slowly. She would come in, she never cleaned anything off, she was always late – an hour late after I started requesting my medicine – and she’d just go in there, bam! And just, you know, I would go OW! Like that, and she wouldn’t clean it off after. A nurse, you know, so I told them… I always have known what to do, to call the director of nursing if there’s somebody giving me a problem. And, when I decided to call them was, they were at shift change, and the nurse I didn’t like was just leaving, and she was talking right outside my door to the nurse who was about to get me. And the nurse said to her, ‘This woman is very patient. You don’t have to give her her medicine. She’ll wait for a long time.’ And I said, oh hell no, oh hell no.

Another participant described not using the call bell because she didn't want to "bother" the nurses, but when it came to her psychotropic medications, it was a different story:

> It didn't really even hit me until I heard my husband say, 'where is her medication?'… I just remember him asking them and realized that it was an issue. And then, when he wasn't there, I was ringing the buzzer. This is so not like me. I had always been so timid and shy and all this kind of stuff, but boy I was ringing that buzzer every ten minutes and stuff and they'd come in and say 'what?' and I'd say 'where's my other medication?'… I was almost apologetic asking for this medicine, but unless you've been through withdrawal from that stuff, or try to get adjusted to it, you wouldn't quite understand it… I don't like bothering people except for my meds, so I would get up and just do it (go to the bathroom) myself. And then they'd yell at me and say 'why'd you get up?' and I'd say, 'well, I didn't want to bother anybody.'

Several participants depended on others, most often a family member, to look out for them. One participant compared two hospitalizations that occurred within weeks of each other. During the first hospitalization, her usual psychotropic medications were not continued: "I wasn't myself (emphatically) because I wasn't getting the medication and that's when I started crying, calling my daughter and telling her I wanted to come home. I couldn't stand it. I needed to get out of there." Her care providers weren't able to accurately assess her as they did not know her baseline: "they didn't know me, and they didn't know how I acted." She didn't realize she wasn't getting her usual medications:

> They gave me a pill for my anxiety upon my request, but I didn't know the name of it, so…I didn't know. They called it different from what I called it so I didn't know that's what it was. So, I went about five to ten days actually without all of my medications…I was very anxious and tense…

When she required rehospitalization, her daughter got involved to ensure she received her psychotropic medication:

> She (daughter) went out and talked to them (nurses) about that specifically, and she said it is very important that she get all of the medications that she has

> ordered. Not just one, not just two, but all of them. So they were real good about it… And they were very good about giving it to me, they did never question it. And she (daughter) would check the next day to be sure I was getting it.

Another participant related how her daughter knew her and was able to negotiate medications prescribed during hospitalization: "(I was on) so many drugs. And my daughter kept saying, 'she can't handle all that.'" Further,

> I just come unglued when they bring me 13 prescriptions I'm supposed to take. No way! You know? And they say, 'we're going to work through this and we're going to eliminate these as fast as we can. Just hang with us.' And so they started experimenting, it's always an experiment, every time it's a new experience. And so I've gotten to the point that I have to rely on my daughter. I mean there's no better support I could have.

Her daughter "kept an eye on me" and such involvement was reassuring.

Managing my mental health

All participants were engaged in the ongoing management of their chronic mental illness, and their mental illnesses were stable at the time of their nonpsychiatric hospitalization. Participants were adherent to prescribed psychotropic medications and psychotherapy. During the hospitalization, participants were concerned about managing their mental health and avoiding a relapse, particularly related to maintaining their pharmacotherapy: "(Nurse practitioner) and I had met and tried different combinations and we finally have it so it's balanced and I just didn't want to stir that up." Additionally, they sought respect for their mental illness as a bona fide concern.

Frequently, participants' psychotropic medication regimen was disrupted during hospitalization.

> All I know that I wasn’t on my meds and they wasn’t given to me and they were trying to… they would just give me like a little bit of something and I was freaking out. I didn’t know why they was doing that to me. There was no reason for it. But, I don’t know if it’s policy or why they held my meds back.

Having a severe mental illness, these individuals had worked diligently with their providers to implement a medication regimen that effectively managed their symptoms and improved their functioning, thereby enhancing their quality of life. Participants understood the implications of maintaining or not maintaining their medication regimen.

> It’s very important… For people that have a mental disability, whatever it’s called, they have got medication and if they’re on medication, come *anything* (emphasis) they should be on their medication. That’s’ why we go to a psychiatrist. That’s why they put us on medication. And when they do, it’s very important that we get it… Medication is very important to people like me and there’s a lot of us.

Yet, participants had difficulties maintaining their usual psychotropic medications regimen while hospitalized.

> The only thing that I had problems with… I take two 60 milligram Cymbalta a day, but not at once. I take one in the morning and I take the other one about 1:00, and they kept wanting to give it to me at bedtime, and I told them I cannot sleep if I take that Cymbalta before I go to bed. I have to take it first thing in the morning and preferably noon or 1:00 at the latest, and I never could get that worked out. I would just have to decline it, tell them I wasn’t gonna take it. Oh, well, we’ll get that taken care of. It never did get taken care of, never did. But, I felt all right, I felt all right. As soon as I came home, I started taking two a day.

Several participants planned ahead in attempt to make sure their psychotropic medications would be continued in the hospital: “At that time I went in for a knee replacement and I had a discussion with my doctor before, that I take lots of antidepressants and I wanted to make sure there was no conflict between what they were giving me and what I was already taking.” She was advised that there would be no conflict, yet she did not receive her usual medications during her hospitalization: "I had typed out a list of my medications. (I kept asking whether) whatever they were giving me was going to have a problem with my medication. Anyway, they kept saying no, but they kept forgetting to bring it." Advance planning failed for another participant as well: "They were fully unprepared for my needs, even thought the doctors had supposedly sent all the information ahead of time to make sure they had the medicine in stock, but it was a nightmare." Similarly, another participant's effort to facilitate uninterrupted pharmacotherapy was not successful:

> They had a list of my medications and they were real good about keeping me on them, except they did not give me all of my medications that I was on for my… problem that I have… And I didn't know until I got home that they were not giving them to me.

While these participants felt the disruption in their medication regimen was an oversight, "I don't think they were intentionally withholding my medication. I just think it kinda slipped through the crack, but it certainly did have an effect on me," another patient related "they just flat out didn't give me three of my meds, yeah, that's just about all of them (psychotropic medications)."

The disruption in medications was distressing. Participants described "feeling horrible," "anxious, depressed, and just kinda going to pieces." One participant described his agitation:

> I went off on them a couple times – got into it with them because they wouldn't give me the psych meds I was on. And I was experiencing symptoms, a lot of anger, anxiety, paranoia, and I didn't have my medicine to calm me down. All I had was the narcotics they was giving me… They wouldn't give me my Seroquel… They tried to put me on another anti-depressant, it's real popular, and I found out and I told them to discontinue it because I didn't even give you all

> permission to tweak my psych meds and put me on something I never took before. And I said you all are giving me the wrong dosages, you all are not giving me two of my medicines. And I cussed them out a couple times for that because I was feeling real – I felt like I was in crisis and they wasn't helping me.

His efforts to obtain his usual medications were unsuccessful: "I want my medicine and they says, 'Well, we're not gonna give you your medicine.' And I don't take benzos, just take simple psych drugs...I kept going round and round with them." Rationale for not providing his usual psychotropic medication was not offered and he felt helpless in managing his mental illness in the hospital.

Participants experienced a focus on their physical care while hospitalized. Though somewhat expected, "When you're in the (nonpsychiatric) hospital, they take care of everything except your mind," there was the sense that attention to their mental health was avoided:

> Nobody would say like, 'How are you doing with depression?' It's like they all knew but nobody wanted to talk about it… What I take, antidepressant meds, (are disclosed) when I fill out the forms, but nobody ever mentions it… but when you're doing knee surgery and that person had something, had cancer, I would expect somebody would discuss that. But since this isn't physical, it's not on the table so to speak. I guess that would be it, just acknowledge that we're not nuts.

In one situation, when asked to consider prescribed psychotropic medications, the physician explicitly stated, "No we don't deal with that kind of thing in the hospital." Another participant related the avoidance to perceived stigma:

> I have antidepressants that I take, but it didn't seem like it was a top priority. Just like, I used to teach special education children and they were always the stepchildren. You know, the time-consuming necessary evil that the schools would just as soon special ed would go away and that's kinda how I feel about my depression. They kinda blew it off. They're looking for the physical problems.

Felt stigma was expressed by another participant: “People don’t understand mental illness or think it’s a valid diagnosis... you know, this is as critical as having a knee operated on…” Another relayed:

> I think they had some nurses on that floor that were bad. I think one was really bad. She’d say, ‘Oh you’re the one who needs psychiatric nurses.’ I long ago stopped apologizing for it. You know, if I had cancer would you say, ‘Oh you’re the one who has cancer? And we’ve gotta give you chemo and stuff?’ I mean really! You know when I first started going through this, I would apologize and I wouldn’t tell people, but not anymore. That’s the truth people.

Participants desired recognition of their mental illness as a valid health concern that deserved attention during their nonpsychiatric hospitalization.

One participant contrasted her experiences of hospitalization at the same hospital – once following a suicide attempt and once for pneumonia.

> I guess the difference is because… the people looked at me when I was in there with pneumonia and let me know life is worth living. And the people that, when I was in there with suicide, were treating me like – it doesn’t matter, you’re going to kill yourself. I never really thought of it before, but it’s like, well she tried to kill herself… I tried to kill myself, so you don’t have to treat me as a human being anymore…it was a horrible, horrible feeling. You’re supposed to be here to help people, not treat them bad. As if I deserved it…

Managing my mental health reflected participants’ desire to maintain their mental health while having their physical health needs addressed. They yearn for care that is holistic – that responds to all facets of their personhood as an integrated whole.

BEING A GOOD PATIENT

The fourth and final theme to be uncovered was *being a good patient.* Participants had a conception of what constituted a “good patient” and attempted to conform to that ideal. *Being a good patient* was understood as adopting a set of behaviors that made it "easy" for the nurses; behaviors included not disturbing nursing staff and being cooperative. There was a sense that "good" patients may get better care, and those who "misbehaved" would face repercussions.

Participants shared the perception that nursing staff were busy, so several participants avoided disturbing nursing staff by using their call light:

> Now, I don't ring the bell. Because I'm aware of how busy everybody is and I will just not ring my call light. Because I don't want to disturb anybody. Because they're already very busy, overworked and… I never rang my call light, ever. Because I'd try to be empathetic to them because I know how hard it is.

Another expressed her attempts to be a "good patient" – someone who would not disturb nursing staff for petty concerns. She described a "good patient" as:

> a person that wanted to be active in their care, ask about their care, but not be obnoxious like 'get me this, get me that, I'm uncovered,' have the nurses running in there every 30 seconds or for frivolous little things that you could still, even though you're sick, you can do yourself. Somebody that wasn't just screaming 'nurse' and being rude to the nurses….

When it was necessary to disturb nursing staff, a "good patient" was very careful about being assertive. One participant shared that she had been provided with a pamphlet about patient rights and an invitation to raise concerns, to which she responded: "I couldn't be like that, you know, demand that I get something. And I was always very polite, you know, 'I'm sorry to bother you but… I really need this medicine'."

Participants were aware that their behavior may have an effect on the nurse's experience and his/her response to them. For example, one participant stated, "I know if I act like an ass, it's so much harder to get things done." Another related how she tried to establish a relationship with nursing staff by being friendly: "I was talkative, and thank you, and sweetie, and how’s it goin’…how’s it goin’ for you?” She stated, “I was always asking questions and like oh wait, this arm’s better than this arm or this is what’s making things easy for them.”

Sometimes nursing staff shared their difficulties with patients, and participants responded by attempting to be cooperative. One participant relayed feeling frustrated that she was not able to obtain her usual psychotropic medication in the evening. After the nurse described the medication dispensing machine and the process for accessing her medication, she backed down from her request: “The nurse, the nice one, said she was fairly new, she had just transferred, I said I won’t make her do this.” Nursing staff shared their challenges with one-to-one (sitter) assignments with one participant:

> The sitters I had on that floor was glad to have me, they said. They said in the other rooms that some of the patients don’t like noise or because they just sleep all the time, they don’t like lights, so they’re sitting in there for 12-hour shifts in the dark with no TV or no nothing. And they can’t talk to the patients and sometimes they spit on them and threaten them with physical violence and stuff.

He responded by being an easy patient: “I’d give them the remote, let them watch whatever they want and we’d watch TV together and watch football together.” And he believed his behavior affected his care: “They treated me a little better because I was cooperative with them and made their 12-hours real easy for them.”

This participant had an earlier episode in which he was in pain and angry with delays in reaching the physician for additional pain medication, so he pulled out his nasogastric tube and was placed in restraints: “They strapped me down to the bed like the Exorcist and they had my arms tied, my feet tied to the bed. They told me that they would let me back out when they put the tube back in, and of course they didn’t let me go. I stayed like that for a while." He worried about the care he would receive while in restraints: "Oh man that was awful! Now I'm in pain, and I'm strapped to the bed. It was terrible. It was like, now they're mad at me; they wouldn't cater to me as much after I pulled them tubes out of my nose from my stomach…" There were consequences for not being cooperative:

> The sitter got mad at me… I was like in trouble. I felt guilty but I was acting out in pain…When you're in disciplinary restraints, you can scream all you want to. It's just like crying wolf then. They just make sure that they do what they're supposed to do and then they leave you alone for a while. They don't come in there and say, 'hey, you need anything, are you alright?'… I thought I was in hell.

Other participants similarly experienced a threat of punishment or negative consequences when not cooperating. One participant described her refusal to use her BiPAP (bilevel positive airway pressure) machine;

> My daughter said they want you to bring that Bipap machine. I said a bad word. I can't, I feel like I'm smothering. But the respiratory therapist saw my BiPAP and he said, 'oh you use that?' I said no, and 'why?' I said, 'Because I feel like I'm smothering,' and he said I should be spanked.

Participants expressed efforts to be a good patient, although at times their own discomfort interfered with that process: "I got more defiant and more ornery and the more they yelled at me, well they didn't yell, but they were more annoyed. I said, 'I'm not doing it.' And they said, 'Tell me why.' I'm scared." Another participant described her attempts to cooperate even though she was experiencing distressing symptoms related to her mental illness:

> I tried very hard not to act that way in front of them, so I don't think they knew (about her mental problem). I mean, I can cover it up pretty good. So I think I did a good job of covering it up and they weren't aware of it. … I wanted to be good so I could get out, because that was my thinking, I wanted to go home.

She further described being "good:" "I wanted to do what they wanted me to do, and I wanted to do it better than anybody else, so that I could get out. So, if they'd say, 'how are you feeling?' Fine, I mean some pain, but not much. I'm ready. They weren't ready to let me go, but I went." But because she pushed herself to prove she was ready for discharge, she was readmitted two days later needing additional reparative surgery.

Participants sometimes interpreted the potential need for an intervention, e.g. catheterization or intravenous therapy, depending on their ability to respond, e.g. void or tolerate oral intake, as threatened punishment:

> I felt like it was almost a punishment when she came in and told me that they almost had done a spinal tap and that they *were* (emphasis) going to do a spinal tap if my mind didn't clear up… 'I'm doing the best I can, please don't stick me with a needle' and I couldn't understand their concern. I'm not sure it was a concern, they were trying to diagnose me.

Another participant commented, "I got yelled at because of all the medications that I take."

Summary

This hermeneutic phenomenological study explored the lived experience of nonpsychiatric hospitalization for persons with severe mental illness. As interview data were analyzed according to methods described by Cohen et al. (2000), four themes were uncovered: *taking care of me, it's my life, on my toes,* and *being a good patient.*

Chapter 5: Discussion and Implications

This chapter provides an overview of the study and situates study findings within current literature. Usefulness of study findings in understanding the phenomenon of concern, as well as limitations, are considered. Finally, implications for nursing education, practice, and research are discussed.

OVERVIEW OF STUDY

The purpose of this study was to uncover the meaning of nonpsychiatric hospitalization for persons with severe mental illness (SMI). Hermeneutic phenomenology provided the philosophical underpinning for conceptualization and design of the study. Clinicians who provide mental health services to persons with severe mental illness facilitated participant recruitment by identifying individuals meeting inclusion criteria and informing them of the study. The researcher followed up with identified participants and interviewed them about their experience. Ten participants shared their story of being hospitalized in a medical-surgical hospital setting. Interview transcripts were analyzed utilizing hermeneutic phenomenological procedures described by Cohen et al. (2000). Four themes characterizing the lived experience of nonpsychiatric hospitalization for persons with severe mental illness emerged from the data. These themes included: *taking care of me, it's my life, on my toes, and being a good patient.*

The shared experience related by participants included both positive and negative encounters during their hospitalization. *Taking care of me* included subthemes of *being cared for* and *not being cared for* which participants interpreted from providers' comportment, perception of the illness, responsiveness, and personalized caring behaviors. *It's my life* reflected participants' desire to be informed about and involved in their care. Two subthemes, *needing an advocate* and *managing my mental health* were reflected in the theme *on my toes* and indicated the need to look out for themselves. The final theme, *being a good patient*, revealed participants' conscious efforts to be perceived as "easy" to care for by the nurses. These themes provide a window into the lived experience of nonpsychiatric hospitalization for persons with severe mental illness.

DISCUSSION OF RESULTS

Themes identified in this study are strikingly similar to other studies exploring patient experiences of hospitalization that are reported in the literature. It would appear that those with a SMI are more alike than different from persons not affected with mental illness in their experience of hospitalization. Yet, persons with SMI evidence disparate hospital outcomes. This section will present study findings within the context of the extant literature and consider how findings may inform approaches to improve outcomes for persons with SMI.

Taking care of me

The individuals in this study described their experiences of *being cared for* and *not being cared for* by nurses and other providers – subthemes of *taking care of me*. Consistent with findings by Shattell et al. (2005), though all participants had both positive and negative experiences with nursing care, negative experiences tended to be minimized, overshadowed by whatever positive caring encounters occurred. Nurses' presence with the patient – comportment, related perception of illness, attentiveness, responsiveness, and personalized caring behaviors – was experienced as *being cared for* or *not being caring for*.

Comportment

Providers communicated levels of caring through their full presence with the patient. Similar to findings of other studies, this presence was not limited to verbal exchanges but included the use of paraverbal and nonverbal behaviors –voice inflections, the use of touch, and discernible attitudes. Sørlie, Torjuul, Ross, and Kihlgren (2006) explored the patient experience of being cared for during an acute hospital stay and described the expressions of care by nurses as *the human touch*: "…how the nurses help them (patients) with their daily hygiene, the way they talk to them, how they can give the patients a friendly or encouraging pat on the shoulder." (p. 1242). This description closely resembles a discussion of caring behaviors by a participant in the current study: "The way she talked to me and she patted me and that kind of thing…" Similarly, Pipe et al. (2008) found that patients' descriptions of meaningful caring behaviors were consistent with social support rather than task behaviors; caring behaviors included listening, supporting, encouraging, teaching and advocacy. Fareed (1996) suggested that reassurance is an attribute of caring expressed by nurses. Interpersonal skills, communication skills, and humanistic traits of the nurses were among the ten themes identified as representative of patients' experiences of reassurance. These themes were characterized by decorum, appropriate intonation, use of touch, and the attitude communicated (e.g. cheerful and pleasant). (Fareed, 1996).

Several researchers describe patterns of experience that correspond to the contrast of caring experiences of *being cared for* and *not being cared for* identified in the current study. Kralik et al. (1997) described (post-operative) inpatient experiences with nursing as engaged or detached. Engagement was characterized by an authentic demeanor – usually happy or smiling, kind and compassionate, friendly and warm, and a gentle, though confident, firm, and supportive touch. Alternately, nurse behaviors of being too efficient and busy, using a sharp or cold approach, and being rough with physical care were associated with detachment. Shattell et al. (2005) identified the patients' sense of connection or disconnection to inpatient staff as a critical element in the patient's experience of the acute care hospital environment. Nurses' friendly or unfriendly behaviors, communicated through their actions, were evaluated as connecting (caring) or disconnecting (uncaring) (Shattell et al., 2005). Another study (Sundin, Axelsson, Jansson, & Norberg, 2000) reported participant experiences of caring provided and caring not provided; if care was not adjusted to the specific "way of caring " desired by the patient, when desired care was not provided, the experience was one of "suffering from care." (p.19).

Perception of illness

Participants wanted recognition of both their mental and physical illnesses as real and worthy of care and treatment during their hospitalization. Some related previous experiences of stigmatizing attitudes regarding their mental illness that negatively affected their care, and they were very appreciative when their mental and physical illnesses were treated as legitimate. How providers' perceived and responded to participants as whole beings, including physical and mental components, contributed to participants' experience of *being cared for* or *not being cared for*.

Clarke et al. (2007) described themes of "attitudes" and "diagnostic overshadowing" (p. 128) that correspond to data in the current study regarding how provider perceptions of physical and mental illness influence the experience of *being cared for*. Clarke et al. (2007) explored the experience of persons with mental illness who sought care from a general emergency department. Patients with mental health issues felt they were less of a priority and experienced feelings of shame and guilt for reporting to the emergency department. Participants related being "labeled and triaged as 'psychiatric'" (p. 128) despite presentation of physical medical concerns. Participants:

> wanted to be perceived as worthy people who were suffering and legitimately seeking assistance. Above all else, they wanted compassionate, respectful, non-judgmental, and attentive care. They wanted to be seen as whole individuals with their complex medical and mental health issues assessed in their entirety. (p. 128)

Similar to participant disclosure in the current study: "I didn't say anything about my depression this time because anytime I've ever been in a hospital, I always tell them that I have major depression and I think that colors my care in a bad way because they tend to think that 'she's just depressed'," Clarke et al. (2007) related that patients sometimes opt not to disclose their psychiatric history despite understanding associated risk of this choice.

In a study exploring mental health patients' experiences of being understood, Shattell et al. (2006) described the vulnerability experienced once the diagnosis of mental illness was known. Patients voiced concern about being viewed through the lens of mental illness and “not seen as a whole person.” (p. 238). Hudelson, Kolly, and Perneger (2009) found that having a disease considered negatively by others, such as mental illness, was perceived as a source of discrimination by patients and was strongly associated with lower ratings of care. Indeed, a stigmatizing view of persons with mental illness by nonpsychiatric providers is well documented (Bailey, 1998; Björkman et al., 2008; MacNeela, Scott, Treacy, Hyde, & O’Mahony, 2012; Rogers & Kashima, 1998; Ross & Gardner, 2009) and such attitudes can negatively affect outcomes in addition to the patient’s experience of care (McDonald et al., 2003; Ross & Gardner, 2009; Thornicroft, Rose, & Kassam, 2007). Stigmatizing attitudes are at least in part related to the provider’s comfort with and competency in caring for persons with mental illness (Küey, 2008; MacNella et al., 2012; Ross & Gardner, 2009). Stereotyped or stigmatized approaches by providers tend to be experienced as *not being cared for* by patients.

Attentiveness

Participants experienced *being cared for* through attentive behaviors such as being present, spending time, and being checked on. Such behaviors were not in response to participant requests or solicitation. Often attentive behaviors occurred during regular hospital routines that caused staff to be present in the patient’s room (e.g. medication administration, treatments, vital sign assessments, etc.).

Attentiveness as a caring behavior has been described in several other investigations. Finch (2008) observed that “responding when needed and without being prompted” (p. 27) characterized one of four identified caring behaviors in her grounded theory study. Shattell et al. (2005) emphasized the significance “just checking in” (p. 163) had on the patient’s experience – brief, frequent contacts contributed to a sense of comfort, safety, and security. Even interactions that are few in number and of short duration were able to support the development of valuable nurse-patient relationships (Shattell, 2004). In another study, patients experienced feelings of safety from the knowledge that nursing staff were “watching over” and monitoring them (Schmidt, 2003, p. 396). Similarly, Fareed (1996) described “being there” (p. 275) as the reassurance patients feel when they experience nurses as accessible and available to them. Contrary views were also experienced as one patient described being “’placed in a room and forgotten’” (p. 397) not unlike the participant in the current study who shared her experience of being “put in the shower on a seat and… left.” Attentiveness is a component of *being cared for* as the patient is assured that staff are proactive in care.

Responsiveness

In contrast to attentiveness, responsiveness was distinguished as behavior that followed a patient request or expectation, such as a nurse’s response to a call bell or fulfillment of a commitment. Participants of the current study were pleasantly surprised when staff were responsive; responsiveness contributed to a feeling of *being cared for*. Patients interviewed by Finch (2008) experienced trust and being cared for when nurses “kept their word and followed through on a promise.” (p. 27). One participant in the current study expressed this dynamic animatedly: “When they said they’d get back with me on something, they got back with me on something!” Another related a contrary case: “…they didn’t do what they said they was gonna do. And they really let me down.”

Schmidt (2003) also found “responding” (p. 396) as influential in how patients perceived their care. Responding included timeliness and appropriateness of the nurse’s response to the patient. Findings by Elliot et al. (2009) confirmed the importance of perceptions of responsiveness to the overall patient experience. While nurse communication was noted to be most important, staff responsiveness was the second most important composite to overall hospital ratings on the Hospital Consumer Assessment of Healthcare Providers and Systems Survey. They further posited that “how well nurses communicate with patients may have a greater bearing on the perceived responsiveness of the hospital staff than is the case for doctors” (p. 847) largely due to the nurses proximity to the patient.

Personalized caring behaviors

Being cared for and *not being cared for* was experienced in the personalization of care and attention to individual needs. Participants in the current study reported examples in which staff went out of their way to make the patient feel unique and special, e.g. making a special effort to say good-bye upon discharge, celebrating a birthday in the hospital. Similarly, Finch (2008) described caring behaviors: “Nurses who did extra ‘little things’ for the patient, such as bring a cup of coffee, an extra blanket, or read a poem conveyed caring.” (p. 27). Schmidt (2003) highlighted the importance of “seeing the individual patient” (p. 395) and providing personalized care that respected the unique nature of the patient. Individualization of nursing care was proposed as essential to patient satisfaction with nursing care. Accordingly, the “way of caring” (Sundin et al., 2000, p. 19) should be adjusted to what the patient desires to avoid suffering from care: “A specific ‘way of caring’ could be experienced as good caring in one specific care situation, but as poor caring or lack of caring in another care situation.” (p. 21). Caring behaviors must be personalized to individual needs.

Not being cared for was experienced when providers failed to appreciate the patient as an individual. Koch et al. (1995) describe patients’ experiences of “conveyor belt” or “routine geriatric style care” (p. 187) and “care deprivation” that resulted in a sense of depersonalization by patients. Staff adherence to routine precluded consideration of personal preferences and individualization of care.

The theme *taking care of me* is consistent with the extant literature exploring patient experiences with hospital experiences. This concordance is irrespective of whether the patient population included persons with or without mental illness. The experience of being cared for or not appears to be a universal experience affected by the provider’s engagement with the patient as a whole person with individual, legitimate needs.

It’s my life

The experience of hospitalization was an episode that interrupted the person’s life trajectory and challenged their ability to resume normalcy. Participants expected the opportunity to be informed and involved in their care – to actively participate in their recovery. They sought a voice in their care and treatment and wanted to be listened to.

This ownership of the recovery process is manifest in the theme *it's my life*. The desire to be informed and involved in care conforms to findings by others who have explored patient experiences of hospitalization. Perhaps the first step of involvement in care is the process of being listened to, as one participant stated: "When I was telling them things, they listened to me. They took everything into account. For some reason they believed me when I told them things about my own body that I knew." Or a contrary case: "There are things I know about this (physical illness) and nobody is listening to any of it." Shattell (2005) described *try to get them to listen* as one strategy patients used to "entice" nurse engagement in a relationship. Additional studies emphasized the importance patients place on being listened to (Birks, Hall, McCaughan, Peat, & Watt, 2011; Finch, 2008; Howe, 2006; Pipe et al., 2008; Sundin et al., 2000; & Wu et al., 2006). Not taking the time to talk or listen to patients or not accepting patients' explanations with confidence was experienced as depersonalizing by older adults (Koch et al., 1995). Listening is important to the process of informing and involving patients in their care.

Being informed was important to current study participants, "…it's important to know," provided a sense of security, "It gives you more time to lay back and get well if you're not worried about what the doctors or nurses are doing to you," and was empowering, "I just wanna find a solution and *we* can take care of this – we can all take care of this *together*." These findings are consistent with the literature. Fareed (1996) found that being informed was an important component of patients' experience of reassurance. Similarly, Sørlie et al. (2006) described gratefulness and the sense of security patients experienced from the flow of information from nurses as well as a sense vulnerability and fearfulness when information was not forthcoming. In another study, teaching was identified by patients as a caring behavior and meaningful intervention (Pipe et al., 2008). Schmidt (2003) defined the category "explaining" (p. 396) in a study exploring patient perceptions of nursing care. Explaining represented how patient information needs were met by nurses. Though information was provided through formal patient education activities, more often "explaining" occurred as nurses answered patients' questions or offered explanations during routine care. Finally, the lack of information provided by nurses was particularly concerning to post-operative patients in a study by Kralik et al. (1997). When detached nurses did not share information, patients sought other avenues for obtaining information, such as listening in on nurse conversations with other patients.

Beyond receiving information, participants in the current study desired involvement in their care. For example, a participant gave an account of experiencing change-of-shift report at the bedside: "I knew more about what was going on… It made me feel like I was part of the team and I really liked that…" Birks et al. (2011) investigated how patients and others could promote safety through involvement in care. A key finding was the significance of providers' behavior and communication in supporting patient involvement. Generally, patients did not perceive their involvement as welcomed. In particular, "Older interviewees and those with mental health problems, anticipated negative rather than positive responses from healthcare professionals in relation to raising concerns about their care or treatment.” (p. 19). Yet, anticipation of a positive response was most supportive of involvement in care. Among the barriers to patient involvement identified by Howe (2006) was mental illness even though “patients with stable physical or mental health chronic conditions/settings are likely to have interest, capacity and expertise… to comment on behavior of professionals, the (mal)functioning of equipment, or contest organizational procedures” (p. 531) and thereby promote their safety.

A significant barrier to patient involvement entails the historical paternalism in healthcare in which providers are motivated by the “patient’s best interests” although views differ as to what that best interest is. (Howe, 2006, p. 529). Participants in the current study experienced blatant paternalism: “And I did ask both of those doctors to just let me know what they’re doing… [the physician said] ‘you don’t need to know. You’re just a patient. We know better than you what your body can and can’t take.’” Another patient related, “She said, ‘I’m your nurse. You shouldn’t ask questions like that.”

MacNeela et al. (2012) described two attitudinal orientations of nurses toward medical-surgical patients with psychiatric co-morbidities. Nurses adopting a risk orientation tended to view such patients as problematic, while a vulnerability orientation saw patients as passive and helpless. Vulnerability oriented nurses “presumed a lack of autonomy and self-direction that required and legitimized nurse-led responses” (p. 209) – a more paternalistic approach. The major finding was that nurses lacked specialized skill in assessing the needs of patients with psychiatric comorbidities and instead relied on “stereotypical and routinized interpersonal responses.” (p. 210). Thus, stigmatized and stereotyped understandings of persons with mental illness affect how providers involve patients in their care.

Searching for autonomy was one of four themes Sundin et al. (2000, p. 20) identified in a phenomenological study in which patients’ experiences of suffering from care were explored. Patients desired information and involvement in their care: “They wanted to be active subjects, not just the passive objects of caring. They wanted to ‘be seen’ and to be ‘someone,’ a person, not just a patient.” (p. 20). When staff did not meet this desire, suffering from care was experienced.

Utilizing grounded theory methodology to explore the meaning of “high quality nursing care,” Irurita (1999, p. 10) described the phenomenon of “vulnerability” which patients deal with through the process of “preserving integrity.” (p. 11). The lack of information or preparation was one of six factors influencing patient vulnerability. Three phases of preserving integrity were identified: knowing what to expect, contributing to care, and eliciting a nursing presence. (p. 15). These aspects of preserving integrity enhanced patients’ feelings of control, safety, and security and are compatible with findings of the current study. Participants desired information and involvement as reflected in the theme *it’s my life*.

On my toes

The third theme to emerge from the data, *on my toes*, involved participants’ discerned need to “look out” for themselves. Participants felt vulnerable in the hospital and recognized their need for advocacy. Yet, they acknowledged that at times they were "too sick" to assume this role themselves – "I was so sick… I wasn't really functioning so where I could look out for myself' – and instead depended on others, family or friends, to look out for them. This phenomenon is subsumed in the subtheme *needing an advocate.* The second subtheme, *managing my mental health,* reflects participants' endeavors to maintain stability of their chronic mental illness while hospitalized.

Needing an advocate

While most participants were attuned to nurses' busyness and consciously engaged in behavior to avoid "bothering" nurses, they also identified the kinds of situations that justified crossing that line. Some had experienced serious adverse events or near misses in previous hospital encounters, such as the participant who recounted a situation in which she experienced anaphylaxis and a near death experience after receiving an antibiotic that she was allergic to in the emergency department. Others acknowledged that they were too sick to be able to fulfill the advocate role and relied on family or friends: "…I've gotten to the point that I have to rely on my daughter. There is no better support I could have." These findings correspond with Shattell's (2005) description of how patients used assertiveness and sometimes relied on a significant other to advocate – to get the nurses to listen. Likewise, Clarke et al. (2007) described a similar phenomenon when people with mental health issues present to general emergency departments: "You're in 'no man's land' if you can't advocate for yourself." (p. 127-128). Individuals dealt with this issue by bringing someone who could advocate for them with them when presenting to the emergency department. Williams (2004) also identified the need for patients with comorbidities hospitalized for acute medical conditions to have an advocate who could look out for the patient's interests.

Despite the professed role of the nurse as patient advocate (American Nurses Association, 2001), participants in the current study, as well as those in the reviewed literature, did not look to the nurse to advocate for their needs. Mantzorou and Mastrogiannis (2011) suggest that knowing the patient enables advocacy – "nurses who have a deep understanding of the patient and his needs can stand up as advocates…" (p. 259). Perhaps the nurse's prescribed role in the current hospital environment does not adequately provide opportunities for nurses to establish the kind of relationships with patients that empower advocacy activities. In order for the patient to look to the nurse as an advocate, the nurse must "know the patient" in relationship.

Managing my mental health

All participants in the current study had a chronic illness – a severe mental illness – for which they were being treated. For all but two participants, their mental illness had been stable prior to admission to the hospital for a medical or surgical issue. Participants disclosed a general concern about maintaining or managing their mental health while hospitalized for an acute condition, particularly with regard to maintaining their medication regimen. This concern is manifested in the *theme managing my mental health*. Though comorbid chronic illnesses are becoming increasingly common among individuals hospitalized for acute conditions, there is a paucity of research regarding the management of comorbidities in the acute care setting (Williams & Botti, 2002). Williams (2004) elicited perceptions of quality of care from patients with comorbidities who experienced an acute hospital stay. Identified themes included: “poor continuity of care for comorbidities, the inevitability of something going wrong during acute care, and chronic conditions persisting after discharge.” (p. 13). Perhaps not surprisingly, “management of the acute problem took precedence over comorbidity” (p. 16), at times even exacerbating the comorbidity. Further, outcomes of care were negatively influenced by comorbidities (Williams, 2004; Williams & Botti, 2002). Williams (2004) concluded: “The acute care setting did not fully acknowledge or accommodate the comprehensive care that these patients required because the primary interest was the diagnosis that caused admission.” (p. 20). This finding resonates with current study findings, perhaps to an even greater extent as participants questioned whether neglected attention to the comorbid mental illness was related to stigma:

> I think there were some nurses on that floor that were bad… she’d say ‘Oh you’re the one who needs psychiatric nurses.’ I long ago stopped apologizing for it. You know, if I had cancer would you say, ‘Oh, you’re the one who has cancer? And we’ve got to give you chemo and stuff?’

Participants in the current study expressed concerns about managing their chronic illness during their acute hospital stay, particularly their medication regimen: “It’s very important… For people that have a mental disability… they have got medication and if they’re on medication, come *anything* they should be on their medication.” As Williams, Dunning, and Manias (2007) noted, participants “felt the stress and anxiety of managing their comorbidities negatively affected comorbidity stability… caring for comorbidities was relentless and required a great deal of self-care." (p. 249). Indeed, in the current study, participants described distress related to disruption in their medication regime: "feeling horrible," "anxious, depressed and just going to pieces," "anger, anxiety, and paranoia." One participant in the current study describes desperate attempts to obtain his usual psychotropic medications: "…I said you all are giving me the wrong dosages, you all are not giving me two of my medicines. And I cussed them out a couple times for that because I was feeling real – I felt like I was in crisis and they wasn't helping me." Koch, Jenkin, and Kralik (2004) suggested that health care professionals recognize persons with chronic illness as experts in self-management and support their self-management practices.

Despite preplanning for the hospitalization, participants in the current study related challenges in continuing treatment (medications) for their comorbid mental illness, "They were fully unprepared for my needs, even though the doctors had supposedly sent all the information ahead of time to make sure they had the medicine in stock, but it was a nightmare." Similarly, Williams et al. (2007) found that, for patients undergoing joint replacement surgery, comorbidity care was poorly coordinated before surgery, as well as during hospitalization and after discharge. Inpatient care instead focused on patient throughput (Williams et al., 2007). *Managing my mental health* involved participants' attempts to maintain stability of their illness – an issue that may be relevant to all persons with chronic illness comorbidities hospitalized for acute conditions.

Being a good patient

Participants in the current study attempted to conform to their notion of a “good” patient – someone who made it “easy” for the nurses – at least in part to avoid negative repercussions. Participants in fact felt threatened or punished at times when not cooperating with treatment. These findings are largely consistent with existing literature. The notion of the “good patient” is frequently referred to when patients are asked about their experience of care or hospitalization (Irurita, 1999; Shattell, 2005; Shattell et al., 2006).

In a grounded theory study exploring patient perceptions of quality nursing care, Irurita (1999) described patients’ strategies to deal with vulnerability through a process of preserving integrity. Being a “good patient” was a perceived role obligation in this process and targeted “attracting more and better care, avoiding negative attention, and working with nurses toward their recovery” (p. 14-15). Consistent with this discussion, a participant in the current study stated, “They treated me a little better because I was cooperative with them and made their 12-hours real easy for them.”

Williams et al. (2007) found that patients avoided complaining and offered praise and gratitude to nurses in order to attract required care. Similarly, a participant in the current study described being friendly and grateful to nurses: “I was talkative, and thank you, and sweetie, and how’s it goin’…how’s it goin’ for you?” Participants tried to adopt behavior concordant with the role of an “easy patient.” Shattell (2005) described patient expectations for a “reciprocal process” in nurse-patient interactions: “Participants believed that their response to their nurse affected the care that they received" (p. 214). Patients responded with behaviors in attempt to "be an easy patient" (p. 214).

Sørlie et al. (2006) identified *compromises* as one of three themes illuminating the patient experience of being cared for on an acute unit. *Compromises* represented patients' acknowledgment that many circumstances – other patients, limited resources, unit routines – affect their experience. Patients made compromises, such as not ringing their bell unless "absolutely necessary," in attempt to alleviate pressure on the nurses. (p. 1243). Participants in the current study also described making compromises in their care to accommodate nurses: "The nurse, the nice one, said she was fairly new, she had just transferred, I said I won't make her do this."

Williams (2004) noted that patients "knew the rules for using the call bell" (p.18), just as a participant in the current study stated:

> Now, I don't ring the bell. Because I'm aware of how busy everybody is and I will just not ring my call light. Because I don't want to disturb anybody. Because they're already very busy, overworked and… I never rang my call light, ever.

Similarly, Birks et al. (2011) described patients' reluctance to speak up about care as they feared they would be labeled difficult and experience negative repercussions. While nurses may appreciate the lack of interruptions, patient reticence to call when assistance is needed may threaten their safety. In fact, a national healthcare accrediting organization, The Joint Commission (TJC), launched a Speak Up™ initiative in 2002 to assist patients taking a more active role in the prevention of errors in healthcare. Yet, the hesitancy to raise concerns is very real as one participant noted after receiving a brochure encouraging her to speak up: "I couldn't be like that, you know, demand that I get something."

While not found elsewhere in the literature, several participants in this study reported events they believed represented negative repercussions for being uncooperative. One participant described being told she should be "spanked" because she refused to use the prescribed BiPAP machine. Another believed he was restrained and ignored because staff were mad at him after he pulled out his nasogastric tube. Two participants perceived being "yelled at." Participants believed they caused or instigated the retaliatory responses by staff.

Persons with SMI are equally cognizant of the concept of *being a good patient* as patients without mental illness. Generally, patients identify with the role of a "good patient" and adopt compliant behaviors to attract care and avoid repercussions.

SUMMARY

While others have discussed patients' experiences of being cared for in the acute hospital environment, the current study is the first to look at the experience from the perspective of the individual with severe mental illness. Perhaps what is most significant in this discussion is how closely current study findings mirror the findings of similar studies that included participants who did not have mental illness. Study findings are consistent with the extant literature and highlight universal perspectives of the shared experience of acute hospitalization.

LIMITATIONS

This investigation sought the lived experience of nonpsychiatric hospitalization for persons with severe mental illness (SMI). Consistent with phenomenology, this study included a small segment of the population of persons with SMI in interviews to explore the meaning of the experience. Therefore, not all voices were heard. As a qualitative study, findings are not intended to transfer broadly to populations. Yet, study design and implementation influenced who had an opportunity to participate and associated study limitations must be acknowledged.

Methodology

The particular sample included persons who were receiving professional care for their mental illness and were deemed stable by their mental health provider. Because generally only 40% of persons with mental illness receive any kind of treatment for their condition (Wang, Lane, Olfson, Pincus, Wells, et al., 2005), this criterion excluded a large number of individuals. Also, because sociodemographics strongly predict who receives mental health services, people who are not under 60 years of age, female, non-Hispanic white, and previously married (Wang et al., 2005) were less likely to be included in this study. While mental health providers supporting the study indicated they were carefully and actively looking for individuals who met criteria for participation, the fact that participants were essentially referred by their providers allowed providers to influence who did or did not have the opportunity to participate in the study.

Although approximately 50% of persons with SMI experience a substance use comorbidity (Regier, Farmer, Rae, Locke, Keith et al., 1990), persons dually-diagnosed with a substance use disorder were excluded in order to primarily target the experience to the perspective of persons with SMI. This criterion excluded a large number of potential participants. The required access to phone or email communication may have excluded a significant number of persons with severe mental illness, such as those who are homeless or living in poverty. Institutionalized individuals were also excluded from this study.

Interviews took place in central Texas and reflect the sociodemographic as well as healthcare culture of the local community. That is, in addition to cultural implications of the local region (ethnicity, socioeconomic status, gender, etc.), participant experiences reflect the organizational cultures of local hospitals and their models for delivering patient care. Therefore, patient experiences in other hospital organizational contexts may differ from those expressed in this study.

Sample

The sample was skewed in that it was predominately female (80%) – women who were 50 years or older, non-Hispanic white, and diagnosed with a mood disorder (either major depressive disorder or bipolar disorder). The two male participants differed from the women in that they were younger (40s), had achieved a lower level of education (11th grade and GED), and had been diagnosed with schizoaffective disorder. Though not evident in this study, it is possible that a sample including additional participants with schizophrenia related disorders, male gender, or younger in age may present different experiences.

Analysis

Hermeneutic phenomenology is interpretive by definition. The analysis of texts and interpretation of meaning reflects the perspective of the researcher at a particular place in time and space. Therefore, the analysis and findings do not represent all possible interpretations, meanings, or applications.

IMPLICATIONS

Study findings were largely consistent with similar research reported in the literature. That is, despite earlier research identifying opportunities to improve the patient experience, challenges in realizing positive patient experiences that include feeling cared for, informed and involved, treated holistically, and accepted persist. This section will address how study findings may inform practice, education, and research in order to improve patient care.

Practice

Study results emphasize the importance of the nurse's comportment – verbal and nonverbal behaviors, attitude, and demeanor – to patient perceptions of caring. Through self-awareness nurses can manage their presence and responsiveness to patients in a manner that communicates caring. Self-awareness involves consciousness of one's self (inner experience of feelings, attitudes, and thoughts) and mindfulness of one's behavior and presence. While self-awareness is deeply embedded in the theory and practice of psychiatric nursing, and a core component of the therapeutic nurse-patient relationship, it's relevance to nursing practice in nonpsychiatric settings may seem less critical. However, the consistency of findings across studies examining patients' experiences and perceptions of nurses would suggest that self-awareness practices are just as important in nonpsychiatric settings. As nurses become more aware of themselves, they may also develop better understanding of how others may interpret their behavior. Nurses may need support in developing self-awareness and reflective practices may facilitate this process.

Reflective practices are those in which one looks back on an experience in effort to improve or grow professionally (Ruth-Sahd, 2003). Reflective practices involve cognitive as well as affective dimensions and are increasingly being used in education and practice settings (Ruth-Sahd, 2003). This study supports the value of efforts to promote reflective practices among nurses particularly with regard to nurses' attitudes and feelings of comfort and competence with persons who experience mental illness. Through such reflection, nurses may gain greater self-awareness regarding their feelings, thoughts, and behaviors and how such responses translate into caring or not caring behaviors toward patients. By identifying feelings of discomfort or unfamiliarity with the care of persons with mental illness, nurses may be empowered to solicit assistance and support to improve their caring practices. There may be a role for psychiatric consultative liaison nurses (PCLNs) to facilitate this process.

For example, participants wanted to be seen as whole persons – to have both their mental and physical illnesses seen as legitimate while hospitalized. Nurses who are uncomfortable with, or lack confidence in, their ability to respond to patients' mental health needs may avoid (not acknowledge) that aspect of patients as they provide care. A PCLN could assist those nurses to identify and verbalize their feelings and then coach or role model therapeutic responses to patients that validate the legitimacy of their mental health needs.

This study presents an interesting perspective on hospital routines. In one sense, hospital routines were comforting to patients. Routines provided a sense that care would be provided or could be anticipated without solicitation, i.e. treatments ordered at set intervals. Routines provided some structure, and this was reassuring to patients. However, routines could also be dehumanizing when patients feel that they serve the routines rather than the other way around. Practices that use routine to provide predictable and consistent care, such as hourly rounding, can contribute to the perception of *being cared for*. However, routines that fail to allow individualization of care may contribute to perceptions of *not being cared for*. Nurses need to be supported in their practice environments to adjust routines, or seek individual modifications (e.g. an alternative to banana flavored contrast for the patient who had an aversion to bananas), in order to use routines to meet patient needs.

A significant number of patients admitted to hospitals for acute conditions experience multiple chronic health conditions, including mental illness. Hospitals and nurses may not be prepared to manage complex patient needs that extend beyond the acute condition precipitating the admission. For example, one study participant related being transferred between the surgical floor and the “respiratory” floor when her chronic obstructive pulmonary disease exacerbated following her knee surgery. She was then transferred back to the surgical floor before discharge so she could receive rehabilitation services. There is a need to develop models of care in hospitals that effectively address the management of chronic conditions within an acute inpatient encounter and appreciate mental illnesses as legitimate chronic illnesses. Such models should recognize the expertise patients have in managing their chronic illnesses and the important contributions patients can make toward their care.

As Lykouras et al. (2006) suggest, persons with mental illness may have fearful attitudes toward physical illness and be resistant to reassurance. Resulting illness behavior may result in perceived difficulty by care providers (Hansen et al., 2001). Further, psychiatric comorbidity has a significant negative effect on somatic and psychosocial aspects of quality of life (QOL) (Baumeister et al., 2005). Nurses who appreciate the negative interplay of medical and psychiatric comorbidities on an individual's QOL may be better poised to respond to illness behaviors in a more supportive manner.

Practices that engage patients in their care need to be developed. While involvement in care appears to be a consistent desire among patients, and a safety initiative over the past decade (Birks et al., 2011; Cavis, Sevdalis, Jacklin, & Vincent, 2012), few strategies have been effectively implemented (Hall, Peat, Birks, Golder, Entwistle et al., 2010). Those that have, such as bedside reporting, should be broadly adopted.

Listening was identified as a necessary component of informing and involving patients. Nurses may be challenged in knowing how to listen to patients – looking for the meaning underlying the behavior, e.g. the participant who described being defiant and refusing to comply, "And they said, 'Tell me why.' I'm scared." Active listening takes time and attention, demands that nurses may find difficult on busy inpatient units.

Finally, models of care that enable nurses to get to know their patients need to be implemented. Two decades ago, Tanner, Benner, Chesla, and Gordon (1993) examined the meaning of knowing the patient in nursing practice, identifying two broad categories: knowing the “patient’s patterns of responses” and “knowing the patient as a person”. (p. 275). The authors assert:

> Knowing a patient is a central aspect of nursing practice and is pervasive in the everyday discourse of nurses. Knowing the patient is a primary caring practice. As a moral concern, knowing the patient creates the possibility for advocacy in its most basic sense… Knowing the patient is essential to patients’ feeling cared for and about. (p. 279)

Complex acute care environments that tend to foster a task focus may not support the interactive process, the development of relationship, required for nurses to get to know their patients. Indeed, Shattell (2005) suggested that the therapeutic nurse-patient relationship does not exist in the contemporary environment of the acute hospital. Because knowing the patient is central to caring for the patient, and knowing occurs in relationship, there is a need for models of care that promote the intentional development of relationship between nurse and patient to be developed and implemented.

For example, The Quality Caring Model© described by Duffy and Hoskins (2003) promotes the development of caring relationships in which feelings of *being cared for* are engendered. Duffy and Hoskins (2003) suggest that caring practices expressed in caring relationships may be an independent factor in improving patient outcomes. The Quality Caring Model© includes structure (staffing patterns, organizational culture, resources), process (technical and interpersonal interventions), and outcome (provider, patient, system) components. Caring relationships occur in the process component and incorporate “physical work (doing), interaction (being with), and relationship (knowing).” (p. 82).

Duffy, Baldwin, and Mastorovich (2007) describe implementation of The Quality Caring Model$^{©}$ on a medical-surgical unit. Staffing patterns were adjusted to promote continuity of care (nurses were assigned the same patients several days in a row); such structure facilitated the opportunity for nurses have time to get to know their patients over the episode of care. Process changes included the delegation of “nonrelational tasks” (p. 549) to unlicensed assistive personnel so that professional nurses could focus on interaction (being with) and relationship (knowing). Relationship-centered caring practices were established as expectations of professional nurses. For example, nurses were *required* to implement and document episodes of “purposeful interaction… dedicated uninterrupted time spent with patients and/or families…at least 5 minutes every 8 hours.” (p. 549). This time was intended to promote mutual familiarity and relationship between nurse and patient. At least one nurse sensitive outcome - patient satisfaction – demonstrated improvement following implementation of The Quality Caring Model$^{©}$. Perhaps nurse practice environments that contribute to positive patient outcomes, such as those described by Aiken et al. (2008), are those which support and expect nurses to get to know their patients. And, because patients with severe mental illness are considered difficult to get to know, intentional efforts, such as those described in The Quality Caring Model$^{©}$, to get to know the patient may improve disparate outcomes for this patient population.

Education

Although psychiatric mental health (PMH) nursing education is required in professional nursing schools in the United States, positive attitudes toward persons with mental illness do not adequately form, or do not endure, as evidenced by multiple studies revealing negative attitudes of nurses toward this patient population. There is an opportunity for generic undergraduate nursing programs to evaluate educational approaches that influence student attitudes toward certain patient populations, such as persons with severe mental illness. Cognitive knowledge of mental illness is necessary but insufficient for the development of empathy and other caring behaviors. Specific teaching and learning strategies that address the affective domain have been identified and should be broadly adopted.

For example, educational experiences in which students are able to encounter individuals with mental illness in mental health settings positively affect nurse attitudes toward persons with mental illness (Chan & Cheng, 2001; Happell & Gaskin, 2012; Happell & Platania-Phung, 2012; Rhode, 1996). The greatest positive attitudinal change occurs when education in the classroom is paired with clinical learning experiences in PMH settings (Happell & Platania-Phung, 2012). As PMH clinical placements become increasingly difficult to acquire for undergraduate nursing students, educators look to alternate approaches for clinical teaching, such as integration of PMH learning experiences within medical-surgical nursing placements (Happell & Platania-Phung, 2012) and clinical simulation. Each of these strategies offers opportunities and challenges.

Attempts to integrate PMH learning experiences with medical-surgical nursing are to be commended and encouraged as such approaches may assist nursing students to see and care for the patient holistically. Students may better appreciate how all their nursing knowledge must come to bear on a clinical situation. However, such integrated experiences should not replace specific clinical experiences in acute or community mental health settings as changes in attitudes toward persons with mental illness is optimized in PMH settings (Happell & Platania-Phung, 2012). Integrated care and a holistic approach to the patient regardless of setting also requires an open attitude of faculty. In order to coach and role model caring behaviors, faculty would need to have a level of comfort with and confidence in caring for mental health needs in nonpsychiatric settings. Integrated teaching-learning approaches that consider the whole person, biopsychosocial and spiritual needs, in every setting – general hospital, psychiatric hospital, community settings – may best prepare practitioners who attend to the whole person and consider the complex interplay of person, health/illness, environment, and role of the nurse.

Simulation in PMH nursing can enable experiential learning that results in attitudinal change. For example, role play has long been used as a teaching-learning approach in PMH nursing. Acting out the behaviors of a patient or a nurse, followed by a debriefing that includes a discussion of feelings (How did you feel when the “nurse” responded to you? How tiring was it for you to act anxious?) can assist students to begin to understand some patient experiences. More recently, an activity designed to simulate the experience of hearing distressing voices has been shown to improve understanding and empathy of nursing students toward persons with mental illness (Dearing & Stedman, 2008; Wilson, Azzopardi, Sager, Gould, Conroy, et al., 2009). Strategic use of such simulation experiences can serve to address the scarcity of PMH clinical placement sites as well as provide consistent learning experiences for students.

Reflective practices involve a process of cognitive and affective self-examination – looking back over an experience in order to develop new understandings (Ruth-Sahd, 2003). Reflective practices facilitate the development of self-awareness and promote personal and professional growth (Ruth-Sahd, 2003). In PMH nursing, reflective practices such as journaling, process recordings, and interactions with others enhance the development of positive attitudes toward persons with mental illness (Cleary, Horsfall, Happell, & Hunt, 2013). It is not known to what extent reflective practices are currently applied in nursing education, however, they should be incorporated in all clinical experiences, not just psychiatric rotations, so that nursing students develop skills in self-reflection and awareness that can extend into their everyday nursing practice.

Finally, nursing has long held "caring" as central to the profession. There may be value in considering how caring is taught and learned. Does learning to care evolve though the very personal reflective processes described above? That is, do educators teach caring when they engage students in reflective processes that develop self-awareness, challenge attitudes, and promote empathy? How do educators learn to guide students through reflective processes to maximize personal learning? Do educators assist nursing students to appreciate the necessity and value of knowing their patient and the importance of the therapeutic nurse-patient relationship within complex task-oriented practice environments?

Research

Limitations of the current study pose opportunities for further research on the topic of the lived experience of nonpsychiatric hospitalization for persons with severe mental illness. The study sample included only those individuals who were actively being treated for their psychiatric condition at the time of hospitalization and all but two individuals lived independently. All participants were actively engaged in treatment, adhering to their prescribed treatment, and vigilant regarding their medication regimen, yet 20-72% of persons with severe mental illness demonstrate medication nonadherence (Julius, Novitsky, & Dubin, 2009). A sample that includes individuals who are not actively engaged in treatment (therapy and/or medication) for their mental illness, may reveal an experience of nonpsychiatric hospitalization that differs from findings of the current study. This perspective is worthy of exploration.

Only two participants had been diagnosed with the most severe mental illness – schizophrenia-related disorders. Future research could investigate the medical-surgical hospitalization experience from the perspective of those who experience schizophrenia-related disorders specifically. Also, people who are homeless or who are dependent on alcohol or drugs tend to be stigmatized. Because 20-25% of homeless persons have a severe mental illness and are unlikely to receive health care (National Center for the Homeless, 2009), a study focusing on this subgroup may offer different insights.

Likewise, the current study excluded individuals with comorbid drug or alcohol dependence or abuse, who comprise approximately 50% of the population of persons with SMI (Regier et al., 1990), thus excluding a significant proportion the population. In fact, several providers indicated that this exclusion limited a number of potential participants they had identified. A study including persons diagnosed with both SMI and substance use disorders may yield additional findings.

A number of challenges were encountered with participant recruitment. In order to promote support in the way of referrals to the study, the researcher met with a number of private practitioners and directors of several community mental health agencies and integrated care programs. As these individuals were often not the providers who would have direct contact with potential participants, communication regarding the study needed to penetrate several organizational layers before the study became known those in a position to notify potential participants of the research opportunity. Some providers commented that an honorarium (e.g. $10 gift card to a general store) may have attracted more participants. Another consideration is whether self-referral, rather than the requirement for provider screening, may have been appropriate. As the study carried minimal risk to participants, it may have been safe and more efficacious to have recruited participants directly rather than through provider referral. Transportation was a significant challenge for 50% of participants who completed the study and 4 of 5 individuals who eventually were unable to meet with the researcher. It may be safe and appropriate to allow interviews to occur at the individual's residence, unless otherwise assessed by the researcher.

The findings in this study highlight the importance and the value of knowing the patient – in order to personalize caring behaviors, to be a patient advocate, to understand how to meaningfully involve patients in their care, to enable patients to trust they will be cared for and not suffer repercussions if they are not "easy." Over and over again, the literature speaks to patient desires for caring behaviors and such research findings appear to be consistent over time. Theories and models of caring in nursing are also found in the literature. The gap appears to be translation of these theories and models into nursing practice. Further research should focus on how nurses can be supported in their acute care roles to come to know the patient and to implement caring behaviors. Appreciative inquiry may provide one approach to examine this phenomenon.

As cited previously, Duffy et al. (2007) described one attempt to implement The Quality Caring Model$^{©}$ and noted positive outcomes with respect to nurse and patient satisfaction. It is not known if other quality indicators such as nurse sensitive patient outcomes were also affected. However, as suggested by Tanner et al. (1993) knowing the patient includes knowing the patient's "patterns of responses" (p. 275) and enables skilled clinical judgments – nurses who know their patients are able to assess subtle cues and respond to avert adverse events. Could the poorer hospital outcomes among patients with severe mental illness be associated with the assertion that they are difficult to get to know?

Research demonstrating the impact of care models that support the development of caring relationships between nurse and patient, and that enable nurses to come to know their patients (in the manner Tanner et al., 1993 suggest), on nurse sensitive indicators is desperately needed. Convincing research emphasizes the importance of the nursing practice environment on patient outcomes (Aiken et al., 2008). Perhaps, an environment that supports nurses in knowing their patients is an important component of a positive nursing practice environment. This question deserves study.

Summary

The lived experience of nonpsychiatric hospitalization for persons with severe mental illness (SMI) described in this study was similar to experiences of other persons hospitalized in acute care environments. Perhaps, these findings are not surprising. Persons with severe mental illness are people first, more like than unlike individuals without a chronic mental illness. How then do findings of this study contribute to improving the care of persons with severe mental illness hospitalized in medical-surgical environments?

Identified themes emphasize the critical importance of the nurse-patient relationship to the patient experience. The literature suggests that persons with SMI may be difficult to get to know, especially amid the organizational constraints of a complex acute care environment. Also, patients with comorbid SMI tend to have longer lengths of stay and poorer outcomes of care. Tanner et al. (1993) suggest the incredible power knowing the patient could have on patient outcomes. The quality of nursing practice environments also has a significant influence on nurse sensitive outcomes (Aiken et al., 2008). Perhaps the missing factor in improving care for this patient population lies in the degree to which the nursing practice environment supports nurses in their ability to get to know persons with SMI. Further efforts are needed to move implications of findings into practice.

Appendices

APPENDIX A: PROVIDER LETTER OF SUPPORT

(Provider)

(date)

Institutional Review Board
University of Texas at Austin
P.O. Box 7426 Mail Code A 3200
Austin, TX 78713

To whom it may concern:

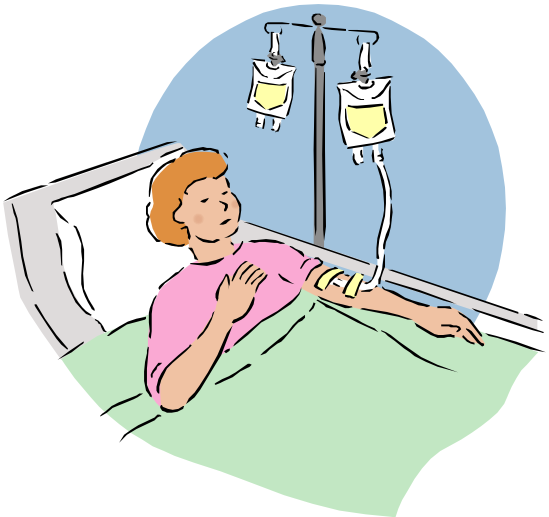
We (I) offer outpatient services and agree to participate in the proposed study “The lived experience of nonpsychiatric hospitalization for persons with severe mental illness.” We (I) agree to identify clients with severe mental illness who have been hospitalized within the past year in a general hospital setting for a nonpsychiatric medical problem. Identified clients will be generally screened for appropriateness – that is, ability to focus attention and process information necessary to respond to interview questions. Clients considered fragile, or easily distressed, will not be referred for participation in the study. Clients assessed to be appropriate will be made aware of the opportunity to participate in the study and provided with a copy of a flyer with contact information. We understand that information regarding the person’s participation in the research study is confidential and will not be shared with us. We also understand that the investigator may contact us if the client indicates distress or a threat of danger to self or others.

Sincerely,

(signature of psychiatric provider(s))

APPENDIX B: RECRUITMENT FLYER

Have you been diagnosed with a severe mental illness (schizophrenia, bipolar disorder, or major depression)? And,



Were you hospitalized for a nonpsychiatric medical illness (for example, pneumonia, diabetes, heart failure) for at least 36 hours in the last year? And,

Would you be interested in participating in
an audio-recorded interview
regarding your hospitalization experience?

Cindy Zolnierek, RN, a doctoral candidate at the University of Texas at Austin,
is interested in understanding your hospitalization experience. If you would be willing to participate in a 60-90 minute interview and share your experience, please contact Cindy at 512-785-1051 (leave message) or email RNresearchUTA@gmail.com.

Thank you!

APPENDIX C: INTERVIEW GUIDE

Think about the time you were hospitalized for (condition) or at (name of hospital/unit).

Tell me about your experience.

1. Why were you hospitalized? (What was the problem?)

2. What was the experience of being hospitalized like for you?

   Possible probes:
   - How did it feel to be in the hospital?
   - What was comfortable or uncomfortable about your hospital stay?
   - Why was it comfortable (or uncomfortable) for you?
   - How was it similar or different from other hospital (e.g. psychiatric) experiences you may have had?

3. Tell me about the people who were involved in your care… (doctors, nurses, other staff).

   Possible probes:
   - What was your experience like with them?
   - Was it similar or different from other experiences you may have had with healthcare?
   - What did they do that was helpful to you?
   - Was there anything they did that bothered you?

4. Tell me about the physical environment…

   Possible probes:
   - How was it supportive (or not) of your recovery?
   - Tell me about your hospital room.

5. If you could advise doctors, nurses, and other hospital staff how to take the best care of patients hospitalized for medical illness, what would you tell them?

6. Any other thoughts or questions you would like to share?

APPENDIX D: DEMOGRAPHIC FORM

Demographics:

Age: ____Sex: M F   Marital Status: S M D W Sep Other:______Ethnicity:_______

Emplymnt: FT PT Disabled Retired Unemplyd Other:_________________________

Living situation: Independent   Group Home   Residential Facility Other: ____________

Education: < HS dip/GED, HS dip/GED, some college, AD, Bachelor's, graduate degree

Previous psychiatric hospitalization? (date/reason)______________________________

____

____

Previous nonpsychiatric hospitalization? (date/reason)___________________________

____

____

Psychiatric diagnosis: ____

Medical diagnoses: ____

Dates of and reason for most recent nonpsychiatric hospitalization: ________________

____

APPENDIX E: INFORMED CONSENT

IRB APPROVED ON: 03/28/2013 EXPIRES ON: 03/27/2014

Title: The lived experience of nonpsychiatric hospitalization for persons with severe mental illness
Conducted by: Cindy Zolnierek, RN, Doctoral Student, 512-492-2384, RNresearchUTA@gmail.com; Deborah Volker, PhD, RN, Associate Professor and Faculty Sponsor, of the University of Texas at Austin, School of Nursing, 512-471-9088, dvolker@mail.nur.utexas.edu.

You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask any questions you might have before deciding whether or not to take part. Your participation is entirely voluntary. You can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time and your refusal will not impact current or future relationships with UT Austin, participating sites, or your healthcare provider. To do so simply tell the researcher you wish to stop participation. The researcher will provide you with a copy of this consent for your records.

The purpose of this study is to understand the experience of nonpsychiatric hospitalization for a person with severe mental illness.

If you agree to participate in this study, we will ask you to participate in a 60-90 minute interview and talk about your experience while in the hospital for a medical/physical illness. The interview will be audio-recorded and the interviewer may take notes during the interview.

Total estimated time to participate in the study is 60-90 minutes plus time to travel to and from the location of the interview.

Risks of being in the study. While there are no known risks of participating in this study, it is possible that you may experience minor stress or anxiety by recalling past events. If you feel uncomfortable answering any questions, you may chose not to answer by letting the interviewer know that you chose not to answer. If you appear distressed during the interview, the interviewer may chose to stop the interview. You may chose to end the interview or withdraw from the research study at any time without any consequences to you.

Benefits of being in the study. There are no direct benefits to you for participating in this study.

Compensation. There is no compensation or costs for participating in this study.

Confidentiality and privacy protections.

- Your name and any other personally identifying information will not be recorded, and the recording and notes will be coded (for example with a number rather than your name) so the data cannot be directly linked to you.
- If a transcription service is used, the service will be asked to provide a non-disclosure agreement and evidence that transcriptionists have received confidentiality training prior to the exchange of any files.
- The data resulting from your participation may be made available to other researchers in the future for research purposes not detailed within this consent form. In these cases, the data will contain no identifying information that could associate you with it, or with your participation in any study.
- The records of this study will be stored securely and kept confidential. Authorized persons from the University of Texas at Austin and members of the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a participant.
- To make future analyses possible, the investigator will retain the transcripts until all the research questions in this area have been answered. Audio recordings will be destroyed once the accuracy of the transcripts has been verified.
- If you disclose information that indicates you may pose an immediate risk of harm to yourself (e.g. suicidal) or to someone else, the interviewer will contact your psychiatric provider and refer you to community resources:
    - 512-472-HELP (4357): licensed counselors provide immediate assessments, crisis intervention services if needed, and referral to additional community resources
    - 211: information and referrals to health and human services and non-profit and faith-based organizations
    - 911: emergency dispatch which can send emergency responders to your location in an emergency.
- Your relationship to the interviewer is limited to the interview. The interviewer is not available to offer services or assistance, other than to answer questions related to the study, following the interview. If you need assistance, please contact your psychiatric provider or one of the numbers identified above.

Contacts and questions:

If you have any questions about the study please ask now. If you have questions about this research study later, want additional information, or wish to withdraw your participation, call the researchers conducting the study. Their names, phone numbers, and email addresses are at the top of the first page.

If you would like to obtain information about the research study, have questions, concerns, complaints, or wish to discuss problems about a research study with someone unaffiliated with the study, please contact the IRB Office at 512-471-8871 The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects at 512-232-2685. Anonymity, if desired, will be protected to the extent possible. As an alternative method of contact, an email may be sent to orsc@uts.cc.utexas.edu or a letter sent to IRB Administrator, P. O. Box 7426, Mail Code A 3200, Austin, TX 78713.

You will be given a copy of this information for your records.

Statement of Consent:

I have read the above information and have sufficient information to make a decision about participating in this study. I consent to participate in the study.

Signature: ____ Date:_______________

____ Date: _______________
Signature of Person Obtaining Consent

Signature of Investigator: ______________________________ Date: _______________

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Vita

Cynthia Diamond Zolnierek received her baccalaureate degree in nursing magna cum laude from Mercy College of Detroit in 1981 and a master's degree in adult psychiatric-mental health nursing from Wayne State University in 1984. Her work experience spans advanced practice, education, administration, and policy development roles. She is currently an assistant professor of nursing at Texas State University

Permanent address (or email): 1703 Olive Street, Georgetown, TX 78626; cindyzoln@yahoo.com

This dissertation was typed by the author.